



Published in final edited form as:

J Cancer Educ. 2019 June ; 34(3): 441–445. doi:10.1007/s13187-018-1320-1.

Prostate Cancer Patients' Understanding of the Gleason Scoring System: Implications for Shared Decision Making

Erin K. Tagai, PhD, MPH¹, Suzanne M. Miller, PhD¹, Alexander Kutikov, MD¹, Michael A. Diefenbach, PhD², Ronak A. Gor, DO¹, Tahseen Al-Saleem, MD¹, David Y.T. Chen, MD¹, Sara Fleszar², and Gem Roy, MD¹

¹Fox Chase Cancer Center/Temple University Health System, 333 Cottman Ave, Philadelphia, PA, 19111, USA

²Northwell Health System, 300 Community Drive, Manhasset, NY, 11030, USA

Abstract

The Gleason scoring system is a main component of a prostate cancer diagnosis. It also serves as a risk communication tool that facilitates shared treatment decision making. However, the system is highly complex and therefore difficult to communicate; factors which have been shown to undermine well-informed and high-quality shared treatment decision making. To systematically explore prostate cancer patients' understanding of the Gleason scoring system (GSS), we assessed knowledge and perceived importance among men who had completed treatment (N = 50). Patients were administered a cross-sectional survey that assessed patient knowledge and patients' perceived importance of the GSS, as well as demographics, medical factors (e.g., Gleason score at diagnosis), and health literacy. Bivariate analyses were conducted to identify associations with patient knowledge and perceived importance of the GSS. The sample was generally well-educated (48% with a bachelor's degree or higher), and health literate ($M = 12.9$, $SD = 2.2$, range = 3–15). Despite this, fewer than 50% had adequate knowledge of the GSS. Patients' perceived understanding of the importance of the GSS was moderate ($M = 2.8$, $SD = 1.0$, range = 0–4) and was significantly associated with GSS knowledge ($p < .01$). Additionally, GSS knowledge was negatively associated with years since biopsy ($p < .05$). Age and health literacy were positively associated with patients' perceived importance of the GSS ($ps < .05$), but not with GSS knowledge. Patient knowledge is thus less than optimal and could benefit from enhanced communication to maximize shared treatment decision making. Future studies are needed to explore the potential utility of a simplified Gleason grading system.

Keywords

Gleason scoring system; Prostate cancer; Shared decision making

Introduction

Prostate cancer patients typically have challenging decisions to make regarding their treatment options and are encouraged to engage in shared decision making with their providers [1]. One component of the decision making process is a patients' Gleason score, which is intended to facilitate risk communication and enhance quality treatment decision making [2]. The Gleason scoring system (GSS) is based on objectification of glandular de-differentiation [3]. The system quantifies a primary and secondary histologic pattern (each graded 1 through 5; grades 1 and 2 are classified as benign lesions) and the two patterns are summed together and reported as the Gleason sum (e.g., 3+3=6, 4+3=7). Gleason sums 6 and 7 are globally considered as low and intermediate risk, respectively, while Gleason sums 8 or higher are regarded as high risk [4]. The GSS has undergone several revisions [5, 6], resulting in a more concordant reporting system between pathologic findings on biopsy and final pathologic specimens [7].

Patient-provider communication is vital to patients' comprehension of their disease, as well as their long-term quality of life [8]. However, providers struggle to effectively communicate the significance of the GSS to prostate cancer patients, creating barriers for quality patient treatment decision making [9]. Patient interviews suggest prostate cancer patients are confused and uncertain as to how to apply their Gleason score to clinical decisions [9]. Barriers to effective comprehension likely stem, in large part, from unnecessary complexities within the GSS (e.g., Gleason score less than 6 is considered benign) [9]. As such, it is important to quantify patient deficits in their understanding of the GSS in order to identify teachable moments for both streamlining provider communication and improvements in patient comprehension.

To systematically explore patient understanding, we conducted a quantitative survey of prostate cancer patients who had completed treatment to assess (a) patients' knowledge of the GSS; (b) patients' perceived importance of the GSS; and (c) the relationship between demographic, medical factors, and health literacy with GSS knowledge and perceived importance.

Materials and Methods

Participants and procedure

Attending urologic oncology providers at Fox Chase Cancer Center (FCCC) recruited prostate cancer patients during a routine clinic visit post-treatment. Patients were eligible if they were between the ages of 40 and 80, had been diagnosed with prostate cancer at FCCC or an outside institution and referred to FCCC for care, able to communicate in English, and be competent to consent. After providing written consent, eligible patients completed a print questionnaire that took approximately 15 minutes to complete. Patients unable to complete the questionnaire while at the clinic were able to complete the questionnaire at home and were provided a pre-addressed and stamped envelope. The FCCC Institutional Review Board approved this study.

