

Uncertainty and anxiety in the cancer of unknown primary patient journey: a multiperspective qualitative study

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To cite: Richardson A, Wagland R, Foster R, *et al*. *BMJ Supportive & Palliative Care* Published Online First: [please include Day Month Year] doi:10.1136/bmjspcare-2013-000482

ABSTRACT

Background Patients with cancer of unknown primary (CUP) have metastatic malignant disease without an identifiable primary site; it is the fourth most common cause of cancer death.

Objectives To explore patients' informal and professional carers' experiences of CUP to inform development of evidence-based, patient-centred care.

Methods Qualitative study involving development of multiple exploratory case studies, each comprising a patient and nominated informal and professional carers, with contextual data extracted from medical records.

Results 17 CUP patients, 14 informal and 13 professional carers participated in the study. Two inter-related themes distinct to CUP emerged: uncertainty and continuity of care. In the absence of a primary diagnosis, patients and informal carers experienced uncertainty regarding prognosis, possible recurrence and the primary's hereditary potential. Professional carers experienced difficulty communicating uncertainty to patients, ambiguity in deciding optimal treatment plans in the absence of trial data and a *test or treat* dilemma: when to discontinue seeking the primary and start treatment. Common problems with care continuity were amplified for CUP patients relating to coordination, accountability and timeliness of care. The remit of multidisciplinary teams (MDTs) often excluded CUP, leading to "MDT tennis" where patients were "bounced" between MDTs.

Conclusions The experience of those with CUP is distinctive and it can serve to amplify some of the issues encountered by people with cancer. The clinical uncertainties related to CUP compound existing shortcomings in continuity of care, increasing the likelihood of a disrupted patient journey. However, while little can be done to overcome uncertainty, more could be done to address issues regarding continuity of care.

INTRODUCTION

Patients with cancer of unknown primary (CUP) have metastatic malignant disease without an identifiable primary site. The type of tumour, extent of spread and treatment outcome vary widely, but most appear to derive from epithelial cells where identification of the primary is critical to treatment choice. It is often viewed as a diagnosis of exclusion as the condition cannot be determined by examination and testing.¹

CUP is the fourth most common cause of cancer death,² and incidence varies from 7 to 12 cases per 100 000 population in the USA, 18–19 cases in Australia and 5.3–6.7 cases in Europe,³ with over 10 000 cases per annum in England and Wales.² CUP accounts for approximately 3–5% of all new cancer diagnoses and prognosis is generally poor.³ Life expectancy statistics vary but one meta-analysis indicated a median survival of 4.5 months, with 1-year survival rate of 20% and 5-year survival rate of 4.7%.⁴

Coping with CUP can be particularly challenging for patients and carers due to diagnostic uncertainty, difficulty understanding the condition, making sense of different tests used during the investigative process⁵ and uncertainty about clinicians' ability to treat them.⁶ Consequently, CUP has been described as "a devastating and bewildering diagnosis for the patient and family".⁷

Care professionals looking after those with such a poorly understood condition similarly face unique challenges. Uncertainty exists over which and how many diagnostic tests to perform, and there is no consensus on reference points

to inform prognostication and optimal treatment.^{2–8} There are also a lack of arrangements to identify and manage patients during the initial phase and shortcomings within care and support.^{2–8} CUP patients often present late with ill-defined symptoms and investigation is frequently a lengthy, iterative process with no defined end point. Clinicians are sometimes over-focused on “chasing the primary”,⁹ with patients sometimes receiving excessive investigations that are inappropriate.¹ The National Institute of Health and Care Excellence (NICE) and the European Society for Medical Oncology have both published clinical guidelines,^{2–10} which identify significant potential for improving the patient pathway. Healthcare providers are currently considering service developments in response to them.

To date, only one ‘patient experience’ exploratory study has been undertaken with a CUP population;⁶ hence, little evidence exists to help providers shape and develop services. Nor is there research to help care professionals better understand the experiences of people affected by CUP or the challenges clinicians encounter when diagnosing and treating this condition. To inform the debate, we undertook an in-depth inquiry seeking to explore experiences of patients, informal and professional carers to improve understanding of the needs of those affected by CUP.

