

# 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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**To cite:** Chia JMX, Goh ZS, Chua ZY, *et al.* 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. *BMJ Open* 2021;**11**:e041070. doi:10.1136/bmjopen-2020-041070

► Prepublication history and additional material for this paper is available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2020-041070>).

Received 29 May 2020  
Revised 26 November 2020  
Accepted 11 January 2021



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## ABSTRACT

**Objectives** Having to access life-sustaining treatment during the emerging COVID-19 outbreak has placed patients with cancer 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 semistructured 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 years 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 prioritising 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.

## BACKGROUND

COVID-19 first hit Singapore's shores on 23 January 2020. In the months that followed,

## 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 patients with cancer 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 generalisability 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.

COVID-19 was declared a pandemic by the WHO 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 front-line healthcare workers, infected patients and the general population that may persist over time.<sup>1–8</sup> Emotional responses such as fear and anxiety have been shown to influence actions, some of which may be undesirable. Self-isolation, stigmatisation, non-disclosure or non-treatment seeking behaviours noted in the Ebola outbreak<sup>9</sup> contributed to community spread and compromised efficiency of healthcare systems.<sup>10 11</sup> 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 patients with COVID-19. While the emotional and behavioural impact of infectious outbreaks are well-documented for the general population, infection survivors and frontline healthcare workers, the literature on patient populations is scarce.<sup>1-5</sup>

For patients with cancer, treatment is often non-deferrable 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.<sup>12 13</sup>

Psychological distress, which may be manifested as a variety of negative emotions from shock, anger, denial to anxiety, depression and fear of recurrence,<sup>14</sup> has been documented in 29%–43% of patients with cancer.<sup>15</sup> Emotional burden and distress is evident across all stages of disease from diagnosis, treatment to survivorship<sup>16 17</sup> and extend to caregivers and family members.<sup>17-19</sup> Despite recognition that the COVID-19 pandemic presents greater challenges to patients with cancer and caregivers,<sup>20</sup> the qualitative and quantitative impact of COVID-19 on their psychosocial well-being 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 patients with cancer and their caregivers.

## METHODS

This study adopted a qualitative methodology involving semistructured interviews. The paper was structured following Consolidated criteria for Reporting Qualitative research guidelines.<sup>21</sup>

### Setting and participants

Study sample included patients with cancer and caregivers recruited between 9 and 13 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 15–20 individuals per group as recommended to achieve theme saturation.<sup>22</sup> 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 years and above and (D) fluent in either English or Mandarin. Those only fluent in dialects or unable to give consent due to cognitive or psychiatric diagnoses were

**Table 1** Overview of the COVID-19 situation in Singapore during study recruitment

Date	New cases (imported)		Overall	Active cases (in ICU)	Significant event(s)	New measures taken
		Discharged				
9 March	10 (3)	3	160	67 (10)	7 local clusters identified Italian cruise ship <i>Costa Fortuna</i> returning as scheduled on 10 March 2020.	
10 March	6	0	166	73 (12)	Singapore allowed 600 passengers to disembark from <i>Costa Fortuna</i> .	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 WHO.	Islamic Religious Council of Singapore announced the closure of all mosques for 5 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.

excluded. Caregivers of eligible patients were recruited if they satisfied criteria C–D and provided consent.

### Data collection

Semistructured 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 (three 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 min. Interviewers included two research coordinators not involved in direct patient care (SMF and DI) and one oncologist (KYNN) 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 (ie, thematic saturation).

