

# Exploring the experiences of informal primary caregivers of women with advanced or terminal gynaecological cancer in a low-resource setting during the COVID-19 pandemic

C Odendaal,<sup>1</sup> H Simonds,<sup>2</sup>  W Mateane,<sup>1</sup>  R Roomaney<sup>1</sup> 

<sup>1</sup>Department of Psychology, Faculty of Arts and Social Sciences, Stellenbosch University, South Africa

<sup>2</sup>Division of Radiation Oncology, Faculty of Medicine and Health Sciences, Stellenbosch University, South Africa

Corresponding author, email: rizwanaroomaney@sun.ac.za

**Background:** Gynaecological cancer patients rely on informal primary caregivers, typically family members, to provide care and support. This can place a heavy burden on caregivers, especially when patients have advanced or terminal cancer. The COVID-19 pandemic affected healthcare systems worldwide, which may have added to the responsibilities and strain of caregivers. However, literature exploring the experiences of informal caregivers of advanced or terminal gynaecological cancer patients during the COVID-19 pandemic is limited within the South African context. To address this gap, we explored the experiences of informal primary caregivers of women with advanced or terminal gynaecological cancers. This description provides insight into caregivers' experiences during a challenging period in their lives.

**Methods:** We conducted an exploratory, qualitative study with 16 informal primary caregivers. The caregivers participated in individual, semi-structured interviews, which were audio-recorded, transcribed, and analysed using reflexive thematic analysis.

**Results:** We identified three themes, namely 1) limited hospital access for caregivers, 2) hypervigilance of caregivers, and 3) an opportunity to bond. The findings highlight the extent to which informal caregivers protected and prioritised the well-being of patients during their illness trajectory. Participants experienced a communication gap with healthcare professionals, making it more challenging for them to administer care to patients at home. Caregivers were hypervigilant and spent much time and effort protecting patients from contracting COVID-19.

**Conclusion:** While COVID-19 introduced additional challenges to caregivers, it also provided an opportunity to strengthen their bond with the patients.

**Keywords:** caregivers, gynaecological cancers, COVID-19

## Introduction

Many women with advanced or terminal gynaecological cancer need consistent support and assistance during their illness trajectory. Informal caregivers often provide patients with physical, emotional, and financial support.<sup>1</sup> They may assist patients by cooking or cleaning for them, providing transport and companionship to medical appointments, or showing care and compassion either verbally or non-verbally. Informal caregivers are often family members such as parents, spouses, siblings, or adult children who care for patients without monetary compensation.<sup>2</sup> They play an important role in South Africa because most of the population seek treatment at public hospitals, where the high disease burden and limited resources such as personnel, beds, and equipment may result in long treatment waiting periods and early discharge from hospitals.<sup>3-5</sup> As a result, caregivers play a crucial role in helping cancer patients with everyday tasks and care normally administered by healthcare professionals.<sup>6</sup> This includes monitoring the patients' symptoms and side effects, and administering medication when needed.<sup>7</sup>

COVID-19 introduced new challenges for patients and caregivers. Patients were required to be even more cautious and self-isolate to prevent the possibility of developing infections. Caregivers

were not allowed inside hospitals to support the patients. These changes meant that there were added responsibilities for caregivers.<sup>8</sup> The restrictions put in place to limit the spread of COVID-19 resulted in limited access to healthcare for both cancer patients and their caregivers, leading to delayed treatment and reduced support from healthcare professionals.<sup>9</sup> This subsequently increased patient dependence on the caregivers.<sup>10</sup> The COVID-19 pandemic also increased psychological distress experienced by caregivers, who had to manage their own anxiety while having to administer care to the patients.<sup>11</sup>

Despite a rigorous search for studies regarding the experiences of informal caregivers of patients with cancer in South Africa during the pandemic, we were unable to locate any studies. Therefore, we aimed to explore the experiences of informal primary caregivers of patients with advanced or terminal gynaecological cancers during the COVID-19 pandemic. Patients with advanced or terminal cancers may need more care than those who are in the early stages of their disease, thus placing greater responsibility on informal caregivers. In addition, patients with gynaecological cancers and their caregivers may experience stigma and isolation, which the COVID-19 pandemic may have exacerbated.<sup>12-14</sup> This study provides insight into the experiences of a vulnerable group during a severely challenging time. By gaining insight into these experiences, we can gauge

the needs of caregivers and develop interventions to provide them with support.

