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Finding the right time to discuss Advance Care Planning with myeloma patients and their carers: an opportunity for nursing

Abstract

Purpose

People with Multiple Myeloma are living longer with incurable disease due to improved treatments. Despite advance care planning (ACP) and palliative care's focus on improving symptom management and quality of life, there remains the perception amongst patients and clinicians that palliative care is only for end-of-life, leading to uncertainty around when to introduce these conversations. This study examines the lived experiences of Myeloma patients and their carers, exploring their views as to when and how they would like to commence meaningful conversations around palliative and end-of-life care.

Methods

Semi-structured online interviews were conducted with Multiple Myeloma patients and their carers (n=15). Verbatim transcriptions were analysed using inductive thematic analysis.

Results

From ten patient and five carer interviews, three themes were identified: Responsibility, Receptivity, and Resources. ACP had either not been discussed, or *would* not have been discussed had the patient or carer themself not initiated the discussion. Responsibility for initiating ACP conversations rested with healthcare professionals as well as patients. There was no one, 'right time' to do this, though diagnosis should be avoided. Conversations depended on resources, whether human, organisational, community or charities to facilitate effective ACP.

Conclusions

ACP conversations with myeloma patients are often delayed. Patients and carers believe it is the responsibility of healthcare professionals to initiate them at the right time. A period of adjustment is required after diagnosis but there was no single 'right time', reflecting the heterogeneity of individual needs.

Implications for Nursing Practice

Nurses across all settings should be open and receptive to ACP conversations at all points along the Myeloma trajectory. Nurses should normalise the initiation of ACP conversations early in the disease trajectory to promote, and remove barriers to, integrated palliative care. Haematology nurses should work collaboratively with palliative care nurses to support early symptom management for Myeloma patients.

Plain English Summary

What we investigated and why

We investigated the perceptions and preferences of Myeloma patients and their carers regarding advanced care planning in order to 1. incorporate this unique perspective into existing research and 2. to contribute to research around Integrating Early Palliative Care and haematological malignancies.

How we did our research

We asked 10 Myeloma patients and 5 carers about their experiences of advanced care planning. We then looked at the common issues they discussed.

What we have found

The patients and carers talked about three important areas to do with planning for the future and what the patient might want at the end of their life. We found that it was important who started the end of life conversations, and when they introduced these conversations, and finally how patients and carers found extra information was important to the participants of this study.

What it means

Our results add to our understanding of unique patient and carer perspectives about by whom, when and how advance care planning should be initiated, alongside exploring their own experiences of advance care planning. Our findings firstly emphasise the importance of therapeutic clinician-patient relationships in initiating advance care planning, and secondly advocate for integrating these discussions early in the Myeloma trajectory. We hope that our findings will be shared amongst Myeloma healthcare - particularly nursing - communities to give them the awareness to broach advance care planning with their patients and in this way begin to normalise conversations about death and dying.

Keywords

Multiple Myeloma, Palliative care, End-of-life care, Advance care planning, carers, cancer, Integrated palliative care.

Highlights

- Patients expect healthcare teams to have the skills to know when to discuss ACP.
- There is no ‘right time’ to discuss ACP but this should be avoided around diagnosis.
- Patients and carers value people and information as resources during ACP.

CRediT author statement

Emma Matthews: Methodology, Project Administration, Investigation, Formal analysis, Writing - Original Draft, Writing - Review & Editing. **Kate Montague-Hellen:** Formal analysis, Writing - Original Draft, Writing - Review & Editing. **Jo Bird:** Conceptualisation, Funding acquisition, Methodology, Investigation, Formal analysis, Writing - Original Draft, Writing - Review & Editing.

Introduction

Multiple myeloma is a plasma cell malignancy, characterised by recurrent periods of relapse and stability. Treatment options have continued to improve with several lines of treatment available, including novel therapies and autologous stem cell transplants[1]. Median survival (5 to 8 years) has consequently improved, though myeloma itself remains incurable[2].

For more than a decade the benefits of integrating early palliative care with standard oncology care for improved quality of life, longer survival and reduction of aggressive treatments[3,4] have been discussed in patients with solid tumours. More recently, research has moved towards haematological malignancies and early palliative care demonstrating that acute myeloid leukaemia patients experience benefits in quality of life following the early integration of palliative care[5]. Patients with haematological malignancies are more likely to receive higher rates of aggressive medical care at end of life and have poorer palliative care experiences than those who have more predictable illness trajectories[6–8]. This unpredictability combined with expanding lines of treatment is associated with a perceived tension between balancing life prolonging treatments with conversations about end of life [9].

