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# A qualitative study of patients with Cancer of Unknown Primary: Perceptions of communication, understanding of diagnosis and genomic testing, and information needs

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## Abstract

**Objective:** Patients with Cancer of Unknown Primary (CUP) commonly report poor understanding of their illness and high levels of psychological distress. Despite the potential benefits to CUP patients, there is a paucity of research exploring the reasons behind poor understanding of a CUP diagnosis. The aim of this study was to understand patients' experiences of communication with doctors, their understanding of diagnosis and the role of genomic testing, as well as their information needs.

**Methods:** Semi-structured interviews explored CUP patients' perceptions of communication with their doctors, understanding of their illness, and their needs regarding medical information. Qualitative inductive thematic analysis of transcribed audio-recordings was employed.

**Setting/Participants:** Nineteen patients were recruited from within a prospective cohort study involving routine genomic testing of CUP patients.

**Results:** CUP patients had varied perceptions of communication with doctors as well as different levels of need, readiness, and capacity for information. Some patients felt well understood and supported by their doctors while others did not. Many patients reported feeling overwhelmed and shocked when receiving their cancer diagnosis and emphasized the importance of family support in receiving and understanding medical information. While patients understood the implications of genomic testing for treatment and diagnosis, few had a detailed understanding of genomic testing.

**Conclusions:** Patients' experience of communication and understanding of CUP could be potentially improved by clinicians' assessment of the communication style preferred by each patient and their family and the development of online resources to meet their evolving information needs.

## KEYWORDS

cancer, cancer of unknown primary, communication, genomic testing, information needs, oncology, psycho-oncology, understanding of cancer

Mileskin Linda and Penelope Schofield contributed equally as senior authors.

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## 1 | INTRODUCTION

Cancer of Unknown Primary (CUP) refers to a diagnosis of metastatic cancer, where the source of primary tumor cannot be identified despite multiple investigations.<sup>1,2</sup> CUP patients may experience high levels of psychological distress given the uncertainty surrounding a clear primary site, lack of treatment options, and low survival rates. They also frequently report insufficient understanding of their illness and have higher requirements for psycho-social care as compared to other metastatic cancers.<sup>3-11</sup>

Advancements in precision oncology driven by genomic analysis provide new hope with regards to identification of the site of origin as well as molecularly-guided treatment opportunities for CUP patients.<sup>12,13</sup> Genomic testing may identify multiple types of molecular abnormalities, which can help guide clinical recommendations regarding cancer treatment and diagnosis.<sup>13</sup> While genomic testing holds great potential to improve outcomes for CUP patients, understanding of genomic results could potentially be challenging for many patients and lead to increased confusion, uncertainty, and psychological distress.<sup>14,15</sup>

A recent UK large-scale national study of unmet needs among over four thousand cancer patients revealed a higher percentage of CUP patients expressed a wish to be better informed about their condition compared with matched non-CUP sample.<sup>6</sup> CUP patients were less likely to indicate they were given written information about their cancer compared with those with a known primary.<sup>6</sup> Also, a significantly lower percentage of CUP patients reported they completely understood the explanation of their illness.<sup>6</sup> Further, over 30% of the CUP patients did not receive sufficient information about their cancer nor understand the explanation provided to them about their illness.<sup>6</sup> Importantly, recent research demonstrated that CUP patients who had poor understanding of their cancer had higher levels of illness uncertainty which led to higher psychological distress.<sup>7</sup> Hence, there is an urgent need to understand and improve the quality of communication between CUP patients and healthcare professionals and to ensure patients have sufficient understanding of their illness in order to minimize distress.

The aim of this study is to explore CUP patients' perceptions regarding communication with their doctors, understanding of their diagnosis and genomic testing, and their information needs. To our knowledge there has been no qualitative investigation into CUP patients' views and needs regarding understanding of genomic testing in CUP, and our study will shed light on this important topic.