METHODS

Case study research seeks to understand complex contemporary phenomena in a “real-life context”¹¹ and involves gathering and synthesising information from several sources to produce generalisable findings. An exploratory design was adopted involving multiple cases, each case comprising a patient and nominated informal and professional carers. Participants were interviewed and data were extracted from hospital records to examine aspects of the patients’ diagnostic and treatment pathway.

Patient recruitment

A convenience sampling approach was taken. Hospital-based oncology and hospital-based and hospice-based specialist palliative care clinicians in Southampton, Portsmouth and the Isle of Wight identified patients with suspected or confirmed diagnosis of CUP, or where no primary had been identified, who were anticipated to live beyond 1 month. Clinicians ascertained whether patients were willing to be contacted by a researcher, who then contacted them to explain the study and arrange a meeting. Patients too physically or psychologically compromised to make an informed decision to participate were excluded. The CUP Foundation assisted recruitment by informing visitors to their website about the study and inviting participation. Of 29 patients introduced to the study, four did not wish to take part, five deteriorated quickly and

became too ill to proceed two died and the primary of another was identified.

Recruitment of ‘cases’

At the point of recruitment, patients nominated for interview an informal carer (ie, a family member or friend) and up to two key professional carers they regarded as important to their care, thereby creating the ‘interview set’ that made up the case. A sample of between 15 and 20 cases was sought to generate sufficient data to achieve a robust cross-case analysis. Informed written consent was obtained from all participants and reviewed verbally at the start of each interview, and separate consent was gained to access patients’ medical records.

Data generation

Interviews were conducted by a researcher (RF), with 7 years’ interviewing experience. Interviews were participant-led, although informed by a script that had been discussed within the team, including one ex-informal carer (JS). RF emphasised that she wished only to understand participants’ experiences and had no influence over treatment received. Interviews took place at a location of the participant’s choice (such as their home or workplace) or over the telephone, and sometimes patients were interviewed together with their informal carers.

Issues covered included the experience of being investigated, diagnosed and treated for CUP; what patients understood by the term CUP; their main concerns and support needs. Interviews lasted between 30 and 90 min and were digitally recorded with consent. Field notes were recorded after each interview.

Professional carers were interviewed about their familiarity with the NICE Guidelines, their experience of caring for the specified patient(s), what they thought patients understood about their disease, its investigation and treatment and information and support needs. Beyond the individual cases, professional carers were asked to reflect on their experiences generally of caring for this group and particular challenges encountered in their interaction with families affected by CUP.

An audit of each patient’s medical notes was undertaken where possible to provide context to the interviews, including route of diagnosis, presenting symptoms, site of metastases, potential primary site, prescribed investigations and treatments and time intervals between these.

Data analysis

Analysis progressed through four different levels: first, specific interviews; second, individual cases; third, the pattern of findings across multiple cases; and finally, a Study Advisory Group reviewed evolving study themes in light of their areas of expertise, knowledge of the literature and experience.¹¹ Interviews were transcribed,

coded separately and then analysed (a) as integrated 'patient/informal carer/professional carer' interview sets and (b) as integrated 'patient' sets, 'informal carer' sets and 'professional carer' sets. Initially, transcripts were coded and analysed thematically by two researchers (RF and RW) in discussion with all other members of the research team (see table 1 for initial coding structure).

A framework based on emerging themes, interview guides and the aims of the study was developed, drawing on methods used in Framework Analysis.¹² As analysis progressed new, overarching themes were identified, such as 'uncertainty' and 'continuity of care', and the framework was refined. Over time, no significant new themes emerged from case studies, indicating thematic saturation.¹³ The framework was used to index the interview transcripts associated with each case and a chart summarising, for each interview set, what was said for each of the themes was created. The framework and its application were frequently discussed within the research team to aid data synthesis and interpretation. Individual case descriptions were developed to profile an individual patient's experience and describe the case in context with a chronology of events incorporating information from both interviews and medical records. Finally, categorical aggregation identified patterns and relationships between themes across the cases and determined similarities and differences.

