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**“It’s a traumatic illness, traumatic to witness.” A qualitative study of the experiences of bereaved family caregivers of patients with cutaneous T-cell lymphoma**

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- **Conflicts of interest**

The authors declare they have no conflicts of interest in relation to this study.

**What’s already known about this topic?**

- Cutaneous t-cell lymphoma (CTCL) is a rare cancer with multiple negative impacts on the quality of life of patients and their carers, particularly in advanced disease
- Care of extensive skin lesions in advanced CTCL is complex and time-consuming.
- A systematic review of the literature on CTCL revealed no exploration of the needs or experiences of family carers

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## What does this study add?

- Care for patients with advanced CTCL is complex and challenging, and family caregivers adopt quasi-professional roles
- Even in advanced CTCL and despite multiple hospital admissions, family caregivers may not expect their relative's death and experience highly variable bereavement support
- Health-care providers should consider the support needs of family caregivers as well as those of patients with advanced CTCL.

## Introduction

Primary cutaneous T-cell lymphomas (CTCL) are rare non-Hodgkin lymphomas affecting the skin. Of these, Mycosis Fungoides (MF) and Sezary Syndrome (SS) are the most common. There is a reported incidence of 7.7 per 1,000,000 person-years with a male: female ratio of 1.72: 1 [1] and doctors in primary care are unlikely to see people with this diagnosis. Whilst median survival in early stage disease (IA and IIA) is 35.9 years and 15.9 years respectively, this drops to 1.4 years in stage IVB disease [2]. Skin can be pruritic and can become extensively and visibly affected with thick plaques, tumours and ulceration which can be challenging to manage. Disease progression involves lymph nodes and potentially mucosa, lung, brain and viscera. Treatment aims to manage symptoms as there is no effective cure, though a stem cell transplant, in itself risky, can result in clinical remission.

Our systematic literature review in 2014 found nothing published on the experiences of carers of patients with CTCL [3] although qualitative research with patients had identified the need for greater understanding of the challenges of living with this disease [4]. We have since reported findings from our study of family members currently caring for patients with CTCL and found CTCL had a profound impact on family dynamics and relationships [6]. However, up to now there have been no studies of bereaved caregivers' experiences of the advanced disease of their relative, the approach of death and bereavement and there is therefore little evidence to inform care delivery for this group. It is possible that their experiences might differ from those of caregivers of people with other forms of advanced cancer given the challenges of widespread skin involvement. In this study we aimed to explore the experiences of bereaved caregivers of patients with CTCL leading up to and beyond the death of the patient.

## Methods

### Design

In-depth, face-to-face, semi-structured qualitative interviews were conducted with bereaved caregivers of patients with CTCL. The study was overseen by a steering group and also a user group of two patients and a carer meeting every 6 months who provided useful guidance on overall study design and the development of the topic guide.

## Setting

Participants were caregivers of patients who had some or all of their care at a supra-regional CTCL clinic.

## Recruitment

Personally addressed letters inviting participation in the research were sent to the next of kin/person registering each patient's death by the consultant who had led the care. The addressees were identified from the patient database at the supra-regional CTCL clinic. In line with the methodology of a major bereavement survey [7], caregivers were not approached in the first four months after the death. As this is a small population, caregivers of patients listed on the departmental database who had died up to three years earlier were approached.

A reply slip was provided, and people were invited to call the lead researcher (ER) or the team psychologist (DO) if they wished. Participants were recruited through this single approach – no follow up letters were sent after the initial invitation. Inclusion criteria were that their deceased relative had CTCL as the primary or secondary cause of death and that they could take part in an interview in English.

## Data collection

Face-to-face single semi-structured interviews were conducted by an experienced medical sociologist (ER) using an interview topic guide (Appendix 1). The topic guide was informed by the literature, and reviewed by the user group. Caregivers were interviewed at a time convenient to them, usually in their homes. Interviews were digitally recorded.