## 2 | METHODS

### 2.1 | Design

This qualitative study was informed by a constructivist approach, which asserts perceived reality is constructed from individual, social, and historical contexts, and this mitigates the existence of an absolute shared truth.<sup>16</sup> The research involved thematic analysis, guided by selected grounded theory techniques of comparative, iterative, and

predominantly inductive analysis.<sup>17</sup> While there is debate about the "right" grounded theory approach,<sup>18</sup> the "Strauss" approach supports using grounded theory procedures, as needed, to produce themes.<sup>17</sup>

### 2.2 | Setting and participants

Participants were recruited through the Cancer of Unknown Primary oncology clinic at Peter MacCallum Cancer Centre in Melbourne, Australia between July 2019 and June 2022 as part of the Solving Unknown Primary CancER (SUPER) project. SUPER is a national cohort study aiming to: (a) improve diagnostic assessment; (b) integrate new diagnostic approaches, specifically, genomic testing for likely site-of-origin and actionable molecular targets; and (c) understand psychosocial needs of patients. Details of the testing and impact on care have been previously reported.<sup>13</sup>

The following inclusion criteria were used in this study: (1) pathological diagnosis of CUP; (2) yet to commence treatment or commenced treatment within the previous 6-month; (3) able to read and write in English; (4) had received results of genomic testing; and (5) provided written informed consent. Patients were excluded from the study if they: (1) were under 18 years; (2) had poor ECOG (Eastern Cooperative Group) health performance status (greater than or equal to 3); or (3) had uncontrolled medical or psychological conditions that may prevent completion of study requirements.

Using convenience sampling, patients were first identified by using the SUPER database at Peter MacCallum Cancer Centre and their treating oncologists were consulted to confirm patients' study eligibility. Eligible patients were provided with the Participant Information Sheet and Consent Form. Follow up phone interviews with CUP patients were scheduled approximately 1-2 weeks after the diagnostic consultation. Ethics approval for the study was granted by PeterMacCallum Cancer Centre ethics committee (number LNR/50657/PMCC-2019).

### 2.3 | Interviews

Interviews were guided by a semi-structured interview schedule developed by the research team (Appendix S1). Audio-recorded phone interviews with CUP patients were conducted. The interview explored patients' perceptions of communication with their doctors, their information needs, understanding of their diagnosis and genomic testing, and suggestions and preferences regarding communication with clinicians that could improve comprehension of illness and genomic testing.

### 2.4 | Data analysis

Audio-recorded interviews were transcribed verbatim. Qualitative data management software ATLAS.ti8 for Windows was employed. Initial analysis involved applying a researcher-created label (code) that characterized the meaning of each manageable interview segment. Coded segments were compared with other segments to

determine similarities and differences. Similar coded segments were grouped under researcher-created categories (labels representing comparable code groups). Categories were also compared, and similar categories grouped together under researcher-created themes (labels representing comparable category and code groups). After an initial analysis, a separate experienced qualitative researcher, also examined all the data using an interrater reliability procedure.<sup>19</sup> This involved KW initially coding the data and then CO, an experienced qualitative researcher, also examining the data and KW's coding. KW and CO discussed coding inconsistencies until mutually agreeing on the set of codes. KW then grouped comparable codes into categories, and comparable categories into themes, which CO also examined. CO and KW continued to discuss comparable and different interpretations of the categories and themes until reaching agreement on the final representation of findings. Study reporting was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ), except data and interpretations were not checked with patients, given they create additional intrusion, and no evidence indicates that they improve research quality.<sup>20-22</sup>

### 3 | RESULTS

Nineteen CUP patients (Male = 63%) participated in semi-structured interviews, which were approximately 30 min long (SD = 8 min). Mean age was 59.15 years (SD 11.98). Participants' characteristics are provided in Table 1. Findings were organized into the three themes and seven categories. Participants' recommendations are presented in Table 2, and factors affecting CUP patients' understanding of cancer as depicted in Figure 1.

