

Health Literacy and the Health Status of Men with Prostate Cancer

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Abstract

Objective: To test the Health Literacy Questionnaire in a sample of men with prostate cancer and examine the components of health literacy that are most strongly associated with mental and physical health-related quality of life in men with prostate cancer.

Method: Members (N=565) of a state-wide prostate cancer support network in Queensland, Australia ($M_{age} = 71.14$, $SD = 8.68$) completed the HLQ along with the Medical Outcomes Study, 36-item short-form health survey (SF-36). Confirmatory factor analysis was employed to assess the internal structure of the HLQ. The effects (*bs*) of each of the nine health literacy factors on mental and physical health status were graphed and compared using Fishers exact test for comparing parameter estimates.

Results: Fit indices including RMSEA (0.069, CI= 0.066 – 0.072), CFI (.853) and TLI (.839), alongside item loadings and internal consistency (Cronbach alphas > 0.80) for the nine factor model supported the robustness of the HLQ for use in this prostate cancer sample. Health literacy factors reflecting social and health provider support, navigating health systems, finding and understanding health information and active engagement with providers shared small to moderate associations with mental health status and little to no association with physical health status.

Conclusion: Findings provide support for the use of the HLQ as a valid and reliable measure of health literacy in men with prostate cancer. Although further research is required to establish causality, interventions that aim to improve skills in connecting and effectively communicating with health care services and providers might lead to better mental health related quality of life for men with prostate cancer.

Keywords: cancer; health literacy; health status indicators; mental health; oncology; prostate cancer; psychometrics

Background

Each year an estimated 1.1 million men worldwide will be diagnosed with prostate cancer ⁽¹⁾. As the second most common cancer in men, prostate cancer accounts for 12.5% of cancer burden in developed nations ⁽¹⁾. In comparison with other malignancies, prostate cancer is often slow and progressive in nature and, although it is associated with high survival rates ⁽¹⁾, many men face long term reductions in physical and mental health-related quality of life ⁽²⁾. For this reason, improving general health and overall quality of life is becoming an increasingly important aim in prostate cancer research ⁽³⁾. Targeting health literacy can be an effective way to empower people with chronic health conditions to achieve better health ⁽⁴⁾ and could potentially be an effective tool in improving quality of life for men with prostate cancer.

Measuring health literacy in men with prostate cancer

According to the WHO definition, ‘health literacy’ refers to “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, use and understand information, in ways which promote and maintain good health” ⁽⁵⁾. Most measures of health literacy, however, reflect only unidimensional definitions of health literacy; focusing solely on reading, comprehension, or numeracy skills ⁽⁶⁾. The Health Literacy Questionnaire (HLQ) was developed as a comprehensive multidimensional measure of health literacy, comprised of nine conceptually different factors including feeling understood and supported by healthcare providers, having sufficient information to manage health, active health management, social support for health, appraisal of health information, ability to actively engage with health care providers, ability to navigate health care systems, ability to find good health information and understanding of health information ⁽⁷⁾.

The HLQ has been applied and tested in a variety of health contexts and populations ⁽⁷⁻¹¹⁾. As the instrument developers suggest, the appropriateness of a tool for any particular

setting can vary and it is important to validate the data the HLQ generates in each specific context before interpreting findings based upon it^(7, 12). To date, the HLQ has not been tested in a sample of men with prostate cancer. Given the HLQ's established psychometric properties and associations with health outcomes in various chronic disease cohorts and settings^(7, 9-11, 13, 14), we expect that it would demonstrate similar function in a prostate cancer population.

Health literacy and mental and physical health-related quality of life

The unique challenges experienced by men with prostate cancer place immense strain on their physical and emotional well-being^(15, 16). Treatments including surgery, radiation therapy, and hormone therapy, often result in side effects that impair urinary, bowel, and sexual functioning, not only causing pain and discomfort, but also negatively impacting social lives and interpersonal relationships⁽¹⁷⁾. In addition, the slow progression of the disease means that many diagnoses are monitored via long term active surveillance rather than treated immediately which can lead to enduring uncertainty regarding cancer outcomes and ongoing strain on mental health^(18, 19). Men with prostate cancer often report specific supportive care needs to assist with the management of psychological distress, sexual issues and enduring symptoms⁽²⁰⁾.

