

CLINICAL CORRESPONDENCE

Isolated already, how COVID-19 has exacerbated anxiety for Australian cancer patients

Danielle Spence

Cancer Strategy and Support, Cancer Council Victoria, Melbourne, Victoria, Australia

Correspondence

Danielle Spence, Cancer Strategy and Support, Cancer Council Victoria, 615 St Kilda Road, Melbourne, VIC 3004, Australia.

Email: danielle.spence@cancervic.org.au

KEYWORDS: cancer, COVID-19, psycho-oncology, psychosocial support, telehealth

As a non-profit organisation providing support to people affected by cancer, Cancer Council Victoria (hereafter referred to as 'Cancer Council') shared our learnings and insights during the COVID-19 pandemic, based on the experiences of people who called our support line.

"I was diagnosed with breast cancer in February this year, just before COVID-19 happened," Emma shared. "I was getting so much help and support... then it all just stopped. It's like a double hit. You're already feeling isolated and your whole world is turned upside down, then with COVID-19, it doubles the feelings of isolation and vulnerability. I was really overwhelmed with everything happening so quickly, my worries with my treatment and what might happen if I contract COVID-19."

Emma's story has been a common experience heard by Cancer Council's nurses during the COVID-19 pandemic. Like many countries, Australia's borders closed, movement was restricted and organisations like ours closed its offices.

Hospitals were overwhelmed, forced to make swift decisions about service delivery within the confines of infectious disease control protocols. Non-urgent surgeries were cancelled, appointments delayed, telehealth hastily introduced and restrictions on visitors enforced – distressing patients and loved ones – particularly those in palliative care.

Thousands of people contacted our national information and support line for help. In the state of Victoria, our support line is staffed by experienced oncology professionals, many of whom work clinically. We provide evidence-based informational, practical and emotional support to people affected by cancer.

During the first 4wk of shutdown, we received on average 183 calls each week, up 15% on the same time last year, and approximately half identified COVID-19 as the primary reason for their call.

Our staff operate within a nationally agreed quality framework that sets out the gold standard and minimum requirements for service delivery. Studies have shown that the service can lead to reduced worry, extended support and increased tools to navigate the healthcare system.^{1,2}

Using the Distress Thermometer as part of the overall assessment, we found that distress levels were heightened, compared with the same period last year.³ Nurses described a shift in calls, with people expressing feelings of anxiety and isolation, culminating in longer and more complex calls.

Cancer Council had to quickly change to the way we delivered support. Our priority was to keep our call centre open, so for the first time, calls were diverted to nurses operating from home. We also set up a postal wig service, using photos of patients to guide wig selection and sending patients options to try in their home.

While we offer online and telephone-based peer support, we have more than 120 support groups that are conducted face-to-face. When it became clear it was unsafe to meet in person, we encouraged these groups to use web-based video conferencing to keep people connected and reduce loneliness and isolation.^{4,5}

However, for people who do not know how to use the internet, particularly in older populations, there were technology barriers to overcome.⁶ To assist, we developed a "tech tips" guide, contacted support group leaders to provide advice and featured groups that had made the transition in our communications. Progress has been slow but steady with more than 20% uptake, and there has been positive feedback.

"Overall the experience of using new technology has been overwhelmingly positive and relatively easy," shared Alison. "We even had people in their 70's embracing the new technology and were enthusiastic about the video calls."

The complexity, diversity and frequently changing nature of patient need has meant the effectiveness of our response depended on our ability to gather continuous feedback and to put patients at the centre of our decision making. With health services challenged by the logistics of consumer consultation during COVID-19, Cancer Council has provided vital leadership to ensure that the consumer perspective was integrated into cancer service design as new models of care were implemented.

In addition, we added fields to our database to track COVID-19-related calls and ran weekly analysis to identify emerging and ongoing needs. Used for internal reporting only, this data informed resource development to meet changing information needs, improvements to service delivery and allowed rapid response to emerging advocacy priorities.