#### 3.1 | Disparate experiences of communication with doctors

##### 3.1.1 | Divergent views about mostly verbal, face-to-face communications

Doctors mainly communicated verbally with patients to explain cancer diagnoses, clinical testing, treatments, and side effects. Clarifications through diagrams, scans, pictures, and take-away written materials were rare. Only two participants recalled receiving genomic testing reports. ID4 said the report, "wasn't easy to understand", whereas ID6 was reassured to receive information shared with her/his medical team and have nothing "hidden". Some patients reported clear, direct, and reassuring clinician communications. ID1 said, "clinicians have been very helpful, willing to listen, and have taken the time, well to listen on the one hand but then to answer questions". Others, however, described confusing, non-supportive, and misinformed communications. ID12 queried, why she was "palmed off all the time ...is it because it's an unknown cancer and it's not worthwhile pursuing?" ID7 was initially given much information about melanoma but then felt confused when told, "they weren't sure" of the diagnosis.

TABLE 1 Participant characteristics.

Demographic variables	N	%
Gender		
Male	12	63%
Female	7	37%
Marital status		
Married/Defacto	14	74%
Separated/Divorced	4	21%
Widowed	1	5%
Highest education level:		
Secondary schooling	8	42%
Tertiary	9	47%
Trade, TAFE, college	2	11%
English as first language	16	84%

Most patients said face-to-face communication with doctors was important, however ID9 preferred phone communication from home, explaining that it was, "very relaxing (because) I could ask, like things came to mind much easier". Several patients also spoke about the importance of receiving prognostic information from doctors, with ID7 disappointed to discover the seriousness of his cancer from oncologist provided written materials.

##### 3.1.2 | Communication management strategies included passive or proactive engagement, humor, and/or empathy

Patients used varied strategies to manage communication with doctors. Some accepted and trusted medical decisions while others were more proactive, wanting involvement in decision-making processes, and asking questions to confirm correct understandings. ID1 explained, "When it's something where potentially your life is involved it's very necessary to come away thinking okay that's what we were talking about, I understand". Establishing a good patient-doctor relationship, including humor, could also be important.

I wanted a script for another medicine which was 6-months' worth and I said I think I'll be around to finish that off and then he said to me, "Yes don't buy any green bananas", so we can have a bit of a joke about it.  
(ID7)

Some patients empathized with doctors' communicative challenges, with ID16 explaining how sometimes "answers weren't sufficient but that's because they didn't know" and ID17 querying whether clinicians "don't want to bombard you and overburden you with all sorts of things that are going on". Several patients also mentioned the importance of good communications across their

TABLE 2 Patients' recommendations (italics) to improve communication and understanding of cancer of unknown primary.

Recommendations	Illustrative comment
Tailored information:	
Amount and individualization	<i>Sometimes I felt that the information I've received has been overwhelming... It's a matter of how much information do you need today, what do you want to know. (ID8)</i>
Take-home materials related to consultations:	
Written	<i>If somebody really just didn't understand what DNA was about, having some sort of document that you could give them they could take home and read. ... so quite often your questions come once you get home. (ID15)</i>
Audio and video recordings	<i>It's hard information to absorb the mind. I could easily feel some sort of video recording that could be sent to you later on that night. (ID7)</i>
Scans, pictures, and diagrams	<i>I needed to see some scans because I'm a visual person and a visual learner. (ID3)</i>
Support person	
During consultation	<i>I rely on her [wife] to be there. Yeah. Sometimes things that you don't grasp, or you haven't heard. (ID13)</i>
Peer consultation	<i>To have someone who's been through that to say ... this is what's happened to me and I'm still here ... one that you can talk to about your fears that's gonna understand fears. (ID9)</i>

