

Expectations of survivors, caregivers and healthcare providers for testicular cancer survivorship and quality of life

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ABSTRACT

Aims and background. We compared expectations of testicular cancer survivors and their caregivers with those of healthcare providers for testicular cancer survivorship care and quality of life to identify experiences and potential expectations in which there was disagreement.

Methods. In a meeting with testicular cancer survivors, their caregivers, and care providers with an interest in testicular cancer, we distributed a structured questionnaire with 24 questions divided into 3 sections: personal information, information on the quality of life of survivors, information on the role of care providers, general practitioners and health-related internet sources in the expectations of survivors.

Results. The overall response rate was 91% (29 of 32) for patients and 100% (14 of 14) for caregivers with all questionnaires evaluable, while among 60 care providers, 42 (70%) responded with 41 (68%) evaluable. Between patients/caregivers and care providers, expectations were most incongruent for the role of primary care physicians in testicular cancer follow-up: important/fundamental for 58% of patients/caregivers and 88% of care providers ($P = 0.010$). Comparing patients/caregivers with care providers in their views of the experience of testicular cancer survivorship, we found several discrepancies: the fear of recurrence was high/very high for 18 of 43 (42%) patients/caregivers and in the perception of 40 of 41 (98%) care providers ($P < 0.001$), and psychological distress was considered as highly relevant by 35% of patients/caregivers and 93% of care providers ($P < 0.001$).

Conclusions. Patients/caregivers and care providers have different perceptions of survivors' experiences and discordant expectations with respect to the roles of primary care providers in testicular cancer survivorship care. Uncertainties about the roles and responsibilities of physicians can lead to deficiencies in care, supporting the need to make survivorship care planning a standard component in cancer management.

Key words: testicular cancer, survivors, caregiver, quality of life.

Acknowledgments: The authors would like to thank Gráinne Tierney for editing the manuscript.

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Received August 11, 2010;
accepted February 3, 2011.