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“If we have information we can be prepared to face it”: Indian cancer patients’ experiences of help-seeking.

Background: Psycho-oncology research has explored help-seeking behaviours mainly through the lens of diagnosis and treatment, i.e., medical help-seeking. However, patients also engage in help-seeking efforts with regard to their information and supportive care needs. This study explores these needs and help-seeking experiences among Indian cancer patients.

Method: Indian patients (n=11; 5 women and 6 men) participated in semi-structured interviews. Participants mean age was 42.8 years and time since diagnosis varied from 3 months (n=3), 6 months (n=3), 1 year (n=2) and more than 1 year (n=3). Interviews were transcribed and analysed using Interpretative Phenomenological Analysis.

Results: Three superordinate themes emerged: (i) clear supportive care needs post-diagnosis to manage the psychosocial consequences of cancer diagnosis and treatment (ii) seeking and receiving help from both healthcare professionals and family members to meet these needs post-diagnosis and (iii) an unmet need for better information about the causes of cancer, diagnosis, and treatment effects.

Conclusions: Indian cancer patients were able to identify their psychosocial needs after diagnosis and described how both their oncologist and family met these needs. However, patients also described how their information needs were not met, and reported inaccurate beliefs about the causes and consequences of cancer, delays in diagnoses, and confusion and distress during treatment. These findings indicate that there is a need for better information provision across the cancer continuum to improve patient care. Research implications include developing and testing interventions focussed on cancer-related knowledge-sharing (e.g., psychoeducation) in India.