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Analysis of local qualitative cancer patient experience alongside the 2019 results of the UK National Cancer Patient Experience Survey.

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ABSTRACT

The National Cancer Patient Experience Survey is completed annually. Limitations of the survey make it hard for healthcare providers to develop accurate improvement plans.

Objectives: This study analyses data from local qualitative interviewing about what matters most to patients with information from the National Cancer Patient Experience survey to formulate an accurate improvement plan. This work seeks to provide a deeper analysis of the results of the 2019 National Cancer Patient Experience survey.

Methods: Qualitative data were collected through a focus group, telephone and virtual interviews from patients in North East London. Ten questions from the National Cancer Patient Experience survey were asked. Interviews were recorded, transcribed verbatim and analysed using an NVivo framework matrix. The results were viewed considering the 2019 National Cancer Patient Experience report.

Key findings: In total 17 patients and four carers participated. The interview answers provided a more in-depth response when compared with the National Cancer Patient Experience survey results, allowing for a deeper understanding of patient experience. This provided an insightful understanding of what matters most to our patients.

Conclusions: The National Cancer Patient Experience survey results are not always reflective of the patient population. It is important to use other data sources such as qualitative interviewing alongside the National Cancer Patient Experience survey. The data collated during this study have been used to identify themes and deliverables for achievable and sustainable improvements to be made.

Keywords: Cancer, information, patient experience, treatment.

INTRODUCTION

In the UK there is expected to be 4 million people living with cancer by 2030 ¹. An optimal patient experience leads to better patient outcomes, improves the reputation of the organisation and is linked to a reduced cost of care ².

The National Cancer Patient Experience Survey (NCPES) is an annual survey undertaken to determine the experience cancer patients have when using the National Health Service (NHS). The survey sample includes adults aged 16 and over who have a confirmed primary diagnosis of cancer who have attended the hospital as an inpatient or day case for a cancer related treatment. The most recent iteration contains 52 questions related to specific points during a patient's journey³. The purpose of the survey is to not only monitor national progress with regards to cancer care but also to provide local information to drive quality improvements ^{4,5}.

There is some concern around the statistical reliability of the survey ^{5,6}. Abel et al 2019 have stated that it is not reliable when comparing the performance of different healthcare providers ⁵. The Spearman-Brown reliability formula was used for each question for each hospital providing a reliability score of between 0 and 1 ⁵. Where a score of < 0.7 was calculated this represented low reliability. A score of ≥ 0.9 represented high reliability. Only 35% of hospital-question pairs reached a reliability score of 0.7 ⁵. Saunders et al showed that healthcare providers with higher response rates have higher experience scores ⁷.

Many of the questions in the NCPES are difficult for patients to answer due to ambiguity and leave healthcare providers with more questions not addressed by the survey⁸. The purpose of this study was to ask a selection of the NCPES questions to our patient population to explore the answers to these in more detail.

The study site is made up of four major hospital sites and several community locations serving around 2.5million people in North East London^{9,10}. The population is one of the most diverse and deprived areas of the UK¹¹.

METHOD

The work was defined as a service evaluation in line with the Health Research Authority decision tool and did not require ethics approval¹². The service evaluation was approved by the local Clinical Effectiveness Unit (project ID: 11426). A steering group made up of two patients and patient experience leads supported the work.

Focus groups were chosen to collect the qualitative data to help create generation of group dynamic conversation¹³. A topic guide was produced and reviewed by the steering group. Ten questions were chosen from the NCPES³ (Box 1). Five of the questions were chosen as the scores were outside the expected lower range for the healthcare provider in 2018³. The other 5 questions were chosen as further exploration of these answers was required and could lead to important quality improvement changes.

Participants

Patient details were collated from the electronic patient record system. Inclusion criteria included patients who had used the hospital cancer services within the last two years. Patients were selected by purposive sampling to achieve a group of participants that reflected the true population¹⁴. The proposed number was 3-6 per focus group¹⁵⁻¹⁷. Recruitment was to continue until data saturation was reached defined as the point at which no new themes emerged¹⁵. Those patients that were selected were invited to take part by telephone. Patient carers were also invited.

