

Loneliness and belonging: Exploring experiences with the COVID-19 pandemic in psycho-oncology

Melanie P.J. Schellekens¹ & Marije L. van der Lee^{1,2}

¹Helen Dowling Institute, Scientific Research, Bilthoven, The Netherlands

² Department of Medical and Clinical Psychology, Tilburg University, Tilburg, the Netherlands

Correspondence: mvanderlee@hdi.nl

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5 keypoints:

1. Patients (n=233) felt being part of society again as everyone is advised to stay home.
2. Patients (45.5%) and family members (41.5%; n=41) experience more peace, as lockdown slowed down the pace of life.
3. Patients worry about getting infected (50.5%) and needing treatment on the intensive care unit (58%).
4. Family members mainly worry about infecting the patient (65.9%).
5. Patients (36.3%) and their family (41.4%) feel lonelier because of lockdown regulations.

The COVID-19 pandemic affects people across the world. While the virus appears to infect people of all ages and health status, those with cancer, may be at higher risk for developing critical illness and death (1,2). Besides physical implications, the psychosocial burden that the pandemic puts on people may be especially high for those whose lives have already been affected by cancer. Although people confronted with cancer can be surprisingly resilient, half of cancer patients suffer from significant psychological distress (3). Almost one third of patients develop a psychiatric disorder, such as anxiety and depression (4). Family members, in particular life partners of cancer patients, also experience psychological problems due to the cancer (5). The additional worries caused by COVID-19 and the social distancing regulations can be detrimental for their wellbeing. To address their needs, we explored experiences with the COVID-19 pandemic in patients or family members who sought help at a mental healthcare institute for psycho-oncology (note that family members sought help for themselves, sometimes independently from the cancer patient).

Setting and survey

On March 12th, the Netherlands went into lockdown. At the Helen Dowling Institute, a mental health care institute specialized in psycho-oncology care, psychological care was continued via video-consults and online therapy. Seven weeks after the lockdown, clients (out-patients and family members) were invited to participate in a survey on the psychosocial burden of the COVID-19 pandemic. The study was approved by the ethical board of the Helen Dowling Institute. Of the 871 invited clients, 274 clients (233 patients and 41 family members) responded within two weeks. Clients were mainly diagnosed with an Anxiety Disorder (including Post Traumatic Stress), Somatic Symptom Disorder or Depressive Disorder (see Table 1 for demographic characteristics).

The 12-item survey included questions regarding loneliness, fear of infection and dying from COVID-19. For example: "Due to corona I worry my chemo or other medical treatment will be cancelled". Answers ranged from 0=do not agree at all to 5= totally agree. Scores ≥ 4 were counted as positive. The last question was open-ended: "What impact does COVID-19 have on your life? Please describe in a few sentences how COVID-19 changed your life." Using the thematic analysis approach, the first author (in discussion with the second author) coded the open-ended answers and grouped the codes into the following themes: fear and loneliness, feelings of peace and belonging.

Fear and loneliness

The pandemic adds uncertainty for many patients, leading to additional worries. Their fears mainly concerned getting infected with COVID-19 (50.5%) and requiring treatment on the intensive care unit (58.0%). Many patients worried about being alone in the hospital (45.6%) and not being able to say

farewell to family and friends in case of dying from COVID-19 (44.5%). Family members are mainly worried about infecting the patient (65.9%).

Next to fear, loneliness appeared to be a main concern of many clients: 36.3% of patients and 41.4% of family members reported feeling lonelier than before the pandemic. Many patients described how isolated they now feel. They miss contact with family and friends, which cannot be replaced by a phone call.

Female patient (≥ 70): *'As someone of age who lives alone with cancer this is a very lonely process. I usually get by very well all by myself. But now that all activities outside my home have been cancelled, this is very difficult. My skin craves to be touched. No hugs...'*

These feelings of loneliness seemed to fuel their worries regarding the cancer. Social outings offered a welcome distraction, leading their thoughts away from cancer. With that gone, their life is completely focused on cancer again.