## Analysis

Interviews were transcribed verbatim by a professional transcriber and anonymised. ID numbers were assigned to each participant. Data were analysed thematically [8] in three stages: (1) the complete set of interview transcripts was read and re-read by the lead author to become familiar with the data, with initial notes made about the content and emerging themes. (2) A draft coding frame was created, using an inductive approach and constant comparison to create a conceptually coherent hierarchy of themes and sub-themes specifically related to caregivers' experiences of the advanced disease of their relative, the approach of death and bereavement. (3) The coding frame was revised through an iterative process of re-interrogating the data and discussing emerging themes with co-authors (LS, RH, TB). Finally, a narrative was constructed with input from all authors.

## Ethical issues

Ethical approval was granted by the UK National Research Ethics Service (NRES reference: 11/H0713/11) and written informed consent obtained from all participants.

In view of the potential for participant distress during the interviews, access to the medical team's clinical psychologist was made available (however none made contact). The interviewer offered to stop the interview for a period if a participant became upset and this happened several times.

## Results

Seventeen invitation letters were sent to potential participants. Two were returned to sender (presumably the addressee having moved). Of the remaining 15, 11 contacted the researcher wishing to participate. Four had family members who had also played a major role in caregiving for the patient and wished to participate.

## Participant characteristics

Participant characteristics are displayed in Table 1. All participants described themselves as White British and were from a range of occupational backgrounds. Seven interviews were with one carer (partner/spouse), and four were joint interviews with a bereaved spouse/partner and their adult son/daughter.

The caregivers' accounts identified that deceased patients had received a variety of treatments over time including Total Skin Electron Beam Therapy, Chemotherapy, Extracorporeal Photopheresis, Bexarotene, Interferon, PUVA, Nitrogen Mustard and Radiotherapy. Two had stem cell transplants for CTCL.

## Findings

Four main themes were identified:

1. Complexity of care and medical intervention
2. Caregiver roles in advanced CTCL
3. Person vs. organisation-centred care in advanced CTCL
4. Knowing and not knowing: reflections on dying, death and bereavement

Sub-themes identified are referred to in the text. Table 2 contains exemplifying quotes (potentially identifying details have been removed). Good communication affects all aspects of patient and caregiver experience from diagnosis, through treatment and to death. In this paper aspects of communication are reflected within individual themes, (particularly themes 2, 3 and 4), rather than being illustrated as an individual theme

## **1. Complexity of care and medical intervention**

Four sub-themes were identified relating to the nature of advanced CTCL i) vivid descriptions of advanced disease, ii) the challenges of skin care and wound dressings, iii) the impact of advanced CTCL and co-morbidities on care options, and iv) variations in health professionals' knowledge about the disease.

### **1.1 Vivid descriptions of advanced disease**

Several caregivers provided vivid descriptions of advanced disease. These included the altered facial appearance of their relative [Q1], deep fissuring of the skin on hands and feet [Q2] and the vast extent of skin involvement and what this meant for patients [Q3, Q4]. Some particularly distressing accounts have been omitted as they risk identifying individual patients. Understandably, witnessing visible disease was not easy. Indeed, one caregiver recalled the consultant asking junior doctors to reflect on their motivation for their chosen career using advanced CTCL as an example of a complex medical situation they might encounter [Q5].

### **1.2 The challenges of skin care and wound dressings**

Bereaved caregivers reported that looking after the skin of the patient, applying specialist dressings and providing skilled care was a major challenge [Q6]. Some caregivers were involved in this care themselves (section 2.1). One suggested the need for specialist dressings which did not need daily changing and another was pleased that a hospice used a form of non-stick bed sheet. In extremis, there was also creative use of high street products (sanitary towels and maternity knickers for wounds in the groin) [Q7]. When in hospital, caregivers said they had appreciated a consistent staff team who knew how to handle their relative's dressings [Q8].