Measures

Demographic and background variables—Demographic variables were assessed via self-report on the questionnaire and included age, race/ethnicity, marital status, and education. Medical background variables were abstracted from patients' charts and included biopsy date, Gleason score at diagnosis, PSA score at diagnosis, stage of cancer at diagnosis, and treatment type. Anxiety was assessed using the Memorial Anxiety Scale for Prostate Cancer subscales: general prostate cancer anxiety (11 items), PSA anxiety (3 items), and fear of recurrence anxiety (4 items). Each item was scored on a 4-point Likert-type scale and were recoded to indicated clinically significant anxiety by multiplying each scale score by 1.5 [10]. Health literacy was assessed using a validated 3-item scale measured on a 5-point Likert-type scale [11]. The three items were summed to create a total score with greater scores indicating greater health literacy.

Gleason scoring system knowledge and perceived importance—GSS knowledge was scored using an author-constructed 4-item scale assessing patient knowledge about the 2005 ISUP Gleason scoring system [6]. Sample items include “Which cancer is more aggressive: $4 + 3 = 7$, $3 + 4 = 7$, or *are both are the same?*” and “Gleason Score $4+4=8$ is considered: *low, intermediate, or high risk?*” Each item was recoded to correct (1) or incorrect (0) and a total score was calculated with a maximum score of 4. The scale demonstrated acceptable reliability ($\alpha = .72$). Patients' perceived importance of the GSS was assessed using an author-constructed 5-item scale. Items were scored on a 5-point Likert type scale and a mean scale score was calculated. Sample items include “My doctor's explanation of the Gleason system made sense to me” and “My understanding of my Gleason score has significantly impacted my treatment decision.” The scale demonstrated acceptable reliability ($\alpha = .79$).

Data analyses

Descriptive statistics (e.g., frequencies, means) were calculated for all variables using SPSS version 24.0 (SPSS, Inc., Chicago, IL). Variables were assessed for normality using the Shapiro-Wilk test. Bivariate associations were then tested between demographic and background variables with GSS knowledge and perceived importance. Bivariate analyses were completed using the Mann-Whitney U, Kruskal-Wallis, and Spearman's rho tests.

Results

A total of 50 eligible patients completed the questionnaire. Patients had a mean age of 63.5 ($SD = 7.5$), were predominantly white (75.0%), married (86.0%), and 48.0% had a bachelor's degree or higher (Table 1). Additionally, patients had a relatively high mean health literacy score of 12.9 ($SD = 2.2$), out of a possible maximum score of 15. The majority of patients had a Stage II cancer diagnosis (74%) with a mean Gleason score of 7.0 ($SD = 0.9$) and a mean PSA score of 6.1 ($SD = 3.4$) at diagnosis. All patients were undergoing follow-up with their treating urologic oncologist and were a mean 3.6 years ($SD = 3.2$) from the date of their prostate cancer diagnosis. Of note, 3 patients (6%) have clinically significant PSA anxiety, 22% have general prostate anxiety and 86% have clinically significant fear of recurrence. Patients had strikingly low knowledge of the GSS,

with a mean score of 1.8 out of a possible 4.0 ($SD = 1.4$). Only 32.0% of patients scored greater than 50.0% on the GSS knowledge scale. Similarly, the mean scale score of patient perceived importance of the GSS was moderately low ($M = 2.8$, $SD = 1.0$, range = 0–4).

Significant bivariate associations were found with GSS knowledge and perceived importance (Table 2). GSS knowledge and patient perceptions of GSS were significantly associated [$r_s(48) = .488$, $p < .01$]. Health literacy was significantly associated with patient perceived importance of the GSS [$r_s(48) = .399$, $p < .01$], however health literacy was not significantly associated with GSS knowledge [$r_s(48) = .190$, $p > .05$]. Lastly, age was positively associated with perceived importance of the GSS [$r_s(48) = .336$, $p < .05$] and Gleason score at diagnosis [$r_s(47) = .491$, $p < .01$].

Discussion

While a patients' Gleason score is a critical part of the decision making process for prostate cancer treatment, many patients are confused about the meaning of their score [9]. Despite revisions over the past 50 years, providers still struggle to describe and convey the meaning of the GSS to patients [9]. Our study findings demonstrate that even among prostate cancer patients undergoing routine post-treatment active monitoring, with high educational attainment and health literacy, the majority have low knowledge about the GSS. Additionally, patients expressed moderate perceived importance of the GSS. GSS knowledge was positively associated with patients' perceived importance of the GSS, suggesting that individuals who have a better understanding of how their Gleason score is calculated have a greater understanding of how important their Gleason score is when making treatment decisions with their providers.