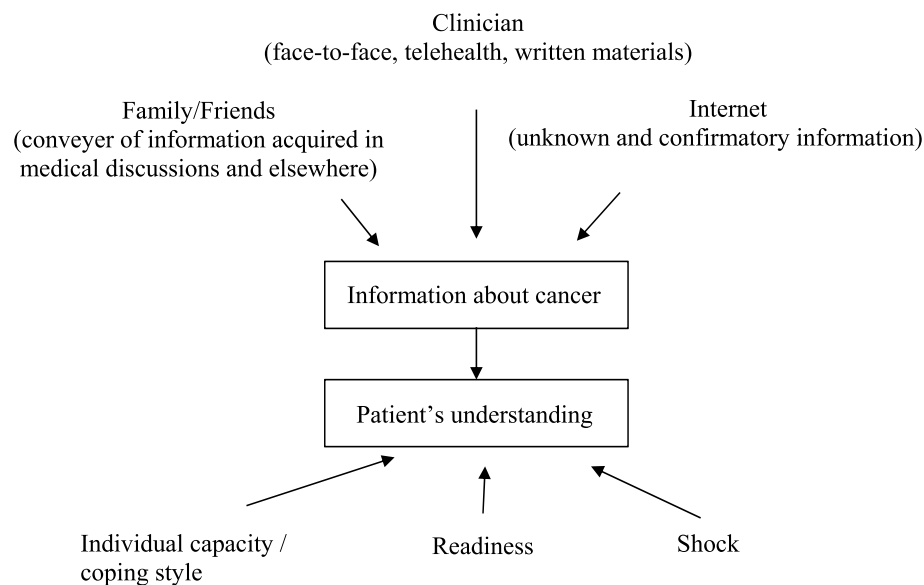


FIGURE 1 Information and factors affecting Cancer of Unknown Primary patients' understanding of cancer.

healthcare team. ID6 explained, "if you've got a good team you don't have a problem because you're all on the same page".

### 3.2 | Infrequent comprehension of the biological mechanism of genomic testing but its clinical implications mainly understood and welcomed

#### 3.2.1 | Broad understanding of genomic testing's potential for identifying primary tumor and suitable treatment

Patients commonly wanted to understand "what the actual testing is trying to achieve" (ID8) and most understood the implications of

genomic testing regarding finding the source of primary cancer and choosing best targeted treatment. ID13 and ID16 said respectively, "DNA testing can help to try and find even primary unknown cancers like mine", and "...all this genomic testing and stuff, my understanding is it was to try and help target the treatment". Consequent knowledge of tumor origin and targeted treatments brought relief because, as ID9 said, "I know for sure that everything that is being done is the right thing".

Some patients felt confused about the differences between genomic testing of the tumor and germline genetic testing. For example, when asked about genomic testing, ID1 queried, "is that to do with your family history or the genes from family?" and ID7 replied, "(to) understand some of the genetic implications of the cancer and what possible treatments you can give to each individual chance".

Understanding genetic test findings and the inheritability of one's cancer was also clearly important for some: "I've had the genetic testing and I actually was impressed with it because it allowed me to know whether my kids were going to inherit what I had or not" (ID6).

### 3.2.2 | Scant understanding and desire to understand details of genomic testing

Few patients understood what genomic testing actually involved. Only ID17 demonstrated in depth understanding: "I'm a carrier for a PALB2. It's a genetic mutation... they potentially think that it may have started in my pancreas." ID9 also provided a good explanation, "My understanding is that they check your DNA and your genetics to see if there's any mutations. They also check them against other people ...". Some had a partial understanding about genomic testing, such as ID10 who explained, "they take little specimens, put them under a microscope and ... like can work out where it's from, like what else can they do ...". However, most had negligible understanding of the testing process. ID8 said, "I understand the principle of DNA but no, I don't understand much about it at all to be truthful." Most patients were not concerned about understanding the science underlying genomic testing. ID8 added, "if the treatment they've used has worked, that's all I really want to know", and ID9 explained, "I've been given the information that relates to me and how it affects me and my family that's really all I need to know".