RESULTS

The characteristics of the 17 patients, 14 informal carers and 13 professional carers who participated in the study are given in table 2. Annotations identify case study interviewees when direct quotes are used. Patients are identified by a consecutive study number

with an alphabetical letter indicating the National Health Service (NHS) organisation from which they were recruited. Informal and professional carer interviews are indicated with reference to the patient.

Patients presented with various symptoms and received a range of treatments. At interview, time since diagnosis ranged from 3 months to 6 years, and while some patients had completed treatment and were living a near normal life, others were very unwell and three died during the study. No 'typical' patient journey was identified, characterised by a predictable set of events shared in common with other CUP patients. However, the different perspectives of patients, informal and professional carers supported two overriding themes within the data that influenced the experience of CUP during the diagnostic and treatment journey: uncertainty associated with a diagnosis of CUP and continuity of care.

Uncertainty

Although a general feature of the cancer experience, uncertainty was magnified with CUP and impacted upon each of the three participant groups. Most patients and informal carers had never heard of CUP and were surprised to learn that despite specialist doctors and modern technology ("nowadays, they can zoom in and split the atom" (A3 Son)), a primary could not be found. The unfamiliar and inconclusive diagnosis ("a lot of "Don't knows", "Can't tell you" (C1 Husband)) left patients and carers feeling "frustrated with the doctors" (A2 Friend) and sometimes believing they "had not been properly diagnosed" (B4 Daughter). However, not all patients and carers viewed the uncertainty of a CUP diagnosis negatively, with a minority taking comfort that the primary could not be found, was "in an early stage" (A2), was

Table 1 Interview coding tree

Categories	Subcategories
Diagnosis	Nature of problem Interactions with professional carers, continuity and support News telling/realisation process Explanation and framing of diagnosis Coping with emotions
Tests and investigations	Investigation plan Significance, value and consequences of testing Number/extent of investigations Understanding of purpose and findings Continuity and support Coping with emotions
Treatment	Treatment type and management Interactions with professional carers, understanding, choice and confidence Treatment outcomes and understanding Support and coping
Living with CUP	General circumstances/attitude Symptoms Telling friends and family Support and coping with emotions

CUP, cancer of unknown primary.

Table 2 Demographic, clinical and interview details of patients

Gender	Women: 10 patients Men: 7 patients
Age	Mean: 60.6 years Median: 59 years Range: 41–78 years
Time from diagnosis	Mean: 13 months Median: 6 months Range: 3–76 months
Site of metastases*	<ul style="list-style-type: none"> ▶ Lung (n=5 patients) ▶ Neck (n=5 patients) ▶ Liver (n=4 patients) ▶ Pelvis (n=3 patients) ▶ Lymph nodes (n=2 patients) ▶ Adrenal glands (n=2 patients) ▶ Spine (n=2 patients) ▶ (Pancreas, ovaries, mediastinum, appendix, mesentera, peritoneum) (n=1 patient with each)
Treatment history	<ul style="list-style-type: none"> ▶ Chemotherapy only (n=6 patients) ▶ Chemotherapy+radiotherapy (n=3 patients) ▶ Radiotherapy only (n=1 patient) ▶ Surgery, chemotherapy+radiotherapy (n=3 patients) ▶ Surgery+radiotherapy (n=3 patients) ▶ Surgery+chemotherapy (n=1 patient)
Recruitment source	<ul style="list-style-type: none"> ▶ University Hospital Southampton NHS Foundation Trust (n=8 patients) ▶ Portsmouth Hospitals NHS Trust (n=5 patients) ▶ Isle of Wight NHS Primary Care Trust (n=1 patient) ▶ Volunteered via CUP Foundation website (n=3 patients)
Informal carers (nominated by patients)†	<ul style="list-style-type: none"> ▶ Spouse (n=6) ▶ Sibling (n=1) ▶ Friend (n=3) ▶ Son/daughter (n=3) ▶ Parent (n=1)
Professional carers (nominated by patients)‡	<ul style="list-style-type: none"> ▶ Oncologist (n=5) ▶ Surgeon (n=2) ▶ Clinical nurse specialists (n=2) ▶ GP (n=2) ▶ Dietician (n=1) ▶ Radiographer (n=1)

*Several patients had metastatic disease in several sites.