Despite advance care planning (ACP) and palliative care's focus on improving symptom management and quality of life, there remains the perception amongst patients and clinicians that palliative care is only for end-of-life[10] and therefore there is uncertainty regarding the best time to commence conversations around ACP[11]. Studies have sought to better understand the barriers to haematologists broaching end-of-life discussions with patients, identifying the close relationship between haematologists and their patients leading to difficulties when introducing new teams[8,12–14]. Prod'homme et al[15] identified a fear amongst haematologists of losing credibility in the patient's eyes, a fear of the patient losing hope alongside a desire to protect the patient. Indeed, Prod'homme et al[15] report a conflict between medical paternalism's purposeful selection of positive data to bolster hope and the importance of reporting the evidence base in a balanced and critical way. A further barrier to introducing conversations about planning towards end-of-life into a patient's care may be the perceived 'fighter' mentality adopted by myeloma patients and a determination to accept all treatments in the hope that a new treatment might again stabilise their disease, as well as a focus on quantity over *quality* of life[9,16,17]. This can lead to tardiness in referrals to palliative care teams[7,9] and inappropriate therapeutic aggressiveness in patients' final days[5].

The limited workforce available to provide specialist palliative care means that resources are directed elsewhere[9]. Consequently, palliative care referrals are not always accepted for patients receiving active treatment unless specific, complex needs are identified. Yet, Pallotti et al[18] also highlight the impact of aggressive treatment for myeloma on use of resources, ie treatments and access to acute and intensive care.

ACP conversations may be started by the haematology team without the immediate need to think about end-of-life care, but patient preferences in this situation are not known. Further research is therefore needed to identify the views of patients living with myeloma and their carers regarding future planning.

Methods

An inductive, qualitative research approach was taken, using thematic analysis as proposed by Braun & Clarke[19]. Semi-structured interviews with myeloma patients and their carers were conducted to better understand their views and experiences of ACP. A total of 15 interviews were conducted by two researchers (EM and JB) over a six month period between January 2022 and June 2022. JB, an experienced qualitative researcher supervised EM who also undertook training in qualitative interviewing prior to the start of data collection. Ten interviews were recorded with myeloma patients and five interviews with their carers. No participants withdrew from the study following consent. All interviews lasted around an hour. Interviews took place online via the Googlemeets application, as a response to the COVID-19 pandemic and meant that recruitment took place nationwide around the UK. Participants were recruited, using convenience sampling, through social media and electronic communications shared by Myeloma UK.

Semi-structured interviews enabled deep understanding of how and when patients and carers would prefer to initiate meaningful conversations about planning towards end-of-life care. Before the start of the interviews, the researcher (EM) was unknown to the participants however their role in the research along with the rationale for the interviews was fully explained during the informed consent process and prior to the start of the interviews. The interviews focused on patient and carer experiences of advanced care planning conversations, *when* conversations about ACP should happen, *who* should initiate the conversation and *what* should be discussed. Fieldnotes were collected during and following each interview by the interviewer.

Audio recordings were transcribed verbatim. The initial interviews were transcribed by the researcher (EM) to aid familiarisation with the data. Subsequent interviews were transcribed by an external, ethically approved transcription provider. Anonymised transcripts were thematically analysed inductively using Braun and Clarke's[19] six stage process. All three researchers independently read the transcripts; they undertook coding and analysis individually, then came together to discuss findings and negotiate their identified codes into themes. Contrasting perceptions of data were resolved through discussion. The decision to stop recruitment was made when data saturation was reached. Due to time constraints, the researchers were unable to return the transcripts to the participants for comment before analysis took place.

Ethical approval was granted by the University of Sheffield (No. 043427) following PPI review by the Yorkshire and Humberside Consumer Research Panel.

Findings

Ten Myeloma patients and five carers took part in this study. Of the patient population, 13 were white British, one participant was East Asian and one was South African of white heritage. All five carers were white British. All participants were over the age of 52.