Health literacy was positively related to perceived importance of the GSS, indicating that patients who have greater capacity to understand health information are better able to understand the importance of their Gleason score when making treatment decisions. However, while health literacy was significantly associated with perceived importance, it was not significantly related to GSS knowledge. Thus, even patients with high health literacy have difficulty understanding the GSS. While providers are well-intentioned in their communication interactions with patients, it is typically difficult to identify patients with low health literacy [12]. Further, patients are often unwilling to disclose their limitations in understanding health information [13]. Accurate assessment of patients' grasp of disease severity is especially critical in an era when efforts to enroll patients into active surveillance protocols are crucial for minimizing prostate cancer overtreatment, but are hindered by patient confusion [14].

Only one significant association was identified between perceived importance of the GSS and background factors, notably age. Age was positively associated with perceived importance of the GSS but was not significantly related to GSS knowledge. Despite low GSS knowledge, older prostate cancer patients understand the importance of their Gleason score in their treatment decision making. This relationship needs to be further investigated to understand the relationship between age and perceptions of the GSS. Age was also associated with patients' Gleason score at diagnosis, which is consistent with previous

research [15]. There were no significant associations between knowledge and background factors. Further, while not significantly associated with knowledge or perceived importance of the GSS, 43 patients (86%) have clinically significant fear of cancer recurrence in spite of the fact they received adequate treatment.

Limitations include the small sample size and retrospective study design. However, the study findings suggest that even patients who have years of experience managing prostate cancer diagnoses are still confused about the GSS. Additionally, the study was conducted with a patient population at a comprehensive cancer center, limiting its generalizability to other clinical settings. Further, the patient population is fairly well educated and has low diversity in terms of racial/ethnic groups. Future research should assess a larger, more diverse patient population over time to assess changes in patient understanding and its relationship with treatment decision making. Lastly, the GSS was not examined alongside other decision making factors (see [16]) that may impact treatment decision making. Further research is needed to examine how the GSS and other decision making factors interact and impact shared treatment decision making for prostate cancer.

To help simplify the GSS and reduce confusion and fear for patients [17], recent revisions to the system were proposed and accepted at the 2014 ISUP Consensus Conference [18] and accepted by the World Health Organization in 2016 [19]. The revisions not only updated the grading of Gleason patterns (e.g., regardless of morphology, all cribriform glands are assigned a Gleason pattern 4), but also revised the prognostic scoring system by dividing it into a five-grade group system [18]. The new five-grade group system may help increase clarity for patients and providers [20]. Despite adoption by the ISUP [18] and WHO [19], and the potential for reduced confusion in treatment decision making [20], the new five-grade group system has yet to enjoy wide-spread adoption. Future work is needed to determine if this new system results in better patient comprehension and understanding, and how this simplified system, in turn, impacts treatment decision making.

Currently, many urologists explain to patients the prognostic implications of their Gleason score similar to what is adopted in the new system. In the present study, most patients understood the importance of the GSS in the treatment decision making process, but the majority of patients were still confused about their Gleason score. As patients are increasingly encouraged to participate in shared decision making with their providers [1], the study findings underscore the importance in providers clearly communicating to the patient how their Gleason score is calculated and what that score indicates. To effectively convey the GSS to their patients, providers should be sensitized to communication skills that enhance prostate cancer patients' understanding of vital health information [21]. Providers who are attentive to these issues initiate more patient-centered communication that can help facilitate patients' understanding of critical health information [22]. While decision aids have shown promise in facilitating treatment decision making [23], few have incorporated the GSS. Existing decision aids that have incorporated the GSS have not yet been tested for efficacy [24, 25]. The findings presented here dovetail with the need for a new system; however, further validation studies are needed to determine if the new system is able to deliver more comprehensible patient information, streamlines the communication process

between providers and patients, and ultimately results in higher quality decision making and care.

