

Background

Across the United Kingdom, 40,000 individuals are diagnosed yearly with a haematology cancer.¹ Haematology cancer is a broad term, which encompasses; Non-Hodgkin Lymphoma, Multiple Myeloma, Leukaemia and Myelodysplastic syndromes.²

‘Experiencing death’ is associated with a progressive illness cancer trajectory leading to death.³ Kendall et al³ reports that it is crucial to acknowledge that there are differences in how death is perceived depending on the illness trajectory experience. Only two retrospective studies^{4,5} have described the experience of dying with haematology cancer, with diagnosis and treatment being the moment where they had to face their mortality. Both studies^{4,5} asked their population sample to describe their experiences of distress and end-of-life care, respectively. Neither study had relapsed participants in their population sample. It was discovered⁴ that distress was associated with any experience that was perceived as life-threatening, but specifically with the experience of bone-marrow transplantation. Participants described ‘*looking*’ or ‘*being*’ ‘*somehow dead*’ when they had to surrender control to be ‘*killed and then hopefully be brought back again*’ during the treatment; as the treatment destroys the patient’s immune system to preimplant healthy cells, which may or may not implant and grow. Where consenting to a stem-cell transplant was described as “*One literally signs over the power over life and death*”^{4(pp131)} Similarly, the end-of-life care of fifty participants who were deemed to have survived their disease⁵, found that not only had they thought about death, but they already had concrete experience of facing their mortality during their treatment for cancer. Obviously, this is not an easy memory to erase, although the fear of imminent death can dissipate, the trauma of experiencing death through treatment does not fade over time and can, in fact, influence the present and the future, giving rise to post traumatic stress syndrome.⁶ It is therefore evident that

haemato-oncology patients have had an experience of death in their pursuit of a cure when receiving a bone marrow transplant. This concept that the experience of dying begins at diagnosis and continues through treatment and accompanied with recurrent fear of death was reported briefly by participants in multiple haemato-oncology patient experience qualitative studies.⁶⁻¹⁴ While the exploration of the dying process for those receiving bone marrow transplant is represented in the literature, the last year of life and the dying process in those with incurable and non-transplantable status is ill defined and under researched. This also makes comparison with different disease subtypes receiving different treatment difficult.⁶⁻¹⁴

There is a significant gap in the knowledge base directing clinical service provision for people with an incurable and non-transplantable haematology cancer in the last year of life. Therefore, this research aims to develop an understanding of the haematology cancer patient's experience of the process of dying to meet this evidence gap. To support this research, the individuals of interest, are those who are incurable from diagnosis or relapse and deemed in the last year of their life.

Methods

This study utilised in-depth semi structured interviews within a constructivist grounded theory approach as described below and in accordance with the consolidated criteria for the reporting of qualitative studies.¹⁵

Setting and participant selection

Participants were sampled from three comparator settings: a large cancer centre, a district general hospital and a hospice in the United Kingdom. Adult participants over 45, were deemed in the last year of life by utilising the ‘surprise question’.¹⁶ Purposive sampling and subsequent theoretical sampling sought variation to support the exploratory aspect of the study and included those: receiving active life prolonging treatment vs no treatment; receiving palliative care vs no palliative care; of mixed haematology cancers, and a range of ages and gender.¹⁷ Exclusion to the study was based on lacking ability to undertake the interview physically and emotionally, and non-English speaking participants.

Data collection

Participants were identified by the hospital or hospice clinical teams, offered the information pack, including the consent sheet to review for at least 24 hours before the researcher (KC) made contact, to recruit, over the telephone and arrange a time and place convenient to the participant. Written consent to be interviewed was sought on the day of interviewing and collected by the researcher (KC) to ensure current willingness to be interviewed. Assurances were reiterated about confidentiality, anonymity, and the ability to stop the interview at any time due to physical or emotional issues. Interviews were conducted over a two-year period from May 2016 till May 2018. This study has University and NHS ethical approval (SERC14/15 Paper No24 Version 1 & 15/SS/0123 respectively).

Data Analysis

A constructivist grounded theory (CGT) approach was chosen to gather data ‘grounded’ in the participants views. The emerging constructs bring a theoretical understanding to the meaning of

the process of dying in the last year of life for the haemato-oncology participants. CTG promotes analysis through the indispensable core techniques to support the generation of theory: theoretical coding and sampling; constant comparative method; coding and categorising and memo writing.¹⁷⁻²⁰

All interviews were audiotaped and transcribed using a General Data Protection Regulation²¹ compliant transcription service. Transcripts were entered into NVivo 12 software programme to facilitate storage and the coding process. Each transcript was subjected to line-by-line open coding. Data were analysed for gerund's (action statement), similarities and differences in an iterative process which started from the first interview and supported reflexivity, the memoing process and theoretical sensitivity towards theory development.¹⁷⁻²⁰ A sample of interview data were sampled by FH and KS and emerging constructs and categories discussed. After each interview the process was repeated where individual scripts and between cases were compared. Once the core category emerged a further analysis of key properties and dimensions and discrepant case was undertaken to broaden the meaning associated with the 'facing death' category and ensure theoretical saturation within the time frame of the study.¹⁶ Established findings were then scrutinised against formal and middle range theory(Figure 1) relevant to the emerging constructs leading to the substantive theory(Figure 2)¹⁷

Findings

Table 1 presents the patient demographics of the participants. Hospital Site 1 Cancer Centre (n=7) Site 2 District General (n=11) Site 3 Palliative care services (n=3); 13 Male: 8 Female; Myeloma (n=8), Leukaemia (n=9), Lymphoma (n=3), average age 63.5 (range from 51 to 85

years of age) where n=13 were over 70 and n=8 were under 70. Interviews ranged between one to two hours.