Three themes were determined: responsibility, receptivity and resources. There was an almost unanimous sentiment across the interviews that ACP had either not been discussed, or *would* not have been discussed had the patient or carer themself not initiated the discussion. This invites us then to ask with whom should the responsibility to initiate/lead on ACP lie. The second theme explores to what extent participants are/were receptive to ACP discussions, considering an appropriate time to initiate ACP. Finally we explore which resources, be it human, organisational, community or charities, facilitate effective ACP.

Responsibility : individual, medical and nursing

Participants discussed their perceptions around who was responsible for leading conversations on ACP within healthcare teams but also discussed their own sense of responsibility. Some felt that the medical team would know when the time is right: '*the person who's going to tell me that there are no further treatments is my haematologist' (P7)* however others discussed a perceived positivity from their consultant which prevented ACP discussions. Participant 9 described their consultant as "*a very optimistic person [who] never sort of wants to dwell on anything negative" (P9).*

Through conversations focusing solely on the positives, participants felt unsatisfied when seeking considered answers from their clinicians. Participants found that stock phrases would be used to end conversations around ACP:

> *‘you responded very well to it, you’re young, I’ve got every hope,’ says the consultant, ‘that you have got plenty of years left in you and you’ve got two or three more rounds of treatment before we run out of stuff that makes a difference to you.’ And, as a consequence of that, I infer that they’ve therefore not really wanted to talk about palliative or end of life scenarios (P3).*

The ‘positive consultant’ character was reflected in other interviews, here Participant 2, a carer, suggests that acknowledging ACP was associated with failure by her husband’s consultant:

> *the outreach lady, did say to me that [consultant’s name] found he almost didn’t want people to talk about end of life care because it was like admitting that, you know, almost from his perspective that you’ve failed… I think he felt he’d let us down even though he kind of moved heaven and earth (P2).*

In contrast to ACP being a consultant’s responsibility, there was an understanding that ACP may fall into the nurses’ remit: “*Yes it’s mostly the nurses I would say rather than the consultants that would be sort of quite prominent in this”. (P9).* The emphasis being on the requisite attributes of the healthcare professional, specifically the need for expertise, sensitivity and being able to encourage the patient to open up:

> *I guess it would be a role for the specialist nurse [who] has day to day responsibilities to the patient to just be an extra antenna to pick up ‘how are you feeling today?’ well the answer they’ll hear is ‘I’m fine’ so they wanna hear the nuance in ‘I’m fine’ ‘oh are you? Are you really? No, I don’t think you are fine’ (P15).*

Participants emphasise the importance of making conversations feel person-centred and not rushed. Participant 8 discusses how their palliative experience was ‘a little too quick’ and that healthcare professionals ‘wanted to tick a lot of boxes’. This was echoed by Participant 6 expressing that healthcare professionals ‘can’t pay lip service to [ACP]’.

Although participants expressed opinions about who should take responsibility for ACP, most reported having minimal experience of ACP themselves. Responding to absent direction from clinical teams, some felt personal responsibility to educate themselves about the Myeloma trajectory, including ACP. Proactivity was expressed in preparing end of life administration, for example writing living wills, DNACPR documents and designating power of attorney. However, these steps relate to a *different* part of advance planning - not necessarily advance *care* planning, or indeed one that involves discussing death in the clinician-patient relationship. Participants commenced legal, financial and practical planning but remained uncertain about the details of ACP. Here, Participant 1 discusses preparing for the end of her mother’s life:

> *I didn't know what she wanted, where she wanted to be buried or what she wanted, all these kind of details really worried me, so we did make those kind of decisions that were sat with us. But I didn't know what other decisions we could have made or should have made that sat outside of our personal responsibility or the more medical decisions I suppose. (P1)*

The burden of responsibility was felt differently between patients and carers in our participant population. Patients expressed a sense of responsibility towards planning, to avoid placing additional burdens or *"the strain or the difficulties that must present for the rest of the family" (P6)*. Whereas carers expressed a sense of responsibility to ensure that they enacted the patient's wishes but needed resources to do this:

> *the weight of being at home with my mum feeling like I'm the main carer as she's dying and there's no one there, it's tough. It was just so scary and so much responsibility… (P1)*

While there was a desire for resources around ACP, there were fears of losing resources related to active treatment. This highlights the inverse of the 'positive consultant' and ultimately suggests that by engaging with ACP, patients are relinquishing clinical teams of the responsibility for active treatment, potentially giving up the associated resources in the form of active treatment.

