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Perspectives of Prostate Cancer Patients on Gleason Scores and the New Grade Groups: Initial Qualitative Study

Stacy Loeb^{a,b,c}, Caitlin Curnyn^b, and Erica Sedlander^b

^aDepartment of Urology, New York University, New York, NY, USA

^bPopulation Health, New York University, New York, NY, USA

^cLaura and Isaac Perlmutter Cancer Center, New York University, New York, NY, USA

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The original Gleason grading system devised in the 1960s assigned architectural patterns into five groups [1]. The most common and second most common were combined into a score ranging from $1 + 1 = 2$ to $5 + 5 = 10$. There have since been several modifications to the Gleason grading system, resulting in a significant grade migration. Currently, the lowest score is a Gleason 6, and it has been suggested that this may make patient counseling difficult and reduce the uptake of active surveillance (AS), as it may not sound like “low-grade” disease [2].

Epstein et al. [3] recently proposed an alternative system using grade groups (GGs) 1–5, indicating Gleason 6, 3 + 4, 4 + 3, 8, and 9–10, respectively. Although the new GGs have been validated to predict biochemical recurrence [4], to our knowledge no study has explored patient preferences about Gleason grading and whether the new GGs actually increase patient comfort with AS. With the adoption of these GGs by the World Health Organization and the International Society of Urological Pathology [5], an understanding of patient perceptions is essential. Overall, patient perspectives on Gleason grading have received little study to date. A systematic PubMed search on “qualitative” or “focus groups” AND “Gleason” or “prostate cancer grade” yielded 102 unique results. After excluding based on title ($n = 100$) and full-text review ($n = 2$), we found no qualitative data on patients’ impressions of Gleason grading.

We conducted seven focus groups with prostate cancer patients from two clinical settings between October 2015 and March 2016, as part of a larger qualitative study on AS. Prostate cancer patients undergoing AS were identified through the electronic health records, and a total of 235 were mailed invitations. Overall, 37 patients with a median age of 66 years (65% white, 30% black, 5% other) participated in focus groups, which included discussion of Gleason scoring. Recruitment stopped when thematic saturation was reached (no new

themes emerged). Focus groups were recorded and transcribed verbatim. Transcripts were coded, and NVivo software (QSR International, Doncaster, Australia) was used for organization and further analysis. Following the focus groups, 25 patients (68%) voluntarily completed an additional survey on Gleason scoring, including four questions using a four-point Likert scale and one free-text response field (Supplemental Table 1).

Although most prostate cancer patients were familiar with the concept of a Gleason score, there was general consensus that traditional Gleason scoring is confusing. Multiple participants expressed difficulty understanding what their scores mean (Figure 1). The overwhelming majority (84%) agreed or strongly agreed that it would be clearer if the Gleason score was on a scale of 1–5, instead of 6–10. Only a few patients disagreed with the new GG (Figure 1). Overall, 88% would prefer to hear they had GG 1 versus Gleason 6, and 80% agreed or strongly agreed that they would feel more comfortable doing AS with GG 1 versus Gleason 6.

In this paper, we provided the first qualitative assessment of the new GG in US prostate cancer patients. While this is a relatively small sample, it affirms that Gleason grading is a significant source of confusion for patients and that most men prefer the revised GG system.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

AS	active surveillance
GG	grade groups

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Quotes: Confusion About Traditional Gleason Grading

"My background is business, not in real estate, not medicine. So there's a lot of jargon, and it's putting all the pieces together. Remembering what the Gleason score is. All I remember is that it exists and a higher number is bad."

"When they start talking about the Gleason scale and especially when at very first they talked about it as kind of, you know, thankfully I didn't know much about this. But like it just sounds like numbers and words and it's common terminology for doctors about that's just between a 2 and 3 on the Gleason scale and the other one was a 3 and that's okay what does that mean? Is it supposed to be less than 5, is it supposed to be less than 100."

"The Gleason scale is a mystery to everyone."

"I am confused about the Gleason score. With my last biopsy, my score was 5. Now I see at the top of this page that the Gleason scores are on a scaled from 6 to 10. Which is it?"

"Totally confusing."

"And one the things, for example, is it talked about the Gleason ratings and what the Gleason score is. And I don't know how many people know what the Gleason score is. I don't even remember it. But we all know the magic numbers; 6, 7, 8. You know? Who do you appreciate, you know?"

Quotes: Opinions About New Grade Groups

"Highly recommend." [Agrees with new scoring]

"The issue is not the scale numbers or the range. The issue is understanding clearly how the Gleason score is generated. What exactly goes into it? It appears to be based largely on judgment, but how is the judgment made and how reliable is it?" [Agrees with new scoring]

"Your definition above is helpful. Why call it a Gleason score by that name when it's a 'prostate cancer gradation?'" [Agrees with new scoring]

"If one has prostate cancer it would not make much of a difference, comfort-wise, if it is referred to as 1, 6 or any other number for that matter." [Agrees with new scoring]

"I understand that the traditional Gleason score is the sum of (1) the rating of the most prevalent type of cell in the sample, and (2) the nature of the next most prevalent type of cell in the sample. But I gather that ratings of '1' and '2' are never used. If so, then you should probably get rid of them, because they do create anxiety and perhaps make patients less receptive to the idea of active surveillance." [Agrees with new scoring]

"Since Gleason score is a combination of several factors it is not logical to start at 1." [Disagrees with new scoring]

"If it's not broke why fix it/why not keep it simple?" [Disagrees with new scoring]

Fig. 1.

Quotes from prostate cancer patient focus groups about traditional Gleason grading and the new grade groups.