## 3.3 | Varied and evolving capacities and desires for understanding cancer information

### 3.3.1 | Different levels of need, readiness, and capacity for information

Most patients wanted information about diagnosis, prognosis, and treatment, however they had varying levels of readiness and capacity for information. Some wanted to receive all the information: "I want to know everything about the treatment and what I need to do" (ID17). Others, however, needed time to process all the medical information, and to feel ready to hear it: "It's hard to understand like the science thing ... your brain concentrating too much, maybe scared a little bit, worried .... It can come with time, you know." (ID4)

Some patients remarked they either stopped listening or didn't take in much information as a way of **avoiding worry, which they thought might contribute to illness progression.**

It's just strange, you know what I mean. I sort of bypass it all and not worry about it if I can ... I think if I think all that it makes me sick, it sort of livens up the cancer.

(ID2)

Many patients spoke about feeling shocked and overwhelmed and hence had limited capacity to process any medical information (Figure 1).

I don't know, you're just being told all these medical terms and what they do and can't do and everything and it's very overwhelming, you can't process it all.

(ID12)

Some described a feeling of disbelief and inability to accept information.

I was in a bit of disbelief and I couldn't get my head around what the doctor was telling me, not that I didn't understand it, but it was more so, "How can this happen to me?"

(ID7)

One patient mentioned that older age could contribute to reduced capacity for information and a minority reported actively pursuing information about their cancer for example, requesting and reading scientific papers provided by the doctor.

### 3.3.2 | Responsibility for receiving and understanding medical information is shared

Some individuals completely entrusted their doctors with their health and didn't need to know much about their illness. ID6 said, "I put my life in their hands and said, 'You know what to do'". Many patients emphasized the importance of keeping family members well informed, to help members understand available medical information and to enable their conveyance of the information to patients later (Figure 1). ID18 said, "We could sit and talk and she asked me questions like you're asking me to see, "Did you understand this dad?" or, you know, and she'd talk to me then about treatments".

Sometimes, family members were more interested in becoming informed than the patients. ID2 stated, "I'm not that worried about it but the wife is, she likes to know and my family, but as I said to you I just act like it's not gonna beat me anyway so don't care what it is". Family members were also regularly involved in "holding" the information until patients were ready to absorb the information.

So he (husband) was the person I'd allocated to take in the information from the oncologists... in the New Year (30 days later) I felt stronger physically and it was at that point where I felt like okay, let's get out the material, let's understand a little bit more about cancer, let's not treat it as such a taboo word.

(ID7)

### 3.3.3 | The Internet is sometimes used to find additional information

Some patients used Internet sites, which were mainly evidence-based, to search for new information to validate their understanding; or to verify accuracy of information about prognosis, treatment, and its side effects (Figure 1),

I'm going into places like Peter Mac or Mayo Clinic. I said, I'm not scouring the net for quick fix quack cures or I'm not listening to general public opinion, I'm only going into recognised medical sites.

(ID18)

While some found Internet resources useful, others reported information searched on Google to be not only inaccurate and unreliable but also distressing and depressing. ID13 felt "traumatized" and "more depressed" after repeatedly exploring Google sites, despite "knowing (that) people say, 'Don't watch Google, don't listen to Google. Don't read up on it, because it's not all true'. And it's always giving you the worst scenario, and all that stuff". (ID13)

## 4 | DISCUSSION

### 4.1 | Main findings

Patients with CUP described varied perceptions of their communication with doctors, which included positive and negative experiences, which is not unexpected given the clinical challenges associated with the diagnosis and management of this condition. Participants reflecting on positive experiences described helpful, clear, and "willing to listen" doctors. Similar experiences have also been reported for patients with ovarian cancer, who described their experience of good communication with clinicians as a vital.<sup>23</sup> The finding that some CUP patients had challenging experiences, including feelings of being unsupported emotionally is consistent with other studies where patients report a need for empathy as well as information during interactions with clinicians.<sup>24</sup>

In order to manage the distress surrounding patient-clinician communication, CUP patients employed various approaches such as humor, which has been shown to play a meaningful role in cancer care.<sup>25</sup> Interestingly, CUP patients experiencing empathy towards their doctors was also an important part of managing communication. While there is considerable research linking empathic communication by oncologists with increased patient satisfaction and lower distress,<sup>26</sup> there is no prior research exploring patients' empathy towards doctors and its potential ramifications.