> *So I think there is this fear that doctors will give up too early. Which if you've made plans, I suppose fear that they will be enacted too early* (P6)

One carer (P8) felt that palliative care would not have been offered to her spouse had she not asked for it, highlighting either a perceived reluctance or poor awareness amongst clinicians to refer to palliative care services:

> *We'd just done kind of fourth line and he were going on to fifth line [...] I honestly don't think she would have offered it [palliative care input] if I hadn't have asked for it at that point (P8).*

Having explored responsibilities around initiating ACP, we sought to understand how Myeloma patients and carers viewed the timings of these conversations.

Receptivity : the wrong time and knowing when the right time is

Participants largely provided suggestions of the 'wrong time' to broach palliative and end-of-life care conversations, placing the responsibility for recognising the 'right time' on healthcare teams while recognising there is no 'right time'. Diagnosis was proposed as an inappropriate time to discuss ACP due to newly diagnosed Myeloma patients feeling *'shell shocked' (P5)*.

> *I think diagnosis is too early. You're already reeling from the knowledge that you've got a fatal disease or condition. I don't think that's the time to talk about palliative care (P9).*

However, Participant 15 proposed that, due to being ill at diagnosis, "*an end of life [conversation] would have been an appropriate discussion then" (P15).* This participant highlights that timelines for ACP conversations may be more appropriately based on the patient's current condition, than the period since diagnosis. For those who were less unwell at diagnosis, ACP felt more accessible after an extended adjustment period, and when they had a clearer understanding of what it means to live with Myeloma:

> *I think it would have been slightly too bleak at that stage [referring to diagnosis]. Whereas now it's almost four years on and I'm kind of used to the idea and I've got more idea of what to expect (P12).*

Participants 9 and 13 agreed that it may not be appropriate to discuss ACP too early on in the Myeloma progression: "when things are going well [participant 13 didn't] really want to think about it" (P13). Participant 9 felt that "*second line or third line treatment [...] that's the time to do it. But in a low key way"* indicating that ACP should be approached in a subtle and considerate manner. Whilst some participants wished to wait until they had come to terms with their diagnosis before conversations around ACP were initiated by their clinical teams, others felt that these conversations shouldn't begin until Myeloma patients had '*run out of treatment options*' (P9) and '*nothing more can be done'* (P5).

Ultimately, the diversity within participants' responses highlights the importance of a person-centred approach to initiating ACP. Moreover, it must be emphasised that any suggested 'right' times came with caveats and questions - nobody expressed with absolute conviction that there was a single, essential moment to broach ACP.

> *You can't legislate and say this must be spoken about at X point. I know you're in for lots of treatment pathways and things these days. But you've got to, it's where the art comes in, I think, of medicine and treating each patient as an individual (P7).*

This perhaps then begs the question, was there a point in asking? Yes, if only to underline the importance of patient-clinician therapeutic relationships. The onus on finding a right time was placed on HCPs who were expected to know the patient well enough to determine an appropriate time to approach the subject where the patient would be receptive to it.

> "*You have to respect people's views… I think the team, the team get to know their patients pretty well and, know how to sort of handle everybody.*" (P9)

> *And I think if you are an observant nurse, you know which patients are ready to be approached and who are not (P10).*

In contrast to finding a 'right' time to initiate ACP conversations, some participants expressed a preference for patients to be *'given the information [then] they can then choose to explore it* *further" (P6).* Regardless of timings, when Myeloma patients are receptive to ACP discussions, they need resources to do this.

Resources : healthcare professionals, information and patient communities
Resources again highlighted the individualised nature of ACP in this population for both patients and carers. These included healthcare professionals working in hospitals, hospices and specialist community services including Macillian and Marie Curie nurses, along with patient run community groups and information from these and wider sources.

Resources within the hospital setting largely consisted of printed literature. Participants discuss being "*in a pretty lonely place*" (P3) in part remedied with the comfort of having well-structured, Myeloma specific literature to guide their thoughts, however, as Participant 3 continues, support is required from healthcare professionals themselves: "*I'm much more of a fan of the chatting it through [...] I do like that interaction*" (P3).