Change in method

Due to COVID-19 only one focus group occurred on 9 May 2020. Patients and carers who had originally consented to attend subsequent focus groups were instead invited for interview via telephone or video call during the period of 23 March – 10 April 2020. A virtual focus group was not conducted as at the time the main author was not experienced at conducting a group virtually and it was unclear whether patient members would have the facilities. All telephone interviews were conducted by the main author using the topic script. The same sample size method was used as for the focus groups.

Data analysis

The focus group and patient interviews were recorded using a Dictaphone and transcribed verbatim. Data was downloaded and stored in a password protected computer file. No patient identifiable information was contained within the recordings. Verbal consent to record was taken. NVivo version 12 was used to analyse the data using a framework matrix by the main author¹⁸. A second author reviewed the matrix to check the categorisation of the quotes. The data within the matrix was triangulated with the data from the 2019 results of the NCPES⁴. Themes were identified from both data sets.

Box 1: Questions used from the NCPES³

RESULTS

Data saturation was reached after a total of 17 patients and four carers had participated. Three patients attended the focus group, three patients who initially were to attend the same focus group but declined due to the current risks associated with COVID-19 submitted their answers to the topic guide script via email and 11 patients and four carers were interviewed virtually (one patient and their husband via zoom and the remainder via telephone). The participants demographic characteristics are shown in Table 1.

The focus group was one hour, and 13 minutes and the average length interview was 40 minutes eight seconds (range eight minutes 37 seconds - one hour eight minutes 35 seconds).

Table 2 displays the raw data from the NCPES 2019 survey for the questions displayed in Box 1⁴. The qualitative responses are divided up per question in the same order as the questions in Table 2.

Table 1: Demographic data of patient participants.

Table 2: Questions and scores from the NCPES 2019 results⁴.

Receiving information

Patients were satisfied with the amount of information provided to them, but some patients felt that the content and format were not always tailored to their specific needs. This can be seen from the explanations below.

Sub theme - receiving information about cancer type

There was a mixed response with regards to whether patients felt they received the right written information with regards to their cancer type. Some interviewed patients were impressed with the written information.

'You're given a very good explanatory book ... my estimation of them [Macmillan Cancer Support Charity] has gone up enormously and reading their literature which is very clear and very not over complicated at all.'

One participant explained how the specialist nurse spent a long time going through information which she appreciated and although the participant would not normally look at leaflets, she did find them helpful.

'I think you know going home with a folder filled with different leaflets and things, although I'm the sort of person who gets the information from the internet, you know, I don't look at leaflets but it was really good to have this with me going home.'

A male participant was unhappy that he was not given enough information about infertility. He explained that this piece of information 'would have been potentially life changing for me'.

Sub theme - receiving information about their operation

Although most patients interviewed (n=10) did feel they had the right amount of information there were a few who would have liked more. One participant explained how she was not given the right information.

'Some NHS Trusts have their own leaflets as a PDF you can download but I couldn't find anything like that relating to Barts.'

A participant explained how she felt anxious as she had not been informed about what happened after the surgery.

'When we went for the pre, the assessment before the op umm he said you'd probably be out on the same day of surgery. And I thought oh gosh that's a bit quick.'

Those who felt they were given the right information felt prepared going into the operation.

'The surgical registrar sat me down and said to me what do you know about your condition? She took me through what I knew first and then just fed things that were additional ... you know it was just such a lovely way to be treated.'

Sub theme - receiving information about radiotherapy and chemotherapy treatment

The interviewed participants (n=7) were positive about the radiotherapy team and the time the staff took to go through the information.

'They explained absolutely every detail, answered every question.'

One of the participants suffering from long term side effects would have liked to have had more information about what long term side effects to expect.

'I think they need to be a bit more honest. I said just like tell me.'