References

1. Mohler James L., Armstrong Andrew J., Bahnson Robert R., D'Amico Anthony Victor, Davis Brian J., Eastham James A., Enke Charles A. et al. 2016 Prostate Cancer, Version 1.2016. Journal of the National Comprehensive Cancer Network 14 (1):19–30. [PubMed: 26733552]
2. Helpap B, and Egevad L. 2006 The significance of modified Gleason grading of prostatic carcinoma in biopsy and radical prostatectomy specimens. Virchows Arch 449 (6):622–627. doi:10.1007/s00428-006-0310-6. [PubMed: 17091254]
3. Mellinger, George T, Gleason D, and Bailar J 3rd. 1967 The histology and prognosis of prostatic cancer. The Journal of urology 97 (2):331. [PubMed: 6018430]
4. McDougal W Scott, Wein Alan J, Kavoussi Louis R, Novick Andrew C, Partin Alan W, Craig A Peters, and Ramchandani Parvati. 2011 Campbell-Walsh Urology 10th Edition Review. Elsevier Health Sciences.
5. Gleason Donald F, and George T Mellinger. 1974 Prediction of prognosis for prostatic adenocarcinoma by combined histological grading and clinical staging. The Journal of urology 111 (1):58–64. [PubMed: 4813554]
6. Epstein JI, Allsbrook WC Jr., Amin MB, Egevad LL, and Isup Grading Committee. 2005 The 2005 International Society of Urological Pathology (ISUP) Consensus Conference on Gleason Grading of Prostatic Carcinoma. Am J Surg Pathol 29 (9):1228–1242. [PubMed: 16096414]
7. Ozok Hakki Ugur, Sagnak Levent, Tuygun Can, Oktay Murat, Karakoyunlu Nihat, Ersoy Hamit, and Alper Murat. 2009 Will the modification of the Gleason grading system affect the urology practice? International journal of surgical pathology.
8. Ernstmann N, Weissbach L, Herden J, Winter N, and Ansmann L. 2016 Patient-physician-communication and health related quality of life of localized prostate cancer patients undergoing radical prostatectomy - a longitudinal multilevel analysis. BJU Int. doi:10.1111/bju.13495.
9. Han PK, Hootsmans N, Neilson M, Roy B, Kungel T, Gutheil C, Diefenbach M, and Hansen M. 2013 The value of personalised risk information: a qualitative study of the perceptions of patients with prostate cancer. BMJ Open 3 (9):e003226. doi:10.1136/bmjopen-2013-003226.
10. Roth A, Nelson CJ, Rosenfeld B, Warshowski A, O'Shea N, Scher H, Holland JC et al. 2006 Assessing anxiety in men with prostate cancer: further data on the reliability and validity of the Memorial Anxiety Scale for Prostate Cancer (MAX-PC). Psychosomatics 47 (4):340–347. doi: 10.1176/appi.psy.47.4.340. [PubMed: 16844894]
11. Chew LD, Bradley KA, and Boyko EJ. 2004 Brief questions to identify patients with inadequate health literacy. Fam Med 36 (8):588–594. [PubMed: 15343421]
12. Seligman HK, Wang FF, Palacios JL, Wilson CC, Daher C, Piette JD, and Schillinger D. 2005 Physician notification of their diabetes patients' limited health literacy. A randomized, controlled trial. J Gen Intern Med 20 (11):1001–1007. doi:10.1111/j.1525-1497.2005.00189.x. [PubMed: 16307624]
13. Parikh NS, Parker RM, Nurss JR, Baker DW, and Williams MV. 1996 Shame and health literacy: the unspoken connection. Patient Educ Couns 27 (1):33–39. [PubMed: 8788747]
14. Loeb S, Bruinsma SM, Nicholson J, Briganti A, Pickles T, Kakehi Y, Carlsson SV, and Roobol MJ. 2015 Active surveillance for prostate cancer: a systematic review of clinicopathologic variables and biomarkers for risk stratification. Eur Urol 67 (4):619–626. doi:10.1016/j.eururo.2014.10.010. [PubMed: 25457014]
15. Muralidhar V, Ziehr DR, Mahal BA, Chen YW, Nezoslosky MD, Viswanathan VB, Choueiri TK, Sweeney CJ, Trinh QD, and Nguyen PL. 2015 Association Between Older Age and Increasing Gleason Score. Clin Genitourin Cancer 13 (6):525–530.e521–523. doi:10.1016/j.clgc.2015.05.007. [PubMed: 26119229]
16. Ross LE, Howard DL, Bowie JV, Thorpe RJ Jr., Kinlock BL, Burt C, and LaVeist TA. 2016 Factors Associated with Men's Assessment of Prostate Cancer Treatment Choice. J Cancer Educ 31 (2): 301–307. doi:10.1007/s13187-015-0837-9. [PubMed: 25893926]