Table1.

Facing Death Core Category

‘Facing death’, core category represents not only from diagnosis but throughout the incurable illness trajectory. Within this core category, four subcategories are presented: transitional phase, chronic phase, dying phase and liminal phase. All the constructs define a process through the four phases but of which the overall status remains ‘incurable’: the transitional phase is where living and dying are both possibilities at one specific episode in time, but eventually a threshold is traversed and extending life is no longer possible. The chronic phase is where the individual will keep living but ‘facing death’ over an uncertain period, due to experiencing a prolongation of life. The dying phase is where ‘facing death’ becomes a certainty. Finally, there is the liminal phase, where physical and psychological concerns create a state of being in limbo and ‘facing death’.

A pattern of alternating periods of remission and relapse underpins this category. The remission-relapse pattern is made possible by the availability of treatment, which extends an individual’s life, but also extends the length of time during which the individual with haematology cancer, is ‘facing death’. In this category, moving towards death, means reaching and traversing the transitional phase. Treatment availability, participant response to treatment, critical care episodes and hospitalisation, therefore, determine the shape of the incurable illness trajectory and experience of ‘facing death’.

The transitional (living or dying) phase

The transitional phase was contingent upon the occurrence of a life-threatening event, which initiated a period where two outcomes were possible simultaneously: living or dying. This period was critical in nature and relied on the results of blood tests and investigations and treatment. The outcome of the life-threatening event determined whether the patient would stay living or move over threshold to death. In last year of life, the participants found themselves in the transitional phase and ‘facing death’ at regular weekly or monthly outpatient appointments, treatment consultations, or upon hospitalisation. Blood sample results were symbolic of legitimatising whether a phase was one of living or dying. Furthermore, because their physical symptoms were limited for some participants, they relied on blood results to alert them to a possible change in moving towards death. The range of symptoms to monitor was contingent upon the disease subtype and trajectory. As those diagnosed with leukaemia, had limited to totally invisible symptoms. In comparison, to those diagnosed with myeloma, suffered from symptoms of pain and organ failure. Those diagnosed with lymphoma, had the physical signs of swollen glands and lumps.

Participants described outpatient appointments as a ‘*interview*’ with its two possible outcomes of passing (living/remission) or failing (dying/relapse). The concept of the transitional phase as a threshold to be crossed from the living/dying to the dying phases emerged as the participants expressed this with statements like ‘*waiting for the doctors to say*’ and ‘*when and if, cause it will*’. The participants believed that there would be a significant change in their disease pathway, signalled by a ‘*nod*’ or ‘*time up*’. In contrast, the threshold was also described as a movement away from death. Here, it was seen as a movement away from ‘*knock back*’ or the ability to ‘*control*’ death. The words ‘*tick*’ and ‘*celebration*’, respectively, to signify stable remission.

Being in the transitional phase is thus something that is experienced regularly due to the frequency of outpatient appointments or hospitalisation.

The Chronic (living) Phase

Within the living phase the participants in the last year of life, on active treatment, describe facing death as a cyclical illness trajectory. The length of the illness trajectory was dependent on the disease type, availability of treatment for the disease and the biological response; with in this study the Lymphoma participants could have lived more than twenty years, myeloma ranged from 2-10 years and Acute Myeloid leukaemia three months to 4 years.

Participants entered a *remission-relapse pattern* of illness where the availability and response can halt the disease process but the reality of this only being a false reversal rather than cure. The participants describe this as creating a welcomed uncertain illness trajectory as the certainty of death is avoided.

Most participants in this phase, were in full or partial remission and described treatment as being the '*last line*' or more future '*options*' being available. Future treatment was referred to as leading to remission and described as levels of treatment, which increased in '*sophistication*' with a greater '*cost*' and less or hopeful for more '*availability*'. An exemplar, below, from a myeloma participant illustrates a ten-year illness trajectory with four different treatment options and hoping that she lasts long enough to see what else is available.

I went into the [hospital] to get the stem cell [1st], it didn't give me that much longer... Then, oh what do you call that, [2nd] Velcade.... then they put me on [3rd] Lenalidomide and at the time there wasn't a lot of people in Scotland on it. I think it

was ...it wasn't an actual trial, but it was just new. That was two years ago, three years ago it's this [4th] Pomalidomide that I'm on now, and it's the last one But I think down in England they are questioning it because of the cost, but [the country] got it, So, it's just the drugs, I'm catching up with them and just waiting on something else coming through.” (Myeloma, Female 60).