## Methods

### Research design

We conducted an exploratory, qualitative study. We chose an exploratory study due to the lack of research conducted on the experiences of informal caregivers of advanced or terminal gynaecological cancer patients in South Africa during the COVID-19 pandemic. Participants were recruited at the Radiation Oncology Department of a tertiary hospital in the Western Cape.

### Participants

We recruited 16 South African informal primary caregivers. For participants to be eligible to participate in this study, they had to be identified as unpaid, primary caregivers of gynaecological cancer patients in the advanced or terminal stage of their illness. The participants also had to provide care for at least one month. Furthermore, participants were required to understand and speak English or Afrikaans, as the interviewer could only conduct the interviews in these languages. Each participant was assigned a pseudonym. Please refer to Table I for more information about the participants and the patients they cared for.

### Procedure

Informal caregivers were not allowed inside the hospital during the COVID-19 pandemic. For this reason, participant recruitment was facilitated by patients. Patients were approached while waiting for treatment, informed about the study, handed a leaflet about the study containing the researchers' contact details, and asked to hand the flyer to their primary caregivers. The primary caregivers then contacted the researchers or asked the patient to share their contact details with the researcher if they did not have money to contact the researchers themselves. Researchers

informed the caregivers about the study telephonically and arranged for interviews.

### Data collection

Data were collected by conducting individual, semi-structured interviews. The caregivers were given the option to participate in person or online. One caregiver opted for an in-person interview, and 15 caregivers opted for telephonic interviews. COVID-19 safety regulations were adhered to for the in-person interview. An interview guide consisting of 14 questions was developed for the interviews. The interview guide was developed by the first author and senior author, a research psychologist with expertise and experience in qualitative interviewing. The interview questions were informed by the literature consulted, the aim and objectives of the study, and the theory. Participants were asked about their experiences as informal caregivers, the challenges they faced, their needs, their experience of providing care during the COVID-19 pandemic, and their relationship with the patients. Interviews lasted between 25 and 120 minutes, were conducted in English or Afrikaans, and were audio-recorded with the participants' permission.

### Ethical considerations

This study was approved by the Health Research Ethics Committee of Stellenbosch University. Permission to conduct this study at a tertiary hospital was obtained from the Western Cape Department of Health. Before each interview, the study's nature, aim, and objectives were explained to the participants. Participants were informed about confidentiality and that the study was voluntary. They were also informed that they could terminate the interview at any point should they wish to do so. Participants provided consent. Pseudonyms were created to protect the participants' identity and adhere to the principle of confidentiality. Free counselling services were offered to participants if they experienced distress after their interviews. The audio-recorded interviews will be stored on the first author's

Table I: Participant demographic information

Caregiver	Relationship to patient	Age	Gender	Employment status	Type of cancer
Shannon	Daughter	47	Female	Full-time	Endometrial (terminal)
Katie	Niece	37	Female	Full-time	Ovarian (terminal)
Jazmin	Adopted daughter	50	Female	Full-time	Vulva (terminal)
Rhule	Son	22	Male	Unemployed	Vulva (terminal)
Kurt	Husband	56	Male	Retired	Ovarian (advanced)
Mary	Mother	67	Female	Pensioner	Cervical (terminal)
Sally	Daughter	49	Female	Unemployed	Cervical (terminal)
Talia	Daughter	38	Female	Unemployed	Cervical (terminal)
Lola	Sister	53	Female	Unemployed	Cervical (terminal)
Nelson	Husband	77	Male	Pensioner	Ovarian (terminal)
Anna	Mother-in-law	62	Female	Pensioner	Cervical (advanced)
James	Husband	64	Male	Retired	Endometrial (terminal)
Peter	Father	73	Male	Pensioner	Ovarian (terminal)
Carmelo	Partner	36	Male	Full-time	Cervical (terminal)
Candice	Mother	69	Female	Pensioner	Cervical (terminal)
Sarah	Daughter	27	Female	Unemployed	Cervical (terminal)

password-protected laptop for five years. Thereafter, the audio recordings will be destroyed.

