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Psychosocial Impact of COVID-19 on Cancer Patients and their Caregivers: A Qualitative Exploration

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Title: Psychosocial Impact of COVID-19 on Cancer Patients and their Caregivers: A Qualitative Exploration

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Abstract

Objectives: Having to access life-sustaining treatment during the emerging COVID-19 outbreak has placed cancer patients at an especially vulnerable position notwithstanding their immunocompromised condition. The present study aimed to elucidate cancer patients' and their caregivers' experiences during this outbreak.

Design: Face-to-face semi-structured interviews were conducted.

Setting: A tertiary cancer care facility.

Participants: 16 patients with cancer and 14 caregivers. Inclusions criteria were a) diagnosed with cancer, b) receiving active treatment or follow-ups, c) aged 21 and above, and d) fluent in English or Mandarin.

Results: Thematic analysis was conducted. Five themes were identified: *heightened sense of threat*, *impact on healthcare experience*, *responsibility falls on oneself*, *striving for normalcy,* and *sense of safety and trust*. Heightened threat of COVID-19 was more pronounced in patients and linked to fearing COVID-19, uncertainty, actions of socially irresponsible others, and its social and economic ramifications. Dominant in their healthcare experience was prioritizing cancer and treatment amidst heightened threat and anticipatory worry about treatment disruptions. Both noted on the importance of taking responsibility for one's health, with caregivers reporting a reinforces sense of duty towards patients. They strived to maintain normalcy by viewing COVID-19 as beyond personal control, downplaying, and living life as usual. Their resolve was supported by a sense of safety from the actions of authorities, hospitals, and trust towards healthcare providers.

Conclusions: Cancer intensifies threat and the emotional impact of COVID-19 and may trigger specific concerns related to treatment. Psychoeducation interventions led by healthcare providers over digital platforms could help address cancer-specific concerns and support patients and caregivers during the pandemic.

(258 words)

Keywords: oncology; thematic analysis; coronavirus; infectious disease; interview

Article Summary

Strengths and limitations of this study

- A timely qualitative analysis of psychosocial impact of COVID-19 on cancer patients and caregivers
- This study highlights the heightened threat and risks cancer patients face during the COVID-19 outbreak and proposes the need for healthcare services to incorporate psychosocial support on cancer management
- The rapidly evolving nature of the COVID-19 situation limits the generalizability of the findings to later phases of the pandemic
- Future qualitative work at later phases of the pandemic and with various population groups is warranted

Background

Following the first reported case in Wuhan in late 2019, the novel coronavirus disease—termed coronavirus disease 2019 (COVID-19)—has since been declared a pandemic by the World Health Organization (WHO) after its rampant spread to multiple countries. Infectious disease outbreaks such as the emerging COVID-19 pandemic present major challenges to global public health and individual health. No less important are the psychological costs and mental health implications. Prior work in SARS and H1N1 alongside emerging work on COVID-19 has documented adverse psychological responses and psychiatric morbidity for frontline healthcare workers, infected patients and the general population that may persist over time (1–8). Emotional responses such as fear and anxiety have been shown to influence actions, some of which may be undesirable. Self-isolation, stigmatization, non-disclosure or non-treatment-seeking behaviors noted in the Ebola outbreak (9) contributed to community spread and compromised efficiency of healthcare systems (10,11). While the emotional and behavioral impact of infectious outbreaks are well-documented for the general population, infection survivors and frontline healthcare workers, the literature on patient populations is scarce (1–5).

Accessing healthcare during infectious disease outbreaks can be challenging and emotionally-laden especially in patient populations for whom treatment cannot be deferred or delivered over telemedicine, such as cancer. Cancer treatment results in an immunosuppressed condition, increasing vulnerability to infection or risk for poor prognosis if infected (12,13). In patients with COVID-19 infections, those with comorbid cancer deteriorated more quickly and were at higher risk of developing severe events (12,13). In addition, a cross-sectional study of patients with diverse health conditions noted poor awareness of COVID-19 and worry about COVID-19 was mixed (14). However, none of these studies have explored the perspectives of individuals affected by cancer regarding COVID-19. To design and effectively optimise psychosocial care and interventions to support cancer patients and their caregivers, it is important to understand their experience with treatment and their needs during the COVID-19 pandemic.

The present study thus sought to explore the emotional impact of and behavioral responses to COVID-19, focusing specifically on cancer patients and their caregivers.

Methods

This study adopted a qualitative methodology involving semi-structured interviews. Ethics was approved by Singhealth Centralised Institutional Review Board (CIRB reference: 2020/2155).The paper was structured following COnsolidated criteria for REporting Qualitative research (COREQ) guidelines (15).

Setting and Participants

Study sample included cancer patients and caregivers recruited between 9th to 13th March 2020 from the National Cancer Centre Singapore (NCCS), a tertiary care facility serving a culturally and ethnically heterogeneous population. During the week of recruitment, WHO declared the outbreak a pandemic and local case numbers rose from 160 to 200 (see Table 1).

Target sample size was 15 to 20 individuals per group as recommended to achieve theme saturation (16). Maximum variation sampling procedures were applied to ensure diversity in terms of cancer treatment. Inclusion criteria for patients were: (a) diagnosed with any type of cancer, (b) receiving active treatment or follow-ups, (c) aged 21 and above, (d) fluent in either English or Mandarin. Those only fluent in dialects or unable to give consent due to cognitive or psychiatric diagnoses were excluded. Caregivers of eligible patients were also recruited if they satisfied criteria (c)-(d) and provided consent.

Data Collection

Semi-structured interviews were conducted during follow-up appointments or active treatment. Informed consent and permission to record were obtained prior to data collection. Interviews were conducted in a private area in NCCS (three were conducted in the ward) in English or Mandarin by two research coordinators (SMF, DI) and one oncologist (KYYN). All interviewers were based in NCCS and had graduate qualifications and experience with qualitative methodology. Interviews were audio-recorded and field notes were noted. Participants' sociodemographic and clinical characteristics were documented. Recruitment stopped upon thematic saturation.

Interview guides were formulated based on relevant literature and incorporated expert input: JYYN and KYYN on clinical perspectives, KG on qualitative health research expertise. Patient and caregiver interview guides were similar, comprising nondirective, open-ended questions about perceptions and experiences of accessing healthcare and cancer treatment, emotions and concerns regarding their risks during the COVID-19 outbreak and their behavioral responses. Questions and prompts were refined iteratively to enable topics which had not been previously identified to be pursued in subsequent interviews (see supplementary materials). Interview content and procedures were pilot tested with two patients and two caregivers, who provided feedback on relevance, clarity and acceptability of questions and procedures, hence serving as critical reference group for data trustworthiness (17).

Patient and Public Involvement

Due to the rapidly evolving COVID-19 situation and measures related to patient contact, it was not possible to engage patients or the public in the development of this study. Patient and caregivers' input with regard to all study procedures was however solicited during the pilot.

Analytical Approach

Thematic analysis was conducted including: familiarization with the data, identifying initial codes, identifying initial themes, reviewing and revising themes, and naming and assigning descriptions to themes (18). Interview audio-recordings were transcribed verbatim by study team (ZYC, ZSG, JMXC). Mandarin interviews were translated directly into English and translations verified. No specialized qualitative software was used. Patient and caregiver interview transcripts were coded and analyzed separately by two sets of coders (Patient: JMXC, ZYC; Caregiver: ZSG, KYYN) under supervision of KG. A combination of deductive and inductive coding was used. Deductive codes first derived from the topic guide were refined and supplemented by inductive codes emerging from interviews. Semantic meanings were first coded, with themes and sub-themes later identified to generate two codebooks (one each for patient and caregivers). These were contrasted and reviewed by study team (ZSG, ZYC, JMXC, KG) and merged into a master codebook which was used to recode all interviews. When relevant, themes unique to either participant group were noted.

The trustworthiness was examined using established criteria (19). To ensure credibility, pretesting and feedback was sought before recruitment. During recruitment, participants were prompted to elaborate on their responses to enrich data (i.e., prolonged engagement). We used investigator triangulation, in which study team discussed the axial and selective coding and data interpretation (20). The specific context was noted and highlighted where relevant to comment on transferability of results. Regarding the dependability and confirmability, an audit trail was kept from project start to data dissemination.

Results

Of the 41 eligible individuals approached, 30 consented (16 patients and 14 caregivers; response rate=73.2%). Six patients and six caregivers were related. Reasons for decline included a lack of time and unwillingness to be audio-recorded. Interviews were conducted in English (*n*=23) and Mandarin (*n*=7). Table 2 presents the socio-demographics of the sample. Mean age was 60.1 for patients (*SD*=14.4) and 53.6 for caregivers (*SD*=11.2). Participants were predominantly Chinese (83.3%). Caregivers tended to be the spouse or the child of the patient. Most patients reported receiving chemotherapy (81.3%), with a minority reporting additional radiotherapy (12.5%) or medication (6.3%).

Themes were found to be highly consistent across both groups except for one subtheme unique to caregivers (i.e. *duty towards the patient*) and one unique to patients (i.e. *beyond personal control*). Codes in patients' and caregivers' interviews were merged to produce five higher-order themes: *heightened sense of threat and risk*, *impact on healthcare experience*, *responsibility falls on oneself*, *striving for normalcy,* and *sense of safety and trust* (see Figure 1 and Table 3 for illustrative quotes for each subtheme).

Heightened sense of threat and risk

The first theme captured the heightened salience of the threat and risk posed by COVID-19, common across patients and caregivers. Four sub-themes were delineated: 1) fearing COVID-19, 2) air of uncertainty, 3) socially irresponsible others, and 4) social and economic implications.

Fearing COVID-19. COVID-19 was regarded as a prominent source of threat and elicited fear and worry among patients and caregivers.

Patients regarded COVID-19 as a dangerous illness, describing strong fears of contracting COVID-19 and were often pessimistic about recovery from COVID-19. “The chances of me surviving, I think it's very slim lah. Because I will be physically very weak, and the virus will go for the weak people” (P03). They perceived the threat of COVID-19 and often related it to their vulnerability from being immunosuppressed. Caregivers also worried over patients being more vulnerable to the disease, as the patient's “immune system is a bit weaker than mine, so I'm more concerned for him than me” (C02). They prioritized the patients' health over themselves: “The risk is not worrying that I get it. The risk is I'm worrying my loved one, my dad will get it” (C27).

Both patients and caregivers expressed worry about increased risk of exposure of COVID-19 in hospitals and from being near other patients. Many desired to minimize time spent at hospitals, wanting to “complete this and leave the hospital as it's more dangerous here” (P16).

Air of uncertainty. For patients and caregivers, uncertainty surrounding COVID-19 was noted to intensify their threat perceptions. This uncertainty was centered on the ambiguity of COVID-19, such as not knowing its “incubation period” (C17). Patients and caregivers were distressed by the possibility of asymptomatic transmissions, stating they “never know if the person beside you might have the illness, such as your friends talking to you” (C15). Many spoke about feeling unsure about how the COVID-19 situation would turn out: “we know that [SARS] ended after eight months but for this one currently we don't know how long it's going to last and how severe it's going to get” (P05).

Socially irresponsible others. Patients and caregivers both attributed the elevated threat to the actions of others. Many described instances in which others exhibited socially irresponsible behaviors such as “falsely declaring their health” (P11) and expressed a lack of confidence in other people’s ability to uphold good hygiene practices.

Social and economic implications. Patients and caregivers alike spoke about facing additional restrictions on their personal life due to COVID-19. Some felt more wary about going out, while others lamented the disruptions to their social arrangements and religious activities. Many raised concerns about the repercussions of COVID-19 on the economy.

For caregivers, their restrictions were self-imposed with the patient in mind: “I told everyone I’m not going out anywhere because his uh lungs is not that well so I will not take a risk” (C27).

Impact on healthcare experience

Despite the heightened threat and uncertainty, patients and caregivers were unanimous in prioritizing cancer and treatment and valued uninterrupted access to services. Additional protocols implemented by healthcare institutions in response to COVID-19 changed the overall experience of accessing care but were deemed necessary by many.

Prioritizing cancer and cancer treatment. COVID-19 was a threat but not as imminent or grave as cancer: “cancer is worse, it kills people. This COVID-19 is for you to take precaution” (P30). Both patients and caregivers were insistent in adhering to their cancer treatment regime and not to defer, emphatically stating that “treatment still has to go on” (C19). They reasoned that deferment may worsen the cancer: “if you deferred, there might be aggressive type of cancer that might that might come back” (C18). Both were worried that treatment may be disrupted by COVID-19: I am just afraid that if I am sick then I cannot do [cancer treatment]. And I have to postpone another month (P16).

Necessary disruptions by new procedures. Several measures were implemented in response to COVID-19 including mandatory temperature screening and a reduction in visitor quota. Both patients and caregivers appreciated their necessity and accepted the associated minor inconveniences as “a bit troublesome but it is a good procedure” (P12).

Responsibility falls on oneself

Both patients' and caregivers' accounts highlight the importance of "taking responsibility" to keep healthy. For caregivers, sense of responsibility included "duty towards the patient".

Recognizing the importance of personal responsibility. Patients and caregivers were concordant in taking enhanced precautions to stay safe such as increasing hygiene practices, wearing masks, avoiding social contact, being proactive in seeking out information related to COVID-19. Some made adjustments to their routines such as only going out during "off peak hours not when the crowd is there" (P20) or staying home as "that's the only safest thing that you can do" (P11). For patients, they reiterated the importance of self-reliance, that "now you have no choice, you can only protect yourself" (P29) against COVID-19. Many of these behaviors were already in place before COVID-19 as result of living with cancer.

Besides making behavioral changes to their routine, patients and caregivers recognized that every individual's actions had on a wider impact on the collective whole. They recognized that managing COVID-19 was a joint effort such that, "if everybody comply, if every individual comply, then your problem is minimized" (C23).

