COVID-19 and Cancer:

An exploratory study of the experiences of people with cancer during the COVID-19 pandemic.

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Contents

1. Executive summary

The COVID-19 and Cancer Study was conducted by the Cabrini Monash University Department of Nursing Research at Cabrini Research from November 2020 to May 2021, involving 16 healthcare professionals working within the area of cancer care and 19 people who had a diagnosis of cancer or were caregivers of someone with cancer. Given the vulnerable position of people with cancer and their caregivers, and the sudden disruptions to healthcare due to COVID-19, it was necessary to conduct this research to identify any increased stressors. The objective was to explore the experiences of people with cancer and their caregivers during the pandemic, in order to contribute to an evidence base to inform future cancer care service provision during infectious crises.

The study had two stages, Stage 1 involved key informant interviews with healthcare professionals working in the area of cancer care. The findings from these interviews were used to inform the Stage 2 interview guide for participants who had a diagnosis of cancer or were caregivers of someone with cancer. The data was thematically analysed using NVivo software. Five interrelated themes were identified in the data: uncertainty and vulnerability; constraints and restrictions; isolation and disconnection; burdens and stressors; and adaptability and resilience. Results from the qualitative study suggest that for people with cancer and their caregivers, concerns relating to their diagnosis outweigh those associated with COVID-19. The most significant area of difficulty to emerge from the data was social isolation. Overall, practice implications centre on increasing the provision of psychosocial and spiritual services and increased attention to those who may experience increased levels of vulnerability.

2. Research Team

The research team consisted of Associate Professor Philip Russo, Director of the Cabrini Monash University Department of Nursing Research at Cabrini Research, Doctor Lucille Kerr, Research Fellow and Specialist Cancer Nurse, and Chanika Ilangakoon, lecturer and researcher at Monash University's Nursing and Midwifery Department.

3. About the Study

For the individual who has a diagnosis of cancer, treatment and survivorship can be an overwhelming journey.[1] Cancer care occurs in a highly complex multidisciplinary environment and often involves harsh treatments which induce distressing side effects.[1] People who have cancer are frequently vulnerable to infectious disease due to their treatment or disease, which may cause significant anxiety.[1] Increasingly, caregivers have been recognised as important members of the cancer care team for their supportive roles (including for decision making, communication and advocacy, practical care, social support), and recommendations follow for enhanced inclusion of them throughout the cancer continuum and in research.[2]

The COVID-19 pandemic has seen mass disruptions to healthcare globally, including in the areas of cancer and palliative care.[3-5] Emerging issues include: increased stress amongst cancer patients and their formal and informal caregivers due to concerns of contracting COVID-19; patient fear of exposure to COVID-19 infection acting as a barrier to seeking help; social isolation relating to general community-wide and healthcare-specific restrictions on social interactions; use of Telehealth and its (assumed) shortcomings; clinical trial delays; alternative treatment schedules and/or methods; and a lack of uniformity to treatment recommendations during the COVID-19 pandemic.[3-7] People with cancer are in a vulnerable position, and treatment teams may be anxious making decisions that try to balance risks associated with malignant disease with those of potential exposure to COVID-19 infection.

Additionally, palliative and end-of-life care is likely to have experienced significant burdens during the pandemic, including problems that relate to visitor restrictions which mean that the person approaching the end of their life may be unable to say goodbye the way they wish to and loved ones may have prolonged and complicated grieving processes.[3] As a result of COVID-19 disturbances, people with cancer and their caregivers may have increased stressors and therefore poor outcomes. There is thus a need for research which explores their experience to inform future cancer and palliative care provision during crises.

The illness experiences of people with cancer and their caregivers are likely to have been detrimentally affected by the COVID-19 pandemic; however, given the emerging nature of this problem, little is currently known. This research sought to explore this issue and help to improve cancer and palliative care service provision into the future.

4. Funding

The study was funded by a Cabrini Research Alan Jackson Research Grant.

5. Ethics Approvals

The low risk study was approved by the Cabrini Research Governance Office (02-03-12-20).

6. Study Objectives

The aim of the study was to explore the experiences of cancer patients and their caregivers during the COVID-19 pandemic to inform future provision of cancer care during infectious disease outbreaks.

7. The Study

a. Study Design

This was a qualitative study involving two stages. Key informant interviews were conducted in Stage 1 with purposively selected cancer care specialists across a variety of professional categories (i.e.

doctors, nurses and allied health). The data from Stage 1 informed Stage 2 interviews with people who have cancer and their caregivers.

b. Setting and sample

All participants were recruited from across Cabrini's cancer care services, including at the Malvern, Prahran and Brighton campuses.

