

Abstract

Evaluating Nursing Case Management at a High-Risk Center: Study Protocol on Patients' Perceptions of the Nurse Case Manager within the Oncogenetic Pathway

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Introduction. Cancer genetics is a rapidly evolving field in the prevention and management of risk among individuals carrying hereditary pathogenic variants. Patients enrolled in surveillance programmes follow complex care pathways involving periodic follow-up, preventive decision-making, and substantial informational and emotional needs. Within this context, the Nurse Case Manager (NCM) may play a pivotal role in care coordination, communication, and patient support. However, few instruments are currently available to assess patient-reported experiences and perceived outcomes within oncogenetic care pathways. The aim of this study was to develop a questionnaire to explore patient-reported experiences and perceived outcomes related to care provided by the NCM within oncogenetic surveillance pathways.

Methods. A structured questionnaire was developed following a literature review on patient-reported outcomes, patient-reported experiences, and case management models in oncology. The instrument includes items designed to investigate the main dimensions of the care experience and underwent internal review to assess clarity and relevance. It is organised into seven sections addressing accessibility of the nursing role, informational support, coordination of the surveillance pathway, decision-making support, and perceived continuity of care. The questionnaire will be administered to patients enrolled in the oncological surveillance programme at the High-Risk Center as of December 31, 2025. Data will be analysed using descriptive statistics.

Results. It is hypothesised that the presence of a dedicated NCM will be associated with higher perceived informational support, better understanding of the surveillance pathway, and more effective coordination of healthcare services. Expected findings include identification of the care-experience dimensions most relevant to patients and a preliminary assessment of the perceived usefulness of the NCM.

Discussion. Systematic evaluation of patient-reported experiences may provide an important basis for improving the quality of oncogenetic pathways and strengthening patient-centred models of care. The findings may contribute to consolidating the role of the NCM in genetic surveillance programmes and inform future research on care outcomes.

Keywords: Nurse Case Manager, Oncogenetics, Patient-Reported Experience

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