Evidence shows that health literacy is positively related to health outcomes and health-related quality of life in individuals with chronic disease^(21, 22). A causal pathway has been conceptualised, whereby health literacy is proposed to lead to better health through access and utilization of health care services, effective engagement with health care providers and ability to manage self-care⁽²³⁾. Drawing from empirical evidence, researchers present several factors, functioning at both patient and system levels that facilitate optimal health outcomes for individuals. For example, health system navigation, knowledge of condition, communication skills, patient participation in decision making and adherence to medication

are all mechanisms by which health literacy skills are proposed to effect health outcomes^(23, 24). Accordingly, men with proficient health literacy skills ought to be more likely to select, and engage effectively with the most appropriate forms of support for their needs, experiencing improved health-related quality of life compared to those who lack these skills.

Study aims

The multi-dimensional design of the HLQ allows researchers to capture the level of ability and/or skill associated with the specific mechanisms proposed to effect health outcomes described above. However, to date, researchers have not explored the specific dimensions of health literacy that are most associated with mental and physical health status in people with chronic conditions. In this exploratory, cross-sectional study, we test the HLQ in a sample of men with prostate cancer and examine the components of health literacy that are most strongly associated with mental and physical health-related quality of life in men with prostate cancer. From this, we aim to identify the health literacy skills that might be of particular importance in determining health-related outcomes in men with prostate cancer.

Methods

Participants and Procedure

The contact details of prostate cancer survivors were requested from the coordinators of Queensland based support groups affiliated with the Prostate Cancer Foundation Australia. Members (N=2,437) were mailed an invitation pack and invited to participate in the study, by completing a mailing back the anonymous survey. From this, 565 surveys were completed and returned to researchers. Participants ($M_{age} = 71.14$, $SD = 8.68$) tended to be married (77%), evenly distributed across SES deciles, with the most common treatment being radical prostatectomy (57%). See [Table 1](#) for a detailed description of participant characteristics. Ethical approval for the study was obtained from the University Human Ethics Committee (ref. PSY/74/14/HREC) and participants provided researchers with written informed consent.

Measures

Participants responded to the 44 items from the HLQ ⁽⁷⁾ on a 4-point response scale indicating the degree to which they agreed or disagreed with a statement (e.g., “*I feel I have good information about health*”) or the level of difficulty they experienced with certain tasks (e.g., “*Confidently filling out medical forms in the correct way*”). The HLQ consists of nine scales including: 1) Feeling understood and supported by healthcare providers, 2) Having sufficient information to manage my health, 3) Actively managing health, 4) Social support for health, 5) Appraisal of health information, 6) Ability to actively engage with health care providers, 7) Navigating the healthcare system, 8) Ability to find good health information and 9) Understanding health information well enough to know what to do. Means are calculated for each scale. Previously, the HLQ has demonstrated robust construct validity, structural stability (items loadings consistently >0.50) and good to excellent internal reliability (Cronbach’s alphas > 0.80) across a variety of settings ⁽⁷⁻¹⁰⁾

Version 2 of the SF-36 was used to measure physical and mental health status. The SF-36 consists of eight subscales reflecting elements of both physical and mental health status and the way in which they affect day-to-day functioning including energy and fatigue, role limitations due to physical and emotional health, physical pain, emotional well-being, social functioning and general health ⁽²⁵⁾. The SF-36 has been widely tested and used extensively as a measure of health-related quality of life in prostate cancer cohorts ⁽²⁶⁾. In the current study, z-scores for each SF-36 subscale were calculated based on each participants’ deviance from Australian population means for males aged 64-75 and weighted by factor scores based general Australian population norms ⁽²⁷⁾. Mental and physical health summary variables were then aggregated and transformed so that they could be directly compared to t-scores ($M=50$, $SD=10$), representing average mental and physical health levels for healthy men of a similar age. Cronbach’s alphas for the mental ($\alpha = 0.82$) and physical health ($\alpha = 0.90$) scales demonstrated excellent internal reliability in the current sample.