### Data analysis

Each audio-recorded interview was transcribed, entered into ATLAS.ti qualitative software, and then analysed. The six stages of reflexive thematic analysis proposed by Braun et al.<sup>15</sup> were used to analyse the data, namely 1) data familiarisation, 2) data coding, 3) generating initial themes and sub-themes, 4) developing and reviewing themes and sub-themes, 5) refining, defining, and naming themes, and 6) producing the report. Data were analysed in the original language as all authors are fluent in both languages. Quotations were only translated from Afrikaans to English if they were used for the publication.

### Trustworthiness

We used several strategies to build trustworthiness in this study. Prolonged engagement was used to enhance credibility. One author worked closely with patients at the hospital, and another author spent a lengthy amount of time at the hospital, observing and engaging with patients and caregivers. Peer debriefings also took place regularly between two of the authors during data collection and analysis. We used purposive sampling and provided a thick description of techniques to enhance transferability. To enhance the dependability of results, the interviewer received interview training, and the person responsible for analysis also received training in qualitative data analysis. In addition, the first author coded all the data, but the senior author reviewed the coding and supervised the analysis. Finally, we engaged in reflexivity throughout the study to enhance confirmability.

### Findings

We identified three themes, namely 1) limited hospital access for caregivers, 2) hypervigilance of caregivers, and 3) an opportunity to bond.

#### Limited hospital access for caregivers

Data were collected during the COVID-19 pandemic when several restrictions were implemented in hospitals. In general, caregivers were not allowed to accompany the patients inside the hospital when they went for treatment. Caregivers were only allowed into the hospital if the patient required physical assistance. Participants reported that this created much anxiety for them due to feelings of uncertainty.

The strict safety precautions put in place to curb the spread of the virus meant that patients often went to the hospital for treatment by themselves. Caregivers explained how these strict precautions elicited concern, fear, and worry, as they could not visit or care for the patients while in the hospital. Talia, a 38-year-old daughter, described her feelings during this time in the statement below:

*When she was in hospital for procedures, you couldn't go and visit her. She was alone and waiting for her to switch her phone on and getting information from her, that makes you*

*anxious. You are anxious because you want to know what's going on.*

The participants also experienced sadness as they were unaware of the well-being of the patients and had to wait for patients to message or call them to let them know how they were doing. Rhule, a 22-year-old son, whose mother became ill in their home and had to be taken to hospital, described how he felt when he could not accompany her:

*I thought she was going to die or something and that made me very sad, it made me very, very sad, and I couldn't be with her.*

Caregivers added that when they were not present at the hospital, they usually did not receive the necessary information about the patients' well-being. This made them feel worried, as they were unaware of the patients' prognosis, medication, and the different ways of administering care to the patients. Even when this information was provided to the patients, they did not always communicate it to their caregivers. This gave rise to information gaps between healthcare providers and caregivers, which may have impacted their ability to care for patients at home.

#### Hypervigilance of caregivers

Participants reported becoming hypervigilant because they did not want the patients or themselves to contract COVID-19. Participants indicated that they were more concerned about patients contracting COVID-19 than themselves due to the patients' susceptibility to infections. The caregivers detailed the precautions they put in place to protect the patients and themselves. These safety measures included constant sanitation, as they kept sanitisers in their homes and cars, and an increased awareness of their surroundings related to their physical hygiene and sanitation. In addition, caregivers asked loved ones not to visit frequently, to limit physical contact, and to reduce the risk of infection. Caregivers were responsible for creating safety bubbles for the patients. In the statement below, Talia explained the measures she put in place:

*Everything needs to be sanitised. Your hands must be washed. Even when we come back from the shop, we wipe down everything, we are super vigilant about that still.*

Caregivers explained that they washed their clothes immediately when they got home if they had been out, especially before administering care to the patients. Shannon explained this in the statement below:

*When I come home, I take off my clothes before I interact with my mother at all.*

Participants said they tried to protect the patients by limiting their physical contact with others. When caregivers allowed visits from loved ones, they insisted on sanitising when they entered at the door and asked the visitors to keep their masks on, especially if they showed flu symptoms. Caregivers reported that they were not bothered by the isolation, as this kept the patients safe. They explained that they were fine with no visitors coming to the house, considering that staying at home and being separated

from others was the norm during that time. Shannon explained this in the statement below:

*We'd rather they don't come over and when they do, they need to stick to mask and stuff like that and sometimes it's a tough call.*

When reflecting on their experiences, participants reported that being vigilant during the COVID-19 pandemic played an important role in protecting the patients from contracting COVID-19.

### **An opportunity to bond**

Most caregivers reported that limited contact with those outside the household facilitated bonding between them and the patients during the pandemic. The caregivers reported that they developed a closer connection to the patients and the members of their households, which they believed would not have occurred without the pandemic. James described the time spent with his wife and children in the description below:

*It was good not having too many people in the house, we were getting like closer together because we spent that time with one another as the family.*

Some caregivers added that the patients appreciated this quality time, considering that healthcare professionals informed some patients that they only had a certain amount of time left to live. Therefore, spending time surrounded by their loved ones became increasingly important and brought joy to the patients. Sarah explained how important it was for her mother to spend time with all her children:

*She still had cervical cancer and she said that one doctor told her that she could have like a max of nine months to live. Having all her children sit around her every day, that if she had to die, at least she had her last days with, with us.*

While restrictions during COVID-19 resulted in families becoming isolated, the caregivers saw this period as an opportunity to bond and appreciate the time with their family members.

## **Discussion**

This research aimed to explore the experiences of informal primary caregivers of women with advanced or terminal gynaecological cancers in South Africa during the COVID-19 pandemic. Our findings are centred around three themes, namely 1) limited hospital access for caregivers, 2) hypervigilance of caregivers, and 3) an opportunity to bond.

Providing care during a pandemic was a challenging experience for caregivers. The caregivers highlighted that they adhered to the COVID-19 regulations, which included sanitation and isolation, and were diligent about keeping themselves and the patients safe. While the literature on this topic is limited, a quantitative study conducted by Akkuş et al.<sup>16</sup> examined the caregivers' experiences providing care to cancer patients during the pandemic in Turkey. They found that 76% of the caregivers were worried about contracting COVID-19, and 82% were worried about the patient contracting COVID-19.<sup>16</sup> While participants in our study often discussed their concerns regarding the

patients contracting COVID-19, they expressed less concern about themselves contracting COVID-19. Their concern with contracting the virus was linked to potentially posing a risk to the patients rather than themselves. This demonstrates the extent to which the lives of caregivers centred around the patients.

The participants reported that the most challenging aspect of providing care during the COVID-19 pandemic was the COVID-19 regulations at healthcare facilities. Participants reported having limited access to healthcare facilities and limited communication with healthcare providers as they could not accompany the patients into the hospital. This meant that patients often went for treatments without their caregivers and that caregivers were provided information that patients gave them. Patients may not have been able to provide comprehensive information about treatment and post-treatment care to their caregivers, considering the stressful nature of their treatment. Participants reported that the lack of information from healthcare professionals made them anxious.

The inability to provide physical support while the patients were in hospital and the limited communication with healthcare providers elicited emotions such as anxiety and sadness within the participants. Similarly, a study exploring cancer caregivers' experiences during the COVID-19 pandemic highlighted that caregivers were not allowed to attend appointments with the patients at hospitals.<sup>17</sup> As a result, the participants felt as though they were not provided adequate information, which concerned them because they could be uninformed about crucial information regarding the patients.<sup>17</sup>

A positive finding reported by participants about providing cancer care during the COVID-19 pandemic was how restrictions facilitated bonding with the patients. Research conducted among South African families found that COVID-19 restrictions facilitated bonding within families.<sup>18</sup> The participants in the current study reported that during the pandemic, they could spend more time with the patients as extended family members and friends were not allowed to visit them often. However, another study found that caregivers experienced feelings of isolation while providing care during the pandemic.<sup>19</sup> This differed from the current study, where participants were grateful to spend quality time with the patients during the pandemic.