With regards to receiving information about chemotherapy all patients (n=12) appreciated the pre-chemotherapy assessment they were offered and found it helpful.

'They were taking in whatever level of understanding I had ... and they would ask if I had any questions and if I did then they would go into something more in depth.'

One patient was not able to attend the pre-assessment for patients who were to undergo a stem cell transplant (SCT). The patient felt that he did not have enough information when he was admitted.

'I did feel almost that I was going in without full knowledge before, before the stem cell transplant. There were a few things during my time there that almost came as a surprise.'

Being involved in decision making

Patient preference and experience varied in terms of being involved in decisions about their care. Some patients were happy to be guided by the medical team while others took pride in their high level of involvement in the decisions.

Two patients explained how they felt informed to make a decision but only because they had done the research around the treatment themselves.

'I found here [the healthcare provider], I found the consultant, I found the trial. I found my own treatment pathway.'

A patient due to have surgery explained she liked the way she was actively told not to make a decision that day but to go away read the information and come back in a week.

'I really, really appreciated that, that they didn't want me to decide right then... I think it was fantastic.'

Having a family member or friend with the patient made a difference for quite a few patients.

'It was vital for me to have somebody with me to listen to the prognosis and also the number of the procedures because it's very confusing at the beginning.'

One patient wanted the surgery to be undertaken at a different hospital site but was told it would have to be done at the same place where her other treatment took place.

'They told me oh there's the same doctor and this because you done chemotherapy in [hospital site] so you have to do surgery there, not have a choice.'

Support from the clinical nurse specialist

A clinical nurse specialist (CNS) is an expert nurse providing patients with a consistent point of contact throughout their pathway. They provide a vital link to the patient's care team as well as ensuring the patient has the information and understanding required.

Most patients interviewed knew who their CNS was and regarded them highly. One patient said she did not have a CNS but then in later conversation revealed that she did have a nurse contact who she referred to as a Macmillan nurse, but she did not see much of her. Another patient explained how when she had primary breast cancer, she did have a CNS but that now she has secondary breast cancer she does not and described it as 'a massive gap.'

There was a consensus that the CNSs were easy to contact. Patients stated that they were not always able to get through on the phone straight away but 'you can guarantee you will hear from them the same day in response to a left message.' Patients accepted this and realised that their CNS had other patients to care for besides themselves.

One patient reported that she left a message requesting some reassurance as to when her surgery date will be, and she did not hear back.

'I did phone my nurse then and leave a message saying I just need some reassurance because I did a nose dive for a week and I just went into depression and I phoned her said I need some reassurance about when it's going to happen ... but I didn't get an answer.'

Being able to discuss worries and fears

Patients on the inpatient wards reported that the doctors provided them with opportunities to discuss worries as they visited every day. This was not the case for everyone, and there was a mixed experience reported by patients across both inpatient and outpatient departments.

'Absolutely, my consultant and his assistants visited me every day, if the consultant was not available then information was communicated back to him.'

A carer felt that her husband was not receiving the right care and was not in an environment where he could discuss his worries, so she took him home. He was later admitted to a hospice for ongoing care. Another patient wished the ward rounds could occur when his partner was present as he found it difficult to convey his feelings and thoughts at the time.

With regards to discussing worries and fears in the outpatient environment patients only felt able to discuss these topics with staff who they knew well. A couple of patients mentioned that staff in the radiotherapy department were very understanding and caring. One patient did say that she would speak to her sisters if she had a concern but did not feel that could talk to a member of staff.

'I don't know who I phone, who do I phone up? Do I phone up my doctor or what if I've got a problem?'

Waiting times

When waiting for outpatient clinics there was a consensus that yes 'you have to wait a long time' but most patients had an understanding that 'it's the NHS, things knock on, emergencies happen.' Patients seemed most upset by the length of waiting required to receive their treatment as an outpatient rather than waiting to see a member of their clinical team.

'One day I was kept there waiting for 3 hours before my actual, before I was even called in to have my treatment.'