Male partner (50-59): *'Being in isolation with my partner who has cancer, I miss those moments of recharging by going out with my friends and being able to put the cancer on pause. Life is continuously focused on only one thing: cancer. How do we keep going? There is no football match, no festival, no street fair to get your mind of things. Life has become empty. Even the contact with the physician is very limited. There is not much left to be happy about.'*

On the positive side: feelings of peace and belonging

For those who have their whole family at home during the lockdown, it was busy, often creating extra tension. However, a large group of patients (45.5%) and family members (41.5%) felt more at ease because of the lockdown. The overload of the external stimuli of daily life had fallen away. This created a sense of peace and seems to ease their worries.

The lockdown offered people time to reflect positively on their lives: 39.8% of patients and 36.6% of family members expressed they were now able to focus more on things that are really important to them.

Female patient (50-59): *'This situation has thrown me back onto myself instead of reaching out to others. Surprisingly, this stimulated my self-reliance which suits me well. I am more in contact with what is truly important/valuable to me. Of course I am bored at times, or think it sucks that contact with others is so limited. But in the end I feel good, less of a victim.'*

Several patients described how they were already used to staying at home. Now that everyone stays indoors, they do not feel left out anymore, which reinstates a sense of belonging.

Female patient (50-59): *'Currently, also all of my colleagues are working from home. Now I am not the only one anymore who dials in (per phone/video) at meetings, and I see that as an advantage.'*

Implications

For many clients, who already suffered from mental problems due to cancer, the COVID-19 pandemic caused additional fears. The loneliness they feel because of the lockdown regulations, seems to increase their worries. For others, the pandemic created a sense of peace. It gave them time to reflect on things that are truly important to them. Moreover, they felt being part of society again, as everyone has to stay home and limit their social contacts.

These positive experiences can provide input for helping patients and family members to cultivate resilience. For example, therapists can help clients to explore what values are important to them and how they can live by these values, also in case their activities are limited due to cancer and lockdown. Acceptance and Commitment Therapy includes exercises for living a meaningful life, that can inspire therapists and clients (6). The sense of peace and belonging that people felt, may be maintained if the stories of these patients become known to the general public. Remembering the restrictions of isolation and knowing that cancer patients and family members are living unremittingly this way, increases understanding, which might mitigate the feeling of being left-out.

To be prepared for a future lockdown, it may be helpful to urge clients to seek safe forms of social contact. E.g. people living alone could choose one or two friends or family members that they keep in (physical) contact with, with the precaution that these contacts should isolate themselves apart from the contact with the patient. Also (online) contact with people in the same boat, that does not focus on cancer, but rather on the consoling things in life, might be helpful.

These findings might facilitate communication between clients and healthcare professionals. When fears and feelings of loneliness are addressed and normalized, it often relieves accompanying distress. Importantly, addressing these feelings might also help to take the step to seek psychological care if needed.

Data availability

The data that support the findings of this study are available from the corresponding author upon reasonable request. The data are not publicly available due to privacy or ethical restrictions.

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Table 1. Demographic characteristics of the 274 survey respondents.

| | 233 patients n (%) | 41 family members n (%) |
|---------------------------------------|------------------------------|-----------------------------------|
| Sex, female | 172 (73.8) | 28 (68.3) |
| Age | | |
| <30 | 8 (3.4) | 1 (2.4) |
| 30-39 | 25 (10.7) | 8 (19.5) |
| 40-49 | 40 (17.2) | 8 (19.5) |
| 50-59 | 77 (33.0) | 12 (29.3) |
| 60-69 | 62 (26.6) | 10 (24.4) |
| ≥70 | 21 (9.0) | 2 (4.9) |
| Living situation | | |
| Alone | 45 (19.3) | 11 (26.8) |
| With partner | 76 (32.6) | 11 (26.8) |
| With partner and children | 98 (42.1) | 14 (34.1) |
| With children | 12 (5.2) | 4 (9.8) |
| With parents | 1 (0.4) | 1 (2.4) |
| Education | | |
| Primary/lower secondary | 12 (5.2) | 3 (7.3) |
| Upper secondary | 90 (39.1) | 12 (29.3) |
| Higher vocational training/university | 124 (53.3) | 25 (61.0) |
| Start psychological treatment | | |
| Prior 2019 | 52 (22.3) | 15 (36.6) |
| Since 2019 | 94 (40.3) | 15 (36.6) |
| Since 2020 | 87 (37.3) | 11 (26.8) |