### **1.3 The impact of advanced CTCL and comorbidities on care options**

The extensive skin involvement of advanced CTCL could stand in the way of taken-for-granted approaches to care (e.g. giving injections, transferring the patient from bed to chair) and basic human contact [Q9, Q10]. For example, one caregiver explained that advanced disease affected options for delivery of analgesia, as syringe drivers were impossible to set up given the condition of the patient's skin [Q11]. Another spoke of the complications of dealing with the sequelae of a stem-cell transplant: what worked for one symptom exacerbated another [Q12]. Advanced CTCL posed

challenges of co-ordination when different specialties were needed whether within the same organisation [Q13], when another more common condition (cardiac problem) was treated at a local hospital and/or when local appointments did not occur [Q14].

#### **1.4 Variations in health professionals' knowledge about CTCL**

Caregivers spoke of local health care providers not having knowledge of CTCL [Q15]. Whilst this is not surprising given the rarity of the disease, it could mean that disease progression was not spotted and symptoms mistakenly attributed to more benign causes. Examples of this were oral involvement being attributed to an ulcer rather than disease progression [Q16] and local health professionals not understanding that there had been a change in colour of a patient's skin [Q17].

## **2. Caregiver roles in advanced CTCL**

To a greater or lesser extent, families of patients with advanced disease found themselves involved in the wider team of medical and nursing staff in a variety of settings. Four sub-themes emerged describing the different roles caregivers took on: caregivers as i) hands-on providers and care-co-ordinators, ii) advocates, iii) decision-makers and iv) contributors to medical knowledge.

### **2.1 Family caregivers as hands-on providers and care-co-ordinators**

Caregivers were involved in a range of practical care and nursing tasks – whether at home or healthcare settings. At home, they carried out practical tasks such as skin care in conjunction with clinical staff [Q18]. Being a caregiver was physically and emotionally demanding in advanced CTCL, and given the nature of wounds, some reached limits in what they could face doing [Q19], or being elderly, were unable to continue [Q20]. Caregivers also provided care within hospitals or hospices, generally when they saw care as inadequate [Q21]. Given the high number of staff involved in the care of some patients who were at home with advanced disease, caregivers could find themselves in the role of a care co-ordinator [Q22].

### **2.2 Family caregivers as advocates**

Some caregivers pushed doctors for information about treatment options when they felt current approaches were not working and hence could be regarded as advocates for their relative [Q23]. Some spoke of bringing short-comings in care to the attention of health care providers [Q24].

Indeed, to the surprise of service providers, one family intervened to take their distressed relative home after she called them complaining of poor care [Q25].

### **2.3 Family caregivers as decision-makers**

Caregivers spoke of being part of the clinical decision-making process with their relative. This was not easy given the complexity of the information involved [Q26]. One relative recalled the dilemma she and her husband faced of whether to agree to medical intervention in the last weeks of his life [Q27].

### **2.4 Family caregivers as contributors to medical knowledge**

Medical care for patients with advanced CTCL could be delivered by multiple hospitals and services, particularly if they lived far from the specialist centre. Some caregivers kept records of treatment [Q28], sometimes in impressive detail which arguably could be of use to non-specialist teams. Caregivers also contributed their experiences and expertise: one offered a post-mortem anticipating this would help the team understand the cause of the patient's approaching death [Q29]. More broadly, caregivers also contributed to expanding knowledge in CTCL through requesting funeral donations to go towards research [Q30].

## **3. Person vs. organisation-centred care**

The reports of some caregivers suggested that care was not always person-centred. Rather than creative solutions being found to address each patient's unique needs towards the end of life, they were sometimes expected to fit into healthcare organisations' systems and processes. Two sub-themes emerged: i) the specific impact of time pressure on care and ii) organisational challenges to person-centred care.

### **3.1 Impact of time pressure on care**

Some caregivers reported that shortages of time and/or staff had adverse impacts on patient care: time pressure affected how dressing changes were managed [Q31], and on occasions some lesions were left without radiotherapy treatment with painful results for the patient [Q32]. One recalled that the simple act of giving of tablets in hospital had not taken into account the time the patient needed to swallow them given his sore mouth [Q33].