Experimental treatment results in an unknown shape and duration of the incurable pathway. This hinders participants' ability to learn from existing knowledge, or adapt from existing shared experience creating an unpredictable journey of facing death:

“The longest time that anybody had been on my palliative drug was 23, 25 months, I can never remember exactly. And I've managed to get to 47... So, it's brilliant, in as much as I'm very pleased to have got that far. The downside has been that I don't particularly like being the front-runner... Because it's no help if you see what I mean. I didn't know anybody else who has had any of the things I've had. So, it's always been a fairly lonely thing... Nobody else has been on it for any... so there's nothing to be learned.” (MDS/AML Female 70)

This uncertainty was increased by the availability of new scientific drug developments, which gave rise to the further availability of treatments, which, in turn, changed the rate and range of response of the incurable care pathway.

The rate and range of response and the availability of treatment varied by disease sub-type. Lymphoma, for example, had a more significant length of prolonged remission (over 20 years), less repeatable remissions, but fewer treatment options. Myeloma had a shorter duration of remission, more repeatable remissions (spanning ten years plus) due to more available treatment

options, but over less time than lymphoma. Leukaemia participants tended to have the least prolonged remission time (year to four years) as well as less opportunity for repeatable remission due to the lack of available treatment.

Even though death could be '*knocked back*' medically, the participants lived with the intrusive thoughts of dying described as routine, pervasive, and permeated daily living, being triggered through different mediums. The participants revealed strategies to 'switch it off':

"You never hear of people...stories of surviving. It's always that someone's died of cancer, you know, and that brings it back to you ... you're listening to it, and it's something you don't want to hear. You'd like to hear the positive side of things... when you're on your own... Yeah, you switch it off, and you think more of the positive things and what's going on and everything else. Just for myself, I've got to keep the morale up because of my mother phones every week." (AML Male 51)

The intrusive thought process is one that occurs during the night and strategies were put in place to switch them off. Participants reported that the strength to carry on was important when facing death.

" But I just say to myself, when I do think about it all, I've just got to be strong, I pray, I'm strong. I mean, I don't go to my church, at all, but I do say an occasional prayer, to an occasional saint, or something, you know, in the night, uh-huh. Just keep me strong; please keep me strong, yeah." (AML Female 60)

When in the hospital the outpatient clinic was a common trigger for intrusive thoughts about dying. The presence of the Specialist Nurse acted as a trigger as they were symbolic of ‘bad news’ consultations and ‘facing death’:

“Well, the very first time we went I think it was {CNS} that was in the roomthat's when they said he had Hodgkin's as well and they can't cure it now... [CNS] was there but just like when she comes into the back of me, and I thought, oh, gosh, what's wrong? we've been here that often that you learn, and you think, oh, something's wrong here.” (Lymphoma, Male 72)

Dying phase

When no treatment is available to extend life, the individual with haematological cancer moves over the *threshold* into the *dying* phase. The duration of facing death depended on the rate of disease progression influencing the pace of dying. If afforded time in this phase, and death was not immediate as represented in the transitional phase, life then consisted of routine weekly monitoring with supportive care transferred to the General Practitioner, along with admission for increasingly regular transfusions. The participants in this phase reported the likelihood of death, with a degree of certainty, of less than six months. The use of words regarding tests were described as ‘*landmark moments*’ between stable counts or signs of deterioration towards death. Invisibility was often incongruent between regular transfusion and perception of dying. The administration of transfusions and ‘*keeping alive*’ still gave hope for the next treatment to achieve remission or that his disease prognosis was incorrect.

For the participant, this was accentuated by the knowledge they had been given about the process of death and the potential signals of dying.

“The doctor did say... but there might come a time when the blood's not going to do anything for me... You can only get transfusions for so long... You build up antibodies or whatever in your and you build up too much iron and different things, I read all that, but who cares, I'm sitting here. I could be a miracle cure, I'm positive, possibly and they may be made the wrong diagnosis, and I said, well, who's making the [blood]..., if you don't give me a transfusion and my bone marrow's not making, who's making the... See, that's a good sign, that's all they ever say, it's a good sign, so what are the good signs, must be some coming from somewhere.”

(Lymphoma/MDS Male 80)

Factors of invisibility of the disease, energy and independence level impacted on the ability to distract themselves from the nature of waiting to die. A comparison of incidents between the participants in this phase revealed a contrast in how the participants utilised the dying phase, where ‘facing death’ had an underlying supporting construct of physical function and energy. The following quote relates to the participants prior experience of ‘facing death’ when he had been in the hospital for an extended period and described ‘being saved’. He related that experience to the one of ‘facing death’ now: The participants revealed not only the repeated facing of death, over a long period of time, but the lack of energy as immobilising, with only the ability to watch the family members suffer now in this phase:

“I never look back, but if your time comes your time comes, but at the moment I don't feel ill. I'd like to know what illness I will have eventually because at the moment... It was just this morning, I just felt sick this morning, but I've anti-sickness tablets for that, but I feel now that if I didn't have this tiredness, I could get on a plane, go on holiday, and enjoy a holiday, but I've not got the energy. I just more or less sit here... So, I've had two death sentences. Put it this way, I was

disappointed I didn't die the first time because I had everything sorted... I had everything sorted out.... What the family are going to do without you and that... only the thing I can think of, nothing else bothers me.” (Lymphoma/MDS Male 80)

In contrast several participants embarked on activity which carried personal meaning. For one woman, writing a book occupied her mind; it was also specifically related to providing a financial cushion for those who would remain.