Duty towards the patient. A deeply held sense of duty to care was uniquely expressed by caregivers that comprised caregiving, COVID-19 related actions and self-care. First, caregivers put it upon themselves to ensure that the patient takes necessary precautions to reduce their risk of contracting COVID-19 by actively enforcing or supporting patients' actions. Second, caregivers will take their own precautions against COVID-19 to ensure that they remain well to continue providing care: "I have to send my son to chemo, that I take care of him, so I have to protect myself" (C25). They expressed the need to protect themselves as they did not want to be the carrier to pass the disease to the patient.

Striving for normalcy

The fourth theme encapsulates patients' and caregivers' cognitive and behavioral responses to preserve normalcy in their lives amidst the COVID-19 outbreak. They viewed the outbreak as beyond one's personal control, rationalized and downplayed threat, and focused on living life as per normal.

Beyond personal control. Specific to patients, many spoke about their belief that circumstances related to COVID-19 were out of their personal control. They described an inability to exert control over contracting COVID-19: "if it's really fated then you have no choice" (P16). This inevitability was present regardless of precautions: "you can get it even if you stay at home. You will get it if you are fated to" (P13).

Downplaying. Despite being threatened by COVID-19, patients and caregivers made attempts to downplay risks and personal relevance. They rationalized and extrapolated based on prior infectious outbreaks: “SARS is more fatal. The COVID-19, if treated properly, is nothing much” (P07). Others likened the nature of COVID-19 to “something like a normal flu” (P12) and perceived possible recovery from COVID-19 should they contract it. While they recognized that patients were more vulnerable given their weaker immunity, many patients and caregivers downplayed the personal relevance of COVID-19 due to them mostly staying home and always wearing masks when outside. Wearing of masks was regarded to provide extra protection from COVID-19: “’cause I know my immunity is low, so I felt that I better wear a mask” (P08) and many felt “more assured” (P14) by wearing masks in crowded spaces or hospitals.

Living life as per normal. Patients and caregivers both described having gone about with their daily routines amidst the COVID-19 situation, as “life still goes on, it doesn’t change much, except that we have to be more vigilant” (P03). Others adopted more precautions, but generally perceived that COVID-19 had no change to their life. Some patients described minimal disruptions to cancer treatment: “I have to prepare myself [for the appointment] and go earlier. So that’s about it the only thing” (P08).

Sense of safety and trust

The final theme reflects the general perception of safety and trust patients and caregivers held in authorities and healthcare providers. Some also expressed hope for cure or vaccine for COVID-19.

Confidence in authorities' management. Patients and caregivers expressed huge confidence in how the local government and healthcare institutions had managed the COVID-19 outbreak and reflected that the local COVID-19 situation was kept under control. They articulated a willingness to comply with government directives and believed that they will be “fine as long as we abide, because we feel that we are very safe- it’s well managed here” (C10). In particular, they spoke about feeling assured by the high healthcare standards, that they “find it safer to be in hospital” (C22).

Trust in healthcare providers. Healthcare providers were regarded as highly competent by both patients and caregivers. This competence was described broadly to encompass several aspects from managing cancer treatment, treating COVID-19 to maintaining good hygiene standards. Many commended healthcare providers and were cognizant of their sacrifices, illustrated in statements like “they're working longer hours… so fatigue comes in, but they don't show it when they're on duty” (P24). Healthcare providers were also relied on for guidance and advice, especially regarding cancer treatment.

Hoping for a cure. Notably, patients and caregivers spoke about wanting a "cure" or a solution to the COVID-19 situation. They hoped that authorities would successfully develop a treatment or vaccine for COVID-19: "just hope that you doctors can quickly have a medication to cure the illness. So that we all can live a peaceful life" (P13).

Discussion

Infection outbreaks bring about changes in all domains of life including healthcare, leaving an emotional toll on healthcare users, healthcare providers and general population. While clinical efforts are duly directed towards those considered more vulnerable, the scarce research on patient populations cannot adequately inform health service optimization during these extraordinary times. This study attempted to bridge the gap by exploring the psychosocial impact of COVID-19 on patients and caregivers during the outbreak in Singapore.

Five themes were generated which were salient in both patient and caregiver accounts: heightened sense of threat and risk, impact on healthcare experience, responsibility falls on oneself, striving of normalcy, and sense of safety and trust. The themes painted a diverse and seemingly contradictory experience whereby heightened threat due to uncertainty and irresponsible others co-occurred with sense of safety and trust, and efforts to pursue and reestablish normalcy. Concurrent positive and negative experiences have also been documented in other qualitative studies (21). Among nursing staff caring for COVID-19 patients, negative emotions of fear, helplessness and guilt dominated the initial stages of the outbreak followed by more positive feelings of gratitude, confidence and calmness (21). This thematic diversity underscores that patients' and caregivers' experiences amid the outbreak are multifaceted and nuanced.

Living with and managing treatment for cancer is an emotionally charged journey that has intensified during the pandemic. Dominating the accounts was a heightened perception of threat specific to COVID-19, adding but not superseding the threat related to cancer. Heightened threat was attributed to uncertainty, limited understanding of virus and disease course, and potential contagion due to socially irresponsible others, as shown in prior work on infectious disease outbreaks (22). COVID-19 was deemed more threatening for patients as their frail health and compromised immunity made them more vulnerable to infection and poorer prognosis, as noted with other patient groups during SARS and H1N1 (23,24). Threat was interlinked with worry and fear. Cancer and need for treatment added to their fears as both parties wondered about cancer treatment during the pandemic. They noted that cancer treatment is dependent on patients' good health and expressed anticipatory anxiety of potential treatment disruptions due to COVID-19 and its impact on cancer outcomes. Both groups were concordant and adamant in prioritizing cancer and would not consider deferment of treatment unless advised by their healthcare providers. This contrasts reports in other (non-cancer) patient groups during SARS and Ebola (10,11). Prioritizing cancer treatment could be regarded as an extension of taking responsibility for one's (or the patient's) health; besides practicing appropriate precautionary measures, both patients and caregivers acknowledge that they had to comply with treatment demands to manage the patient's condition.

Counterbalancing the threat of COVID-19, patients and caregivers expressed safety and trust in regulatory measures and stepped up actions of personal responsibility and actions to maintain normalcy (25). They detailed behaviors such as handwashing, avoiding social interactions and crowds, or wearing of masks to reduce likelihood of infection. For some, these behaviors had already been cultivated into established routines prior to COVID-19 due to cancer. They both emphasized the importance of playing their part for the collective good. Unique to caregivers was an unwavering duty towards patients that encompassed care towards self and patients. The pandemic had spurred caregivers to be more conscientious about their own health so as to maintain their capacity to care for patients. However, this can lead to additional burden, stress and negatively affect caregivers' health (26,27).

To navigate the pandemic, patients and caregivers strived for normalcy. This theme referred to cognitive processes and behaviors, namely reframing threat as beyond personal control, downplaying risk and living life as per normal. Downplaying risk involved a reassurance of safety that was linked to behaviors such as staying home or wearing masks, or prior experience with SARS. Patients discussed COVID-19 as beyond their control (often with term "fated") that prompts them to redirect attention on living life and treatment. This suggests in the face of an unpredictable and novel threat, fatalism may be adaptive and reflect acceptance of the situation. Patients' and their caregivers' experiences with cancer could have conferred a general hardiness or resilience (28,29) that extended to their experience with COVID-19.

The sense of safety and trust towards authorities also buffered the heightened sense of threat and risk and provided a semblance of normalcy. During data collection, the number of confirmed cases in Singapore bordered on 200 with no fatalities and ranged from 1 to 12 new cases each day. These relatively low numbers may have boosted patients' and caregivers' confidence in accessing healthcare. Safety was discussed both as a general feeling of security and preparedness by authorities/hospitals, and trust towards healthcare providers. Patients and caregivers held a deep appreciation for healthcare providers for their contributions during the pandemic and relied on them to navigate health-related matters.

Clinical Implications

Findings have important implications for clinical practice. It is evident that access to cancer treatment remains at the forefront of patients' and caregivers' agenda as they continue to prioritize cancer treatment over COVID-19 threats, underscoring the need for continuity in health services. Services need to incorporate psychosocial support as patients report elevated threat, worry and fear related to COVID-19 and its impact on cancer management. Efforts should target both general COVID-19 concerns that pertain to the whole community and cancer-specific concerns about COVID-19 unique to individuals stricken by cancer. Cancer-specific concerns involving disruptions to treatment-related procedures cause anticipatory anxiety that may compromise emotional wellbeing. These concerns may not be proactively shared in consultations but should be elicited and addressed. The firm trust placed on oncology healthcare providers strategically positions them to support such conversations. Alternative arrangements such as tele-consultations can facilitate psychological support and scaffolding. These platforms become even more pertinent during the times of pandemic with social distancing policies and visitor limitations (30). Caregivers should also be supported to buffer against burnout. Ensuring caregiver wellbeing has important implications for the patients' care. Caregiver support in the form of dyadic coping influences the level of psychological distress and adjustment in patients across various cancer contexts (31–34). Finally, while institutional safety measures implemented may incur additional inconveniences, our study suggests it bolsters confidence in the institution and provide patients and caregivers with a sense of safety.

Study Limitations

Study limitations should be acknowledged. As the COVID-19 pandemic is rapidly evolving, the time-sensitive nature of the findings limits the generalization to later phases of the pandemic or to other countries. Selection bias may be present as patients and caregivers who do not present at NCCS would not have been approached and been indirectly excluded from the study. At the time of writing, local cases have breached the thirty-thousand mark with foreign worker dormitories facing the brunt of new infections. Future work should seek to elucidate the impact of the pandemic at later phases and from different population groups, particularly those who may have opted to stray from treatment care. This would serve to inform and improve health-related policies to better meet the needs of these healthcare users.

The threat induced by COVID-19 has amplified concerns surrounding cancer treatment among cancer patients and their caregivers. Patients and caregivers intensify precautionary behaviors and strive to maintain normalcy but worry of risks to patients and impact of the pandemic on cancer treatment plans. Digital mental health services led by healthcare providers could serve address these specific concerns and provide a sustained line of support to patients and caregivers during these tumultuous times.

Author Contributions

KYYN, DN, ZSG, ZYC, JMXC, KG, JYYN conceived, designed the study. KYYN, DN, SMF collected the data. JMXC, ZSG, ZYC, KYYN, KG analyzed the data. All authors interpreted the data and were involved in the development, review, and approval of the manuscript.

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Competing Interest Statement

The authors have no conflicts of interest to disclose.

Data Availability

The thematic data that support the findings of this present study are available from the corresponding author upon reasonable request.

References

1. Lu T-H, Chou Y-J, Liou C-S. Impact of SARS on healthcare utilization by disease categories: Implications for delivery of healthcare services. Health Policy (New York). 2007;83(2–3):375–81.

2. Teasdale E, Yardley L. Understanding responses to government health recommendations: Public perceptions of government advice for managing the H1N1 (swine flu) influenza pandemic. Patient Educ Couns [Internet]. 2011;85(3):413–8. Available from: http://dx.doi.org/10.1016/j.pec.2010.12.026

3. Wong ELY, Wong SYS, Lee N, Cheung A, Griffiths S. Healthcare workers' duty concerns of working in the isolation ward during the novel H1N1 pandemic. J Clin Nurs. 2012;21(9–10):1466–75.

4. Cava MA, Fay KE, Beanlands HJ, McCay EA, Wignall R. Risk perception and compliance with quarantine during the SARS outbreak. J Nurs Scholarsh. 2005;37(4):343–7.

5. Tiwari A, Chan S, Wong A, Tai J, Cheng K, Chan J, et al. Severe acute respiratory syndrome (SARS) in Hong Kong: Patients' experiences. Nurs Outlook. 2003;51(5):212–9.

6. Hategan A, Abdurrahman M. Hidden in plain sight: Addressing the unique needs of high risk psychiatric populations during COVID-19 pandemic. Psychiatry Clin Neurosci [Internet]. 2020 May 5;n/a(n/a). Available from: https://doi.org/10.1111/pcn.13022

7. Shigemura J, Ursano RJ, Morganstein JC, Kurosawa M, Benedek DM. Public responses to the novel 2019 coronavirus (2019-nCoV) in Japan: Mental health consequences and target populations. Psychiatry Clin Neurosci [Internet]. 2020 Apr 1;74(4):281–2. Available from: https://doi.org/10.1111/pcn.12988

8. Sani G, Janiri D, Di Nicola M, Janiri L, Ferretti S, Chieffo D. Mental health during and after the COVID-19 emergency in Italy. Psychiatry Clin Neurosci [Internet]. 2020 Apr 4;n/a(n/a). Available from: https://doi.org/10.1111/pcn.13004

9. Zhu X, Wu S, Miao D, Li Y. Changes in emotion of the Chinese public in regard to the SARS period.(severe acute respiratory syndrome)(Report). Soc Behav Personal an Int J. 2008;36(4):447.

10. Chang H-J, Huang N, Lee C-H, Hsu Y-J, Hsieh C-J, Chou Y-J. The impact of the SARS epidemic on the utilization of medical services: SARS and the fear of SARS.(Severe acute respiratory syndrome)(Brief Article). Am J Public Health. 2004;94(4):562.

11. Carter SE, O'Reilly M, Walden V, Frith-Powell J, Umar Kargbo A, Niederberger E. Barriers and Enablers to Treatment-Seeking Behavior and Causes of High-Risk Practices in Ebola: A Case Study From Sierra Leone. J Health Commun.

2017;22(sup1):31–8.

12. Liang W, Guan W, Chen R, Wang W, Li J, Xu K, et al. Cancer patients in SARS-CoV-2 infection: a nationwide analysis in China. Lancet Oncol. 2020;21(3):335–7.