During Stage 1, key informants were approached based on their role. Emails were sent to oncologists and haematologists and wards were visited to recruit nursing and allied health professionals. The inclusion criteria for Stage 1 was: healthcare professional working in oncology/hematology during the COVID-19 pandemic; aged over 18; and English speaking.

In the second stage of data collection, nurse unit managers assisted in identifying suitable patients. Recruitment posters were also displayed in various places which see a high traffic of people with cancer and their caregivers inviting them to participate in the study. Patients were interviewed in their rooms/chairs on the wards and also over the phone or online. Inclusion criteria for Stage 2 were: person with cancer or caregiver of a person with cancer; aged over 18; and English speaking. A small monetary gift was given to show gratitude to Stage 2 participants for their time.

c. Data Collection

The data was collected through semi-structured interviews, which allowed for open-ended exploration of the topic. Stage 1 interviews were comprised of four questions relating to the healthcare provider's perspective of the experiences of people with cancer and their caregivers: what first comes to mind; sources of stress; positive change; and how cancer care could better meet their needs. The themes identified in Stage 1 then informed the Stage 2 interview guide, which addressed the following areas: background information and cancer journey prior to COVID-19; what the COVID-19 pandemic changed for them; feelings of uncertainty, vulnerability, and isolation; experiences of restrictions; sources of stress; and adaptation/coping. Data collection was delayed at times due to imposed restrictions. Interviews were audio recorded and transcribed verbatim for analysis.

d. Data Analysis

Braun and Clarke's steps of inductive thematic analysis were used to analyse the data.[8] A team-based approach to analysis was employed. The first phase involved reading the transcriptions and making notes for potential codes. The second phase consists of initial coding of the data. Finally, in the third phase the codes were grouped into themes, which were discussed and refined by the team. All transcripts were coded into the theme using the qualitative research software NVivo 12.

8. Results

Thirty-five interviews were conducted which ranged from 8 to 96 minutes in length. The average time for Stage 1 interviews was 16 minutes, and 28 minutes for Stage 2 interviews. Key informants had a diverse range of professional backgrounds (see Table 1). For Stage 2 participants, there was a range of cancer diagnoses, and two participants were informal caregivers (see Table 2). The age range of participants in Stage 2 was 24-84 years (participants in Stage 1 were not asked for their age). Across the study, most participants were female (68.5%, n=24).

Table 1: Stage 1 (key informant) participant characteristics.

Pseudonym	Sex	Professional Background
Andrew	M	Oncologist
Louise	F	Haematologist
Gregory	M	Oncologist
Clyde	M	Oncologist
Jonathan	M	Oncologist
Angelina	F	Nurse educator
Vincent	M	Pastoral care
Elena	F	Music therapist
Felicity	F	Occupational therapist
Hillary	F	Palliative care nurse
Heidi	F	Oncology/haematology nurse
Wendy	F	Speech pathologist
Bethany	F	Nurse unit manager
Rebecca	F	Community palliative care nurse
Mary	F	Community palliative care nurse
Veronica	F	Community palliative care nurse

Table 2: Stage 2 (people with cancer and their caregivers) participant characteristics

Pseudonym	Sex	Age	Diagnosis
Emma	F	58	Lymphoma
Anne	F	45	Lymphoma
Joe	M	61	Oesophageal
Isabel	F	78	Chronic lymphocytic leukaemia
Henry	M	66	Lymphoma
William	M	76	Prostate
Joan	F	73	Breast, caregiver
Michael	M	68	Duodenal, prostate
Patricia	F	81	Bowel, lymphoma
Robert	M	67	Lymphoma
Susan	F	51	Ovarian
Carol	F	66	Breast
Sarah	F	72	Bowel
Elizabeth	F	57	Ovarian
Charlotte	F	24	Lymphoma
Julie	F	84	Uterine

Margaret	F	73	Lung
Gretchen	F	66	Cholangiocarcinoma
Tim	M	67	Caregiver

Five interconnected themes make up the results: uncertainty and vulnerability; constraints and restrictions; isolation and disconnection; burdens and stressors; and adaptability and resilience. These themes influenced, and were influenced by each other – for example, the constraints and restrictions contributed to increasing feelings of isolation and disconnection.

Uncertainty and vulnerability
In terms of the concerns associated with uncertainty and vulnerability, those that were associated with cancer generally outweighed fears associated with COVID-19. Participants continued to be most focused on their cancer diagnosis and treatment. Some participants emphasised that they did not feel any uncertainty related to COVID-19, whilst others described experiences of heightened anxiety. Our participants were aware that they were more vulnerable to severe illness if they contracted COVID compared with the general population, due to their compromised immune system. However, many participants also stated that they felt safe given the precautions they took to protect themselves and the imposed government restrictions. Participants also described uncertainty about the future and how long it would take for things to go back to 'normal', or if they ever would.