“I'm determined not to let it [book] sit in that computer, you know, and do nothing... But interestingly enough, which actually boosted me a wee bit, there was quite a big article about [topic] in one of the papers. And I thought, oh I must get this story written. So, that's the reason for the determination, that's the underlying reason. So, I don't think of other things during the day... Because I probably have to concentrate so much on it, it cancels out everything else... I do worry about that a bit - where is he going to stay - I do think about that. Which is slightly the reason I'm trying for the book. But honestly, that's probably a wee bit far-fetched. But you've got to try, you know.” (AML Female 60)

Liminal phase

The liminal phase is associated with an extended period of 'facing death', where the individual oscillates between believing that they may live or die. The participant experience of the liminal phase was created after receiving initial treatment, but not yet reaching remission, or created when the participant lost time during episodes of hospitalisation.

Not knowing if treatment is working

The liminal phase could be created close after receiving a diagnosis, but before achieving the first remission. It was described as an inability to look further than short-term weekly goals.

“I’ve had two periods of chemotherapy. And the news was that everything’s progressing nicely.... Which is very good news... Aye, they [family] asked him [doctor] all these questions... Could you, if that would do, and undertake this period of chemotherapy, and could we fit [treatment] in between now and July, so that I could go on holiday... And the man [doctor] said, oh of course, if it can make you feel a bit better, and I was like, if I’m still gonna be here in July [laughing].” (AML Male 78)

For this participant, this oscillation was heightened by the fact of being cared for in pleasant surroundings by extremely competent staff. As he said:

“It’s kind of creepy, to be perfectly honest with you. Because they really go overboard to make sure that you feel really comfortable... And you feel like you’re dying, you know.” (AML Male 78)

This referred to the existential contradiction that he faced: being in remission through treatment while, at the same time, being moved towards death by his experience of the care environment.

How to act in the liminal phase

‘Not knowing how to act’ relates to an overwhelming and conflicting feeling, which results in participants restricting their own behaviour. Below describes an incident where the participant was in remission but talking as if she were in a dying phase, which overwhelmed her psychologically. The complexity of the situation was contingent upon the invisibility of her AML. They were an independent and fit individual, but believed that their death was inevitable, which resulted in disengagement from social activity through a loss of confidence. The

participant was confused by which state of the illness she was in and needed reassurance and information about how to act when in remission.

“But... so I’m frustrated in that I’m not able to move about as I would [like]. Some of it is lack of confidence. I don’t understand where this illness is going. I don’t know if it’s going anywhere... Whereas I would possibly have taken a train somewhere or a bus somewhere, I now think, what if when I did that, I found myself in a strange place. Partly, partly because I’m frightened that if I did go out and do something, something that I don’t as yet know might happen, happened, what would happen.” (AML Female 80)

This participant could not understand why her family were not treating them like they were dying, expecting that they would be flocking to their side. This example showed that a liminal phase is often linked to uncertainty and fear, and to not being able to measure progress or assess the probable length of remission.

Losing time

Due to disorientation or delirium, participants were unable to recall when they were admitted to hospital because of an emergency, but they were aware they had been seriously ill. The participants used words like ‘*I am led to believe*’ and ‘*can’t remember anything*’, illustrating that being near death was experienced through others. These participants related their experience of ‘facing death’ in the language and emotion of their family members. Since they were delirious, they were unaware of ‘facing death’.

“But I was seriously ill. I was, you know, I was kind of at death’s door... As I’m led to believe that everything was packing up.” (Myeloma Male 75)

“See, I can’t remember getting a wheelchair into hospital... I can’t remember anything of that day... Aye, I mean, apparently, I was quite ill, but I didn’t realise that.” (Lymphoma Male 72)

Alignment with the social theory

Figure 1

To aid further analyse within constructivist grounded theory approach¹⁷ the findings were thus scrutinised through the lens of theories about: Awareness of Dying,²² Time for Dying;²³ Status Passage;²⁴ Liminality^{25, 26} and Uncertainty in illness.²⁷⁻³⁰

The Substantive Theory: Incurable illness trajectory and facing death

Figure 2

From Left to right: the last year of life is mostly lived in the chronic phase (circular arrows), which is a cycle of false reversal/remission-relapse. Here, the availability of and response to the treatment can halt the disease process, but only for a time. The amount of this time is unpredictable, creating uncertainty and liminality, where ‘facing death’ is a regular feature of clinical visits and hospitalisation. The transitional phase contains the critical juncture (red box), which is experienced as a life-threatening event of ‘facing death’; here, living and dying are possible outcomes. At this juncture, if new treatment achieves a false reversal, the individual moves back to the chronic phase of the illness trajectory (the circular arrows). If no treatment is available to extend life, the individual moves over a threshold (blue rectangle) towards the dying phase (blue arrow towards the right). Once reached, the nature of the dying phase depends upon the progression of the disease, which determines the rate and pace of the illness trajectory. This rate and pace can be associated with a pervasive uncertainty and liminal experience of being in

in-between phases over time (blue arrow moving left and right). The patient once over the threshold moves from the phase of uncertainty to certainty of death.

Discussion

This is the first study undertaken to explore patient experience in the last year of life for a mixed population of haematology disease types . Despite receiving life prolonging therapy, this study found that haematology cancer patients face the reality of death on a regular basis through routine clinic appointments, critical episodes of care and not just when life prolonging treatment is no longer an option. Furthermore, this study also adds to the understanding that the length of the incurable pathway has varying degrees between the disease types, but this does not negate regularly experiencing facing death.