[\[insert Table 1\]](#)

Analysis

Two nine-factor confirmatory models were tested using HLQ data to assess the internal structure in the current sample, one including a higher order overall health literacy factor and one without. Factor analyses were conducted in Mplus Version 8 using full information maximum likelihood estimation technique. The models were highly restricted in that item cross-loadings and correlations amongst residuals were not permitted. RMSEA, CFI and TLI statistics were used to assess model fit as Chi Square tests tend to be over-sensitive to large sample sizes; RMSEA values of $<.07$ and CFI/TLI values $\geq .90$ indicating good fit⁽²⁸⁾. Cronbach's alpha statistics were calculated to test the internal reliability of each scale. No patterns were evident in missing data analysis. Missing HLQ and SF-36 were imputed with subscale means in cases where $< 50\%$ items in the subscale were missing. Where participants had $> 50\%$ items missing in any one subscale ($n= 24$), they were excluded from regression analyses in a pairwise manner. Linear regression models conducted in SPSS Version 23 tested the strength of associations between each of the nine HLQ factors and physical and mental health status controlling for age, relationship status, SES and education; factors that shared variance with both the HLQ and SF-36 subscales in preliminary analyses. To reduce the probability of a Type I error when running multiple analyses, a false discovery rate adjustment was applied to significance values, which adjusts p-values based on the expected proportion of family-wise error from k analyses⁽²⁹⁾. Standardized beta weights were plotted and compared for statistically significant differences using a Fisher's r to z transformation for comparing parameter estimates⁽³⁰⁾.

Results

Confirmatory Factor Analysis

Model fit statistics for the restricted nine factor model without a higher order factor suggested that the model was a reasonably good fit. Although, comparative and normative indices were just below the .90 cut off (CFI = 0.853, TLI = 0.839), the RMSEA (0.069, CI= 0.066 – 0.072) indicated the model fit the data well. All fit indices matched closely to those reported alongside the initial development of the scale, CFI = 0.936, TLI = 0.930, RMSEA = 0.076⁽⁷⁾. Chi Square comparisons between models with χ^2 (866) = 3181.46, $p < 0.0001$ and without χ^2 (893) = 3764.76, $p < 0.0001$ the higher order factor suggested that removing the higher order factor led to significantly better model fit ($p < 0.01$). As shown in [Table 2](#), item loadings on each factor were high (all $b_s > 0.60$, $p_s < 0.01$) and very little deviance was evident in item loadings on each factor from those reported earlier^(7, 9, 10) demonstrating sound structural stability in this sample. Cronbach's alpha statistics for sub-scales were all above 0.80 (except for 5) Appraisal of health information $\alpha = 0.78$), indicating high internal reliability. The inter-factor correlation matrix largely demonstrates discrimination between factors with most coefficients between 0.40 and 0.60, demonstrating very good discrimination between most of HLQ scales. However, high correlations were observed between 6) Active engagement with health providers, 7) Navigating the health care system, 8) Ability to find good health information and 9) Understanding health information (all $r_s > 0.75$, $p_s < 0.01$).

[\[insert Table 2\]](#)

Regression analyses

[Table 3](#) presents the current sample means and standard deviations alongside the standardized regression coefficient between each of the HLQ scales and mental and physical health status scales, controlling for age, SES, relationship status, and education level. A comparison of mental ($M = 41.60$, $SD = 11.72$) and physical health ($M = 49.78$, $SD = 10.14$) t-

score means suggests that the current sample reported significantly larger deviance from male 64-75 population norms on mental compared to physical health status, $t(559) = 14.31, p < 0.01$). Regression analyses showed the strongest associations were between mental health status and HLQ scales, specifically with 4) Social support for health, 6) Active engagement with healthcare providers, 7) Navigating the healthcare system, 8) Ability to find good health information, and 9) Understanding health information well enough to know what to do (all $b > 0.250, p < 0.01$). Furthermore, 2) Having sufficient information to manage my health, 3) Active engagement with healthcare providers, 7) Navigating healthcare system and 8) Ability to find good health information were also associated with physical health status, but weakly so (all $b < 0.200, p < 0.01$). The HLQ scales 3) Actively managing my health and 5) Appraisal of health information did not share any significant association with either mental or physical health status ($p > 0.01$).