†The carers of three patients declined to be interviewed.

‡Several patients nominated the same professional carers to be interviewed as part of their case study.

CUP, cancer of unknown primary.

“small” or might have “disappeared” or “been ejected” (D1). For others with advanced disease, concerns about deteriorating health, a terminal diagnosis and debilitating treatment overshadowed the significance of a CUP diagnosis (“I think the uncertainty has been and gone...We were given some vague ideas as to where it started, but I think we moved on very quickly from that.” (C3 Husband)).

Both patients and carers voiced concerns about treatment suitability (“Well why do they want to do radiotherapy if they haven’t found the cancer?” (A3)). Some also perceived disagreements about treatment between professional carers or a lack of consistent

information regarding treatment, which heightened anxiety and frustration (“One [care professional] said that she [patient] wouldn’t need the radiotherapy treatment,...but the other one said ‘Well yes she will’” (D2 Friend)).

However, patients and carers sometimes emphasised different concerns related to the uncertainty of the primary site. The few patients whose condition appeared to be in remission were particularly anxious about the potential for recurrence (“an unknown primary can come up anywhere, anytime. It’s like you’re waiting” (B1)). Informal carers were more likely to express concerns regarding possible genetic

predispositions to the primary “I’m very unsure as to whether it’s something that might be hereditary” (B4 Daughter).

Patients and carers also differed slightly in their information seeking. In the majority of cases, patients sought information about their illness to overcome uncertainty and take control of their condition (whatever’s happening I want to know, don’t keep me in the dark (B1)). Nevertheless, the ambiguity of information left other patients unsure of their treatment options, preferring to place their faith solely in professional carers, rather than seek further information themselves (“I’ll listen to the doctors, I’ll do as they say,...but I’m not researching anything” (A8)). Informal carers, in contrast, were more consistently assiduous in their search for answers and expressed greater frustration at their lack (“What do you mean you don’t know where it started? You’re a doctor, of course you know where it [is].” (A2 Friend)).

The professional carers interviewed in this study also described how medical uncertainty could be amplified in CUP. There is little clinical evidence on which to base treatment decisions and prognoses (“you can’t base it so clearly on clinical trial data or stage data” (A6 Oncologist)) compared with that available for known primary treatments that were “much more certain” (A1 Oncologist). Different *bespoke* treatment approaches were described by oncologists, tailored to individual circumstances, but it was acknowledged that “you really just don’t know what evidence of benefit [the treatment] has” (B1 Oncologist).

Several professional carers discussed how best to communicate uncertainty to CUP patients, who ‘like doctors to be able to say “this is the problem, this is the solution”’, but are often left instead “with a feeling of uncertainty [which] is bound to...undermine their confidence” (A3 Oncologist). Professional carers recognised patients’ need to be kept informed, but acknowledged their difficulty comprehending a CUP diagnosis and treatment options. They sometimes worried their own uncertainty was conveyed to patients causing anxiety and distrust.

A particular issue arising from medical ambiguity surrounding CUP was the *test or treat dilemma*: whether to start treatment based on the limited information available or await further test results in the hope of determining the primary, thereby delaying treatment, possibly “while the patient is going downhill in front of you” (A1 Oncologist). The impact of this dilemma was that “sometimes people don’t get treatment for quite a while because we’re spending so much time trying to work out what the actual primary site is” (A5 Oncologist).

Continuity of care

Continuity of care relates to the coordination, accountability and timeliness of care over time and is facilitated or obstructed by how services are organised

and managed.¹⁴ Uncertainties involved with a CUP diagnosis made this group particularly susceptible to disruptions in care continuity, especially when presenting symptoms were vague or undefined. A lack of care continuity was also often associated with a phenomenon described by some care professionals as multidisciplinary team (MDT) *tennis*, where patients were “bounced” between different MDTs in a way that could disrupt and delay care. There were six discernible cases of this phenomenon in the sample. MDT tennis was sometimes the product of coordination problems that arose from the boundaries that delimit the work of MDTs, likened by one oncologist to “blinkers” (A5 Oncologist). Patients no longer considered as falling within an MDT’s remit could be referred, sometimes repeatedly, to other MDTs (“there are certainly situations where somebody says “well it’s not lung, refer to gastrointestinal (GI)” and they say “well it’s not GI refer to lung” and somebody has to bite the bullet and take the patient.” (A5 Oncologist)). Described by one patient as “a bit of ping pong” (B1), MDT tennis greatly increased uncertainty among patients and carers, who felt left “in the middle” (B1) and “abandoned” (A6).