Transitional and Chronic Phases

The core category details the routine experience of facing death for patients over a long period of time. Whether this experience is in the foreground or remains in the background depends on the availability of treatment, the relapse-remission pattern, and the patient's physical and emotional responses. Arantzamendi et al.³¹ also describes that treatment failures and physical suffering bring an awareness of dying to the forefront.

The concept of 'facing death' regularly over a longer period in an undulating, unpredictable illness trajectory is mentioned by Lowrie et al.,³² but their patient population was gathered solely from the dying phase, defined as where there was no active treatment.

Other solid tumour studies^{33,34} concurred with the haemato-oncology patients' findings of wanting to 'knock back' the disease process, found that their participants' lives were dominated by life-prolonging treatment and monitoring of symptoms. The availability of treatment is the single most important factor driving the length of facing death. A myeloma study³⁵ highlights

that, out of five countries, patients in the UK experience a greater number of treatments than those in France, Germany, and Italy, and a similar number to those in Spain. This indicates the global diversity that potentially exists for myeloma patients. There was no comparable evidence for patients with leukaemia or lymphoma, however. When reviewing the extent of global drug development, this has increased more rapidly for leukaemia and lymphoma during the last five years of this study than for myeloma³⁶. This would indicate the growing availability of treatment to extend the leukaemia and lymphoma illness trajectory.

Three models³⁷⁻³⁹ showing similarities were found between the core category of ‘facing death’ and participants experiencing intrusive thoughts: Paterson’s³⁷ model, where the patient can shift from a well perspective to an illness perspective even when they are not ill during the frequent hospital visits, with their reminders of the inevitability of death. Guilhot et al.’s³⁸ and Bell’s³⁹, models where participants described moving from crisis to adaption. These models see illness as cyclical, conceived as movements backwards and forward or as linear, but not as having an end point, of moving across the threshold towards death. The transitional phase had similarities with Guilhot et al.’s³⁸ concept of a crisis and the overall direction of the illness trajectory over time. However, these studies focus solely on long-term management and exclude the outcome of death.

Liminality

Liminality related to the psychological uncertainty of waiting for remission, losing time when hospitalised, and waiting for death during the dying phase. Unlike in Maher & De Vries’s,⁹ study several of the participants found uncertainty to be a welcome liminal space, which they described as a way of living to ‘knock back’ death. It changed the emphasis from fear of relapse to fear of no treatment after having relapsed.^{29,40,41} Hulin³⁵ concurred that subsequent relapses caused

patients less distress as they knew what to expect, but that it increased again when treatment options were becoming exhausted. Other studies have^{29,33,40,41} drawn similar conclusions, namely that uncertainty gives hope and acts as a buffer against the certainty of impending death for those with incurable haemato-oncology and advanced cancer.

Several explorations of liminality⁴²⁻⁴⁶ identify a liminal space as a time of waiting for what will come next, be that test results, future treatment, or death itself; the participants in my study found such things psychologically challenging as well. Adorno⁴⁵ states that liminality is increased by the advent of biomedical technologies, which cause a greater blurring between living and dying. However, the study again, is writing from the standpoint that the technological advances are futile, referring to them as late-stage cancer-directed therapy that interferes with or is caused by our societal inability to discuss death.⁴⁵ However, the participants described in this study accepted treatment, embracing the possibility that they might achieve a remission, but realised when they were running out of options to ‘knock back’ death. That said, it cannot be ignored that prolonging life may be at the cost of the physical and emotional well-being of the patient and their families.

Dying Phase

During the study, three of the AML/MDS participants moved over the threshold towards death. It has been stated that the patient must learn to ‘unbecome a cancer patient’ in the dying phase, where the pace and focus change, with less appointments.⁴⁷ This has also been described as ‘waiting – in between ness’, which can be a positive state, but is more commonly depicted as a negative one, as purgatory.⁴⁸ This sense of purgatory was expressed by participants in this study when facing death repeatedly over time in both the chronic and dying phases.

Energy and [in]dependence were key influencers in how the participants dealt with waiting for death. This has been described as holding onto life and is associated with living in the presence of death. Here, control and [in]dependence underpin the efforts a patient makes to stay connected to life to preserve their independence.⁴⁹ This has also been expressed as '*a desire to live normally while being aware of the proximity of death*'^{50 (pp 553)} and how people at the end-of-life attempt to manage the dilemma of living in the present while preparing for death.⁵⁰

Strengths and limitations

Strengths of this study include the methodological rigor of the grounded theory approach, the in-depth ontological understanding generated from a heterogeneous population to understand the process of palliative care in the last year of life across three different health care settings. The time frame of the study was challenging to performing true theoretical sampling in this population but was limited by the variation in the sample. There were a few participants who were not interested in participating and further recruitment was hampered by deterioration of participants or the inability to schedule an appointment due to emergency care requirements. Due to the lack of funding for an interpretation service the views of non-English speakers were not included.