13. Williamson E, Walker AJ, Bhaskaran KJ, Bacon S, Bates C, et al. OpenSAFELY: factors associated with COVID-19-related hospital death in the linked electronic health records of 17 million adult NHS patients. medRxiv [Internet]. 2020 Jan 1;2020.05.06.20092999. Available from: http://medrxiv.org/content/early/2020/05/07/2020.05.06.20092999.abstract

14. Wolf MS, Serper M, Opsasnick L, O'Conor RM, Curtis LM, Benavente JY, et al. Awareness, Attitudes, and Actions Related to COVID-19 Among Adults With Chronic Conditions at the Onset of the U.S. Outbreak. Ann Intern Med. 2020;

15. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. Int J Qual Heal Care. 2007;19(6):349–57.

16. Creswell JW. Qualitative Inquiry and Research Design. Qualitative Inquiry and Research Design. 2013.

17. Wadsworth Y. What is Participatory Action Research? Action Res Int [Internet]. 1998;Paper 2(November):1–23. Available from: www.scu.edu.au/schools/gcm/ar/ari/p-ywadsworth98.html

18. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.

19. Elo S, Kääriäinen M, Kanste O, Pölkki T, Utriainen K, Kyngäs H. Qualitative Content Analysis: A Focus on Trustworthiness. SAGE Open [Internet]. 2014 Jan 1;4(1):2158244014522633. Available from: https://doi.org/10.1177/2158244014522633

20. Korstjens I, Moser A. Series: Practical guidance to qualitative research: part 4: trustworthiness and publishing. Eur J Gen Pract. 2017;1–5.

21. Sun N, Wei L, Shi S, Jiao D, Song R, Ma L, et al. A qualitative study on the psychological experience of caregivers of COVID-19 patients. Am J Infect Control [Internet]. 2020;000:3–9. Available from: https://doi.org/10.1016/j.ajic.2020.03.018

22. Teasdale E, Santer M, Geraghty AWA, Little P, Yardley L. Public perceptions of non-pharmaceutical interventions for reducing transmission of respiratory infection: Systematic review and synthesis of qualitative studies. BMC Public Health. 2014;14(1).

23. Siu JYM. Another nightmare after SARS: Knowledge perceptions of and overcoming strategies for h1n1 influenza among chronic renal disease patients in Hong Kong. Qual Health Res. 2010;20(7):893–904.

24. Rubin GJ, Amlôt R, Carter H, Large S, Wessely S, Page L. Reassuring and managing patients with concerns about swine flu: Qualitative interviews with callers to NHS Direct. BMC Public Health. 2010;10.

25. Lazarus RS, Folkman S. Transactional theory and research on emotions and coping. Eur J Pers. 1987;1(3):141–69.

26. Hodges LJ, Humphris GM, Macfarlane G. A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers.(Author Abstract). Soc Sci Med. 2005;60(1):1.

27. Bevans M, Sternberg EM. Caregiving burden, stress, and health effects among family caregivers of adult cancer patients.(Case study). JAMA, J Am Med Assoc. 2012;307(4):398.

28. Seiler A, Jenewein J. Resilience in cancer patients. Front Psychiatry. 2019;10(April).

29. Walshe C, Roberts D, Appleton L, Calman L, Large P, Lloyd-Williams M, et al. Coping well with advanced cancer: A serial qualitative interview study with patients and family carers. PLoS One. 2017;12(1):1–25.

30. Blackstone E, Lipson AR, Douglas SL. Closer: A videoconference intervention for distance caregivers of cancer patients. Res Nurs Health. 2019;42(4):256.

31. Regan TW, Lambert SD, Kelly B, McElduff P, Girgis A, Kayser K, et al. Cross-sectional relationships between dyadic coping and anxiety, depression, and relationship satisfaction for patients with prostate cancer and their spouses. Patient Educ Couns [Internet]. 2014;96(1):120–7. Available from: http://dx.doi.org/10.1016/j.pec.2014.04.010

32. Badr H, Herbert K, Bonnen MD, Asper JA, Wagner T. Dyadic coping in patients undergoing radiotherapy for head and neck cancer and their spouses. Front Psychol. 2018;9(OCT).

33. Feldman BN, Broussard CA. Men’s adjustment to their partners’ breast cancer: A dyadic coping perspective. Heal Soc Work. 2006;31(2):117–27.

34. Van Schoors M, De Paepe AL, Lemiere J, Morez A, Norga K, Lambrecht K, et al. Family Adjustment When Facing Pediatric Cancer: The Role of Parental Psychological Flexibility, Dyadic Coping, and Network Support. Front Psychol. 2019;10(December):1–12.

Table 1

Overview of the COVID-19 situation in Singapore during study recruitment

Date	New cases (Imported)	Discharged	Overall	Active cases (In ICU)	Significant event(s)	New measures taken
9 March	10 (3)	3	160	67 (10)	7 local clusters identified Italian cruise ship Costa Fortuna returning as scheduled on 10 March 2020	
10 March	6	0	166	73 (12)	Singapore allowed 600 passengers to disembark from Costa Fortuna	Suspension of activities for seniors
11 March	12 (1)	3	178	82 (9)		
12 March	9 (5)	0	187	91 (9)	COVID-19 announced a pandemic by the World Health Organization	Islamic Religious Council of Singapore announced the closure of all mosques for five days from 13 March for disinfection

13 March	13 (9)	1	200	103 (11)		Singapore suspends events and gatherings of 250 people or more Singapore announced a ban on visitors arriving from Italy, France, Spain and Germany from 15 March Singapore ceased port calls for all cruise vessels with immediate effect

Table 2

Sample socio-demographic and clinical characteristics

Characteristics	**Patients (*n* = 16)**	**Caregivers (*n* = 14)**
Age in years, Mean ± *SD*	60.1 ± 14.4	53.6 ± 11.2
Gender—female, *n* (%)	6 (37.5)	10 (71.4)
Ethnicity (%)		
Chinese	81.3	85.7
Malay	12.5	7.1
Indian	0	7.1
Others	6.3	0
Educational attainment (%)		
Primary school	6.3	0
Secondary school	56.3	35.7
Polytechnic diploma	12.5	7.1
Graduate degree	18.8	35.7
Post-graduate degree	6.3	14.3
Other	0	7.1
Employment status (%)		
Employed full-time	31.3	64.3
Employed half-time	6.3	7.1
Retired	56.3	7.1
Homemaker	0	21.4
Missing data	6.3	0
Monthly personal income (%)		
Below $2,500	18.8	7.1
$2,500 to $4,999	18.8	21.4
$5,000 to $7,500	6.3	21.4
Above $7,500	6.3	21.4
N/A (retired or homemaker)	50	28.6
Relationship status (%)		
Married	87.5	71.4
Divorced or Widowed	6.3	7.1
Single	6.3	21.4
Relation to patient (%)		
Spouse		35.7
Parent		7.1
Child		35.7
Sibling		14.3
Friend		7.1
Treatment type (%)		
Chemotherapy only	81.3	
Chemotherapy and radiotherapy	12.5	
Chemotherapy and medication	6.3	
Cancer stage (%)		
I	6.25	
II	12.5	
III	18.8	
IV	62.5	

Table 3

Illustrative quotes for each theme

Themes	**Illustrative Quotes**	
	Patients (*n* = 16)	**Caregivers (*n* = 14)**
Heightened sense of threat and risk		
Fearing COVID-19	For the case of myself, if I contact it, the chances of me surviving, I think it's very slim lah. [laughs] Because I will be physically very weak, and the virus will go for the weak people (P03)	Ya his risk is higher because of his immune system and the treatment that he is getting. Definitely he is of higher risk than our normal people (C18)
Air of uncertainty	Cause seasonal flu is quite normal, you go to the clinic you get treated and then it's okay. You get well. But I understand this COVID takes quite some time. And then also, uh I do not know whether you will, even if you get well, you will get it again or not. Because it's something unknown (P08) We don't know who are the people around us who are carriers of the virus. This is terrifying" (P16)	We are out and about everyday. You will never know if the people you meet are already carriers of the virus. So everyone- everyone has risks. Unless you isolate yourself completely. You don't go out to be in contact with others. But this is impossible. (C17)
Socially irresponsible others	How do we know if they have an illness. They may not tell you even if they are sick. Right? They will keep quiet, so if we are unlucky we will contract the disease. (P24) I think in the newspaper it came up, even in the news, I think this couple was charged in court for I think falsely declaring their health and so on. I think there was some news you know. So, we have people like that who just can't be bothered (P11)	Sometimes in the market when I see a lot of people not wearing mask and buying stuff as per usual, and even sneeze and cough with only a tissue paper and throw it in the dustbin. They don't care about anything. They even cough or sneeze in front of us. (C15) I have no confidence. Because they ask if you have travelled to whatever countries, some people who have went can decide to hide the fact they have travelled to those countries. (C15)
Social and economic implications	Look at those doing business, they don't have business now. Nobody is coming out now. Who dares to come out? (P13)	Because of the poor economy as a result of COVID-19, my son has been unemployed for over a month. He works as an insurance agent, and he gives out pamphlets in shopping center, and his job was terminated because of COVID-19 outbreak (C15)

	I like to go downstairs for like walk you know? But now I also don't want to go out, because I will also, you know? So actually COVID-19 really limited a lot of things eh, I dare not go out. (P29)	I don't go to buffets anymore, um no holiday plans, no business trips. (C27)
Impact on healthcare experience		
Prioritizing cancer and cancer treatment	Even with the condition with this presence of the COVID-19, I am still going to follow what is scheduled. What I need to do, I'm going to do it. I'm not going to get myself frustrated or I'm not going to get myself uh upset about it. If we have to go through, or we have to go through this process, then I think we have to go (P11)	I will not defer, because his illness is more, although COVID-19 is important, his illness condition is also important. Although COVID-19 has been spreading, we can wear mask to protect ourselves, for protection. But his treatment has to continue. I am worried that if he stops treatment, his tumor will become bigger (C15)
	I felt that my treatment be interrupted, because uhhh my treatment I'm supposed to go weekly you see? Then sometimes we have to cancel one or two appointments I was just wondering whether it will affect the treatment or not (P08)	He is in a pretty late stage of his condition, and then delaying it might cause, might might cause the cancer cells to come back again, that is why again like it is like no choice right? (C02)
Necessary disruptions by new procedures	I think it's a necessary procedure lah. Because you need to trace those who have the virus, you need to trace them. So that you have to try and arrest the spread. So, it is very necessary so we understand it and we have to cooperate (P03)	Reducing the number of people here is good. But have to have at least one person [to accompany the patient], like now, she is here but she will feel more assured with me here. People who are doing treatment are most afraid of loneliness. They have to face this alone. So to allow one person to accompany the patient is a good thing. They will not feel demoralized and overthink (C17)
Responsibility falls on oneself		
Recognizing the importance of personal responsibility	You must be responsible for your own safety lah. If you are irresponsible you go to places that are, where the virus has occurred, then you are putting yourself into… your own situations (P09)	To wash hands more often, so in our daily lives we are more cognizant of our personal hygiene. And the hygiene at home. This is also a good habit. (C17)
	As a human being we must be responsible for our action. If we feel that we have the, we have the symptoms, then we have to seek help from the hospital, and we should not be attending any other functions (P03)	Everybody got to hold their responsibility lah … we all have to play a part also. Everybody will play a part lah, yeah (C19)

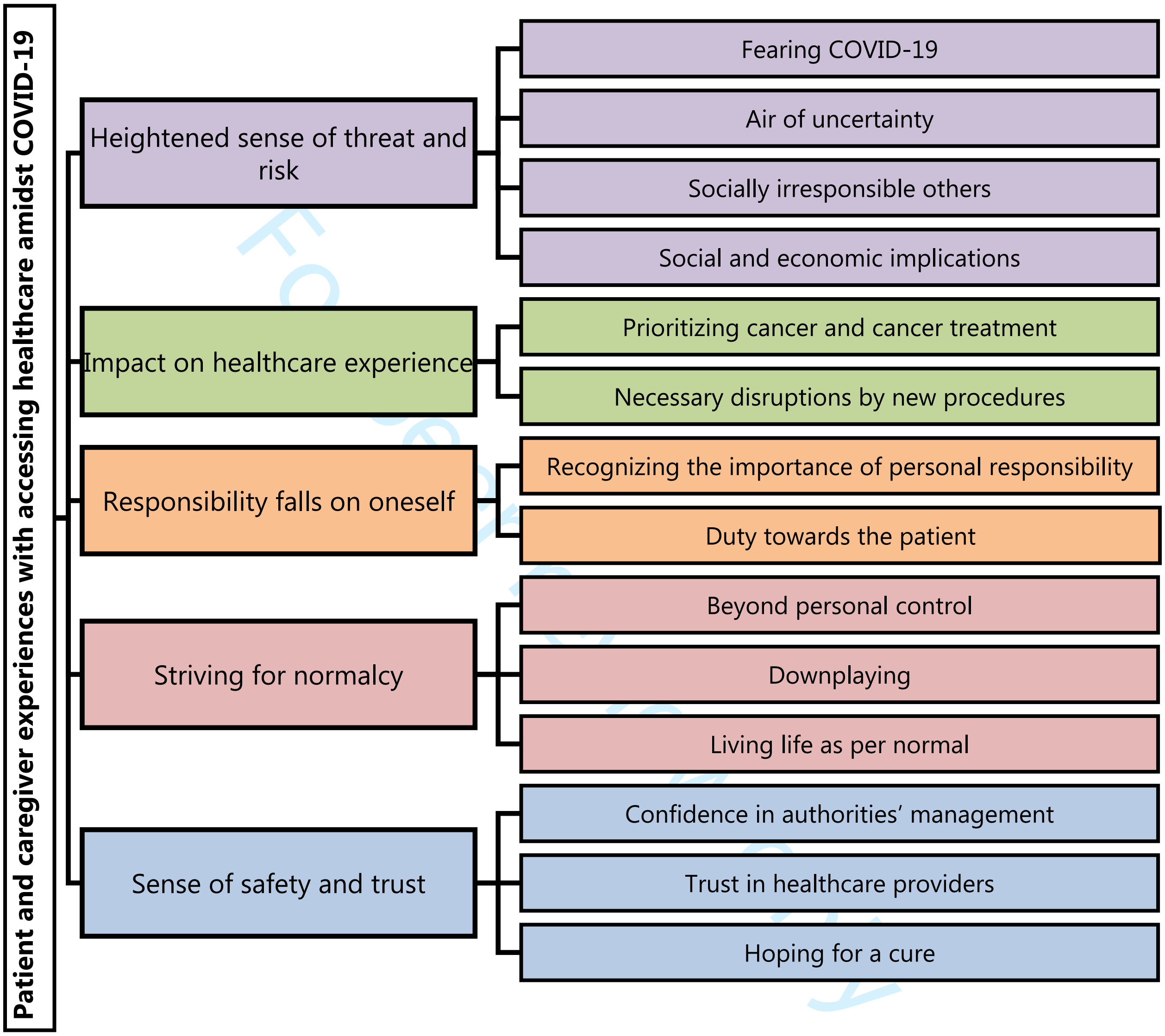
Duty towards the patient		My wife- while my wife is not well. So I cannot get sick and then who is going to bring her here? Ah. that's the problem. I must get well. (C19) I have to send my son to chemo, that I take care of him, so I have to protect myself. So whenever I step out from the house, I have to put on mask (C25)
Striving for normalcy		
Beyond personal control	I think this is life you know. Right or not? If you- if this is- epidemic it's epidemic. So you can't stop this. True or not? this is how I feel. If time for you to die you die, if time for to have it you have it. So I don't think this is either human transmission or anything it's something that's fated. I think it's also- this is also in the life cycle. Every ten years, something like this will happen (P01)	
Downplaying	I think it doesn't affect us because we… we don't go out so much, so we don't go out then we are not in contact with those who have COVID and we are quite safe lah (P03) If we got SARS, ten days ah, will kill you, you know? The [SARS] virus kill you, you know? But this one [COVID-19] is not so bad, you get early treatment ah, I think can be saved (P30)	My mother, I think less likely la, cause she's retired and she stays at home most of the time so I think it's less likely la, yeah (C26)
Living life as per normal	Virus is already there so what can I do? I cannot like avoid it right? So we have to move on and just lead out lives as per normal. If it hits, it hits la. If it doesn't then... we leave it and see (P28) Time to live and continue living you are given the chance, you- you continue living (P01)	Change our lifestyle? … life still goes on as normal… maybe to a lesser extent we go out less and we are more careful of our hygiene, and also notice that the hawker centers are also stepping up the cleanliness (C27)
Sense of safety and trust		
Confidence in authorities' management	If without this healthcare system I think we, nobody would know what to do, alright? So with the healthcare in place, the protocol, the system, with uh daily information and advice from the ministries and hospitals, do this do this,	So things got in place very fast and confidently done you know eh with a lot of knowledge and details put in and. I think eh without which it would not have been like this one. I