In April, COVID-19 was confirmed at a Melbourne hospital and claimed the lives of three cancer patients. It highlighted the vulnerability of patients and heightened fears of attending appointments.

Mother of four Susan is expecting her fifth child and has recently been diagnosed with breast cancer.

"At the moment it feels like cancer has to take a back seat; we have to deal with the coronavirus," Susan said. "It's lonely. All of a sudden it feels like all this support has just been pulled away from you. I'm feeling overwhelmed and anxious but considering how everything's going I'm doing okay."

Unprecedented challenges created impetus for improved sector-wide collaboration.

Cancer Council supported the acute cancer sector to ensure supportive care remained for patients when hospitals rationalised services in planning for the pandemic. We worked closely with one of Victoria's primary treatment centres, which was overwhelmed with calls from current and former patients and carers. Non-urgent calls unrelated to current treatment regimens were redirected to our nurses.

Cancer Council Australia convened a national working group of like-minded cancer charities and our organisation was invited to join the Victorian COVID-19 Cancer Taskforce, established to support clinicians. Our role was to champion the patient voice to influence the delivery of care and information to the cancer community. The taskforce responded quickly to emerging concerns, shared resources, coordinated advocacy and liaised with patient groups and government.

Cancer Council Australia translated "Cancer and COVID-19" fact sheets into 12 languages, and frequently asked questions from patients and carers were developed with leading clinicians and updated regularly to ensure they were relevant and evidence-based.

Most alarming has been the steady decline that Australia has seen in cancer referrals, people visiting their GP, cancer screening and pathology testing.⁶ Concerns that the lack of screening will lead to delayed diagnosis and poorer cancer outcomes is being tackled with a clinician-fronted campaign to allay fears and urge people to visit their doctors.^{6,7}

With the unemployment rate reaching 7.1%, its highest level since 2001,⁸ we are hearing from patients concerned about the loss of income combined with the cost of cancer.

Many studies highlight the out-of-pocket costs associated with a cancer diagnosis.⁹⁻¹² One Australian study found the average out-of-pocket cost for breast cancer was \$4192.¹⁰ Another Australian study reported out-of-pocket costs for prostate cancer was \$9205, with three-quarters of respondents spending up to \$12 000.¹¹ These costs can lead to increased stress and anxiety and decreased quality of life.^{11,12}

Key Points

- Cancer helplines have a long history of offering supportive care around the world
- When COVID-19 reached Australia, the needs of callers changed dynamically and rapidly
- Collaboration across the sector between acute, non-profit and government was critical to providing relevant and timely support
- Opportunity now to embed supportive care into Australia's Optimal Care Pathways

Our financial counsellors have seen inquiries increase in both volume and complexity. Discussions involve alleviating immediate financial pressures through cash grants for groceries and utilities and navigating applications for available social benefits.

"After a successful surgery, the bills all came in, amenities, rent, car registration etc., and a massive ambulance bill," said Vicki, a lung cancer patient diagnosed in March. "I felt like I was drowning and couldn't concentrate on recovery as I thought I would leave hospital to become homeless and have debt collectors chasing me down. Because of this I was suffering shocking nightmares and waking each morning crying my eyes out."

For Australia, early interventions have so far contained the spread of COVID-19 in most states although Victoria is now seeing the impact of a second wave. Despite this resurgence in our state we are seeing positive changes in the healthcare sector that we hope will be long lasting. Collaboration across the sector has been unprecedented on this level, the speed with which information has been developed and shared has been exceptional and decision making because of real-time patient feedback has improved the service delivery.

Yet when restrictions ease, there is further opportunity to look at the way cancer care is delivered. The pressure placed on the acute care system by COVID-19 meant that supportive care was unable to be prioritised. Organisations like ours have helped to fill this gap, demonstrating that people affected by cancer have continued to receive optimal care throughout their cancer experience.

