What are survivorship needs of cancer caregivers?

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Introduction

- Following cancer treatment, patients can experience ongoing physical and psycho-social stress. These same cancer diagnoses and treatment experiences may also impact the well-being of caregivers of these patients.
- Historically, there has been inattention to caregiver issues (burnout, depression, anxiety, caregivers' own physical health deterioration, unmet social needs, inadequate knowledge/ resources/skills).
- *Survivorship Care Plans* (SCP) - focus on survivors completing curative intent treatment, providing useful information for ongoing care. However, SCPs are not designed to address family / caregiver needs.[1]
- These unaddressed caregiver needs can be severe and disabling. It is important not to overlook complex issues of patients' personal support teams.[2]
- Through semi-structured interviews and quality of life surveys, this study aims to identify the post-treatment needs of caregivers, and to determine if there is a role for a tailored SCP specifically for caregivers (*SCP-C*).

Objectives

- Explore caregiver's experience at the end of a loved one's cancer treatment via semi-structured interviews.
- Characterize caregivers' concerns and needs via open-ended questioning, and analyze manifest and latent content to identify common themes.
  - ➢ *Hypothesis: Caregivers have specific emotional and psychosocial needs at completion of a loved one's treatment for cancer. Identifying needs may improve survivorship care for both caregivers and primary patients.*

Caregiver Definition and Study Aims

Definition: A ***caregiver*** is defined as "***the person who assisted with care and health-related matters during the cancer treatment.[3]"*** The term "Caregiver" in this context refers not to medical personnel or members of a professional care team, but to the individual(s) who is/are the primary person(s) attending to the patient's daily needs. This is often an unpaid family member, friend, or neighbor who maintains a close relationship with the patient. This lay caregiver is relied upon to manage diverse, and often stressful, daily tasks during cancer treatment.

Study Aims:

- This study aims to identify short and long-term needs of the primary caregiver's quality of life (QOL); including social, financial, psychologic, sexual impacts on QOL.
- This study also aims to create a *Survivorship Care Plan for Caregivers (SCP-C)* to address these unmet needs.

Methods and Data Collection

Part I. Patients.

A convenience sample of participants with gynecological malignancies were recruited from the Lifespan Cancer Institute

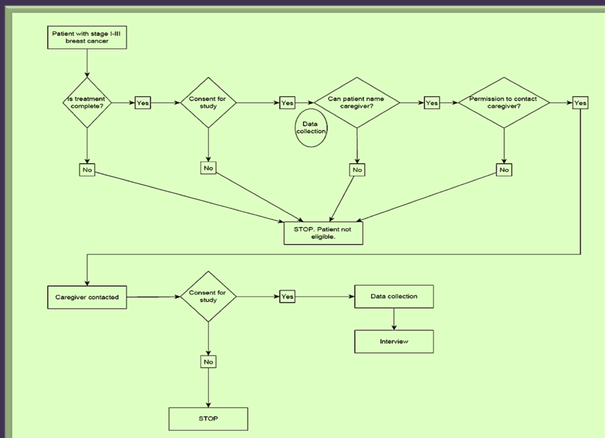
- **Record review and Survey**: Disease-related and treatment-related demographic data collected by chart review. Also, patients complete the National Comprehensive Cancer Network Survivorship Assessment Survey to identify further needs.
- **Patient eligibility Interview**: All patients asked to name their primary caregiver using the definition. Patients are asked four questions in order to identify the appropriate person:
  1. Looking back on your treatment, who would you name as your primary caregiver-meaning, the one who helped you the most with medical care and health-related matters?
  2. Who is your primary support?
  3. Who is your emergency contact?
  4. Who would you want to make decisions for your as your health care proxy?

Part II. Caregivers.

With patients' permission, caregivers are contacted and consented to participate in this study by phone contact. For those who consent, the following data collection tools and methods are utilized:

- **Interview**: Semi-structured phone interviews with caregivers. Sessions are recorded and contain open-ended questions so caregivers can provide feedback that they identify as important. Interviews are de-identified and transcribed.
- **Analysis**: Thematic analysis will be performed to identify themes in caregiver responses across demographics and age groups. Results will be used to create an improved survivorship plan optimizing caregiver needs (SCP-C).
  - ➢ We will use STATA 15.1 for descriptive statistics of our cohort including within subgroups based on age and relationship to each other (e.g. spouse vs relative vs friend).

Consenting Methodology



Future Directions

- Study in progress; data collection/interviews ongoing
- Analysis to identify manifest/latent themes in responses
- STATA 15.1 Analysis will be performed to compare demographic statistics of cohort.
- Study Aim: create improved SCP *("SCP-C")* to include the needs of primary caregivers as well as patients.
- Develop robust strategies to assess SCP-C impact.

References

1. "History of the National Coalition for Cancer Survivorship (NCCS)." NCCS - National Coalition for Cancer Survivorship. Accessed February 23, 2019. https://www.canceradvocacy.org/about-us/our-history/.
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3. Jones, Barbara L. "The challenge of quality care for family caregivers in pediatric cancer care." *Seminars in oncology nursing*. Vol. 28. No. 4. WB Saunders, 2012.

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