	keep your hands clean, keep your home clean, everything. I think with that I think this is this is the basic that we can do (P11) I see our government doing a lot of, taking a lot of measures, going all out for contact tracing and keep, and uh reminding people you know to be socially responsible and all that. I think that gives a lot of assurance and uh our our healthcare is really tip-top (P20)	think quite quite quite ok. Quite I mean very well managed. I think it it is the very best situation we can hope for (C25) It is not an easy situation for for the government so eh we we just pray and hope that they will make right and good decision and we will just follow la. Follow their decision (C23)
Trust in healthcare providers	If the doctor thinks I should defer then I will defer. No choice. So that's why I tell you. They are the professionals. We're not. If there are any issues, they'll explain to us. So whatever they say, I will have to follow (P14)	It is really good that Singapore no death case. So I think err I mean the hospital side [the healthcare providers] are doing a good job, they are really taking care and also taking it seriously (C22)
Hoping for a cure	Just hope that you doctors can quickly have a medication to cure the illness. So that we all can live a peaceful life. They we will all be okay. Otherwise, if there is no cure, it can kill many people (P13)	Hopefully one day we eliminate the virus so that we won't be facing any... any fear or worry of being infected with the COVID ah, yeah (C26)

Figure 1

Thematic schema

[refer to file]


Patient and caregiver experiences with accessing healthcare amidst COVID-19
Heightened sense of threat and risk
Fearing COVID-19
Air of uncertainty
Socially irresponsible others
Social and economic implications
Impact on healthcare experience
Prioritizing cancer and cancer treatment
Necessary disruptions by new procedures
Responsibility falls on oneself
Recognizing the importance of personal responsibility
Duty towards the patient
Striving for normalcy
Beyond personal control
Downplaying
Living life as per normal
Sense of safety and trust
Confidence in authorities' management
Trust in healthcare providers
Hoping for a cure

NCC COVID-19 Study Interview Guide for Patients

A. Introduction

- ➔ Interviewer introduces themselves
- ➔ Explain the aims of the project
- ➔ Explain that the interview will be recorded
    - ◆ Ask for permission to voice record
- ➔ Explain what will happen with the data
    - ◆ Interview will be transcribed for analysis
- ➔ Confidentiality and anonymity
- ➔ Participant is free to stop or pause at anytime of the interview
- ➔ Ask if they are comfortable to continue with the interview

B. Interview questions

1. What do you understand of the current health situation with COVID-19?
2. How do you think COVID-19 is transmitted?
    a. Examples of route of transmission; droplets, air-borne, physical contact
3. What are some of your concerns or fears about COVID-19? What worries you the most and why?
    a. Describe specific problems or disruptions you experienced related to the COVID-19
    b. Are there any specific concerns you may have when visiting NCC for treatment or follow up?
    c. What about your family – what concerns if any they may have?

4. How has your experience accessing and receiving healthcare changed since the COVID-19 outbreak?

    a. How much have you used health services since the outbreak?
    b. What changes have you noted/observed when you access health services (what is different, what has not changed; what for better or worse)
    c. What challenges have you faced in relation to your health treatment in context of current health situation with COVID-19 (e.g. appointment; treatment)

5. How do you feel about accessing care in the current health situation with COVID-19? Probe emotions and why.

   a. Examples of emotions; anxiety, worry, regret

   b. Would you prefer if your treatment is deferred? Why is that so? Probe on how they feel about such delays.

6. How confident are you of NCC's screening/safety process? How do you feel when going through the screening process?

   a. What scares you; what do you find reassuring or helpful in these procedures
   b. What else / other measures may help you or other people that need to continue medical treatment in this situation

7. Given that you have to access healthcare, what are your hopes and needs and how can we best support you?

8. How likely do you think it is for you to contract COVID-19? Do you think you are more likely to contract COVID-19 than other people? Tell me more.

9. Do you think that COVID-19 is a greater threat/more serious for you in relation to:

   a. Other infections and cancer related complications
   b. H1N1/seasonal flu

10. What kind of precautionary measures have you taken to reduce your risk of contracting COVID-19?

   a. Examples of precautionary measures; stocking of medical supplies, avoiding going out (if they have done some degree of social distancing/isolation, probe about feelings - how did this impact your life/treatment etc)

11. How likely do you think it is for you to recover from COVID-19 if you contracted it? How likely do you think you will recover from COVID-19 in comparison to other people?

12. You are faced with your own health diagnosis/condition - how do you manage/cope with this? To what extent has the COVID-19 outbreak changed your approach or outlook?

   c. Examples of source of coping; family, friends, HCPs

   d. Examples of problems with coping; unable to cope, unable to access source of coping

Thank you very much for your feedback. We have come to the end of our questions but we would all be keen to hear if there may be anything else we haven’t managed to discuss today that you think is important to share?

C. Wrapping up

- ➔ Ensure that the participant had the opportunity to tell you everything they think is important
- ➔ Ask if they have any questions; clarify doubts, check emotions.
- ➔ Explain again what will happen to the data
- ➔ Thank participants
- ➔ Reimbursement

NCC COVID-19 Study Interview Guide for Caregivers

A. Introduction

- ➔ Interviewer introduces themselves
- ➔ Explain the aims of the project
- ➔ Explain that the interview will be recorded
    - ◆ Ask for permission to voice record
- ➔ Explain what will happen with the data
    - ◆ Interview will be transcribed for analysis
- ➔ Confidentiality and anonymity
- ➔ Participant is free to stop or pause at anytime of the interview
- ➔ Ask if they are comfortable to continue with the interview

I will ask you several questions related to your experience since the COVID-19 outbreak. We are keen to hear your thoughts/concerns and experience as well as how you think this may be affecting your loved one.

B. Interview questions

1. What do you understand of the current health situation with COVID-19?
2. How do you think COVID-19 is transmitted?
    a. Examples of route of transmission; droplets, air-borne, physical contact
3. What are some of your concerns or fears about COVID-19? What worries you the most and why?
    a. Describe specific problems or disruptions you experienced that may be related to the COVID-19.
    b. Are there any specific concerns you or the patient may have when visiting NCC for treatment or follow up?
    c. What about others in your family – what concerns have they discussed with you?
4. How has your experience (and the patient's experience) with accessing and receiving healthcare **changed** since the COVID-19 outbreak.

   a. How much have the patient and/or you used health services since the outbreak?
   b. What changes have you noted/observed when you or the patient access health services (what is different, the same, better or worse)
   c. What challenges have you faced in relation to the patient's (or yours, if applicable) health treatment in context of the current health situation with COVID-19 (e.g. appointment; treatment)?

5. How do you feel about you/the patient accessing healthcare in the current health situation with COVID-19? Probe emotions and why.
   a. Examples of emotions; anxiety, worry, regret
   b. Would you prefer that the patient's treatment (or your treatment) is deferred? Why is that so? Probe on how they feel about such delays.
6. How confident are you of NCC's screening/safety process? How do you feel when going through the screening process?
   a. What scares you; what do you find reassuring or helpful
   b. What else / other measures may help you or other people that need to continue medical treatment in this situation
7. How likely do you think it is for **you** to contract COVID-19? Do you think you are more likely to contract COVID-19 than other people? Tell me more.
   a. What about for **the patient**? How likely do you think it is for your family member who gets treatment to contract COVID-19? Do you think they are more likely to contract COVID-19 than other people?
8. Do you think that COVID-19 is a greater threat/more serious for you (/the patient) in relation to:
   a. Other infections and cancer complications for the patient
   b. Seasonal influenza/H1N1
9. What kind of precautionary measures have you (and the patient) taken to reduce the risk of contracting COVID-19?
   a. Examples of precautionary measures; stocking of medical supplies, avoiding going out (if they have done some degree of social distancing/isolation, probe about feelings - how did this impact your life/treatment etc)

10. How likely do you think it is for you to recover from COVID-19 if you contracted it? How likely do you think you will recover from COVID-19 in comparison to other people? How about **the patient?**

11. You, as family, are faced with patient’s health condition that can be challenging. How do you manage/cope with this? To what extent has the COVID-19 outbreak changed your approach or outlook?

   a. Examples of source of coping; family, friends, HCPs
   b. Examples of problems with coping; unable to cope, unable to access source of coping

13. As it is essential that you and your family members access healthcare for treatment, what are your hopes and needs and how can we best support you

14. Thank you very much for your feedback. I have no more questions on my end but we would all be keen to hear if there may be anything else we haven’t managed to discuss today that you think is important to share?

C. Wrapping up

- ➔ Ensure that the participant had the opportunity to tell you everything they think is important
- ➔ Ask if they have any questions; clarify doubts, check emotions.
- ➔ Explain again what will happen to the data
- ➔ Thank participants
- ➔ Reimbursement

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

BMJ Open

Managing Cancer in Context of Pandemic: A Qualitative Study to Explore the Emotional and Behavioural Responses of Patients with Cancer and their Caregivers to COVID-19

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Title: Managing Cancer in Context of Pandemic: A Qualitative Study to Explore the Emotional and Behavioural Responses of Patients with Cancer and their Caregivers to COVID-19

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Abstract

Objectives: Having to access life-sustaining treatment during the emerging COVID-19 outbreak has placed cancer patients at an especially vulnerable position notwithstanding their immunocompromised condition. The present study aimed to elucidate cancer patients' and their caregivers' experiences during this outbreak.

Design: Face-to-face semi-structured interviews were conducted.

Setting: A tertiary cancer care facility.

Participants: 16 patients with cancer and 14 caregivers. Inclusions criteria were a) diagnosed with cancer, b) receiving active treatment or follow-ups, c) aged 21 and above, and d) fluent in English or Mandarin.

Results: Thematic analysis was conducted. Five themes were identified: *heightened sense of threat*, *impact on healthcare experience*, *responsibility falls on oneself*, *striving for normalcy,* and *sense of safety and trust*. Heightened threat of COVID-19 was more pronounced in patients and linked to vulnerability and fear, uncertainty, and actions of socially irresponsible others. Dominant in their healthcare experience was prioritizing cancer and treatment amidst heightened threat and anticipatory worry about treatment disruptions. Both noted on the importance of taking responsibility for one's health, with caregivers reporting a reinforced sense of duty towards patients. They strived to maintain normalcy by viewing COVID-19 as beyond personal control, downplaying, and living life as usual. Their resolve was supported by a sense of safety from the actions of authorities, hospitals, and trust towards healthcare providers.

Conclusions: Cancer intensifies threat and the emotional impact of COVID-19 and may trigger specific concerns related to treatment. Psychoeducation interventions led by healthcare providers over digital platforms could help address cancer-specific concerns and support patients and caregivers during the pandemic.