In some cases, MDT tennis also appeared to be closely related to the *test or treat* dilemma. Investigations could consequently be “rather protracted” (A1 Oncologist), with some patients “over-investigated” (B2 Oncologist), especially those with vague symptoms. Nevertheless, no patients objected to the number of investigations they underwent, attributing symbolic as well as clinical value to extensive investigations by demonstrating commitment among professional carers. Indeed, care professionals were aware that some patients “want more stones turned” (A5 Oncologist) to locate the primary, even when no clinical benefit would result.

Confusion regarding accountability of care often occurred when patients were referred between MDTs, with CUP patients sometimes “perceived as a bit of a lost tribe in that sometimes it’s not clear who is going to be responsible” (A6 Oncologist). Among care professionals, the role of clinical nurse specialists (CNSs) in particular was considered important for both accountability and quality of care for CUP patients, although access to a CNS usually required one specific MDT taking responsibility for the patient (“it’s all very tumour site specific so, if you’ve not got a dedicated tumour site, you know, you don’t get the specialist nurse and all those other things.” (A6 Oncologist))

Some patients had access to a CNS throughout their hospital treatment journeys, others lost contact with the CNS in one specialty when referred to another MDT, while some patients were never allocated a CNS (“I haven’t been allocated a specific nurse who is a specialist in that field. I understand that there are some cancers you have a nurse who is a specialist.”

(C3)). Several professional carers believed the potential introduction of a CUP specialist nurse would “make a massive difference” (A1 Oncologist) to the accountability and quality of care for patients with CUP.

DISCUSSION

This study illustrates the distinctiveness of the CUP experience for patients and carers, with difficulties often experienced as a result of a cancer diagnosis in general frequently amplified in CUP. Uncertainty and disruptions in continuity of care were important features of participants’ experiences and strong connections were found to exist between them. When acting together, these features have the potential to compound one another and lead to the phenomenon of MDT tennis. However, evidence suggested effective continuity of care could mitigate participants’ feelings of uncertainty.

The uncertainty of not knowing the primary site engendered anxiety and frustration for some patients and informal carers, and exacerbated associated fears concerning treatment effectiveness, prognosis, potential recurrence and genetic predisposition. For the patient, CUP is effectively a non-diagnosis and continued uncertainty can have a devastating impact upon well-being.^{15 16} Although no information exists concerning the effects of uncertainty on distress levels in this population, a ‘bad’ diagnosis may be less detrimental to well-being than one that is absent.¹⁷ Anxiety increased for patients who detected uncertainty, indecision or disagreement among professional carers, and care professionals knew this.

Issues of uncertainty led to dilemmas that challenged professionals caring for CUP patients.¹⁸ One such issue was deciding what constitutes an optimal treatment plan. Lack of published trial data⁴ and the lack of primary staging data for CUP could leave professionals facing a *test or treat* dilemma—whether and when to cease diagnostic testing or oncological treatment with curative intent.⁹ Communicating uncertainty to patients was also an area of ambiguity for care professionals.¹⁹

Providing a prognosis for a CUP patient is particularly challenging as care professionals look to the primary as the main point of reference,⁸ so treatment follows an empiric, varied and often “an educated guess” approach.⁴ Disclosing poor prognoses to patients while seeking to maintain their hope is one of the most difficult tasks for professional carers,²⁰ and reluctance to convey bad news is held in check by the need to ensure patients have realistic expectations about treatment.²¹ Although no evidence was found for this in the present study, the reluctance of professionals to engage in difficult conversations concerning cessation of testing could potentially result in a default position of over-investigation, doing “just one

more test”, as the easiest short-term option for clinician, patient and informal carer.⁹