> *My anxiety was a massive thing, I was constantly so nervous about getting COVID…. [there was a] massive sense of uncertainty there about if I got COVID what was going to happen to me.*
>
> - Charlotte, 24, lymphoma

Constraints and restrictions
All participants discussed the effects of government restrictions and other constraints on daily life which were the result of measures to limit the spread of COVID-19. Mostly, participants reported that they were not greatly affected by this, and many stated they would have restricted their activities regardless of COVID during their treatments for cancer. There were diverse opinions about the constraints; it could be a source of frustration at other people in the community who did not follow restrictions and some thought the restrictions were too severe. A few participants considered the restrictions as a good thing because they had time to themselves, felt safe or had the opportunity to spend more time with their loved ones at home. Commonly, participants talked about the constraints and restrictions in terms of what it meant for social isolation.

Specifically relating to health services, participants described that accessing services was easier due to facilities having fewer people around. On the other hand, constraints within healthcare meant that attending appointments could be lonely and provoke anxiety. Others struggled with visitor restrictions which meant they could not see their loved ones when they were an inpatient. Several participants also raised the problem that less access to face-to-face services resulted in delayed diagnoses.

> *A lot of people, they'll say 'oh I'm okay' and you may not be, people are missing things, and then they all of a sudden find out that the cancer has gotten a lot worse because… that's the trouble, things get missed when you haven't gotten to see your doctor face-to-face.*
>
> - Joan, 73, breast cancer and caregiver

Isolation and disconnection

This theme covers comments made by participants about isolation and disconnection relating to both COVID restrictions and to living with cancer. Some participants were deliberately isolating themselves beyond the community-wide restrictions, which could be because of fear of the virus, but also because they wanted to distance themselves from people who they believed were over-reacting or spreading misinformation. Mandatory wearing of facemasks and social distancing was seen to contribute to feelings of social disconnection. Participants experienced isolation and disconnection in different ways depending on their individual circumstances. The two participants who reported being highly distressed at times were a young adult and the mother of young children. Many participants used technological means to overcome isolation. Some participants discussed the benefits of isolation as a time for themselves, and that not having social obligations during treatment could be a relief if people did not have energy for socialising or did not want others to see them unwell. Participants expressed that they thought there was generally more appreciation of social connection because of COVID-19.

> *It's allowed people to step up and think, 'oh well I could smile at the person walking past because I haven't actually seen anyone for two or three days,' whereas I don't think, generally, in our fastpace, that's what we do, and we need to, because quite clearly you can't live, you're not an island and you can't survive by yourself.*
>
> - Elizabeth, 57, ovarian cancer

Burdens and stressors

For participants of this study, the fear and stress from cancer far outweighed that of COVID-19. In terms of day-to-day stressors, most said they did not increase, and for many they decreased (e.g. not having to travel into work). There were several comments which discussed strained interpersonal relationships from being stuck at home, resulting in stress. The vaccine was seen by some participants to have reduced their levels of stress relating to contracting COVID-19. Other sources of stress stemmed from people 'not doing the right thing' and the media. One participant experienced significant stress from financial concerns, and others experienced stress resulting from physical aspects of cancer treatment and older age. Participants reported some increased stress of visiting healthcare in-person due to perceived high transmission risk, and there was some reported avoidance, however, the threat of cancer generally outweighed this.

> *It was calmer because there's less you can do, less you have to worry about.*
>
> \- Susan, 51, ovarian cancer

Adaptability and resilience

Methods of adaptation and resilience were commonly discussed by participants. Many related this to the inevitability of having to accept and come to terms with what was happening. Some participants stated that they coped by avoiding thinking about the pandemic. Several participants talked about their general dispositions in life, that is, that they tend to look on the bright side and are less prone to stress. Some participants reported they had difficulty adapting to their cancer diagnosis, but this was not the case in relation to the pandemic. Participants expressed that they adapted their behaviour in pragmatic and sensible ways to keep themselves safe. There were a variety of activities that people engaged in to keep themselves occupied during lockdowns: walking, baking, jigsaws, craft, art, et cetera. There were many adaptations within healthcare, which showed strong resiliency. These included increased protective measures and use of technology (including Telehealth consultations).

9. Use of the findings

Healthcare professionals and services may use the findings to inform their provision of cancer care. An important finding is that much of the distress experienced by people with cancer during the COVID-19 pandemic stems from social isolation. This highlights the importance of continuing and increasing psychosocial support, including through Telehealth means. The results also suggest that there is a need for nuanced and individualised approaches, with special consideration given to those who may be most vulnerable (e.g. younger people, families, people in precarious financial positions).

10. Dissemination

This findings from this study will be disseminated throughout Cabrini, and through a peer-reviewed publication.

11. Acknowledgements

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