(254 words)

Keywords: oncology; thematic analysis; coronavirus; infectious disease; interview

Article Summary

Strengths and limitations of this study

- A timely qualitative analysis of the emotional and behavioural impact of COVID-19 on cancer patients and caregivers
- This study highlights the heightened threat and risks cancer patients face during the COVID-19 outbreak and proposes the need for healthcare services to incorporate psychosocial support on cancer management
- The rapidly evolving nature of the COVID-19 situation limits the generalizability of the findings to later phases of the pandemic
- Future qualitative work at later phases of the pandemic and with various population groups is warranted

Background

The coronavirus 2019 disease (COVID-19) first hit Singapore's shores on January 23rd, 2020. In the months that followed, COVID-19 was declared a pandemic by the World Health Organisation after its rampant spread to most of the world. Infectious disease outbreaks such as COVID-19 present major challenges to global public and individual health. No less important are the psychological costs and mental health implications. Prior work in SARS and H1N1 alongside emerging work on COVID-19 documented adverse psychological responses and psychiatric morbidity for frontline healthcare workers, infected patients and the general population that may persist over time (1–8). Emotional responses such as fear and anxiety have been shown to influence actions, some of which may be undesirable. Self-isolation, stigmatization, non-disclosure or non-treatment-seeking behaviors noted in the Ebola outbreak (9) contributed to community spread and compromised efficiency of healthcare systems (10,11). In response to the outbreak, Singapore implemented several precautionary measures including quarantine for travellers, contact tracing for infected patients, and prioritising healthcare resources to treating COVID-19 patients. While the emotional and behavioral impact of infectious outbreaks are well-documented for the general population, infection survivors and frontline healthcare workers, the literature on patient populations is scarce (1–5).

For patients with cancer, treatment is often nondeferrable and cannot be delivered over telemedicine. This means they are potentially exposed to the risks of infection at the clinics and while being outside. Furthermore, immunosuppression from cancer treatments such as chemotherapy could result in increased vulnerability to infection and rapid deterioration of health should they be infected (12,13).

Psychological distress, which may be manifested as a variety of negative emotions from shock, anger, denial to anxiety, depression and fear of recurrence (14), has been documented in 29 to 43% of cancer patients (15). Emotional burden and distress is evident across all stages of disease from diagnosis, treatment to survivorship (16,17) and extend to caregivers and family members (17–19). Despite recognition that the COVID-19 pandemic presents greater challenges to cancer patients and caregivers (20), the qualitative and quantitative impact of COVID-19 on their psychosocial wellbeing are not well understood. It is important to elucidate their experiences with treatment and specific needs during this pandemic to design and effectively optimise psychosocial care.

The objectives of this study are to explore the emotional impact of and behavioural responses to COVID-19, focusing specifically on cancer patients and their caregivers.

Methods

This study adopted a qualitative methodology involving semi-structured interviews. Ethics was approved by Singhealth Centralised Institutional Review Board (CIRB reference: 2020/2155).The paper was structured following COREQ guidelines (21).

Setting and Participants

Study sample included cancer patients and caregivers recruited between 9th to 13th March 2020 from the National Cancer Centre Singapore (NCCS), a tertiary care facility serving a culturally and ethnically heterogeneous population. During the week, the outbreak was declared a pandemic and local cases rose from 160 to 200 (see Table 1).

Target sample size was 15 to 20 individuals per group as recommended to achieve theme saturation (22). Maximum variation sampling procedures were applied to ensure diversity in terms of cancer treatment. Inclusion criteria for patients were: (a) diagnosed with any type of cancer, (b) receiving active treatment or follow-ups, (c) aged 21 and above, (d) fluent in either English or Mandarin. Those only fluent in dialects or unable to give consent due to cognitive or psychiatric diagnoses were excluded. Caregivers of eligible patients were recruited if they satisfied criteria (c)-(d) and provided consent.

Data Collection

Semi-structured interviews were conducted once during follow-up appointments or active treatment at NCCS. Several measures had been implemented following the outbreak: temperature screening stations, declaration of travel and symptom checklist before entry, physical distancing at all premises, wearing of masks, and restriction of visitors in clinics. Access to NCCS was only possible for NCCS staff and patients (with one accompanying caregiver). Interviewers obtained informed consent and permission to audio-record. They conducted the interviews in a private area in the outpatient clinics (3 were conducted in inpatient wards) in either English or Mandarin based on participants' preference. Patients and caregivers were interviewed separately for an average of 35 minutes. Interviewers included two research coordinators not involved in direct patient care (SMF, DI) and one oncologist (KYYN) with access to inpatient wards but not directly involved in the care of the patients recruited there. All interviewers had graduate qualifications and experience with qualitative methodology. Interviews were audio-recorded with field notes taken. Participants' sociodemographic and clinical characteristics were also documented. Recruitment stopped when no new themes emerged in two consecutive interviews (i.e., thematic saturation).

Two interview guides (one each for patients and caregivers) were formulated based on relevant literature and expert input on clinical perspectives (JYYN, KYYN) and qualitative health research (KG). Patient and caregiver interview guides comprised similar nondirective and open-ended questions about their experiences accessing healthcare and cancer treatment during the COVID-19 outbreak (e.g., perceptions and concerns about risks, emotions, and behavioural responses). Questions and prompts were refined iteratively to enable novel topics to be pursued in subsequent interviews (see supplementary materials). Interview content and procedures were pilot tested with two patients and two caregivers, serving as critical reference group for data trustworthiness (23). Feedback about relevance, clarity, and appropriateness of questions in the interview guide were sought from the pilot.

Patient and Public Involvement

Due to the rapidly evolving COVID-19 situation and measures related to patient contact, it was not possible to engage patients or the public in the development of this study. Patient and caregivers' input on all study procedures was solicited during the pilot.

Analytical Approach

Thematic analysis was conducted including: familiarization with the data, identifying initial codes, identifying initial themes, reviewing and revising themes, and naming and assigning descriptions to themes (24). Interview audio-recordings were transcribed verbatim by study team (ZYC, ZSG, JMXC). Mandarin interviews were translated directly into English and translations verified. No specialized qualitative software was used. Patient and caregiver interview transcripts were coded and analysed separately by two sets of coders (Patient: JMXC, ZYC; Caregiver: ZSG, KYYN) under KG's supervision. A combination of deductive and inductive coding was used. Each pair of coders independently identified codes from participant responses and confirmed agreement. The initial codes were subsequently categorised into potential (sub-)themes and the sub-themes into higher-order themes. This process was iterative with codes, sub-themes and themes reviewed against recordings, and discussed and refined by coders and KG to ensure relevant and distinctiveness of resulting themes. Two codebooks were generated (one each for patients and caregivers). These were reviewed and contrasted, and only merged into a master codebook when deemed comparable. The master codebook was used to recode all interviews. When relevant, themes unique to either participant group were noted.

Trustworthiness was examined using established criteria (25). To ensure credibility, pretesting and feedback was sought before recruitment. During the interviews, participants were prompted to elaborate on their responses to ensure clarity and minimize misinterpretation by interviewers. We used investigator triangulation, in which study team discussed the axial and selective coding and data interpretation (26). Regarding the dependability and confirmability, an audit trail was kept from project start to data dissemination.

Results

Of the 41 eligible individuals approached, 30 consented (16 patients and 14 caregivers; response rate=73.2%). Six patients and six caregivers were related. Reasons for decline included a lack of time and unwillingness to be audio-recorded. Interviews were conducted in English (*n*=23) and Mandarin (*n*=7). Mean age was 60.1 for patients (*SD*=14.4) and 53.6 for caregivers (*SD*=11.2). Participants were predominantly Chinese (83.3%). Caregivers tended to be the spouse or the child of the patient. All patients were on chemotherapy, with 12.5% and 6.3% on additional radiotherapy and medication respectively (see Table 2).

Codes in patients' and caregivers' interviews were merged to produce five higher-order themes: *heightened sense of threat and risk*, *impact on healthcare experience*, *responsibility falls on oneself*, *striving for normalcy,* and *sense of safety and trust.* Themes were found to be highly consistent across both groups except for one subtheme unique to caregivers (i.e., *duty towards the patient*) and one unique to patients (i.e., *beyond personal control*). Illustrative quotes for each subtheme are presented in Figure 1 and Table 3.

Heightened sense of threat and risk

The first theme captured the heightened salience of the threat and risk posed by COVID-19, common across patients and caregivers. Three sub-themes were identified: 1) vulnerability and fear, 2) uncertainty, and 3) socially irresponsible others.

Vulnerability and fear. COVID-19 was regarded as a prominent source of threat that elicited fear, worry and perceptions of vulnerability. Both patients and caregivers recognised that patients were highly vulnerable to COVID-19 due to cancer, their treatment-induced immunosuppressed state, and risk of exposure due to their need to access hospitals for treatment. Even at these early stages of pandemic, patients already viewed COVID-19 as a dangerous threat for them, feared infection and were pessimistic about prognosis of their changes for recovery if infected. “The chances of me surviving, I think it's very slim lah. Because I will be physically very weak, and the virus will go for the weak people” (P03). They worried about accessing hospitals and being around other patients and noted that they would like to minimise time spent at hospitals.

Caregivers however appeared unconcerned about their personal vulnerability to COVID-19 but expressed high anxiety and worry about patients. They worried over patients' risk and prognosis and prioritized the patients' health over themselves "The risk is not worrying that I get it. The risk is I'm worrying my loved one, my dad will get it" (C27).

Uncertainty. Being a new virus, the uncertainty surrounding COVID-19 intensified patients and caregivers' threat perceptions. Participants discussed uncertainty in terms of the virus per se (clinical manifestations/severity, symptoms, transmission), the prognosis (course of pandemic, duration, numbers to be affected), and the broader implications of COVID-19 and related measures for personal finances or national/global economies.

Participants noted how little was known and understood about COVID-19 especially with regards to transmission and symptom presentation. They highlighted that the symptoms of COVID-19 may be too generic, vague, or mild to recognise and respond in time and pondered about the possibility and threat of asymptomatic transmissions. As shared by one caregiver "you never know if the person beside you might have the illness" (C15).

There was also uncertainty about the course, trajectory, and magnitude of the pandemic. Patients and caregivers were concerned about how long the COVID-19 situation would last, how many people would become infected and if/when a vaccine or treatment would become available. Linked to the uncertainly about future were the concerns about the broader long-term impact of COVID-19 and containment measures on finances and the economy. One patient remarked "Look at those doing business, they don't have business now. Nobody is coming out now. Who dares to come out?" (P13).

Socially irresponsible others. Both patients and caregivers attributed heightened threat to the irresponsible actions of other people. This was shaped by both media reports and first-hand accounts.

Patients and caregivers recounted media reports on members of public providing false declaration of travel history, and worried that many others in community may potentially be deceitful e.g., not disclosing symptoms or travel history and providing inaccurate information. For instance, one patient raised an example of a couple charged in court for falsely declaring their health status (P11). These unlawful actions were viewed as immoral for impeding transmission containment measures and placing others at risk.

For patients and caregivers, socially irresponsible behaviours also included poor hygiene practices such as coughing or sneezing in front of others. Despite the government's recommendation at the time of interviews to only don masks when unwell, the lack of masks was still regarded as inconsiderate and socially irresponsible:

"Sometimes in the market when I see a lot of people not wearing mask and buying stuff as per usual... They don't care about anything. They even cough or sneeze in front of us" (C15). Participants had no confidence in others practicing good hygiene, which amplified worry and perceived threat.

Impact on healthcare experience

The second theme comprised two sub-themes: prioritizing cancer and cancer treatment and necessary disruptions caused by new procedures.

Prioritizing cancer and cancer treatment. Cancer and cancer treatment remained a top priority for both patients and caregivers despite the outbreak. While COVID-19 was regarded as a serious threat, it was not described to be as imminent or grave as cancer: "cancer is worse, it kills people. This COVID-19 is for you to take precaution" (P30). They were insistent in adhering to the patients' cancer treatment regime and opted not to defer for fear that deferment may worsen the cancer: "if you deferred, there might be aggressive type of cancer that might that might come back" (C18). They discussed two potential treatment disruptions due to COVID-19. First, patients and caregivers expressed concerns that contracting COVID-19 would mean that cancer treatment may have to be postponed. Second, while active cancer treatment proceeded as usual, the suspension/limited operational capability of laboratory services may disrupt diagnostic services and delay subsequent treatment.

Necessary disruptions by new procedures. Several measures were implemented in response to COVID-19 but were seen as necessary to protect everybody: "I think it's a necessary procedure lah. Because you need to trace those who have the virus... So that you have to try and arrest the spread. So, it is very necessary so we understand it and we have to cooperate" (P03). The screening stations led to slight delays to enter the premises, to which most responded by arriving earlier. Visiting was restricted to one visitor per patient and only during specified visiting hours. One inpatient lamented that his spouse could no longer keep him company overnight but acknowledged that it as a sacrifice he could make. In general, patients and caregivers appreciated the extra measures taken and accepted the associated minor inconveniences, dubbing them as troublesome but good procedures.

Responsibility falls on oneself

Both patients' and caregiver emphasised the importance of own agency and taking responsibility to keep healthy. For caregivers, sense of responsibility included duty towards the patient.

Recognizing and taking responsibility. Patients and caregivers were concordant in making behavioural adjustments to stay safe. These precautions primarily involved increasing hygiene practices, wearing masks, minimizing social activities, and proactively seeking out information related to COVID-19. There was great variability in social adjustment in response to COVID-19. This ranged from minimizing exposure to crowds, only going out during off-peak hours, to staying home and avoiding social contact whenever possible. For patients, they reiterated the importance of self-reliance: “now you have no choice, you can only protect yourself” (P29). Notably, many of these self-care and precautionary behaviours were already in place before COVID-19 as a result of living with cancer. “I used to play golf, so I stopped golfing, so that, I used to meet my friends in the club. I cut that down. So…yes, because of my treatment I have, my social life has changed... So, whether there’s COVID or no COVID, it doesn’t matter to me because, uh, my, my lifestyle has changed” (P03).

Besides personal behavioural adjustments, patients and caregivers recognized that managing COVID-19 required a collective effort and actions. They acknowledged that every individual had to play their part to practice responsible behaviours and comply with safety regulations.

Duty towards the patient. Caregivers expressed a strong sense of duty that comprised providing care for the patient, endorsing COVID-19 precautionary measures and self-care. First, caregivers took the initiative to ensure that the patient takes necessary precautions to reduce their risk of contracting COVID-19. Often, this occurs by actively enforcing or supporting patients’ actions, such as practicing good hygiene, regular handwashing, or reducing contact with crowds.