Implications for practice and research

It is important that clinical practice acknowledges those participants living within an incurable illness trajectory are only avoiding death rather than having the ability to cure the disease. If we can conceptualise the pathway as living within episodic illness, then it becomes apparent that the incurable patient requires their holistic needs to be assessed and that assessment should discuss the dying trajectory. The patient should especially be assessed after each episodic, life-threatening event to ensure that care preferences are updated. This research also has implication

for the process of dying associated with the advanced solid tumour cancer patients who are increasingly being offered life-prolonging drugs.

Further research is required to understand the implementation and impact of a holistic needs assessment or patient reported outcomes to understand how to optimise personalised care. More research associated with the utilisation of medical technology or remote monitoring of both physical and emotional needs would formulate a better picture of the haemato-oncology patient's needs in the chronic and dying phases over time. The conceptual framework would improve the ability to categorise and disseminate data describing the sample population more succinctly and to better aggregate this data, which, in turn, will facilitate more meaningful clinical comparisons when patients are in the chronic or the dying phase of the illness trajectory.

In Conclusion

This study presents the findings from this unique study capturing the process of dying in haematology cancer patients in the last year of life. This study provides evidence that the haematology cancer patient is 'facing death' perceived in four phases: chronic, transitional, dying and liminal phase. The incurable pathway is seen primarily as a medical transition, signalled by the end of available cancer-controlling treatment and the subsequent move over the threshold towards death.

References

1. Cancer Research UK. <https://www.cancerresearchuk.org> . Accessed July 22, 2022.
2. Blood Cancer. <https://bloodcancer.org.uk> . Accessed July 22, 2022.
3. Kendall M, Carduff E, Lloyd A, et al. Different Experiences and Goals in Different Advanced Diseases: Comparing Serial Interviews With Patients With Cancer, Organ Failure, or Frailty and Their Family and Professional Carers. *J Pain Symptom Manage*. 2015;50(2):216-224. doi:10.1016/j.jpainsymman.2015.02.017
4. Potrata B, Cavet J, Blair S, et al. Understanding distress and distressing experiences in patients living with multiple myeloma: an exploratory study. *Psycho-Oncology*. 2011; 20: 127-134. doi.org/10.1002/pon.1715
5. McGrath P. End-of-life care in hematology: update from Australia. *J Soc Work End Life Palliat Care*. 2013;9(1):96-110. doi:10.1080/15524256.2012.758608
6. Dahan JF, Auerbach CF. A qualitative study of the trauma and posttraumatic growth of multiple myeloma patients treated with peripheral blood stem cell transplant. *Palliat Support Care*. 2006;4(4):365-387. doi:10.1017/s1478951506060470
7. Cuffe CH, Quirke MB, McCabe C. Patients' experiences of living with multiple myeloma. *Br J Nurs*. 2020;29(2):103-110. doi:10.12968/bjon.2020.29.2.103
8. Cormican O, Dowling M. Managing relapsed myeloma: The views of patients, nurses and doctors. *Eur J Oncol Nurs*. 2016;23:51-58. doi:10.1016/j.ejon.2016.04.003
9. Maher K, de Vries K. An exploration of the lived experiences of individuals with relapsed multiple myeloma. *Eur J Cancer Care (Engl)*. 2011;20(2):267-275. doi:10.1111/j.1365-2354.2010.01234.x

10. Nørskov KH, Overgaard D, Lomborg K, Kjeldsen L, Jarden M. Patients' experiences and social support needs following the diagnosis and initial treatment of acute leukemia - A qualitative study [published correction appears in *Eur J Oncol Nurs*. 2019 Oct;42:162]. *Eur J Oncol Nurs*. 2019;41:49-55. doi:10.1016/j.ejon.2019.05.005
11. Hackett F, Dowling M. Lymphoma survivors' experiences at the end of treatment. *J Clin Nurs*. 2019;28(3-4):400-409. doi:10.1111/jocn.14658
12. LeBlanc TW, Fish LJ, Bloom CT, et al. Patient experiences of acute myeloid leukemia: A qualitative study about diagnosis, illness understanding, and treatment decision-making. *Psychooncology*. 2017;26(12):2063-2068. doi:10.1002/pon.4309
13. Osborne TR, Ramsenthaler C, de Wolf-Linder S, et al. Understanding what matters most to people with multiple myeloma: a qualitative study of views on quality of life. *BMC Cancer*. 2014;14:496. Published 2014 Jul 9. doi:10.1186/1471-2407-14-496
14. Crawford R, Sully K, Conroy R, et al. Patient-Centered Insights on Treatment Decision Making and Living with Acute Myeloid Leukemia and Other Hematologic Cancers. *Patient*. 2020;13(1):83-102. doi:10.1007/s40271-019-00384-9
15. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007 (6):349–57. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/17872937>
16. Gerlach C, Goebel S, Weber S, Weber M, Sleeman KE. Space for intuition - the 'Surprise'-Question in haemato-oncology: Qualitative analysis of experiences and perceptions of haemato-oncologists. *Palliat Med*. 2019;33(5):531-540. doi:10.1177/0269216318824271
17. Charmaz K. *Constructing grounded theory: A practical guide through qualitative analysis*. London: SAGE;2006.