Two interview guides (one each for patients and caregivers) were formulated based on relevant literature and expert input on clinical perspectives (JYYN and KYNN) and qualitative health research (KG). Patient and caregiver interview guides comprised similar non-directive and open-ended questions about their experiences accessing healthcare and cancer treatment during the COVID-19 outbreak (eg, 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 online supplemental material). Interview content and procedures were pilot tested with two patients and two caregivers, serving as critical reference group for data trustworthiness.<sup>23</sup> 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: familiarisation with the data, identifying initial codes, identifying initial themes, reviewing and revising themes, and

naming and assigning descriptions to themes.<sup>24</sup> Interview audio-recordings were transcribed verbatim by study team (ZYC, ZZSG and JMXC). Mandarin interviews were translated directly into English, and translations were verified. No specialised qualitative software was used. Patient and caregiver interview transcripts were coded and analysed separately by two sets of coders (patient: JMXC and ZYC; caregiver: ZZSG and KYNN) 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 subthemes into higher order themes. This process was iterative with codes, subthemes 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.<sup>25</sup> 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 minimise misinterpretation by interviewers. We used investigator triangulation, in which study team discussed the axial and selective coding and data interpretation.<sup>26</sup> 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 (ie, *duty towards the patient*) and one unique to patients (ie, *beyond personal control*). Illustrative quotes for each subtheme are presented in figure 1 and table 3.

**Table 2** Sample sociodemographic and clinical characteristics

Characteristics	Patients (n=16)	Caregivers (n=14)
<b>Age in years, mean±SD</b>	60.1±14.4	53.6±11.2
<b>Gender—female, n (%)</b>	6 (37.5)	10 (71.4)
<b>Ethnicity (%)</b>		
Chinese	81.3	85.7
Malay	12.5	7.1
Indian	0	7.1
Others	6.3	0
<b>Educational attainment (%)</b>		
Primary school	6.3	0
Secondary school	56.3	35.7
Polytechnic diploma	12.5	7.1
Graduate degree	18.8	35.7
Postgraduate degree	6.3	14.3
Other	0	7.1
<b>Employment status (%)</b>		
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
<b>Monthly personal income (%)</b>		
Below \$2500	18.8	7.1
\$2500–\$4999	18.8	21.4
\$5000–\$7500	6.3	21.4
Above \$7500	6.3	21.4
N/A (retired or homemaker)	50.0	28.6
<b>Relationship status (%)</b>		
Married	87.5	71.4
Divorced or widowed	6.3	7.1
Single	6.3	21.4
<b>Relation to patient (%)</b>		
Spouse		35.7
Parent		7.1
Child		35.7
Sibling		14.3
Friend		7.1
<b>Treatment type (%)</b>		
Chemotherapy only	81.3	
Chemotherapy and radiotherapy	12.5	
Chemotherapy and medication	6.3	
<b>Cancer type (%)</b>		
Colon	31.3	
Lung	12.5	

Continued

**Table 2** Continued

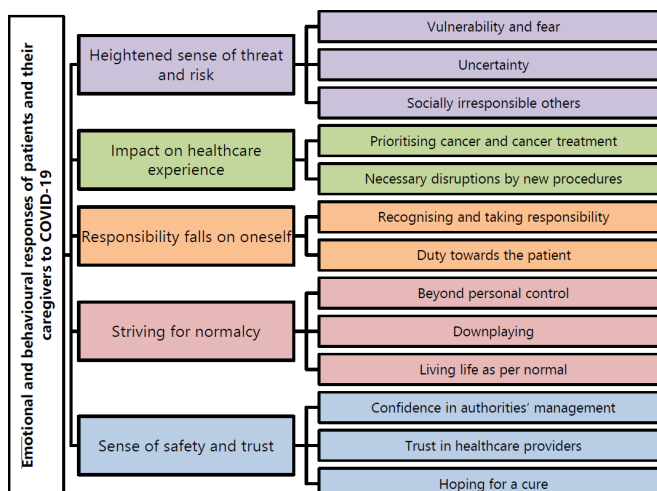
Characteristics	Patients (n=16)	Caregivers (n=14)
Lymphoma	12.5	
Prostate	6.3	
Pancreas	6.3	
Stomach	6.3	
Adrenal	6.3	
Brain	6.3	
Nose	6.3	
Germ cell tumour	6.3	
<b>Cancer stage (%)</b>		
I	6.3	
II	12.5	
III	18.8	
IV	62.5	