Second, caregivers will take their own precautions against COVID-19 to ensure that they do not contract COVID-19. The motivation to remain well was related to the need to continue providing care: “I have to send my son to chemo, that I take care of him, so I have to protect myself” (C25). Some caregivers also reported striving to stay healthy to avoid being the carrier to pass the disease to the patient.

Striving for normalcy

The fourth theme encapsulates patients’ and caregivers’ cognitive and behavioural responses to preserve normalcy in their lives amidst the COVID-19 outbreak. They viewed the outbreak as beyond one’s personal control, rationalized and downplayed threat, and focused on living life as per normal.

Beyond personal control. Specific to patients, many spoke about their belief that circumstances related to COVID-19 were out of their personal control. They described an inability to exert control over contracting COVID-19: “if it’s really fated then you have no choice” (P16). This inevitability was present regardless of precautions: “you can get it even if you stay at home. You will get it if you are fated to” (P13).

Downplaying. Despite facing the threat of COVID-19, patients and caregivers made attempts to downplay risks and personal relevance. They rationalized and extrapolated based on prior infectious outbreaks: “SARS is more fatal. The COVID-19, if treated properly, is nothing much” (P07). Others likened the nature of COVID-19 to the common flu and perceived possible recovery from COVID-19 should they contract it. While they recognized that patients were more vulnerable given their weaker immunity, many patients and caregivers downplayed the personal risks of COVID-19 due to them mostly staying home and always wearing masks when outside, which they report protects them from COVID-19. Many felt more assured by wearing masks in crowded spaces or hospitals.

Living life as per normal. Patients and caregivers both described having continued with daily routines amidst the COVID-19 situation: “life still goes on, it doesn’t change much, except that we have to be more vigilant” (P03). Some reasoned that life had to go on and continued with various activities including grocery shopping, attending religious services, or meeting friends. Others adopted more precautions—notably stepping up hygiene practices and wearing masks—but generally perceived that COVID-19 had no change to their life. Patients also described minimal disruptions to cancer treatment: “I have to prepare myself [for the appointment] and go earlier. So that’s about it the only thing” (P08).

Sense of safety and trust

The final theme reflects the general perception of safety and trust patients and caregivers held in authorities and healthcare providers. Some also expressed hope for cure or vaccine for COVID-19.

Confidence in authorities' management. Patients and caregivers expressed huge confidence in how the local government and healthcare institutions had managed the COVID-19 outbreak. They reflected that the local COVID-19 situation was kept under control and articulated a willingness to comply with government directives: “I’m fine as long as we abide, because we feel that we are very safe- it’s well managed here” (C10). Many felt encouraged by the extensive contact tracing and quarantine measures conducted to ringfence potential new cases. Others were satisfied with the clear dissemination of official information that involved regular updates on new confirmed cases. Patients and caregivers also spoke about feeling assured by the high healthcare standards, and found it safer to be in the hospital.

Trust in healthcare providers. Healthcare providers were regarded as highly competent by both patients and caregivers. This competence was described broadly to encompass several aspects from managing cancer treatment, treating COVID-19 to maintaining good hygiene standards. Many commended healthcare providers and were cognizant of their sacrifices, illustrated in statements like “they're working longer hours… so fatigue comes in, but they don't show it when they're on duty” (P24). Healthcare providers were also relied on for guidance and advice, especially regarding cancer treatment.

Hoping for a cure. Notably, patients and caregivers spoke about wanting a cure or a solution to the COVID-19 situation. They hoped that authorities would successfully develop a treatment or vaccine for COVID-19: “just hope that you doctors can quickly have a medication to cure the illness. So that we all can live a peaceful life” (P13).

Discussion

The COVID-19 pandemic has brought about changes in all domains of life including healthcare, leaving an emotional toll on healthcare users and healthcare providers alike. While clinical efforts are duly directed towards those considered more vulnerable, the scarce research on patient populations cannot adequately inform health service optimization during these extraordinary times. This study attempted to bridge the gap by exploring the emotional and behavioural impact of COVID-19 on patients and caregivers during early stages of the outbreak in Singapore.

Five themes were generated which were salient in both patient and caregiver accounts: heightened sense of threat and risk, impact on healthcare experience, responsibility falls on oneself, striving of normalcy, and sense of safety and trust. The themes painted a diverse and seemingly contradictory experience. Heightened threat induced by vulnerability and fear, uncertainty and irresponsible others was countered with perceptions of safety and trust towards HCPs alongside their own efforts to re-establish normalcy. Among respondents in China, greater satisfaction with risk communication i.e., provision of timely and credible information by health authorities about COVID-19 was found to be associated with subsequent reduced anxiety and emotional contagion (27). Perceptions of safety in our sample therefore may have been attributed to prompt risk communication by local authorities. This in turn likely helped to mitigate but not fully eliminate threat perceptions. This thematic diversity underscores that patients’ and caregivers’ experiences amid the outbreak are multifaceted and nuanced.

Living with and managing treatment for cancer is an emotionally charged journey that has intensified during the pandemic. Dominating the accounts was a heightened perception of threat specific to COVID-19, adding to but not superseding the threat related to cancer. Heightened threat was attributed to uncertainty, limited understanding of virus and disease course, and potential contagion due to socially irresponsible others, as shown in prior infectious disease outbreaks (28). COVID-19 was deemed more threatening for patients as their frail health and compromised immunity made them more vulnerable to infection and poorer prognosis, as noted with other patient groups during SARS and H1N1 (29,30). This threat of COVID-19 was interlinked with worry and fear. Cancer and need for treatment compounded these fears as both parties perceived that proceeding with cancer treatment was dependent on patients' good health. The duality of the threat posed by COVID-19 in directly compromising health and disrupting cancer treatment had elicited anticipatory anxiety among both patients and caregivers. Both groups were adamant in prioritizing cancer and would not consider deferment of treatment unless advised by their healthcare providers. This contrasts reports in other (non-cancer) patient groups during SARS and Ebola (10,11). Prioritizing cancer treatment could be regarded as an extension of taking responsibility for one's (or the patient's) health; besides practicing appropriate precautionary measures, both patients and caregivers acknowledge that they had to comply with treatment demands to manage the patient's condition.

Counterbalancing the threat of COVID-19, patients and caregivers expressed safety and trust in regulatory measures and stepped up actions of personal responsibility and actions to maintain normalcy (31). They detailed behaviours such as handwashing, avoiding social interactions and crowds, or wearing of masks to reduce likelihood of infection. For some, these behaviours had already been cultivated into established routines prior to COVID-19 due to cancer. They both emphasized the importance of playing their part for the collective good. Unique to caregivers was an unwavering duty towards patients that encompassed care towards self and patients. The pandemic had spurred caregivers to be more conscientious about their own health to maintain their capacity to care for patients. However, this increased health surveillance can lead to additional burden, stress and negatively affect caregivers' health (32,33).

To navigate the pandemic, patients and caregivers strived for normalcy. This was manifested as both cognitive processes and behaviours, both of which could be construed as emotion-focused or avoidance coping (34). Downplaying risk involved a reassurance of safety that was linked to behaviours such as staying home or wearing masks, or prior experience with SARS. Patients discussed COVID-19 as beyond their control (often using the term "fated") that prompts them to redirect attention on living life and treatment. This suggests in the face of an unpredictable and novel threat, fatalism may be adaptive and reflect acceptance of the situation. Patients' and their caregivers' experiences with cancer could have conferred a general hardiness or resilience (35,36) that extended to their experience with COVID-19. These cognitive and behavioural processes involved an active disengagement from the threat posed by COVID-19, allowing for patients and caregivers to self-soothe and regulate their emotions.

The sense of safety and trust towards authorities also buffered the heightened sense of threat and risk and provided a semblance of normalcy. During data collection, the number of confirmed cases in Singapore bordered on 200 with no fatalities and ranged from 1 to 12 new cases each day. These relatively low numbers may have boosted patients' and caregivers' confidence in accessing healthcare. Safety was discussed both as a general feeling of security and preparedness by authorities/hospitals, and trust towards healthcare providers. Patients and caregivers held a deep appreciation for healthcare providers for their contributions during the pandemic and relied on them to navigate health-related matters.

Clinical Implications

Findings have important implications for clinical practice. The priority placed cancer treatment over COVID-19 threats comprises a major aspect of patients' and caregivers' healthcare experience. Evidently, access to cancer treatment remains at the forefront of their agenda. Crucially, this underscores the need for continuity in health services. Services need to incorporate psychosocial support as patients report elevated threat, worry and fear related to COVID-19 and its impact on cancer management. Efforts should target both general COVID-19 concerns that pertain to the whole community and cancer-specific concerns about COVID-19 unique to individuals stricken by cancer. Cancer-specific concerns involving disruptions to treatment-related procedures cause anticipatory anxiety that may compromise emotional wellbeing. These concerns may not be proactively shared in consultations but should be elicited and addressed. It may then be useful to leverage on the firm trust and confidence placed in oncology healthcare providers which strategically positions them to support such conversations. To assuage general COVID-19 concerns, many of which involve risk of heightened exposure to COVID-19, alternative arrangements such as tele-consultations provide patients and caregivers with a safer and more convenient medium to access health services remotely. These platforms become even more pertinent during the times of pandemic with social distancing policies and visitor limitations (37).

Caregivers should also be supported to buffer against burnout. Clinicians may consider inviting caregivers to attend patients' consultation sessions and allocate some time to address caregivers' concerns in session. Engaging caregivers directly in session alerts clinicians to signs of elevated psychological distress which may warrant a referral to medical social workers or psychologists for counselling. Ensuring caregiver wellbeing has important implications for the patients' care. Caregiver support in the form of dyadic coping influences the level of psychological distress and adjustment in patients across various cancer contexts (38–41). Finally, while institutional safety measures implemented may incur additional inconveniences, our study suggests it bolsters confidence in the institution and provide patients and caregivers with a sense of safety.

Study Limitations

Possible limitations related to face-to-face qualitative interviews exist. Selection bias may be present, as patients and caregivers who do not present at NCCS would not have been approached and been indirectly excluded from the study. Social desirability bias may also be present, as participants selectively share and elaborate opinions that they perceive to be more acceptable or socially desirable (e.g., prioritizing cancer vs. rejecting treatment). Lastly, all interviews had to be conducted by NCCS staff as non-NCCS staff were not permitted to enter the premises as part of COVID-19 management measures. We have sought to minimize potential bias by engaging research coordinators and one oncologist not involved in direct care of the patients they interviewed.

At the time of writing, local cases have breached the thirty-thousand mark. As the present study was conducted during the earlier stages of the pandemic in Singapore, its impact is likely to have evolved as the pandemic unfolds. Future work can seek to elucidate the impact of the pandemic at later phases and from different population groups, particularly those who may have opted to stray from treatment care. This would serve to inform and improve health-related policies to better meet the needs of these healthcare users.

The threat induced by COVID-19 has amplified concerns surrounding cancer treatment among cancer patients and their caregivers. Patients and caregivers intensify precautionary behaviours and strive to maintain normalcy but worry of risks to patients and impact of the pandemic on cancer treatment plans. Digital mental health services led by healthcare providers could serve address these specific concerns and provide a sustained line of support to patients and caregivers during these tumultuous times.

Author Contributions

KYYN, DI, ZSG, ZYC, JMXC, KG, JYYN conceived, designed the study. KYYN, DI, SMF collected the data. JMXC, ZSG, ZYC, KYYN, KG analysed the data. All authors interpreted the data and were involved in the development, review, and approval of the manuscript.

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Competing Interest Statement

The authors have no conflicts of interest to disclose.

Data Availability

The thematic data that support the findings of this present study are available from the corresponding author upon reasonable request.

References

1. Lu T-H, Chou Y-J, Liou C-S. Impact of SARS on healthcare utilization by disease categories: Implications for delivery of healthcare services. Health Policy (New York). 2007;83(2–3):375–81.
2. Teasdale E, Yardley L. Understanding responses to government health recommendations: Public perceptions of government advice for managing the H1N1 (swine flu) influenza pandemic. Patient Educ Couns [Internet]. 2011;85(3):413–8. Available from: http://dx.doi.org/10.1016/j.pec.2010.12.026
3. Wong ELY, Wong SYS, Lee N, Cheung A, Griffiths S. Healthcare workers' duty concerns of working in the isolation ward during the novel H1N1 pandemic. J Clin Nurs. 2012;21(9–10):1466–75.
4. Cava MA, Fay KE, Beanlands HJ, McCay EA, Wignall R. Risk perception and compliance with quarantine during the SARS outbreak. J Nurs Scholarsh. 2005;37(4):343–7.
5. Tiwari A, Chan S, Wong A, Tai J, Cheng K, Chan J, et al. Severe acute respiratory syndrome (SARS) in Hong Kong: Patients' experiences. Nurs Outlook. 2003;51(5):212–9.
6. Hategan A, Abdurrahman M. Hidden in plain sight: Addressing the unique needs of high risk psychiatric populations during COVID-19 pandemic. Psychiatry Clin Neurosci [Internet]. 2020 May 5;n/a(n/a). Available from: https://doi.org/10.1111/pcn.13022
7. Shigemura J, Ursano RJ, Morganstein JC, Kurosawa M, Benedek DM. Public responses to the novel 2019 coronavirus (2019-nCoV) in Japan: Mental health consequences and target populations. Psychiatry Clin Neurosci [Internet]. 2020 Apr 1;74(4):281–2. Available from: https://doi.org/10.1111/pcn.12988
8. Sani G, Janiri D, Di Nicola M, Janiri L, Ferretti S, Chieffo D. Mental health during and after the COVID-19 emergency in Italy. Psychiatry Clin Neurosci [Internet]. 2020 Apr 4;n/a(n/a). Available from: https://doi.org/10.1111/pcn.13004
9. Zhu X, Wu S, Miao D, Li Y. Changes in emotion of the Chinese public in regard to the SARS period.(severe acute respiratory syndrome)(Report). Soc Behav Personal an Int J. 2008;36(4):447.
10. Chang H-J, Huang N, Lee C-H, Hsu Y-J, Hsieh C-J, Chou Y-J. The impact of the SARS epidemic on the utilization of medical services: SARS and the fear of SARS.(Severe acute respiratory syndrome)(Brief Article). Am J Public Health. 2004;94(4):562.
11. Carter SE, O'Reilly M, Walden V, Frith-Powell J, Umar Kargbo A, Niederberger E. Barriers and Enablers to Treatment-Seeking Behavior and Causes of High-Risk Practices in Ebola: A Case Study From Sierra Leone. J Health Commun.