[\[insert table 3\]](#)

[Figure 1](#) visually depicts the relative difference in strength of association between each HLQ subscale and mental and physical health statuses, with variables above the diagonal line sharing stronger associations with mental health than physical health status. Z-score comparison of standardized beta weights confirmed that 4) Social support for health ($z = 4.36, p < 0.01$), 6) Ability to actively engage with healthcare providers ($z = 3.68, p < 0.01$), Navigating the healthcare system ($z = 3.98, p < 0.01$), 8) Ability to find good health information ($z = 2.50, p < 0.01$), 9) Understanding health information well enough to know what to do ($z = 3.15, p < 0.01$) and 1) Feeling understood and supported by healthcare providers ($z = 2.80, p < 0.01$) were significantly more strongly associated with mental health status than they were with physical health status.

[\[insert Figure 1\]](#)

Discussion

Findings from the current study provide two key contributions to our understanding of health literacy and health outcomes in men with prostate cancer. Firstly, the HLQ maintains structural stability, internal reliability, as well as convergent and discriminant validity as multidimensional measure of health literacy in this population. It also demonstrates associations with health-related quality of life outcomes, particularly those pertaining to mental health. Secondly, health literacy skills that facilitate access and engagement with health services and providers are associated with better mental health-related quality of life.

Previous literature supports the validity and reliability of the HLQ as a sound multidimensional measure of health literacy in a variety of contexts ⁽⁷⁻¹²⁾. Based on current findings the psychometric properties of the measure remain stable and can confidently be extended to prostate cancer samples and potentially to other cancer, chronic disease, and older all-male samples. Interestingly, a higher order “health literacy” factor did not improve the fit of the data, suggesting that, in the current context at least, the nine-factors may not reflect a subset of dimensions underlying a latent “health literacy” construct, but rather they may represent a set of distinct constructs in and of themselves. In saying this, correlations between scales that measured participant level of difficulty with an activity, as opposed to those measuring level of agreement with a statement, were almost all <0.90 in the current sample; a typical finding in reports of HLQ psychometrics properties ^(7, 9). This potentially suggests that refining and/or combining these scales into one “difficulty utilizing health services” may be suitable. However, previous variable content analysis, and the different patterns of strengths and weaknesses that have been observed in practice settings suggest that the individual scales provide valuable information for research and clinical teams ^(31, 32).

It is well established that men with prostate cancer experience reduced physical and emotional well-being ⁽¹⁷⁻²⁰⁾. Average mental health t-scores in this sample reflect this, indicating that men with prostate cancer fare less well in mental health status compared to

healthy males of a similar age. Consequently, it is a promising finding that several health literacy skills may help to improve the mental and emotional well-being in men with prostate cancer. Skills in navigating health care systems and engaging with different forms of support were moderately associated with mental health-related quality of life; the strongest association being between active engagement with providers and mental health status. This finding is in line with a well-established body of evidence showing that people who report positive interactions with health care providers experiences better health outcomes⁽³³⁾. Educating and assisting men to seek and engage effectively with appropriate health services might, therefore, facilitate improvements in emotional distress, social connections and interpersonal relationships so often negatively impacted by a prostate cancer diagnosis. Health literacy skills such as the ability to appraise information and to actively pursue the management of one's own health, were not associated with health status in the current study. Self-reliance and avoidance are common barriers to men seeking support for sensitive issues related to prostate cancer (i.e., bowel, urinary and sexual dysfunction)⁽³⁴⁾ and our findings could potentially support the notion that the autonomy involved in self-care is not as conducive to improvements in mental health as skills that involve working together effectively with health providers.

Very few domains of the HLQ shared more than a small positive association with physical health-related quality of life. Similar findings were evident in a study using a measure of health literacy based largely on reading ability⁽²²⁾. In this study, higher scores on the Rapid Estimate of Adult Literacy in Medicine (REALM) were associated with mental, but not physical outcomes in (n=1531) men with prostate cancer⁽²²⁾. Health literacy skills may not be as important in determining physical health-related quality of life given that management of physical symptoms (e.g., pain and discomfort) tends to be embedded in standard medical care⁽³⁵⁾ whereas management of emotional symptoms may not be. Thus,

improving health literacy skills may not prove to be substantially beneficial in relieving physical symptoms and side effects of prostate cancer and its treatment.

