

## Abstract

**Purpose/Aims:** Uptake and delivery of cancer services across the United Kingdom have been significantly impacted by the COVID-19 pandemic. This study aimed to understand the impact of the pandemic on the working practices of clinical nurse specialists and their patient interactions across different cancer specialties.

**Design:** We performed a cross-sectional survey exploring nurses' experiences of delivering care during the pandemic, as well as their perceptions of the concerns that cancer patients were experiencing.

**Methods:** Clinical nurse specialists working in London cancer services were invited to complete an online questionnaire. Nurses' experiences and their perceptions of patients' concerns were analyzed descriptively.

**Results:** 54 nurses participated. Almost half had been redeployed to other clinical areas during the pandemic (n=19). COVID-19 discussions added 5-10 minutes on average to most consultations, with nurses either working longer/unpaid hours (34%) or spending less time talking to patients about cancer (39%) to deal with this. Approximately 50% of nurses would have liked additional information and support from their hospital.

**Conclusions:** Clinical nurse specialist time and resources have been stretched during the COVID-19 pandemic. Hospitals need to work with nursing staff to ensure the specific information needs of cancer patients are being met.

## Introduction

The COVID-19 pandemic has significantly impacted on the uptake and delivery of cancer services across the United Kingdom.<sup>1,2</sup> During several phases of the pandemic, the public were instructed to stay at home and protect the National Health Service (NHS). Primary Care referral criteria for urgent cancer pathways were restricted to exclude lower-risk patients, specialist services were limited and often delivered through private sector partnerships. These unprecedented changes were implemented at pace to expand NHS capacity for COVID-19, while maintaining essential cancer services for high-risk and time-critical cases. Cancer referrals fell by up to 80% during the first lockdown in 2020.<sup>1</sup> Diagnosis rates may have reduced by 25-50%<sup>2-4</sup> and delayed diagnosis could increase mortality by 5-15%.<sup>5,6</sup> Patients who were treated during the crisis-phase sometimes had non-standard and/or sub-optimal management, whereas low-to-medium risk cases were either temporarily treated with non-surgical treatments or put on-hold entirely.

These dramatic deviations in cancer management included aspects of treatment which significantly affect quality of life for patients. Examples include the lack of immediate reconstruction for breast cancer patients undergoing mastectomy; open rather than laparoscopic surgery for gastro-intestinal cancers; and cessation of recruitment into many clinical trials for cancer treatment. Affected patients may suffer worse quality of life (e.g. lack of breast reconstruction, functional problems following open abdominal surgery) and incur future morbidity and healthcare costs to address these issues.

These changes in management required detailed consultations with patients and frequently increased the demands upon clinical nurse specialists (CNSs) and the wider multi-disciplinary

team.<sup>2</sup> CNSs in the UK are experienced nurses with postgraduate nursing qualifications who provide direct patient care in a specific specialty. In the cancer nursing setting, CNSs undertake vital patient-facing interactions, such as supporting, informing, and counseling patients at every stage of the cancer pathway including diagnosis, investigation, treatment and follow-up. Their work is largely outpatient based, but they also provide inpatient support. The relationships between cancer patients and CNSs are frequently closer and more open than with other members of the multi-disciplinary team.<sup>3</sup> These special relationships often bring to light patient factors and concerns that can significantly influence the choices that patients make. Information gathered by CNSs greatly facilitates clinical decision making and underpins personalized management.<sup>4</sup>

However, when frontline services were under most pressure, CNSs were frequently redeployed to nursing roles in other wards and services within the hospital to directly support the COVID workload, while those remaining within cancer services were required to significantly change their working practices. The experience of CNSs and patients on the cancer pathway during the pandemic is likely to have differed between organizations and between individual cancer specialties.

The aim of this study was to better understand the impact of the pandemic on the working practices of CNSs and their patient interactions across different cancer specialties in a large London teaching hospital. Specifically, our goal was to identify the acute concerns reported by cancer patients to CNSs, which represent barriers to engagement with healthcare, as well as CNSs' service-related concerns.

Understanding the impact of the pandemic on specialist cancer nurses and their interactions with patients is key to the prompt restoration of cancer services and high-quality management, which are essential to address the excess death rate and quality of life for cancer patients. Although considerable efforts are underway to return capacity and high-quality cancer services, current efforts alone will not be sufficient<sup>5</sup>. Successful outcomes depend on the extent to which these services are taken up by patients and there is an urgent need to restore appropriate health-seeking behavior<sup>6</sup>. The reasons why patients are not fully re-engaging with cancer services are under-explored and anecdotal. This study provides evidence of the experience of CNSs (across specialties) in terms of issues reported to them by patients and the impact of the pandemic on their own ability to carry out their duties. These factors are key to bridge the demand-capacity gap in cancer diagnostics and treatment, which may increase and recur during future phases of the pandemic.