'On two occasions I was there all day waiting for the chemotherapy to arrive ... was expected to sit in my wheelchair all day waiting in the reception area.' This patient was informed about the wait but the 'message was delivered to me in an unacceptable delivery of voice.'

Patients were well informed about delays in radiotherapy treatment.

'Oh yes if there were delays they'd come out and say during whilst you were there, they'd come and say sorry there's a delay.').

DISCUSSION

Qualitative data allows for a deeper explanation of the same questions used in the NCPES. Utilising two data sources provides a more comprehensive picture for service improvement¹⁹.

Limitations

Patients are more likely to be honest in an anonymous national survey compared to partaking in an interview. Due to the differing methods of data collection comparisons between the NCPES data and the qualitative data cannot be made but the data can be collated and utilised as a whole. The ethnicity of the patients involved is not diverse and may not reflect the patient population but may reflect the population of other healthcare providers. Not all the questions were answered by every participant.

Patients are provided with a collection of written material at diagnosis. From the discussion with the participants this is happening but some information for example regarding fertility is missing. Patient experience can be enhanced by asking what information patients are interested in to provide individualised education. Some participants preferred information to be communicated in other ways such as online or verbally face-to-face and therefore may disregard written information which may impact the answer they give in the NCPES^{20, 21}.

Patients reported that information prior to an operation could have been better. The NCPES score for this question was 94%. This score is higher than expected given the results from the interviews. One patient highlighted the fact that not only is it important to provide the right information, but to consider the way in which to say it. This is an important suggestion which can be utilised in other scenarios^{22, 23}.

With regards to receiving the right amount of information prior to radiotherapy, participants spoke highly of the radiotherapy department therefore it might have been expected that the NCPES score of 84% should be higher. A discussion around long term side effects was missing for one participant, but others were impressed by the time staff took. For receiving the right level of information prior to chemotherapy the NCPES score of 80% was reflective. One method for improving information for patients who are due to start treatment is to run workshops with groups of patients^{24,25}. This is an area whereby pharmacy staff can provide their expert knowledge of side effects and how to manage them.

Participants had varied experience when making decisions about their treatment and care²⁶. This NCPES question is broad as patients will have to make decisions at multiple points throughout their treatment and their want of involvement will vary throughout. The response of 75% in the NCPES is therefore difficult to interpret. Some patients may base this on the general feeling of decision making throughout their care whereas others may base their answer on one decision. It is important for clinicians and pharmacy staff to be able to recognise, understand and adjust their conversations accordingly.

CNSs are a vital component to the care of a cancer patient²⁷. The Trust scores for the two questions related to CNS are high at 95% for patients knowing the name of their CNS and 81% for being able to contact their CNS. The NCPES score of 95% reflects the interview answers well as all patients who had a CNS knew who they were. Unfortunately, one patient identified that not having a CNS was a noticeable issue and a couple had inconsistent care. The score of 81% is lower when comparing to the interview conversations about contacting the CNS. Patients did explain that they rarely got through first time when contacting their CNS but the CNS would call back sometimes in as little time as an hour.

The NCPES 2019 scores for whether patients felt able to discuss their worries and fears during an inpatient and outpatient visit are 47% and 59% respectively. From the patient interviews it could be expected that the value of 47% would be higher. Patients recognised that when their doctors visited each day on a ward round this was an opportunity to discuss any concerns which they utilised. There was one case where the carer did not feel this was the case. As expected for discussing worries and fears patients felt more likely to open up to staff who they had a relationship with. Staff need to be empathetic towards patients and build relationships quickly to gain trust²⁸. Providing the patient with a holistic needs assessment can provide opportunities for patients to feel safe to open up²⁹. These points are relevant to pharmacy staff as it is important for patients to trust in what their pharmacy team member is advising them on and for that staff member to provide the patient with an opportunity to share any concerns.