18. Birks M, Mills, J. *Grounded Theory: A Practical Guide*. SAGE Publications; 2015.
19. Urquhart C. *Grounded Theory for Qualitative Research: A Practical Guide*. London: SAGE Publications; 2012.
20. Gibson B, Hartman J. *Rediscovering Grounded Theory*. London: SAGE Publications; 2014.
21. *General Data Protection Regulation (GDPR) 2018*–Available at: <https://gdpr-info.eu/> [Accessed: March 2022].
22. Glaser BG, Strauss AL. *Awareness of Dying*. Taylor & Francis;1965.
23. Glaser BG, Strauss AL. *Time for Dying*. Aldine Publishing;1968.
24. Glaser BG, Strauss AL. *Status Passage*. Taylor & Francis;1971.
25. Turner VW. *Process, Performance, and Pilgrimage: A Study in Comparative Symbolology*. Concept publishing company New Delhi; 1979.
26. Little M, Jordens CF, Paul K, Montgomery K, Philipson B. Liminality: a major category of the experience of cancer illness. *Soc Sci Med*. 1998;47(10):1485-1494. doi:10.1016/s0277-9536(98)00248-2
27. Mishel MH. The measurement of uncertainty in illness. *Nursing Research*. 1981; 30(5): 258-263. doi.10.1097/00006199-198109000-00002
28. Mishel MH. Uncertainty in illness. *Image J Nurs Sch*. 1988;20(4):225-232. doi:10.1111/j.1547-5069.1988.tb00082.x
29. Mishel MH. Reconceptualization of the uncertainty in illness theory. *The Journal of Nursing Scholarship*. 1990; 22(4): 256-262. doi.10.1111/j.1547-5069.1990.tb00225.x
30. Mishel MH, Padilla G, Grant M, Sorenson DS. Uncertainty in illness theory: a replication of the mediating effects of mastery and coping. *Nurs Res*. 1991;40(4):236-240.

31. Arantzamendi M, García-Rueda N, Carvajal A, Robinson CA. People With Advanced Cancer: The Process of Living Well With Awareness of Dying. *Qual Health Res.* 2020;30(8):1143-1155. doi:10.1177/1049732318816298
32. Lowrie D, Ray R, Plummer D, Yau M. Examining the transitions between living and dying roles at end-of-life. *Death Stud.* 2019;43(10):601-610. doi:10.1080/07481187.2018.1504836
33. Lobb EA, Lacey J, Kearsley J, Liauw W, White L, Hosie A. Living with advanced cancer and an uncertain disease trajectory: an emerging patient population in palliative care?. *BMJ Support Palliat Care.* 2015;5(4):352-357. doi:10.1136/bmjspcare-2012-000381
34. Reed E, Corner J. Defining the illness trajectory of metastatic breast cancer. *BMJ Support Palliat Care.* 2015;5(4):358-365. doi:10.1136/bmjspcare-2012-000415
35. Hulin C, Hansen T, Heron L, et al. Living with the burden of relapse in multiple myeloma from the patient and physician perspective. *Leuk Res.* 2017;59:75-84. doi:10.1016/j.leukres.2017.05.019
36. Global Oncology Trends. Innovation, Expansion and Disruption. IQVIA Institute for Human Data Science. 2018.
37. Paterson BL. The shifting perspectives model of chronic illness. *J Nurs Scholarsh.* 2001;33(1):21-26. doi:10.1111/j.1547-5069.2001.00021.x
38. Guilhot F, Coombs J, Szczudlo T, et al. The patient journey in chronic myeloid leukemia patients on tyrosine kinase inhibitor therapies: qualitative insights using a global ethnographic approach. *Patient.* 2013;6(2):81-92. doi:10.1007/s40271-013-0006-3

39. Bell R. Developing a Clinical Program Based on the Needs of Patients With Chronic Lymphocytic Leukemia: Preparing for Illness Episodes. *J Adv Pract Oncol*. 2017;8(5):462-473.
40. Etkind SN, Bristowe K, Bailey K, Selman LE, Murtagh FE. How does uncertainty shape patient experience in advanced illness? A secondary analysis of qualitative data. *Palliat Med*. 2017;31(2):171-180. doi:10.1177/0269216316647610
41. Drevdahl DJ, Dorcy KS. Transitions, decisions, and regret: order in chaos after a cancer diagnosis. *Advances in Nursing Science*. 2012; 35(3): 222-235.
doi.10.1097/ANS.0b013e318261a7a7
42. MacArtney JI, Broom A, Kirby E, Good P, Wootton J. The Liminal and the Parallax: Living and Dying at the End of Life. *Qual Health Res*. 2017;27(5):623-633.
doi:10.1177/1049732315618938
43. Willig C, Wirth L. A meta-synthesis of studies of patients' experience of living with terminal cancer. *Health Psychol*. 2018;37(3):228-237. doi:10.1037/hea0000581
44. Willig C, Wirth L. Liminality as a dimension of the experience of living with terminal cancer. *Palliat Support Care*. 2019;17(3):333-337. doi:10.1017/S1478951518000536
45. Adorno G. Between Two Worlds: Liminality and Late-Stage Cancer-Directed Therapy. *Omega (Westport)*. 2015;71(2):99-125. doi:10.1177/0030222815570589
46. Bruce A, Shields L, Molzahn A, Beuthin R, Schick-Makaroff K, Shermak S. Stories of Liminality: Living With Life-Threatening Illness. *Journal of Holistic Nursing*. 2014;32(1):35-43. doi:[10.1177/0898010113498823](https://doi.org/10.1177/0898010113498823)
47. Syme A. Learning to be a dying person: being outside/inside cancer treatment systems. *Canadian Oncology Nursing Journal*. 2011:150-153.

