PROJECT TITLE: Mapping the Journey of Patients Diagnosed with Sarcoma: Experiences and Unmet needs

FIELD OF RESEARCH CODE: 1701

PROJECT SYNOPSIS:

Sarcoma is a group of very rare primary bone and soft tissue tumours. Sarcomas can occur in children, adolescents, young adults and in adults over 55 years. In Australia approximately 1200 new cases are diagnosed each year, accounting for 1% of all adult malignancies and 15% of paediatric malignancies. Two in five patients diagnosed with sarcoma will die from their disease. Once diagnosed patients may receive surgery, chemotherapy or radiotherapy, or they will be referred to palliative care depending on their diagnosis, prognosis and the location of the tumour. Treatment can lead to structural impairments as well as activity and participation restrictions, and affect a patient’s quality of life. Psychological distress is reported in approximately 33% of patients.
To date, there has been a paucity of studies focusing on the experiences of sarcoma patients and treatment trajectory. To understand the burden of sarcoma, we need to track patients’ experiences over time.

The aim of this study is to map the journey of sarcoma patients over a 12 month period retrospectively and prospectively to explore experiences and unmet needs.

Methods

Design: This study will used a mixed method approach consisting of both qualitative and quantitative components.

1. **Longitudinal Qualitative Interviews**

Participants: Twenty patients will be recruited within 3 months of their diagnoses. Eligibility criteria: 14 years of age or over at the time of diagnosis; diagnosed with sarcoma within the last 3 months; received diagnosis in Western Australia; and able to converse in English. We will conduct multiple interviews across a 12 month period. This will enable us to understand patients’ perspectives on experiences and unmet needs at different points.

Recruitment: Eligible participants will be identified by nurses and treating clinicians in the Sarcoma clinic at Sir Charles Gairdner and Hollywood Private Hospitals and through Sock it to Sarcoma.

Data Collection: Semi-structured interviews will be conducted, either face-to-face, or via video conference or telephone depending on patients’ preferences and COVID-19. An interview guide and prompts will be used to gather rich data over time. The interview guide will be reviewed by a consumer panel that will be established. We will also collect data on distress over time. We will use the Distress Thermometer, a simple, validated tool where people indicate distress from 0-10. This also has a checklist so that people can indicate the source of the distress. This will enable a recording of distress over time for each person.

Analysis: Interviews will be transcribed verbatim and analysed using thematic analysis. Braun and Clarke’s seven phases for thematic analysis will be used to derive the themes: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the final manuscript. Thematic analysis enables emphasis on each participant’s experiences.

Quality and Rigour: An audit trail of all decisions will be kept. To ensure transferability, demographic information of participants will be collected and presented in a clear way.

2. **Case Study Review: Retrospective Audit of Patient health Records**

Cases: A retrospective 12 month audit of health record data of 40 WA sarcoma patients will be conducted. Patient health records will be accessed via the sarcoma clinics at Sir Charles Gairdner and Hollywood Private Hospitals.

Analysis: Data collected from the retrospective patient health records will be analysed using process mapping. This enables the identification of key events such as treatment decisions; changes in regimens; end of active treatment; referral to palliative care; supports accessed; misdiagnoses or delays; and who was involved.

Team

The supervisors have a close collaboration with Sock it to Sarcoma and received funding from the Foundation to explore (a cross-sectional study) unmet needs of patients and carers; the
role of the sarcoma nurse, delays in diagnosis; and hospitalisation for sarcoma patients with Professor Rachael Moorin in Public Health. An Honours student also looked at bereavement experiences of carers. The unmet needs article is under review and we have addressed revisions. Three manuscripts are in the final stages of preparation for submission. We have a team of authors including clinicians and collaborators from the Eastern States.

Expected Outcomes and Translation

To our knowledge, this will be the first Australian work to attempt to describe longitudinally the experience and treatment trajectory of Sarcoma. These findings will be directly transferrable to health settings, as there is a lack of knowledge about the experiences of sarcoma patients.

Future Research

We will apply for funding from NHMRC and Cancer Australia, and explore partnership opportunities to evaluate interventions to improve the care of patients diagnosed with sarcoma in Australia.

References


FEASIBILITY AND RESOURCING – DESCRIPTION OF THE SUPPORT THIS PROJECT WILL RECEIVE:

The supervisors have co-supervised a number of students to completion. They also have many collaborators in the community and health arena so recruitment is facilitated and clinical input is available.
The Schools are well resourced to support HDR students via regular research activities, and there is excellent support for milestones and timely completions.

Infrastructure support is available. The School of Psychology has recently been given approval for a lab space that will include space for HDR students.

The WA Cancer Prevention Research Institute (WACPRU) is also well placed to support HDR students in the cancer field.

THE SIGNIFICANCE OF THE PROJECT/ PROGRAM FOR THE ENROLLING SCHOOL OR INSTITUTION:

WACPRU is a centre of research excellence and a strategic focus in the school and, as part of our brief, we are encouraged to attract HDR students on projects related to cancer. This project also has a clear link with Nursing, Midwifery and Paramedicine’s strategic directions in health and nursing research. At a later stage, if successful, we will add a supervisor from the Medical School as this project aligns closely with medical research and will involve clinicians. The project also aligns with the strategic direction of the Faculty of Health Sciences, which has a focus on health and wellbeing.

Students must express interest in this scholarship opportunity by emailing the Project Lead listed below. Please provide a copy of your current curriculum vitae and detail your suitability to be involved in this strategic project.

PROJECT LEAD CONTACT:

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