17. Epstein JI, Zelefsky MJ, Sjoberg DD, Nelson JB, Egevad L, Magi-Galluzzi C, Vickers AJ et al. 2016 A Contemporary Prostate Cancer Grading System: A Validated Alternative to the Gleason Score. *Eur Urol* 69 (3):428–435. doi:10.1016/j.eururo.2015.06.046. [PubMed: 26166626]
18. Epstein JI, Egevad L, Amin MB, Delahunt B, Srigley JR, and Humphrey PA. 2016 The 2014 International Society of Urological Pathology (ISUP) Consensus Conference on Gleason Grading of Prostatic Carcinoma: Definition of Grading Patterns and Proposal for a New Grading System. *Am J Surg Pathol* 40 (2):244–252. doi:10.1097/pas.0000000000000530. [PubMed: 26492179]
19. Humphrey PA, Moch H, Cubilla AL, Ulbright TM, and Reuter VE. 2016 The 2016 WHO Classification of Tumours of the Urinary System and Male Genital Organs-Part B: Prostate and Bladder Tumours. *Eur Urol* 70 (1):106–119. doi:10.1016/j.eururo.2016.02.028. [PubMed: 26996659]
20. Magi-Galluzzi C, Montironi R, and Epstein JI. 2016 Contemporary Gleason grading and novel Grade Groups in clinical practice. *Curr Opin Urol* 26 (5):488–492. doi:10.1097/mou.0000000000000320. [PubMed: 27308734]
21. Davis Terry C., Williams Mark V., Marin Estela, Parker Ruth M., and Glass Jonathan. 2002 Health Literacy and Cancer Communication. *CA Cancer J Clin* 52 (3):134–149. doi:10.3322/canjclin.52.3.134. [PubMed: 12018928]
22. Street RL Jr., Gordon H, and Haidet P. 2007 Physicians' communication and perceptions of patients: is it how they look, how they talk, or is it just the doctor? *Soc Sci Med* 65 (3):586–598. doi:10.1016/j.socscimed.2007.03.036. [PubMed: 17462801]
23. Stacey D, Legare F, Lewis K, Barry MJ, Bennett CL, Eden KB, Holmes-Rovner M et al. 2017 Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 4:Cd001431. doi:10.1002/14651858.CD001431.pub5.
24. Colella KM, and DeLuca G. 2004 Shared decision making in patients with newly diagnosed prostate cancer: a model for treatment education and support. *Urol Nurs* 24 (3):187–191, 195–186. [PubMed: 15311487]
25. Kaplan AL, Crespi CM, Saucedo JD, Connor SE, Litwin MS, and Saigal CS. 2014 Decisional conflict in economically disadvantaged men with newly diagnosed prostate cancer: baseline results from a shared decision-making trial. *Cancer* 120 (17):2721–2727. doi:10.1002/cncr.28755. [PubMed: 24816472]

Table 1.

Patient characteristics (N=50)

Variable	N (%) or M (SD)
Age	63.5 (7.5)
Race/ethnicity	
White	37 (74.0)
Other ^a	13 (26.0)
Marital status	
Married	43 (86.0)
Other	7 (14.0)
Education	
High school diploma	14 (28.0)
Some college	12 (24.0)
Bachelor's degree	16 (32.0)
Graduate degree	8 (16.0)
Years since date of biopsy ^b	3.6 (3.2)
Gleason score at diagnosis ^b	7.0 (0.9)
PSA score at diagnosis ^c	6.1 (3.4)
Stage of cancer at diagnosis ^d	
Stage I	5 (10.4)
Stage II	36 (75.0)
Stage III	7 (14.6)
Treatment type	
Prostatectomy	42 (84.0)
Radiation	4 (8.0)
Prostatectomy + radiation	2 (4.0)
Active surveillance	2 (4.0)
General prostate cancer anxiety	
Yes	11 (22.0)
No	39 (78.0)
PSA anxiety	
Yes	3 (6.0)
No	47 (94.0)
Fear of recurrence	
Yes	43 (86.0)
No	7 (14.0)
Health literacy (max score = 15)	12.9 (2.2)
GSS knowledge (max score = 4)	1.8 (1.4)
Perceived importance of the GSS (mean scale score)	2.8 (1.0)

Note: PSA = Prostate Specific Antigen. GSS = Gleason scoring system.

^aRacial/ethnic groups (Non-Hispanic Black=10, Asian=2, Hispanic = 1) collapsed into "other" due to low sample size

^bN=49

^cN=43

^dN=48

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 2.

Correlations of prostate cancer patients' knowledge and perceptions of the Gleason Scoring System

	1	2	3	4	5
1. Age	–				
2. Gleason score	.491 **	–			
3. Health literacy	.218	.142	–		
4. GSS knowledge	–.055	.040	.190	–	
5. Perceived importance of the GSS	.336 *	.218	.399 **	.488 **	–

Note: Only variables with at least one significant association are shown. GSS = Gleason Scoring System

* $p < .05$

** $p < .01$