### **Implications**

Caregivers play an essential role in the well-being and treatment of patients with gynaecological cancers. During the pandemic, caregivers could not communicate effectively with healthcare practitioners, placing an additional burden on their caring responsibilities. This demonstrates the importance of communication between caregivers and healthcare practitioners, and we encourage practitioners to engage more with caregivers when they have patient consent. Information sharing between healthcare practitioners and caregivers may also benefit both parties and, ultimately, the patient. However, it must be done within the constraints of confidentiality and only with the explicit consent of patients. Caregivers may also benefit from written information aimed specifically at them about cancer and how to



care for and support the patients. This information should be in a language accessible to caregivers.

We recommend that future research explore the informational needs of caregivers to develop useful content. In addition, we recommend that quantitative research be conducted on the impact of caring for a patient with cancer. Aspects to explore include changes to quality of life, well-being, stress, and coping. Finally, it is vital to acknowledge the role of primary caregivers and provide them with sufficient support during the patients' illness trajectory.

### Limitations

This study was limited because data were collected at one point in time and not longitudinally. Collecting data throughout the COVID-19 pandemic may have allowed us to explore the experiences as the pandemic and associated restrictions changed. A second limitation was that interviews were only conducted in English and Afrikaans. While these are two of the most popular languages in the Western Cape, valuable information may have been excluded from caregivers who did not speak these languages. Finally, most of the interviews were conducted telephonically, which may have limited the ability to build rapport and produce richer data.

### Conclusion

This study highlighted the positive and challenging aspects of providing care for patients with advanced or terminal gynaecological cancer during the COVID-19 pandemic. Caregivers prioritised the patients' needs and created safety bubbles to shield the patients from COVID-19. Having to care for and isolate with patients resulted in strong bonds between patient and caregiver. The pandemic provided opportunities for bonding that may not have otherwise existed. Despite this, more attention and resources should be allocated to informal caregivers.

### Acknowledgements

We acknowledge the participants who shared their experiences.

### Data availability statement

We do not have ethical approval to share our qualitative interview recordings and transcriptions publicly.

### Conflict of interest

The authors declare no conflict of interest.

### Funding source

Miss Odendaal acknowledges financial support provided to her from a National Research Foundation grant.

### Ethical approval

Ethical approval was obtained from the University of Stellenbosch Human Research Ethics Committee (Ref: S21/04/075).