The NHS is known for poor waiting times³⁰. The NCPES score for waiting times is low at 52%. Although patients reported long and multiple waits, their language and tone of voice was not used in a manner of complaint but as a matter of fact. Patients knew that they would be given the time during their consultation with a clinician, so they were understanding of the wait. Patients did complain when waiting for treatment for example their chemotherapy. Nottingham, Johnson et al. (2018) showed that overall patient satisfaction was affected when the wait was 45 minutes or longer, male patients tended to be more satisfied with information about current waiting times and patients who were highly satisfied with their time with the healthcare professional were more likely to recommend the service³¹.

A theme that threads itself amongst the answers is that of empathy. If staff can empathise with patients and their situation, they will offer their time to explain information in more detail, ensure they understand what options are available and provide the opportunity to discuss concerns³².

The NCPES is limited in that the data is not broken down by hospital site and healthcare providers are not provided with ethnicity demographics. Needs of cancer patients from ethnic minority backgrounds are often not met. Breaking down the data per ethnicity would support healthcare providers to focus on supporting these groups³³⁻³⁵.

Conclusion

The NCPES is a useful tool for sourcing data from a large sample size and for benchmarking against other healthcare providers. The results of this evaluation show that the results are not always reflective of the detailed response when patients are queried further in an in-depth interview. The results of the NCPES and other national or even international surveys should not be used alone but utilised with other sources of data to develop a wider and more accurate piece of work for local improvement of cancer patient experience. The authors of this article actively promote speaking to the users of the service to provide an accurate indication of what matters most to patients.

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Box 1: Questions used from the NCPES ³

When you were told you had cancer, were you given written information about the type of cancer you had?

Beforehand, did you have all the information you needed about your operation?

Beforehand, did you have all of the information you needed about your radiotherapy treatment?

Beforehand, did you have all of the information you needed about your chemotherapy treatment?

Were you involved as much as you wanted to be in decisions about your care and treatment?

Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?

How easy or difficult has it been for you to contact your Clinical Nurse Specialist?

During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?

While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?

Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?

Table 1: Demographic data of patient participants.

Patient +/- carer (participant no.)	Age of patient at time of call	Ethnicity of patient	Sex of patient	Diagnosis of patient
Wife (1)	79	White - Other	Male	Pancreatic
Patient (2) + husband (3)	47	Asian - Other	Female	Breast
Patient (4) + wife (5)	51	Asian - Bangladeshi	Male	Rectal cancer
Patient (6)	45	Black - African	Female	Breast
Patient (7)	49	Other	Male	Myeloma
Patient (8)	67	White - Other	Female	Pancreatic
Patient (9)	66	White - British	Male	Prostate
Patient (10) + wife (11)	77	White - British	Male	Myeloma
Patient (12)	43	White - British	Female	Breast
Patient (13)	33	White - Other	Male	Testicular
Patient (14)	49	White - Other	Female	Breast
Patient (15)	63	White - Irish	Female	SCLC
Patient (16)	34	White - British	Male	Testicular
Patient (17)	68	White - British	Male	Myeloma
Patient (18)	70	White - British	Female	Sinonasal
Patient (19)	55	Other	Female	Uterine
Patient (20)	52	White - Other	Female	Breast
Patient (21)	66	Asian - Other	Female	Uterine

Table 2: Questions and scores from the NCPES 2019 results ⁴.

Question type	Unadjusted score for 2019
Patient given easy to understand written information about the type of cancer they had	65%
Beforehand, patient had all the information needed about the operation	94%
Beforehand patient completely had all information needed about radiotherapy treatment	84%
Beforehand patient completely had all information needed about chemotherapy treatment	80%
Patient definitely involved as much as they wanted in decisions about care and treatment	75%
Patient given the name of a Clinical Nurse Specialist (CNS) who would support them through their treatment	95%
Patient found it very or quite easy to contact their CNS	81%
Patient definitely found hospital staff to discuss worries or fears during their inpatient visit	47%
Patient definitely found hospital staff to discuss worries or fears during their outpatient or day case visit	59%
Patient felt length of time for attending clinics and appointments for cancer was about right	52%