Cancer support services play a vital role in complementing clinical care, by assessing and addressing the unmet needs of people affected by cancer. As healthcare continues to evolve in a post-COVID-19 world, there is an opportunity to further integrate supportive care into promising new models of care like telehealth and chemotherapy in the home.

"When I hung up from that phone call, it was like this huge weight had been taken off my shoulders," said Emma. "The value in that one phone call I had was just incredible. It really has meant the world, not just for me but for my family. And it really has allowed me to focus on healing and getting better."

Please note: 1. Data collected by our organisation during this pandemic was not originally planned for public dissemination or inclusion as

controlled research; therefore, our experiences outlined above are intended to be anecdotal. 2. This article refers to initiatives by both Cancer Council Australia and Cancer Council Victoria. Unless specified, initiatives and experiences outlined are from our organisation, Cancer Council Victoria.

ACKNOWLEDGEMENTS

No specific funding was associated with the preparation of this manuscript. The author would like to thank the individuals who shared their experiences, which was included in this article. The author would also like to acknowledge the assistance of Tamara Blackmore, Amanda Piper, Katherine Lane and Lucy Boyd in preparing the manuscript.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

None.

CONSENT FOR PUBLICATION

None.

CONFLICT OF INTEREST

The author declares that he has no competing interests.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

REFERENCES

- Boltong A, Ledwick M, Babb K, Sutton C, Ugalde A. Exploring the rationale, experience and impact of using cancer information and support (CIS) services: an international qualitative study. *Support Care Cancer*. 2017;25(4):1221-1228.
- Boltong A, Byrnes M, McKiernan S, Quin N, Chapman K. Exploring the preferences, perceptions and satisfaction of people seeking cancer information and support: implications for the cancer council helpline. *Aust J Cancer Nurs*. 2015;16(1):20.
- National Comprehensive Cancer Network. NCCN clinical practice guidelines in oncology: distress management (V2) 2020 [Available from: https://www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf].
- Boyes A, Turon H, Hall A, Watson R, Proietto A, Sanson-Fisher R. Preferences for models of peer support in the digital era: a cross-sectional survey of people with cancer. *Psychooncology*. 2018;27(9):2148-2154.
- Tilkeridis J, O'Connor L, Pignalosa G, Bramwell M, Jefford M. Peer support for cancer patients. *Aust J Gen Pract*. 2005;34(4):288.
- Segelov E. How COVID-19 is impacting cancer treatment in Australia: challenges of 'waiting for the storm'2020; (02/07/2020). Available from: <https://ecancer.org/en/news/17710-how-covid-19-is-impacting-cancer-treatment-in-australia-challenges-of-waiting-for-the-storm>.
- Ijzerman M, Emery J. *Is a Delayed Cancer Diagnosis a Consequence of COVID-19?* Melbourne: University of Melbourne; Pursuit [Internet]. 2020; 2020(01/06/2020).
- Australian Bureau of Statistics. *Labour force, Australia, Detailed, Quarterly*. ACT, Australia: Commonwealth of Australia Canberra; 2020.
- Goldsbury DE, Yap S, Weber MF, et al. Health services costs for cancer care in Australia: estimates from the 45 and up study. *PLoS One*. 2018;13(7):e0201552.
- Gordon LG, Elliott TM, Olsen CM, Pandeya N, Whiteman DC. Out-of-pocket medical expenses for Queenslanders with a major cancer. *Med J Aust*. 2018;208(11):497.
- Gordon L, Walker S, Mervin M, et al. Financial toxicity: a potential side effect of prostate cancer treatment among Australian men. *Eur J Cancer Care*. 2017;26(1):e12392.
- Paul CL, Fradgley EA, Roach D, Baird H, eds. *Impact of Financial Costs of Cancer on Patients-the Australian Experience*. Cancer Forum: The Cancer Council Australia; 2017.

How to cite this article: Spence D. Isolated already, how COVID-19 has exacerbated anxiety for Australian cancer patients. *Psycho-Oncology*. 2020;29:1427-1429. <https://doi.org/10.1002/pon.5478>