## **Methods**

### *Design and setting*

An online cross-sectional survey was conducted in University College London Hospitals NHS Foundation Trust and partner hospitals in London, between the 13<sup>th</sup> of July 2020 and 9<sup>th</sup> September 2020. A study team comprising cancer doctors and surgeons, behavioral scientists and a research operations specialist, worked to develop a survey exploring the experiences of cancer CNSs during the pandemic. We conducted cognitive interviewing of the survey with 5 CNSs to check their understanding and interpretation of the survey items, which were modified and improved accordingly.

### *Participants*

All CNSs working for the hospital group caring for cancer patients in the three months before the survey were eligible to participate. There were approximately 80 eligible CNSs at the time of survey, of which 54 (67.5%) completed the survey. Potential participants were approached via informal networks by email and asked to complete the survey online. One follow-up email was sent as a reminder to participants to complete the survey.

### *Variables*

The 87-item, 30-minute survey explored CNS experiences of delivering care during the pandemic, as well as their perceptions of the concerns that cancer patients were experiencing. Data was collected through a combination of free text, multiple choice, interval scale and ordinal scale questions. The full survey is reported in Supplementary Material. We also collected data on speciality and whether CNSs had been redeployed during the pandemic to another clinical area.

### *Sample size*

54 CNSs completed the survey, of approximately 80 eligible in the hospital group.

### *Statistical analysis*

This study was exploratory in design and descriptive statistics are presented as numerators with frequencies or medians with ranges for the quantitative data. Missing data were not imputed. Thematic analysis was performed on the qualitative data. Two analysts coded the responses, categorized them by theme and reviewed the categorization together.

### *Ethical considerations*

This survey was a service evaluation and did not require formal ethical approval. We adhered to the British Psychological Society ethical guidelines for the conduct of the survey. All CNSs provided written consent.

## **Results**

Fifty four CNSs contributed data to the survey, representing a response rate of 68% of those eligible. Thirty three (61%) provided complete data for the survey. There were respondents from 13 different specialty groups, with the majority from Haematological (12; 22.2%), Genito-urinary (11; 0.4%) and Breast (9; 16.7%) cancer specialties. Table 1 shows a full breakdown of respondents' specialities. Table 2 shows the responses to multiple choice questions in the survey. In the 3 months preceding the survey, the majority of nurses (76%) reported having fewer than 20 in-person patient interactions per week. 88% had 20-50+ phone interactions per week, while only 31% reported having any video calls with their patients.

### *Impact of the pandemic on CNSs delivery of cancer care*

Nineteen of the 54 CNSs (35.2%) had been redeployed away from their specialist roles to help with the pandemic in the preceding 3 months. Redeployment lasted for a median period of 6 weeks (range 2-16 weeks).

Approximately 61% of CNSs stated that all patients wanted to discuss COVID-19 during consultations. These discussions were taking an additional 5-20 minutes per patient (72.2%). Only 1 CNS had been given additional time to have these discussions. The remaining CNSs

were spending less time talking about cancer management with patients (13 of 48; 27%) or working longer/unpaid hours (8 of 48; 16.6%).

The greatest proportion of CNSs reported being 'fairly confident' of their knowledge about COVID-19 and the impact on patients (42.6%), with 33.3% being 'a little confident' of their ability to communicate the risks/benefits of changing (or continuing with) cancer patients' treatment during the pandemic. Of those who answered the question, most were using information provided by their organization (50%) to respond to patients' questions, with 34% using information provided by Government and 16% using information from colleagues.

The most frequently reported patient questions that CNSs found hardest to answer were those regarding the impact of changes to treatment on prognosis (16% reported this) and regarding the future of the pandemic (10% reported this). Examples of questions asked by patients are listed below:

*'As my treatment was changed or paused for a period over COVID (Sic) what is my prognosis now?'*

*'If I delay my treatment due to Covid 19, will my situation get worse'*

*'Will there be a second peak? Will my treatment stop if there is a second peak?'*

Of those who answered the question, CNSs reported that they wanted to provide patients with additional information (50%) and definitive information would have provided greater reassurance or emotional support (27%). Two CNSs stated:

*'It would be better if there were good clear instructions on cancer care and covid - especially on shielding. At the moment, I'm using general govt guidelines.'*

*'Reassurance. But we are all not aware if Covid 19 is here to stay and no established studies yet that we can reflect on.'*

When asked what the hospital could have done better to support CNSs to deliver cancer care, the CNSs reported that they wanted more standardized advice/guidance (25%) and more effective communication to nursing teams (25%), while a further 25% reported that the hospital was very supportive. Suggestions from CNSs included:

*'Provided the CNS team with more specific instructions and standardised advice'*

*'They didn't reply to emails when I raised concerns over the cancer centre and staff and PPE to protect our vulnerable patients'*

*'Think the response was excellent, I felt informed and supported'*

*Perceptions of patients' concerns and questions*

CNSs reported that patients frequently asked questions about their susceptibility to COVID-19 infection (26% reported this) and regarding the safety or risk of attending hospital (20%).