48. Kellehear A. *The Inner Life of the Dying Person*. Columbia University Press; 2014.
49. García-Rueda N, Carvajal Valcárcel A, Saracíbar-Razquin M, Arantzamendi Solabarrieta M. The experience of living with advanced-stage cancer: a thematic synthesis of the literature. *Eur J Cancer Care (Engl)*. 2016;25(4):551-569. doi:10.1111/ecc.12523
50. Horne G, Seymour J, Payne S. Maintaining integrity in the face of death: a grounded theory to explain the perspectives of people affected by lung cancer about the expression of wishes for end of life care. *Int J Nurs Stud*. 2012;49(6):718-726. doi:10.1016/j.ijnurstu.2011.12.003

Figure 1

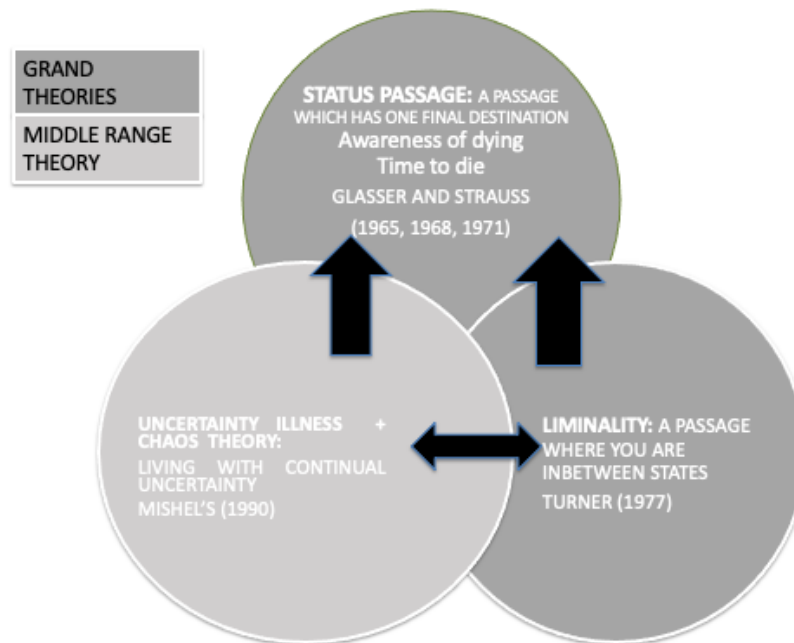


Figure 2

Core category 'Facing Death': transitional phase, chronic phase, dying phase, liminal phases

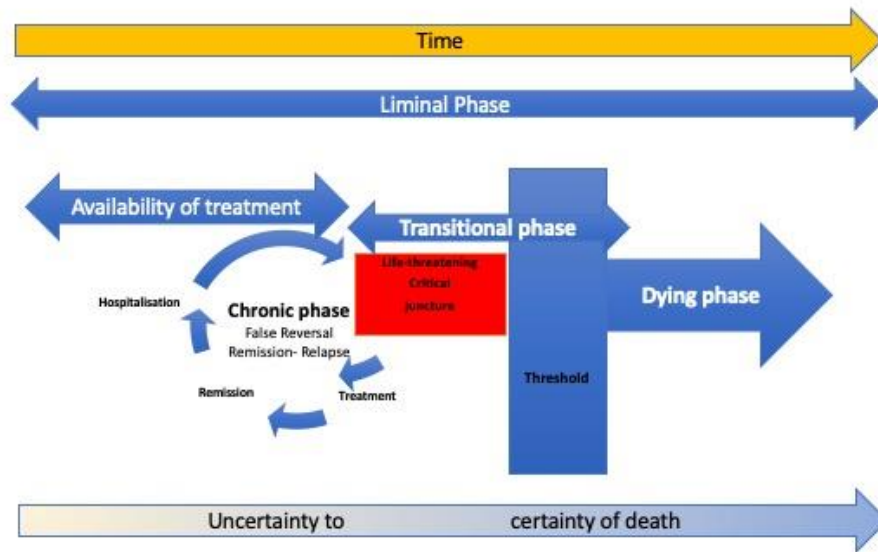


Table 1: Patient Characteristics

Gender	Interview took place	Disease process	Age	Years from Diagnosis
M	Home	Myeloma	85	2.5
M	Hospital	AML	78	0.25
M	Home + wife	Myeloma	75	3
M	Home + wife	AML	75	2
F	Home	AML	73	1
F	Home	AML	78	1
M	Home	AML	52	20
M	Home + other	Myeloma	68	2
F	Home	MDS/AML	60	1

M	Home + wife	Lymphoma	72	20
F	Home	Myeloma	60	10
M	Hospital	AML	51	1.5
M	Home + wife	Myeloma	60	10.5
F	Home	Myeloma	76	1
F	Home	MDS/AML	70	4
F	Home + Daughter	AML	82	0.75
M	Home + wife	Myeloma	54	7
M	Home	Myeloma	66	3
F	Home	Myeloma	74	10
M	Home	Lymphoma	80	15
M	Home + Wife	Lymphoma/M DS	85	5