As discussed in the Responsibility section, hospitals can be "*a minefield*" (P8), with patients being unsure of who is the most appropriate person to discuss their planning concerns with. For Participants 3 and 13, their clinical nurse specialists (CNS) were a guide to support them through the "*hospital machine*":

> "*[My nurse specialist] is really the glue that holds the whole thing together [...] What I'd not twigged, [...] was quite how important that role was to helping me work my way through the ups and downs of being part of the hospital machine. [...] I now use them as my first source of all sorts of [...] question*" (P3)

However, this support provision is not consistent with several of the participants being unable to contact their CNS with some patients referring to staffing shortages. Staff shortages were not limited to the acute setting. Participant 1 describes how her mother wanted to die at home but "*It was clear that actually it was very difficult for the hospice because you're so under resourced and so understaffed in the community [...] you just don't have the staff available to respond to turn up at people's houses and administer the care that's needed. [...] there's only one nurse on call for the whole of the district, one palliative nurse that can come out, one! How many people need that care?"* (P1)

Hospices provide the prospect of ACP by healthcare professionals outside of the hospital system. The prospect of discussing future planning in a hospice environment was generally seen as favourable amongst the participants but there is some stigma about accessing palliative care from organisations which are synonymous with end of life care. Once the barriers of accessing hospice care were overcome, the benefits, particularly over hospital centred resources, were felt. Hospices were viewed as being a *"safe*" and "*professional*" (P11) environment where staff had the capacity to address patients' palliative care needs. Hospices were not only seen as an appropriate place to discuss future care, they acted as a relaxed environment for participants to meet with other patients with similar experiences, providing an opportunity to build a community.

Where hospice provision isn't available around the country, the role of national charities, particularly those with an online presence and communities, are important resources for ACP. Within charities, the role of nurses continues to be important in providing information. The generalised information was echoed by Participant 13:

> *"With Myeloma UK I've dabbled, I've dipped in, but at no point have I yet felt like I've had the full 9 yards. [...] it was more of a group thing, there wasn't chance to ask [personal] questions*." (P13)

Although Participants noted that the resources provided by charities are wide ranging, including individual counselling to group seminars, many of the participants sought comfort, and resources from the community that these charities foster. Meeting other people living with Myeloma helped participants to understand their disease and its trajectory, providing them with a means to be "*proactive*" (P11). Participants 12 and 14 agreed that "*having the ability to speak to other myeloma patients and/or their carers makes it more real than speaking with professional people"(P14)* which gave participants "*confidence that oh well it's not just me" (*P12). Participant 10 also expressed a desire to reciprocate: *"I can give people support as well" (P10).*

The theme of proactivity and supporting others is echoed in the role of those caring for Myeloma patients. Carers discuss the work involved in accessing ACP resources. This group would have benefited from the support of Clinical Nurse Specialists, and their equivalents in the community, taking the time to provide resources on how to have "*constructive [...], open conversations*" (P4) about ACP with their loved ones at the appropriate time.

> "*I know [the patient] was very frightened. He told me that he was very frightened. And I just couldn't say anything really. I sort of just held his hand. [...] I really want to know that I've said what I need to say and I've said it in a controlled or in the proper way. I don't want it to be done wrong. I want it to be done properly. I want the conversations to be good conversations. I don't want them to be wailing and gnashing of teeth. [...] the only way to do that is by talking to your CNS or other healthcare professionals who can advise you so that you can do it properly*" (P4)

Discussion

Advance care planning needs to be approached by the appropriate person, at the appropriate time, and in the appropriate way, yet all three of these factors are individual to the Myeloma patient and their carer. Barriers to ACP conversations focused around the concept of the 'positive consultant' known as therapeutic optimism[20], where medical teams appear to put off conversations around palliative and end-of-life care, in some cases until the very end of life. This finding is shared across global studies[21] and has led to calls for integrated palliative care to be initiated at diagnosis by clinical teams[21–23]. Fears felt by Myeloma patients and their carers taking on the burden of ACP centre around the concern that their ACP actions may indicate a desire to step back from active treatment. These fears, supported by consultant 'positivity', indicate that integrated palliative care is not filtering down into clinical practice. Additionally, ACP conversations near to diagnosis were supported in the literature[25], however we have shown that the variance from patient to patient, and carer to carer, highlight the individual nature of ACP. This person-centred care further puts the responsibility of ACP in the hands of healthcare professionals to develop relationships with Myeloma patients in order to accurately assess the optimal time for ACP to begin. This finding was echoed in the literature where the emphasis has been put on healthcare professionals to improve communication[26–28] and normalise ACP conversations irrespective of health or diagnoses[25].