2017;22(sup1):31–8.

12. Liang W, Guan W, Chen R, Wang W, Li J, Xu K, et al. Cancer patients in SARS-CoV-2 infection: a nationwide analysis in China. Lancet Oncol. 2020;21(3):335–7.

13. Williamson E, Walker AJ, Bhaskaran KJ, Bacon S, Bates C, Morton CE, et al. OpenSAFELY: factors associated with COVID-19-related hospital death in the linked electronic health records of 17 million adult NHS patients. medRxiv [Internet]. 2020 Jan 1;2020.05.06.20092999. Available from: http://medrxiv.org/content/early/2020/05/07/2020.05.06.20092999.abstract

14. Singer S. Psychosocial impact of cancer. In: Goerling U, Mehnert A, editors. Recent Results in Cancer Research. Cham: Springer International Publishing; 2018. p. 1–11.

15. Zabora J, Brintzenhofeszoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. Psychooncology. 2001;

16. Costanzo ES, Ryff CD, Singer BH. Psychosocial Adjustment Among Cancer Survivors: Findings From a National Survey of Health and Well-Being. Heal Psychol. 2009;

17. Caruso R, Nanni MG, Riba MB, Sabato S, Grassi L. The burden of psychosocial morbidity related to cancer: patient and family issues. Vol. 29, International Review of Psychiatry. 2017. p. 389–402.

18. Northouse L, Williams AL, Given B, McCorkle R, Netter FH. Psychosocial care for family caregivers of patients with cancer. Journal of Clinical Oncology. 2012.

19. Kim Y, Baker F, Spillers RL, Wellisch DK. Psychological adjustment of cancer caregivers with multiple roles. Psychooncology. 2006;

20. Archer S, Holch P, Armes J, Calman L, Foster C, Gelcich S, et al. “No turning back” Psycho-oncology in the time of COVID-19: Insights from a survey of UK professionals. Psychooncology. 2020;

21. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. Int J Qual Heal Care. 2007;19(6):349–57.

22. Creswell JW. Qualitative Inquiry and Research Design. Qualitative Inquiry and Research Design. 2013.

23. Wadsworth Y. What is Participatory Action Research? Action Res Int [Internet]. 1998;Paper 2(November):1–23. Available from: www.scu.edu.au/schools/gcm/ar/ari/p-ywadsworth98.html

24. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.

25. Elo S, Kääriäinen M, Kanste O, Pölkki T, Utriainen K, Kyngäs H. Qualitative Content Analysis: A Focus on Trustworthiness. SAGE Open [Internet]. 2014 Jan 1;4(1):2158244014522633. Available from: https://doi.org/10.1177/2158244014522633

26. Korstjens I, Moser A. Series: Practical guidance to qualitative research: part 4: trustworthiness and publishing. Eur J Gen Pract. 2017;1–5.

27. Jin Z, Zhao K Bin, Xia YY, Chen RJ, Yu H, Tamunang Tamutana T, et al. Relationship Between Psychological Responses and the Appraisal of Risk Communication During the Early Phase of the COVID-19 Pandemic: A Two-Wave Study of Community Residents in China. Front Public Heal. 2020;

28. Teasdale E, Santer M, Geraghty AWA, Little P, Yardley L. Public perceptions of non-pharmaceutical interventions for reducing transmission of respiratory infection: Systematic review and synthesis of qualitative studies. BMC Public Health. 2014;14(1).

29. Siu JYM. Another nightmare after SARS: Knowledge perceptions of and overcoming strategies for h1n1 influenza among chronic renal disease patients in Hong Kong. Qual Health Res. 2010;20(7):893–904.

30. Rubin GJ, Amlôt R, Carter H, Large S, Wessely S, Page L. Reassuring and managing patients with concerns about swine flu: Qualitative interviews with callers to NHS Direct. BMC Public Health. 2010;10.

31. Lazarus RS, Folkman S. Transactional theory and research on emotions and coping. Eur J Pers. 1987;1(3):141–69.

32. Hodges LJ, Humphris GM, Macfarlane G. A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers.(Author Abstract). Soc Sci Med. 2005;60(1):1.

33. Bevans M, Sternberg EM. Caregiving burden, stress, and health effects among family caregivers of adult cancer patients.(Case study). JAMA, J Am Med Assoc. 2012;307(4):398.

34. Leventhal H, Brissette I, Leventhal EA. The common-sense model of self-regulation of health and illness. In: The Self-Regulation of Health and Illness Behaviour. 2012.

35. Seiler A, Jenewein J. Resilience in cancer patients. Front Psychiatry. 2019;10(April).

36. Walshe C, Roberts D, Appleton L, Calman L, Large P, Lloyd-Williams M, et al. Coping well with advanced cancer: A serial qualitative interview study with patients and family carers. PLoS One. 2017;12(1):1–25.

37. Blackstone E, Lipson AR, Douglas SL. Closer: A videoconference intervention for distance caregivers of cancer patients. Res Nurs Health. 2019;42(4):256.

38. Regan TW, Lambert SD, Kelly B, McElduff P, Girgis A, Kayser K, et al. Cross-

sectional relationships between dyadic coping and anxiety, depression, and relationship satisfaction for patients with prostate cancer and their spouses. Patient Educ Couns [Internet]. 2014;96(1):120–7. Available from: http://dx.doi.org/10.1016/j.pec.2014.04.010

39. Badr H, Herbert K, Bonnen MD, Asper JA, Wagner T. Dyadic coping in patients undergoing radiotherapy for head and neck cancer and their spouses. Front Psychol. 2018;9(OCT).

40. Feldman BN, Broussard CA. Men's adjustment to their partners' breast cancer: A dyadic coping perspective. Heal Soc Work. 2006;31(2):117–27.

41. Van Schoors M, De Paepe AL, Lemiere J, Morez A, Norga K, Lambrecht K, et al. Family Adjustment When Facing Pediatric Cancer: The Role of Parental Psychological Flexibility, Dyadic Coping, and Network Support. Front Psychol. 2019;10(December):1–12.

Table 1

Overview of the COVID-19 situation in Singapore during study recruitment

Date	New cases (Imported)	Discharged	Overall	Active cases (In ICU)	Significant event(s)	New measures taken
9 March	10 (3)	3	160	67 (10)	7 local clusters identified Italian cruise ship Costa Fortuna returning as scheduled on 10 March 2020	
10 March	6	0	166	73 (12)	Singapore allowed 600 passengers to disembark from Costa Fortuna	Suspension of activities for seniors
11 March	12 (1)	3	178	82 (9)		
12 March	9 (5)	0	187	91 (9)	COVID-19 announced a pandemic by the World Health Organization	Islamic Religious Council of Singapore announced the closure of all mosques for five days from 13 March for disinfection

Date	New cases (Imported)	Discharged	Overall	Active cases (In ICU)	Significant event(s)	New measures taken
13 March	13 (9)	1	200	103 (11)		Singapore suspends events and gatherings of 250 people or more Singapore announced a ban on visitors arriving from Italy, France, Spain and Germany from 15 March Singapore ceased port calls for all cruise vessels with immediate effect

Table 2

Sample socio-demographic and clinical characteristics

Characteristics	**Patients (*n* = 16)**	**Caregivers (*n* = 14)**
Age in years, Mean ± *SD*	60.1 ± 14.4	53.6 ± 11.2
Gender—female, *n* (%)	6 (37.5)	10 (71.4)
Ethnicity (%)		
Chinese	81.3	85.7
Malay	12.5	7.1
Indian	0	7.1
Others	6.3	0
Educational attainment (%)		
Primary school	6.3	0
Secondary school	56.3	35.7
Polytechnic diploma	12.5	7.1
Graduate degree	18.8	35.7
Post-graduate degree	6.3	14.3
Other	0	7.1
Employment status (%)		
Employed full-time	31.3	64.3
Employed half-time	6.3	7.1
Retired	56.3	7.1
Homemaker	0	21.4
Missing data	6.3	0
Monthly personal income (%)		
Below $2,500	18.8	7.1
$2,500 to $4,999	18.8	21.4
$5,000 to $7,500	6.3	21.4
Above $7,500	6.3	21.4
N/A (retired or homemaker)	50.0	28.6
Relationship status (%)		
Married	87.5	71.4
Divorced or Widowed	6.3	7.1
Single	6.3	21.4
Relation to patient (%)		
Spouse		35.7
Parent		7.1
Child		35.7
Sibling		14.3
Friend		7.1
Treatment type (%)		
Chemotherapy only	81.3	
Chemotherapy and radiotherapy	12.5	
Chemotherapy and medication	6.3	
Cancer type (%)		
Colon	31.3	
Lung	12.5	
Lymphoma	12.5	
Prostate	6.3	

Characteristics	**Patients (*n* = 16)**	**Caregivers (*n* = 14)**
Pancreas	6.3	
Stomach	6.3	
Adrenal	6.3	
Brain	6.3	
Nose	6.3	
Germ cell tumour	6.3	
Cancer stage (%)		
I	6.3	
II	12.5	
III	18.8	
IV	62.5	

Table 3

Illustrative quotes for each theme

Themes	**Illustrative Quotes**	
	Patients (*n* = 16)	**Caregivers (*n* = 14)**
Heightened sense of threat and risk		
Vulnerability and fear	For the case of myself, if I contact it, the chances of me surviving, I think it's very slim lah. [laughs] Because I will be physically very weak, and the virus will go for the weak people (P03)	Ya his risk is higher because of his immune system and the treatment that he is getting. Definitely he is of higher risk than our normal people (C18) The risk is not worrying that I get it. The risk is I'm worrying my loved one, my dad will get it (C27)
Uncertainty	Cause seasonal flu is quite normal, you go to the clinic you get treated and then it's okay. You get well. But I understand this COVID takes quite some time. And then also, uh I do not know whether you will, even if you get well, you will get it again or not. Because it's something unknown (P08) We don't know who are the people around us who are carriers of the virus. This is terrifying" (P16)	We are out and about everyday. You will never know if the people you meet are already carriers of the virus. So everyone- everyone has risks. Unless you isolate yourself completely. You don't go out to be in contact with others. But this is impossible. (C17)
Socially irresponsible others	How do we know if they have an illness. They may not tell you even if they are sick. Right? They will keep quiet, so if we are unlucky we will contract the disease. (P24) I think in the newspaper it came up, even in the news, I think this couple was charged in court for I think falsely declaring their health and so on. I think there was some news you know. So, we have people like that who just can't be bothered (P11)	Sometimes in the market when I see a lot of people not wearing mask and buying stuff as per usual, and even sneeze and cough with only a tissue paper and throw it in the dustbin. They don't care about anything. They even cough or sneeze in front of us. (C15) I have no confidence. Because they ask if you have travelled to whatever countries, some people who have went can decide to hide the fact they have travelled to those countries. (C15)
Impact on healthcare experience		

Themes	Illustrative Quotes	
Prioritizing cancer and cancer treatment	Even with the condition with this presence of the COVID-19, I am still going to follow what is scheduled. What I need to do, I'm going to do it. I'm not going to get myself frustrated or I'm not going to get myself uh upset about it. If we have to go through, or we have to go through this process, then I think we have to go (P11)	I will not defer, because his illness is more, although COVID-19 is important, his illness condition is also important. Although COVID-19 has been spreading, we can wear mask to protect ourselves, for protection. But his treatment has to continue. I am worried that if he stops treatment, his tumor will become bigger (C15)
	I felt that my treatment be interrupted, because uhhh my treatment I'm supposed to go weekly you see? Then sometimes we have to cancel one or two appointments I was just wondering whether it will affect the treatment or not (P08)	He is in a pretty late stage of his condition, and then delaying it might cause, might might cause the cancer cells to come back again, that is why again like it is like no choice right? (C02)
Necessary disruptions by new procedures	I think it's a necessary procedure lah. Because you need to trace those who have the virus, you need to trace them. So that you have to try and arrest the spread. So, it is very necessary so we understand it and we have to cooperate (P03)	Reducing the number of people here is good. But have to have at least one person [to accompany the patient], like now, she is here but she will feel more assured with me here. People who are doing treatment are most afraid of loneliness. They have to face this alone. So to allow one person to accompany the patient is a good thing. They will not feel demoralized and overthink (C17)
Responsibility falls on oneself		
Recognizing and taking responsibility	You must be responsible for your own safety lah. If you are irresponsible you go to places that are, where the virus has occurred, then you are putting yourself into… your own situations (P09)	To wash hands more often, so in our daily lives we are more cognizant of our personal hygiene. And the hygiene at home. This is also a good habit. (C17)
	As a human being we must be responsible for our action. If we feel that we have the, we have the symptoms, then we have to seek help from the hospital, and we should not be attending any other functions (P03)	Everybody got to hold their responsibility lah … we all have to play a part also. Everybody will play a part lah, yeah (C19)
Duty towards the patient		My wife- while my wife is not well. So I cannot get sick and then who is going to bring her here? Ah. that's the problem. I must get well. (C19)

