European Association of Urology

Brief Correspondence

Survivorship Data in Prostate Cancer: Where Are We and Where Do We Need To Be?

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Article info

Abstract

Cancer survivorship was recently identified as a prostate cancer (PCa) research priority by PIONEER, a European network of excellence for big data in PCa. Despite being a research priority, cancer survivorship lacks a clear and agreed definition, and there is a distinct paucity of patient-reported outcome (PRO) data available on the subject. Data collection on cancer survivorship depends on the availability and implementation of (validated) routinely collected patient-reported outcome measures (PROMs). There have been recent advances in the availability of such PROMs. For instance, the European Organisation for Research and Treatment of Cancer Quality of Life Group (EORTC QLG) is developing survivorship questionnaires. This provides an excellent first step in improving the data available on cancer survivorship. However, we propose that an agreed, standardised definition of (prostate) cancer survivorship must first be established. Only then can real-world data on survivorship be collected to strengthen our knowledge base. With more men than ever surviving PCa, this type of research is imperative to ensure that the quality of life of these men is considered as much as their quantity of life.

Patient summary: As there are more prostate cancer survivors than ever before, research into cancer survivorship is crucial. We highlight the importance of such research and provide recommendations on how to carry it out. The first step should be establishing agreement on a standardised definition of survivorship. From this, patient-reported outcome measures can then be used to collect important survivorship data.

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Over the past few decades, the survival rate for prostate cancer (PCa) in Europe has continued to improve owing to early detection and advances in management. PCa has the third highest incidence among cancers in Europe [1], so greater survival means an increase in the prevalence of individuals surviving and living with the disease, otherwise known as cancer survivorship. Fitzhugh Mullan was the first to document "cancer survivorship" in 1985, defined as acute, extended, and permanent survivorship [2]. Mullan [2] supported the notion that survivorship should be studied as its own phenomenon rather than as a by-product of research into cancer treatments. Although this term has

been used for several decades, there are different definitions of cancer survivorship in the literature (for all cancers) that are not aligned [3]. Some define a "cancer survivor" as anyone diagnosed with cancer for 5 yr or more [3]. Conversely, some look beyond this basic definition of survivorship and consider broader conceptual frameworks that cover the complete patient journey from the point of diagnosis to "living with and beyond cancer" (LWBC) [4]. The UK National Cancer Research Institute, for example, intends to use LWBC instead of "survivorship" to describe this research area, as it recognises that the latter term means different things to different people [5].

PIONEER, a European network of excellence for big data in PCa, has prioritised PCa research questions and identified survivorship, as it is currently understood, as a priority [6]. The core outcome sets (COS) in PIONEER have highlighted the most important outcomes to evaluate among key stakeholders, including patients and health care professionals, and the tools to use [7,8]. This provides further insight into what could be regarded as necessary for quality-of-life data (thereby covering some of the major aspects of survivorship, including longitudinal data) but is unlikely to be comprehensive enough. Although survivorship has been identified as an important research topic and there is knowledge of what needs to be collected, there is a paucity of data on survivorship, particularly long-term data, to address this unmet need, and we hope to raise awareness of this issue in this Brief Correspondence.

The COS developed by PIONEER for both localised and metastatic PCa identified functional and quality-of-life outcomes that were best captured using PROMs through assessment of their psychometric properties using the Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN) guidelines [7–9]. PIONEER therefore recommends the EORTC quality of life core 30 (QLQ-C30) and prostate cancer 25 (QLQ-PR25) questionnaires for localised PCa [7] and the Functional Assessment for Cancer Therapy-Prostate (FACT-P) and the Brief Pain Inventory (BPI) for metastatic PCa [9]. Although adoption by cancer registries across Europe means that collection of these clinical and treatment-related patient-reported outcome data is relatively advanced, survivorship data also cover other aspects, including physical, psychological, social, and occupational/financial health.