### ORCID

H Simonds  <https://orcid.org/0000-0002-4442-6068>

W Mateane  <https://orcid.org/0000-0002-8289-4700>

R Roomaney  <https://orcid.org/0000-0002-3585-4992>

### References

1. Adejoh SO, Boele F, Akeju D, et al. The role, impact, and support of informal caregivers in the delivery of palliative care for patients with advanced cancer: a multi-country qualitative study. *Palliat Med.* 2021;35(3):552-62. <https://doi.org/10.1177/0269216320974925>.
2. Dang S, Looijmans A, Ferraris G, Lamura G, Hagedoorn M. Exploring the needs of spousal, adult child, and adult sibling informal caregivers: a mixed-method systematic review. *Front Psychol.* 2022;13:832974. <https://doi.org/10.3389/fpsyg.2022.832974>.
3. Gambe RG, Clark J, Meddick-Dyson SA, et al. The roles and experiences of informal carers providing care to people with advanced cancer in Africa-a systematic review and critical interpretive analysis. *PLOS Glob Public Health.* 2023;3(4):e0001785. <https://doi.org/10.1371/journal.pgph.0001785>.
4. Babalola TK, Moodley I. Technical efficiency and productivity of public district hospitals in Kwazulu-Natal province, South Africa. *J Public Health Res.* 2020;9(1):1741. <https://doi.org/10.4081/jphr.2020.1741>.
5. Ramutumbu NJ, Ramathuba DU, Maputle MS. Barriers to accessing oncology services for effective cancer care in the public health institutions in Limpopo province, South Africa: a qualitative study. *Nurs Rep.* 2023;13(3):956-68. <https://doi.org/10.3390/nursrep13030084>.
6. Molassiotis A, Wang M. Understanding and supporting informal cancer caregivers. *Curr Treat Options Oncol.* 2022;23(4):494-513. <https://doi.org/10.1007/s11864-022-00955-3>.
7. Najjuka SM, Iradukunda A, Kaggwa MM, et al. The caring experiences of family caregivers for patients with advanced cancer in Uganda: a qualitative study. *PLoS One.* 2023;18(10):e0293109. <https://doi.org/10.1371/journal.pone.0293109>.
8. Su Z, McDonnell D, Liang B, et al. Technology-based health solutions for cancer caregivers to better shoulder the impact of COVID-19: a systematic review protocol. *Syst Rev.* 2021;10(43). <https://doi.org/10.1186/s13643-021-01592-x>.
9. Ezenwankwo EF, Nnaji CA, Moodley J. Cancer service delivery and the impact of the COVID-19 pandemic in sub-Saharan Africa: a scoping review. *Ecanermedscience.* 2022;16:1485. <https://doi.org/10.3332/ecancer.2022.1485>.
10. Salha LA, Silva JCS, Martins CA, et al. Caregivers of individuals with cancer in the COVID-19 pandemic: a phenomenological study. *Int J Environ Res Public Health.* 2021;19(1):185. <https://doi.org/10.3390/ijerph19010185>.
11. El-Jawahri A, Greer JA, Park ER, et al. Psychological distress in bereaved caregivers of patients with advanced cancer. *J Pain Symptom Manage.* 2021;61(3):488-94. <https://doi.org/10.1016/j.jpainsymman.2020.08.028>.
12. Bandieri E, Borelli E, Gilioli F, et al. Stigma of palliative care among patients with advanced cancer and their caregivers on early palliative care. *Cancers (Basel).* 2023;15(14):3656. <https://doi.org/10.3390/cancers15143656>.
13. Nyblade L, Stockton M, Travasso S, Krishnan S. A qualitative exploration of cervical and breast cancer stigma in Karnataka, India. *BMC Womens Health.* 2017;17(58). <https://doi.org/10.1186/s12905-017-0407-x>.
14. Shrestha G, Mulmi R, Phuyal P, Thakur RK, Siwakoti B. Experiences of cervical cancer survivors in Chitwan, Nepal: a qualitative study. *PLoS One.* 2020;15(11):e0234834. <https://doi.org/10.1371/journal.pone.0234834>.
15. Braun V, Clarke V, Hayfield N, Terry G. Thematic analysis. In: *Handbook of research methods in health social sciences.* Singapore: Springer Singapore; 2019. p. 843-60. [https://doi.org/10.1007/978-981-10-5251-4\\_103](https://doi.org/10.1007/978-981-10-5251-4_103).
16. Akkuş Y, Karacan Y, Ünlü K, Deniz M, Parlak A. The effect of anxiety and spiritual well-being on the care burden of caregivers of cancer patients during the COVID-19 pandemic. *Support Care Cancer.* 2022;30(2):1863-72. <https://doi.org/10.1007/s00520-021-06611-0>.
17. Santin O, Mc Mullan J, Jenkins C, Anderson LA, Mc Shane CM. Supporting someone with cancer during the COVID-19 pandemic: a mixed methods analysis of cancer carer's health, quality of life and need for support. *Health Soc Care Community.* 2022;30(5):e3246-52. <https://doi.org/10.1111/hsc.13768>.
18. October KR, Petersen LR, Adebisi B, Rich E, Roman NV. COVID-19 daily realities for families: a South African sample. *Int J Environ Res Public Health.* 2021;19(1):221. <https://doi.org/10.3390/ijerph19010221>.
19. Butt SS, Khalid R. Unsung heroes of cancer care: loneliness, social support, and quality of life in informal cancer caregivers during COVID-19 pandemic. *Pak J Psychol Res.* 2023;38(2):207-36. <https://doi.org/10.33824/PJPR.2023.38.2.13>.