Most CUP patients wanted to be well informed about their cancer, consistent with previous literature,<sup>6</sup> however their capacity and readiness for medical information varied. Some deliberately disengaged from receiving information as part of their avoidant coping mechanism, a behavior found in many patients with various cancer

types.<sup>27</sup> Some reported being unable to absorb information when feeling overwhelmed and shocked after receiving their cancer diagnosis, which could explain why many CUP patients in Wagland's study<sup>6</sup> indicated insufficient understanding of their illness. Notably, it was important for most CUP patients to have their family members present at medical appointments and to share the responsibility of receiving and understanding medical information with them. Previous studies highlighted the importance of clinicians attending to family members' information needs when present during medical consultations.<sup>28-30</sup>

CUP patients had poor understanding of the technical details of genomic testing, which is consistent with several studies in other cancer types.<sup>14</sup> However, most CUP patients had good understanding of the clinical implications of genomic testing, which was the more important for them. This finding contrasts with a systematic review that indicated only 20%–38% of cancer patients were aware of genomic testing's link with identifying targeted treatment.<sup>14</sup>

### 4.2 | Clinical implications

Previous research highlighted psychological distress as an outcome of CUP patients' poor understanding of cancer.<sup>7</sup> Thus, improving the information exchange between doctors and patients is of paramount clinical importance. In this study several potential avenues for improvement have been revealed, such as ensuring face-to-face medical consultations, providing take home resources including diagrams, audio-visual and written materials, and tailoring the amount and type of information to individual needs of each patient. Another useful strategy that could be the development of high quality online resources about CUP that patients and their families could be directed to. Additional clinically meaningful supports could include providing patients and their families with a list of appropriate resources to look at on the Internet, development of specific resources for carers such as tips for family members about how to better assist CUP patients' understanding of their illness.

Furthermore, to facilitate optimal communication, it would be helpful for clinicians to determine what patients already understand and also ask about how much information they would like to receive at the start of a consultation in order to tailor the discussion. Some patients can feel overwhelmed if they receive detailed biological information if they only wanted treatment diagnostic and treatment information related to genomic testing, whereas others want more. Clinicians also need to be aware that patients can confuse genomic testing and genetic testing and take time to explain the differences and whether one or both types of testing are being done. Future research could focus on exploring CUP patients' empathy for their clinicians as it could potentially affect patients' expectations.

### 4.3 | Study limitations

While this is the first study that explored the information needs of CUP patients, the transferability of the findings may be limited since

only English-speaking participants were recruited in a single academic cancer centre, which clinicians experienced in genomic testing. In addition, patients were recruited as part of a study in which multiple types of genomic testing were being performed. We also didn't explore patients' understanding that genomic testing sometimes may not work or may be uninformative. Unfortunately, only 19 interviews could be collected. Further data collection, especially in other clinical contexts and cultures, may provide further insights.

## 5 | CONCLUSIONS

This study provides meaningful insights into the experiences of CUP patients pertaining to their understanding of diagnosis and genomic testing as well as their information needs. Patients' communication with their doctors and understanding of their cancer could be improved by providing individually tailored information. Online resources which meet CUP patients' evolving needs for comprehending diagnosis and genomic testing also need development.

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## CONFLICT OF INTEREST STATEMENT

All authors of this article declare they have no conflicts of interest.

## DATA AVAILABILITY STATEMENT

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

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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