While existing research has explored broader elements of the Myeloma patient experience[29,30], and patient and carer perspectives around serious illness conversations *following* serious illness conversations[31], our study adds a unique and specific perspective insofar as our participants had little to no experience of ACP discussion, therefore working with a population who were mostly ACP-naive. Our findings suggest that, in the absence of early ACP, Myeloma patients and their carers may experience barriers around accepting palliative care[11,32]. Explorations of why ACP should not start earlier in Myeloma trajectories led to patients and their carers stating that they needed time to come to terms with the Myeloma diagnosis itself. This reflects the liminality experienced by haematology patients and suggests that ACP conversations are being delayed until the threshold into the dying phase has been reached[33]. This delay indicates that the way that healthcare professionals broach ACP conversations needs attention. End-of-life care is surrounded with the stigma around death and dying. ACP should be introduced from a palliative perspective with a focus on improved symptom management, and therefore building supportive relationships with palliative teams earlier in the process[11,32]. This process must be supported by intertwining haematological and palliative care teams when supporting Myeloma patients[34].

Limitations

Recruitment was achieved via study adverts promoted by Myeloma UK. The self-selecting nature of the participants provided the benefit of participants who were committed to participating in the study; however, the sample achieved may not have been representative of the entire myeloma patient population[35]. Due to the nature of this sampling method, participants will have already been engaged with Myeloma UK and have displayed a level of digital literacy. A limitation of this study is therefore that this approach may have excluded those who either do not have access to digital technology or are engaged with this type of communication. Access to digital healthcare technologies may therefore exacerbate the healthcare inequalities experienced by the global majority. Additionally, our findings call for conversations around ACP to be normalised by clinical nurse specialists. Our research took place within the context of the National Health Service in the UK, we acknowledge that the role of nurses, and clinical nurse specialists specifically, varies significantly across the European Union and globally. For this reason, our recommendations may have to be adapted to fit the healthcare professional structures and processes in the readers' respective countries.

Conclusion

The life limiting nature of myeloma lends itself to ACP conversations but these are often not started until later in the disease trajectory, when no further treatment is available. ACP is often hindered by the concept of therapeutic optimism initiated by medical teams, though patients and carers feel that it is the responsibility of medical and nursing teams to commence ACP at the right time. While no right time was universally identified, participants suggested various ‘wrong’ times. Rather than suggesting that ACP should simply *not i*n that case be broached, it invites us to reframe conversations about palliative care, to ensure that patients and carers are in a position to accept support. Prospective research is needed to assess whether early ACP conversations lead to improved outcomes in this population. There is also a need to understand the view of healthcare professionals involved in myeloma care around the introduction of ACP conversations to contextualise this work.

Recommendations for nursing practice

- Nurses within the acute and community settings should be open and receptive to ACP conversations at all points along the Myeloma trajectory.
- Nurses should normalise the initiation of ACP conversations early in the disease trajectory to promote, and remove barriers to, integrated palliative care.
- Haematology nurses should work collaboratively with palliative care nurses to support early symptom management for Myeloma patients.

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Data Sharing Statement

Anonymised transcripts relating to this work have been deposited in the University of Sheffield repository.

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Table 1

Participant demographics	Patient demographics

Number	Patient or carer	Gender	Ethnicity	Age	Years since diagnosis*	Line of Treatment	Previous SCT
1	Carer	F	White British	NK	12 (2)	NK	Yes
2	Carer	F	White British	NK	3 (0)	2	Yes
3	Patient	M	White British	55	4	1	Yes
4	Patient	F	White British	NK	5	2	Yes
5	Carer	F	White British	58	3	1	Yes
6	Patient	F	White British	NK	4	1	Yes
7	Patient	F	White British	60	8	1	Yes
8	Carer	F	White British	NK	5 (1)	5	Yes
9	Patient	F	White British	70	3	2	No
10	Patient	F	East Asian	76	6	1	Yes
11	Carer	F	White British	NK	3 (1)	>1	No
12	Patient	M	White British	53	4	>1	Yes

13	Patient	M	White British	54	3	2	Yes
14	Patient	M	White British	58	3	2	Yes
15	Patient	M	South African	NK	12	NK	Yes

*Brackets indicate the number of years after the patient’s death that the carer’s interview took place where applicable.

SCT = Stem Cell Transplant