Concerns included:

*Would their cancer influence their risk of getting Covid?'*

*'Will I be safe to have my treatment in the hospital where patients are treated with COVID-19?'*

92% of CNSs reported that patients frequently or always raised concerns about using public transport to get to and from the hospital.

*Who needs support and what do they need?'*

CNSs perceived that cancer patients living alone or isolated (15% chose this group), those who are clinically vulnerable (13%) and the elderly (11%) needed the most support during the pandemic. Patients whose treatment continued during the pandemic, most commonly reported concerns about their susceptibility to COVID-19 (28% of CNSs reported this), about attending hospital (22%) and about transport to hospitals (13%). Patients whose treatment was on-hold or interrupted, most commonly reported concerns about disease progression and recurrence (37% of CNSs), long-term prognosis (30%) and the timeline of the treatment changes (15%). Finally, CNSs reported that patients whose treatment was altered commonly expressed concerns about the effectiveness of the new treatment decision (30% of CNSs reported this), the impact of the treatment decision on long-term prognosis (24%) and practical concerns regarding how to access treatment/tests (13%).

## **Discussion**

The COVID-19 pandemic has had, and continues to have, an unprecedented impact on cancer services<sup>7</sup>. The impact has been seen across the cancer pathway, with patients in this study reporting concerns at diagnosis through to treatment and beyond. The time of CNSs was stretched due to staff being redeployed elsewhere in the NHS, at a time when patients were requiring more and new information about their condition.

Both information and time were lacking for the CNSs who responded. CNSs were coping with the extra demands placed on them by working longer and often unpaid hours or spending less time on cancer care. Many felt that the hospital could have better supported them by providing more information and for this to be communicated more effectively.

While it is understandable that complete and definitive information was not available at the start of the first crisis phase, it remains important for organizations to work with nursing staff to ensure that the specific information needs of their patients are being met.

CNSs identified that the same group of patients who were vulnerable to the impact of the pandemic in general, were also vulnerable to greater impact on their cancer care.

Individuals who were living alone, those who were older and clinically vulnerable, were likely to have increased needs, compounded by the effects of social isolation as a result of the pandemic. Patients also had specific concerns about travelling to and from hospital using public transport, which is likely to be particularly relevant to older adults and those with lower incomes. It will be essential moving forward, to place greater focus on these

patient populations, considering the ongoing impact of the pandemic on their ability to cope with and manage their cancer diagnosis and treatment.

It is clear that the pandemic has had a wide-ranging impact on CNSs, some of which will have been difficult to avoid. However, our results suggest that hospitals can take actions to mitigate the impact on services. Firstly, information provision for CNSs should be a priority with clear guidelines and effective communication. Hospitals should acknowledge that CNS will require additional time with patients to discuss this information, as well as to discuss the implications of the pandemic for their treatment; allow reassurance of the safety of hospitals; and proposed changes to cancer management. Vulnerable patients and those who are digitally excluded may require more support and time when planning their care. This support should be ongoing: where possible, redeployment of CNSs to other clinical areas should be avoided or minimized to allow for continuity of care.

This study is among the first seeking to understand the barriers to cancer management from patients and CNSs during the COVID-19 pandemic. Limitations of this study include that it was conducted in a single geographical area in London, which may limit external validity for smaller or more rural healthcare settings. Although possible to draw conclusions about the wider system, this survey primarily provides the foundation for larger and more comprehensive studies. We considered the CNS's perspective of patient concerns to be highly relevant, as they are often the first line of contact and interacted with a large number of patients during the pandemic. However, even these interactions may not fully reflect the true extent of concerns that patients may themselves report in a research context.

The pandemic has undoubtedly affected cancer services in numerous and wide-reaching ways. This study provides unique insights into the particular impact on CNSs and patients' concerns, highlighting approaches which hospitals can take to support staff and maintain patient care as the pandemic evolves. Additional protected time for CNSs to discuss cancer management in the context of COVID-19, along with the provision of high quality information to support patients, are key to enabling healthcare professionals to continue their role effectively.

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