### 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 subthemes 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

**Figure 1** Thematic schema.

**Table 3** Illustrative quotes for each theme

Illustrative Quotes	
Themes	Caregivers (n=14)
<b>Heightened sense of threat and risk</b>	
Vulnerability and fear	<p>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)</p> <p>The risk is not worrying that I get it. The risk is I'm worrying my loved one, my dad will get it. (C27)</p>
Uncertainty	<p>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)</p>
Socially irresponsible others	<p>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)</p> <p>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)</p>
<b>Impact on healthcare experience</b>	
Prioritising cancer and cancer treatment	<p>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)</p> <p>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)</p>
Necessary disruptions by new procedures	<p>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)</p>
<b>Responsibility falls on oneself</b>	

Continued

Table 3 Continued

Illustrative Quotes	
Themes	Caregivers (n=14)
Recognising and taking responsibility	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) 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) You can get it even if you stay at home. You will get it if you are fated to. (P13)
Downplaying	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	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 hawkker centers are also stepping up the cleanliness. (C27)
Sense of safety and trust	

Continued

Table 3 Continued

Illustrative Quotes	
Themes	Caregivers (n=14)
Confidence in authorities' management	<p><b>Patients (n=16)</b></p> <p>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, 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)</p> <p>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 healthcare is really tip-top. (P20)</p>
Trust in healthcare providers	<p>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)</p>
Hoping for a cure	<p>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)</p>

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 prioritised 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 and transmission), the prognosis (course of pandemic, duration and 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 uncertainty 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, for example, 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 practising good hygiene, which amplified worry and perceived threat.

### Impact on healthcare experience

The second theme comprised two subthemes: prioritising cancer and cancer treatment and necessary disruptions caused by new procedures.

#### Prioritising 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 is 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.

### Recognising and taking responsibility

Patients and caregivers were concordant in making behavioural adjustments to stay safe. These precautions primarily involved increasing hygiene practices, wearing masks, minimising 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 minimising 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-19 or no COVID-19, it doesn't matter to me because, uh, my, my lifestyle has changed' (P03).

Besides personal behavioural adjustments, patients and caregivers recognised 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, rationalised 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 rationalised 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 influenza and perceived possible recovery from COVID-19 should they contract it. While they recognised 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 optimisation 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 that 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 healthcare providers alongside their own efforts to re-establish normalcy. Among respondents in China, greater satisfaction with risk communication, that is, provision of timely and credible information by health authorities about COVID-19, was found to be associated with subsequent reduced anxiety and emotional contagion.<sup>27</sup> 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.<sup>28</sup> 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.<sup>29 30</sup> 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 prioritising 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.<sup>10 11</sup> Prioritising cancer treatment could be regarded as an extension of taking responsibility for one's (or the patient's) health; besides practising 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.<sup>31</sup> 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 emphasised 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.<sup>32 33</sup>

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.<sup>34</sup> 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<sup>35 36</sup> 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 well-being. 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 that 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 teleconsultations 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.<sup>37</sup>

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 that may warrant a referral to medical social workers or psychologists for counselling. Ensuring caregiver well-being 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.<sup>38-41</sup> 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 (eg, prioritising 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 minimise 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 30 000 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 patients with cancer 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.

**Acknowledgements** The authors would like to thank Dr Tonia Griva, the healthcare professionals at National Cancer Centre Singapore, and all study participants for their support in the research study.

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

**Funding** This work was supported by the National Medical Research Council Clinician Scientist Award (NMRC/CSA-INV/0017/2017) and administered by the Singapore Ministry of Health's National Medical Research Council.

**Competing interests** None declared.

**Patient consent for publication** Not required.

**Ethics approval** Ethics was approved by Singhealth Centralised Institutional Review Board (CIRB reference: 2020/2155).

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available on reasonable request. The thematic data that support the findings of this present study are available from the corresponding author on reasonable request.

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## 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