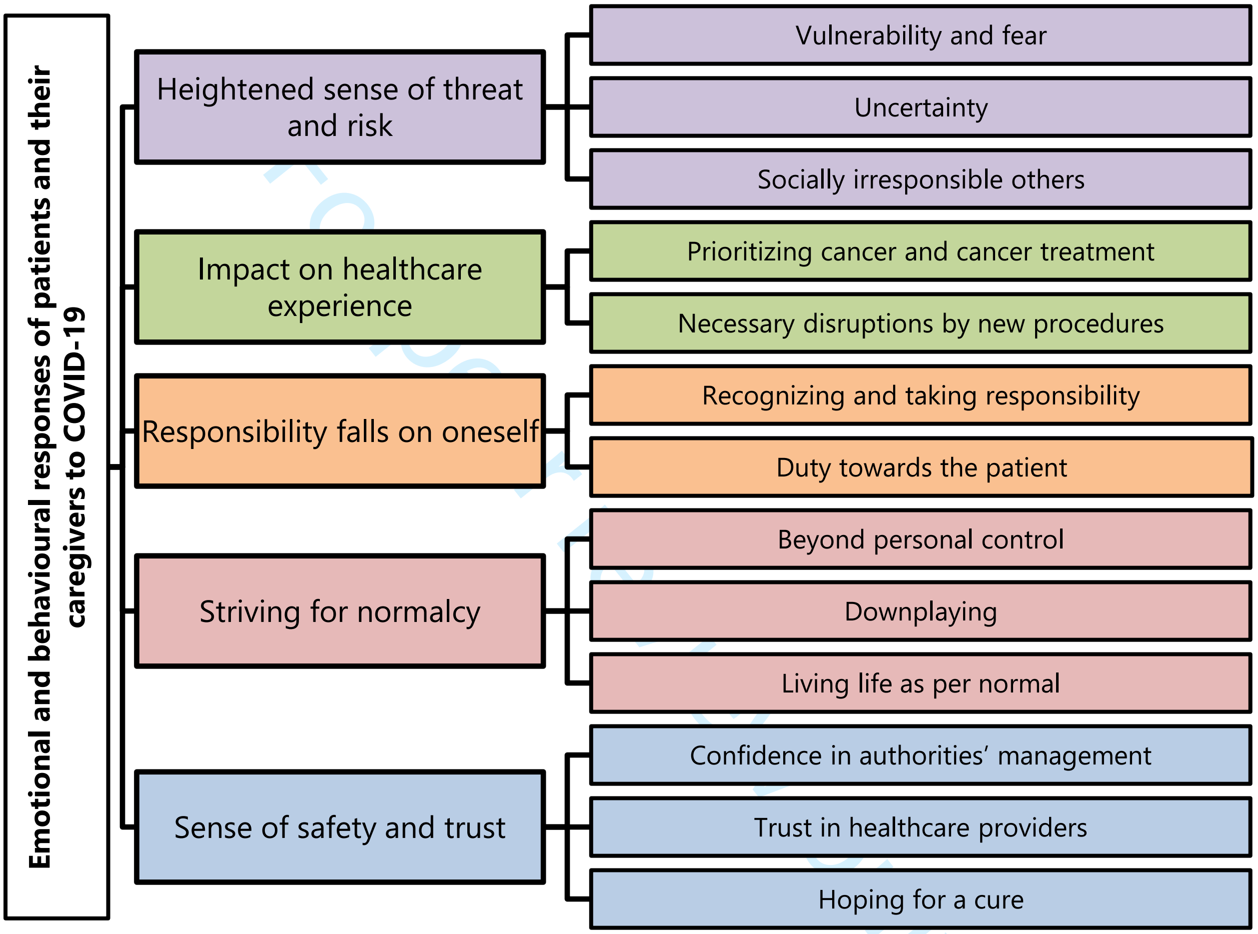
Themes	**Illustrative Quotes**	
		I have to send my son to chemo, that I take care of him, so I have to protect myself. So whenever I step out from the house, I have to put on mask (C25)
Striving for normalcy		
Beyond personal control	I think this is life you know. Right or not? If you- if this is- epidemic it's epidemic. So you can't stop this. True or not? this is how I feel. If time for you to die you die, if time for to have it you have it. So I don't think this is either human transmission or anything it's something that's fated. I think it's also- this is also in the life cycle. Every ten years, something like this will happen (P01) You can get it even if you stay at home. You will get it if you are fated to (P13)	
Downplaying	I think it doesn't affect us because we… we don't go out so much, so we don't go out then we are not in contact with those who have COVID and we are quite safe lah (P03) If we got SARS, ten days ah, will kill you, you know? The [SARS] virus kill you, you know? But this one [COVID-19] is not so bad, you get early treatment ah, I think can be saved (P30)	My mother, I think less likely la, cause she's retired and she stays at home most of the time so I think it's less likely la, yeah (C26)
Living life as per normal	Virus is already there so what can I do? I cannot like avoid it right? So we have to move on and just lead out lives as per normal. If it hits, it hits la. If it doesn't then... we leave it and see (P28) Time to live and continue living you are given the chance, you- you continue living (P01)	Change our lifestyle? … life still goes on as normal… maybe to a lesser extent we go out less and we are more careful of our hygiene, and also notice that the hawker centers are also stepping up the cleanliness (C27)
Sense of safety and trust		
Confidence in authorities' management	If without this healthcare system I think we, nobody would know what to do, alright? So with the healthcare in place, the protocol, the system, with uh daily information and advice from the ministries and hospitals, do this do this,	So things got in place very fast and confidently done you know eh with a lot of knowledge and details put in and. I think eh without which it would not have been like this one. I

Themes	Illustrative Quotes	
	keep your hands clean, keep your home clean, everything. I think with that I think this is this is the basic that we can do (P11) I see our government doing a lot of, taking a lot of measures, going all out for contact tracing and keep, and uh reminding people you know to be socially responsible and all that. I think that gives a lot of assurance and uh our our healthcare is really tip-top (P20)	think quite quite quite ok. Quite I mean very well managed. I think it it is the very best situation we can hope for (C25) It is not an easy situation for for the government so eh we we just pray and hope that they will make right and good decision and we will just follow la. Follow their decision (C23)
Trust in healthcare providers	If the doctor thinks I should defer then I will defer. No choice. So that's why I tell you. They are the professionals. We're not. If there are any issues, they'll explain to us. So whatever they say, I will have to follow (P14)	It is really good that Singapore no death case. So I think err I mean the hospital side [the healthcare providers] are doing a good job, they are really taking care and also taking it seriously (C22)
Hoping for a cure	Just hope that you doctors can quickly have a medication to cure the illness. So that we all can live a peaceful life. They we will all be okay. Otherwise, if there is no cure, it can kill many people (P13)	Hopefully one day we eliminate the virus so that we won't be facing any... any fear or worry of being infected with the COVID ah, yeah (C26)

Figure 1

Thematic schema

[refer to file]


Emotional and behavioural responses of patients and their caregivers to COVID-19
Heightened sense of threat and risk
Vulnerability and fear
Uncertainty
Socially irresponsible others
Impact on healthcare experience
Prioritizing cancer and cancer treatment
Necessary disruptions by new procedures
Responsibility falls on oneself
Recognizing and taking responsibility
Duty towards the patient
Striving for normalcy
Beyond personal control
Downplaying
Living life as per normal
Sense of safety and trust
Confidence in authorities' management
Trust in healthcare providers
Hoping for a cure

NCC COVID-19 Study Interview Guide for Patients

A. Introduction

- ➔ Interviewer introduces themselves
- ➔ Explain the aims of the project
- ➔ Explain that the interview will be recorded
    - ◆ Ask for permission to voice record
- ➔ Explain what will happen with the data
    - ◆ Interview will be transcribed for analysis
- ➔ Confidentiality and anonymity
- ➔ Participant is free to stop or pause at anytime of the interview
- ➔ Ask if they are comfortable to continue with the interview

B. Interview questions

1. What do you understand of the current health situation with COVID-19?
2. How do you think COVID-19 is transmitted?
    a. Examples of route of transmission; droplets, air-borne, physical contact
3. What are some of your concerns or fears about COVID-19? What worries you the most and why?
    a. Describe specific problems or disruptions you experienced related to the COVID-19
    b. Are there any specific concerns you may have when visiting NCC for treatment or follow up?
    c. What about your family – what concerns if any they may have?

4. How has your experience accessing and receiving healthcare changed since the COVID-19 outbreak?
    a. How much have you used health services since the outbreak?
    b. What changes have you noted/observed when you access health services (what is different, what has not changed; what for better or worse)
    c. What challenges have you faced in relation to your health treatment in context of current health situation with COVID-19 (e.g. appointment; treatment)

5. How do you feel about accessing care in the current health situation with COVID-19? Probe emotions and why.

   a. Examples of emotions; anxiety, worry, regret

   b. Would you prefer if your treatment is deferred? Why is that so? Probe on how they feel about such delays.

6. How confident are you of NCC’s screening/safety process? How do you feel when going through the screening process?

   a. What scares you; what do you find reassuring or helpful in these procedures
   b. What else / other measures may help you or other people that need to continue medical treatment in this situation

7. Given that you have to access healthcare, what are your hopes and needs and how can we best support you?

8. How likely do you think it is for you to contract COVID-19? Do you think you are more likely to contract COVID-19 than other people? Tell me more.

9. Do you think that COVID-19 is a greater threat/more serious for you in relation to:

   a. Other infections and cancer related complications
   b. H1N1/seasonal flu

10. What kind of precautionary measures have you taken to reduce your risk of contracting COVID-19?

   a. Examples of precautionary measures; stocking of medical supplies, avoiding going out (if they have done some degree of social distancing/isolation, probe about feelings - how did this impact your life/treatment etc)

11. How likely do you think it is for you to recover from COVID-19 if you contracted it? How likely do you think you will recover from COVID-19 in comparison to other people?

12. You are faced with your own health diagnosis/condition - how do you manage/cope with this? To what extent has the COVID-19 outbreak changed your approach or outlook?

   c. Examples of source of coping; family, friends, HCPs

   d. Examples of problems with coping; unable to cope, unable to access source of coping

Thank you very much for your feedback. We have come to the end of our questions but we would all be keen to hear if there may be anything else we haven’t managed to discuss today that you think is important to share?

C. Wrapping up

- ➔ Ensure that the participant had the opportunity to tell you everything they think is important
- ➔ Ask if they have any questions; clarify doubts, check emotions.
- ➔ Explain again what will happen to the data
- ➔ Thank participants
- ➔ Reimbursement

NCC COVID-19 Study Interview Guide for Caregivers

A. Introduction

- ➔ Interviewer introduces themselves
- ➔ Explain the aims of the project
- ➔ Explain that the interview will be recorded
    - ◆ Ask for permission to voice record
- ➔ Explain what will happen with the data
    - ◆ Interview will be transcribed for analysis
- ➔ Confidentiality and anonymity
- ➔ Participant is free to stop or pause at anytime of the interview
- ➔ Ask if they are comfortable to continue with the interview

I will ask you several questions related to your experience since the COVID-19 outbreak. We are keen to hear your thoughts/concerns and experience as well as how you think this may be affecting your loved one.

B. Interview questions

1. What do you understand of the current health situation with COVID-19?
2. How do you think COVID-19 is transmitted?
    a. Examples of route of transmission; droplets, air-borne, physical contact
3. What are some of your concerns or fears about COVID-19? What worries you the most and why?
    a. Describe specific problems or disruptions you experienced that may be related to the COVID-19.
    b. Are there any specific concerns you or the patient may have when visiting NCC for treatment or follow up?
    c. What about others in your family – what concerns have they discussed with you?
4. How has your experience (and the patient's experience) with accessing and receiving healthcare **changed** since the COVID-19 outbreak.

   a. How much have the patient and/or you used health services since the outbreak?

   b. What changes have you noted/observed when you or the patient access health services (what is different, the same, better or worse)

   c. What challenges have you faced in relation to the patient's (or yours, if applicable) health treatment in context of the current health situation with COVID-19 (e.g. appointment; treatment)?

5. How do you feel about you/the patient accessing healthcare in the current health situation with COVID-19? Probe emotions and why.

   a. Examples of emotions; anxiety, worry, regret

   b. Would you prefer that the patient's treatment (or your treatment) is deferred? Why is that so? Probe on how they feel about such delays.

6. How confident are you of NCC's screening/safety process? How do you feel when going through the screening process?

   a. What scares you; what do you find reassuring or helpful

   b. What else / other measures may help you or other people that need to continue medical treatment in this situation

7. How likely do you think it is for **you** to contract COVID-19? Do you think you are more likely to contract COVID-19 than other people? Tell me more.

   a. What about for **the patient**? How likely do you think it is for your family member who gets treatment to contract COVID-19? Do you think they are more likely to contract COVID-19 than other people?

8. Do you think that COVID-19 is a greater threat/more serious for you (/the patient) in relation to:
   a. Other infections and cancer complications for the patient
   b. Seasonal influenza/H1N1

9. What kind of precautionary measures have you (and the patient) taken to reduce the risk of contracting COVID-19?

   a. Examples of precautionary measures; stocking of medical supplies, avoiding going out (if they have done some degree of social distancing/isolation, probe about feelings - how did this impact your life/treatment etc)

10. How likely do you think it is for you to recover from COVID-19 if you contracted it? How likely do you think you will recover from COVID-19 in comparison to other people? How about **the patient?**

11. You, as family, are faced with patient’s health condition that can be challenging. How do you manage/cope with this? To what extent has the COVID-19 outbreak changed your approach or outlook?

   a. Examples of source of coping; family, friends, HCPs

   b. Examples of problems with coping; unable to cope, unable to access source of coping

13. As it is essential that you and your family members access healthcare for treatment, what are your hopes and needs and how can we best support you

14. Thank you very much for your feedback. I have no more questions on my end but we would all be keen to hear if there may be anything else we haven’t managed to discuss today that you think is important to share?

C. Wrapping up

➔ Ensure that the participant had the opportunity to tell you everything they think is important
➔ Ask if they have any questions; clarify doubts, check emotions.
➔ Explain again what will happen to the data
➔ Thank participants
➔ Reimbursement

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.