Clinical Implications

Our findings support calls for the assessment of health literacy as a common practice in health care settings ⁽²⁴⁾ as well as an increased focus on the mental and emotional well-being of men with prostate cancer in treatment settings ⁽³⁶⁾. Several studies have shown that a substantive subgroup of men diagnosed with prostate cancer experience heightened psychological distress that for some persists over the long term ^(36, 37). A recent systematic review concluded cognitive behavioral and psycho-educational interventions were effective in improving men's psychosocial outcomes after prostate cancer ⁽³⁸⁾. Furthermore, patient navigation interventions that provide the knowledge and skills required to engage effectively with healthcare services have been a successful in improving early cancer detection, treatment and survival ^(39, 40). The present results also suggest that strategies that empower men with the skills and self-efficacy to seek appropriate support and discuss sensitive issues associated with their experiences following treatment are indicated.

Study limitations

Although there is some theory to support a casual pathway between health literacy and outcomes ^(23, 24), it is plausible that good health actually facilitates one's ability to access and engage effectively with health providers. In reality, it might be that the relationship is cyclical in nature, however, our findings are based on cross-sectional research and therefore causality cannot be assumed. Although our finding provide a strong basis for further enquiry, longitudinal or experimental work is needed to establish casual pathways between health literacy and health outcomes in men with prostate cancer. The consent rate in the current study was low (23%). Given that capacity to respond to surveys is potentially higher for those with better health and more likely if patients are willing to engage with health service and

information, we advise caution when generalizing the associations reported here due to potential selection bias. Nevertheless, distributions in the current study indicate participants with a comprehensive range of scores on health literacy and health status variables were captured.

Conclusion

The current study provides psychometrically robust evidence in support of the HLQ as a measure of health literacy in men with prostate cancer. Several specific subscales may be particularly useful in predicting mental health related quality of life and this may be helpful both in identifying those men that may need more in depth intervention and support as well as guiding the development of such interventions. Although further research is required to establish causality, interventions that aim to improve skills in connecting and effectively communicating with health care services and providers might lead to better mental health outcomes for men with prostate cancer.

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Conflicts of Interest

The authors have no conflicts of interest to declare.

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Table 1. Participant characteristics (n=565)

	%	n
Income		
\$0 – 19,999	14.7%	83
\$20,000 - 39,999	30.4%	172
\$40,000 – 59,999	17.0%	96
\$60,000 – 79,999	10.4%	59
\$80,000 +	11.9%	67
Did not answer	15.4%	87
Disadvantage		
1 st quintile (lowest)	18.2%	102
2 nd quintile	18.6%	104
3 rd quintile	20.2%	113
4 th quintile	28.8%	161
5 th quintile (highest)	14.3%	80
Education		
No formal education or incomplete primary school	1.2%	7
Primary school	9.7%	55
Junior high school	20.4%	115
Senior high school	13.6%	77
Trade or technical certificate or diploma	35.4%	200
University or college degree	18.6%	105
Relationship status		
Married	77.7%	439
De facto	3.7%	21
Separated or divorced	8.5%	48
Widowed	6.0%	34
Never married	2.5%	14
Treatment type[†]		
Radical prostatectomy	57.0%	322
External beam radiation	34.5%	195
Hormone therapy	27.1%	153
Orchidectomy	1.8%	10
Active surveillance	3.0%	17
Watchful waiting	3.9%	22
Brachytherapy	9.7%	55
Other treatment	5.5%	31

†Participant could select more than one treatment option.