In a more general cancer setting, a review by Jung et al. [10] identified 85 studies, including 35 surveys, conducted and published between 2011 and 2019 among cancer survivors across the USA and Canada [10]. Most of the studies were longitudinal in nature and the domains studied varied greatly, including medical characteristics, medical conditions, costs, employment, symptoms and/or side effects, psychosocial factors and coping, perceived quality of care, and health behaviours [10]. Thus, while there are questionnaires on survivorship, there is heterogeneity in what domains they cover, and a more concerted effort is required to collect the data necessary for survivorship research.

Moreover, existing questionnaires may not be appropriate for use in patients who are no longer undergoing active treatment and/or are disease-free survivors. To help in overcoming this problem, the European Organisation for

Research and Treatment of Cancer Quality of Life Group (EORTC QLG) is developing a new survivorship questionnaire, the 100-question QLQ-SURV100 instrument, via a multistep process. Researchers are now carrying out phase 4 of the study, which involves large-scale international validation of the questionnaire. To address the need for survivorship data in the field of PCa, PIONEER undertook a comparison of the PCa COS data points and the QLQ-SURV100 questionnaire, as this questionnaire also has a PCa-specific component (Table 1). However, there is very limited overlap (Table 2); hence, we identified a gap in data collection for the specific purposes of survivorship.

To advance research on PCa survivorship, we recommend that first efforts be directed towards a standardised and agreed definition of survivorship, that is, at what point a PCa patient becomes a PCa survivor. While there have been improvements in defining survivorship from organisations such as the US National Cancer Institute, the UK National Institute for Health and Care Research, and the EORTC, wider consensus is still required. An agreed definition will allow for homogeneity in high-quality data collection, preferably via validated PROMs. The latter also need to be agreed on if these efforts are to bear fruit in terms of standardised data amenable to appropriate pooling across studies or within big data projects.

The way in which PROM data collection is implemented must be carefully thought through. For example, as survivorship concerns may fluctuate over time, the timing of

Table 1 – Summary of core and site-specific survivorship questionnaires being developed by the European Organisation for Research and Treatment of Cancer

Questionnaire	Tumour type	Status
QLQ-SURV100	All	
BR-SURV40	Breast	Large-scale international
CR-SURV33	Colorectal	phase 4 validation
PR-SURV19	Prostate	

Table 2 – Summary of concept overlap between the PIONEER prostate cancer COS data points and the European Organisation for Research and Treatment of Cancer PR-SURV19 module

Concept	COS-PRO	PR-SURV19
Localised prostate cancer		
Bowel dysfunction	Present	Present
Faecal incontinence	Present	Present
Urinary dysfunction	Present	Present
Stress incontinence	Present	Not present
Sexual dysfunction	Present	Present
Side effects of hormonal therapy	Present	Not present
Overall quality of life	Present	Present
Metastatic prostate cancer		
Performance status	Present	Not present
Bowel dysfunction	Present	Present
Assessed using PROMs	Present	Present
Side effects of systemic therapy	Present	Not present
Sexual dysfunction	Present	Present
Urinary dysfunction	Present	Present
Emotional dysfunction	Present	Present
Physical dysfunction	Present	Present
Pain	Present	Not present
Fatigue	Present	Not present
Quality of life	Present	Present

COS = core outcome set; PROMs = patient-reported outcome measures.

PROM deployment must also be considered and implemented in a harmonised way. To do this, there must be consensus on the best time to start collecting data on survivorship. Furthermore, we must also be mindful of the context in which PROMs are collected (where and when), as this may affect the information gathered.

In conclusion, PCa survivorship has been identified as a priority for patients, health care professionals, and researchers. A standardised and universally agreed definition is required, and there must also be agreement on the PROMs to use to assess survivorship. While the focus is on PCa in this article, the process is just as important for all cancer types. A concerted effort is required for longitudinal data collection. This vision outlines a long-term strategy, but hard work now will pay dividends in the future. PIONEER is paving the way for this future in PCa by identifying survivorship as a research priority and recommending the use of certain PROMs. In the next phase, PIONEER+ will continue research into PCa survivorship.

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