Many of the shortcomings of the health system appear to be magnified for CUP patients leading to increased likelihood of disrupted patient journeys, characterised by poor coordination and accountability, investigation and treatment delays. MDT tennis was central to most disrupted patient journeys, which in some cases appeared to be closely related to the *test or treat* dilemma. Since 2000 all cancer patients within the UK should be formally reviewed by a specialist MDT to improve patient outcomes,²² but MDTs have boundaries that potentially exclude patients with CUP. Patients not deemed to come under the remit of one MDT may be “bounced” to another team. Moreover, if not under the responsibility of an MDT, patients with CUP may lack access to CNS support. The importance of the CNS role was particularly emphasised by study participants and has previously been acknowledged.²³ It has also been argued that continuity of clinical management is better facilitated when patients and informal carers can develop enduring relationships with key professional carers.²⁴

Ultimately, perhaps little can be done to overcome the uncertainty associated with CUP, but more could be done to address issues regarding care continuity. In England, NICE recommended each NHS Trust establish a specialised CUP team consisting minimally of one oncologist, palliative care physician and CNS, accessible to patients once diagnosed with an unknown malignancy.² If developed, these teams could address issues related to MDT tennis and the need for a managed care pathway for CUP patients. However, this will be a challenge for healthcare providers given current economic constraints. Nevertheless, these findings should enhance care professionals’ understanding of this group’s needs and enable locally determined responses regarding the most appropriate point of referral of CUP patients to an MDT with experience of CUP, access to a CNS and processes to minimise the impact of MDT tennis.

Study limitations

The sample was not fully representative of CUP patients in terms of symptom presentation, treatment pathways, age profiles and survival rates.² In part this is due to CUP patients presenting with advanced disease involving poor and rapidly declining health status. Moreover, as clinicians decided whether patients were sufficiently well and willing to participate in the study, they may have limited the representativeness of the sample. Finally, many patients with an initial classification of CUP will eventually have a primary diagnosis, and these individuals’ experiences were not included in this study. Nevertheless, the purpose of the study was to inform clinicians of the period of ambiguity prior to diagnosis.

CONCLUSION

Difficulties experienced by patients, their informal and professional carers following any cancer diagnosis are often amplified in CUP, making it a distinctive condition. Shortcomings in continuity of patient care are compounded by clinical uncertainties associated with CUP, increasing the likelihood of disrupted patient journeys and causing further anxiety for patients and their families. Central to much discontinuity is the phenomenon of 'MDT tennis', with patients being bounced between site-specific MDTs whose remits often exclude CUP. Although uncertainties are likely to remain, more could be done to develop managed care pathways and promote continuity of care for CUP patients.

Acknowledgements We are grateful to our clinical colleagues at University Hospital Southampton NHS Foundation Trust, Portsmouth Hospitals NHS Trust, Isle of Wight NHS Primary Care Trust and the Hampshire and Isle of Wight Comprehensive Local Research Network who helped with identification and recruitment of participants. We thank members of our project advisory group Dr Wheeler, Ms Howard-Jones and Professor Hopkinson and finally Ms Hughes who contributed to the analysis.

Contributors JS, CF and JA-H conceived the idea, undertook protocol development and analysis. RF and RW undertook data collection, analysis and contributed to write up. AR, CD and LB contributed to data analysis and write up.

Funding Supported by Dimbleby Cancer Care.

Competing interests None.

Ethics approval Ethical approval was obtained from Southampton and South West Hants local research ethics committee (B) and the research ethics committee of Faculty of Health Sciences. Governance approval was obtained from three NHS Trusts in Central South Coast region: Southampton University Hospital NHS Trust (CAN0679), Portsmouth Hospital NHS Trust (PHT/2011/60) and the Isle of Wight NHS PCT (CSP:26904). Informed written consent was obtained from all patients at the beginning of the study. Informal and professional carers identified by the patient were asked independently for their consent to participate.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement Unpublished data include anonymised transcripts of interviews. A data sharing agreement that details the criteria for access and conditions of research use would be drawn up with any investigator or research team requesting permission for data sharing.

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BMJ Support Palliat Care published online November 19, 2013

doi: 10.1136/bmjspcare-2013-000482

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