Table 2. HLQ item loadings and internal reliability for each scale in the nine-factor confirmatory factor analysis model

Item*	<i>b</i>	SE	<i>a</i>
1) Feeling understood and supported by healthcare providers			0.87
I have at least one healthcare provider who...	0.736	0.022	
I have at least one healthcare provider I can...	0.858	0.015	
I have the healthcare providers I need...	0.765	0.021	
I can rely on at least one healthcare provider	0.875	0.014	
2) Having sufficient information to manage my health			0.80
I feel I have good information about health	0.535	0.035	
I have enough information to deal...	0.772	0.022	
I am sure I have all the information I need...	0.767	0.022	
I have all the information I need to...	0.821	0.020	
3) Actively managing my health			0.80
I spend quite a lot of time actively managing...	0.542	0.034	
I make plans for what I need to do to be...	0.755	0.024	
Despite other things in my life, I take time...	0.777	0.022	
I set my own goals about health and fitness	0.570	0.033	
There are things that I do regularly...	0.756	0.024	
4) Social support for health			0.82
I can get access to several people who understand and support me	0.700	0.026	
When I feel ill, the people around me really understand...	0.662	0.028	
If I need help, I have plenty of people I...	0.826	0.019	
I have at least one person who can come to medical appointments with me	0.560	0.033	
I have strong support from...	0.731	0.024	
5) Appraisal of health information			0.78
I compare health information from different sources	0.657	0.030	
When I see new information about health...	0.668	0.031	
I always compare health information from different sources...	0.723	0.028	
I know how to find out if the health information...	0.602	0.034	
I ask healthcare providers about the quality...	0.609	0.034	
6) Ability to actively engage with healthcare providers			0.91
Make sure that healthcare providers understand...	0.835	0.015	
Feel able to discuss your health concerns with a healthcare provider	0.801	0.017	
Have good discussions about your health with doctors	0.811	0.016	
Discuss things with healthcare providers until...	0.825	0.015	
Ask healthcare providers questions to get...	0.851	0.014	

Item	<i>b</i>	SE	<i>a</i>
7) Navigating the health care system			0.90
Find the right health care	0.735	0.021	
Get to see the healthcare providers I need to	0.742	0.021	
Decide which healthcare provider you need...	0.824	0.016	
Decide which healthcare provider you need ...	0.864	0.013	
Find out what healthcare services you are...	0.728	0.022	
Work out what the best care is for you	0.756	0.020	
8) Ability to find good health information			0.88
Find information about health problems	0.755	0.020	
Find health information from several...	0.760	0.020	
Get information about health so you are...	0.747	0.021	
Get health information in words you understand	0.813	0.016	
Get health information by yourself	0.768	0.019	
9) Understanding health information well enough to know what to do			0.85
Confidently fill medical forms in the correct way	0.713	0.024	
Accurately follow the instructions from...	0.616	0.029	
Read and understand written health information	0.842	0.016	
Read and understand all the information...	0.763	0.021	
Understand what healthcare providers are...	0.759	0.021	

* Items are truncated. Full items are available from the authors.

Table 3. Means, standard deviations and regression coefficients between HLQ factors and mental and physical health from the SF-36.

HLQ sub-scale		SF36 Physical Health (<i>t</i> -scores)	SF36 Mental Health (<i>t</i> -scores)
	Mean (SD) →	49.78 (10.14)	41.60 (11.72)
	Mean (SD)	<i>b</i>	<i>b</i>
1) Feeling understood and supported by healthcare providers	3.12 (0.47)	0.027	0.194*
2) Having sufficient information to manage my health	2.89 (0.45)	0.184*	0.177*
3) Actively managing my health	2.93 (0.41)	0.099	0.076
4) Social support for health	3.00 (0.46)	0.020	0.277*
5) Appraisal of health information	2.83 (0.44)	-0.004	0.021
6) Ability to actively engage with healthcare providers	4.02 (0.57)	0.164*	0.370*
7) Navigating health care system	3.93 (0.54)	0.126*	0.352*
8) Ability to find good health information	3.89 (0.56)	0.161*	0.308*
9) Understanding health information well enough to know what to do	4.04 (0.52)	0.105	0.288*

* = significant at $p < 0.01$ with False Discovery Rate adjustment

*Significantly different beta weights for mental and physical health ($p < .01$)

Figure 1. Scatterplot of standardized beta weights comparing strength of associations between each HLQ factor and mental and physical health