### **3.2 Organisational challenges to person-centred care**

One caregiver contrasted the approach of staff working in a separate hospital department, only one of whom he believed took the pain of the patient into account when a referral was made for inpatient tests [Q34]. Another recalled her husband telling his medical team he thought he was being seen as a set of separate biological systems rather than a whole person [Q35]. There were also comments that the organisation of patient transport and appointment times did not always take patient fatigue and extreme skin discomfort into consideration.



Challenges about the location of care sometimes emerged if patients outlived initial expectations. One caregiver was aware of debate in a hospice clinical team regarding where her relative could receive care as the hospice could not admit patients for extended periods [Q36]. Despite the intensity of carer involvement (section 1.4), significant choices were sometimes made by others: one caregiver was distraught that despite her specific request, a paid carer coming to the home had not woken her when her husband's condition had deteriorated on the day of his death [Q37], which also illustrates poor communication on the part of the paid carer at this delicate time.

#### **4 Knowing and not knowing: reflections on dying, death and bereavement**

Four sub-themes relating to caregivers' experiences of their relative's death and their own subsequent bereavement were identified: (i) understanding of prognosis and approaching death, (ii) admissions and interventions at the end of life, (iii) reflections on death with CTCL, and (iv) bereavement support.

##### **4.1 Understanding of prognosis and approaching death**

Bereaved family caregivers varied in the extent to which they had been aware of the prognosis and likelihood of approaching death. In part this related to early consultations in which varying amounts of information had been given. Looking back, one family was surprised at the severity of CTCL and thought they would have asked more questions had they known what might happen [Q38]. In contrast, another was pleased with the communication and grateful that the severity had been clarified from the outset, as this had enabled practical matters to be addressed [Q39]. Bereaved family caregivers also varied in how much they would have welcomed detailed information at diagnosis: looking back some would have wanted more clarity [Q40], while others were glad not to have had much detail [Q41].

##### **4.2 Admissions and interventions at the end of life**

Towards the end of life, some patients experienced cycles of hospital admissions and discharges. Caregivers reported not expecting that any single admission would be the last, and surprise when their relative died [Q42, Q43]. One caregiver of patient with a lengthy hospital stay commented that not expecting death led to a lack of practical preparations [Q44]. Even in the last weeks of life, some carers recalled their relative undergoing multiple medical procedures [Q45].

##### **4.3 Reflections on death with CTCL**

Bereaved family caregivers' accounts of the approach of death included its traumatic nature [Q46], and painful and lingering aspects [Q47]. One spoke of the 'sheer awfulness' of the final month, yet ultimately 'a good death' in hospital, the patient having felt safe in his hospital room [Q48]. Given the suffering he witnessed, another caregiver wondered whether he ought to have 'put (his) wife to sleep' had he had the means to do so [Q49].

##### **4.4 Bereavement support**

Letters of condolence from doctors were highly appreciated – families had built relationships with consultants over what had often been a long disease trajectory [Q50, Q51]. One caregiver also mentioned the presence of ward staff at the funeral following a lengthy admission.

Support in bereavement varied considerably, from multiple offers from different sources [Q52] or a referral to psychotherapy, which turned out to be a helpful year long process [Q53], to little help having been offered at all and the family having to seek this out themselves [Q54]. Finally, the passage of time helped some, as their difficult experiences gradually faded from memory [Q55].

## Discussion

This is the first study to explore the experiences of bereaved family caregivers of patients with CTCL. While CTCL does not progress to death for all patients [2], the experiences reported here offer a rarely glimpsed picture of the challenges of advanced CTCL not just for the patient but for the family. The challenges encountered by caregivers were considerable and their dedication was clear. Witnessing a relative with CTCL progress from diagnosis to death was for many family caregivers a prolonged and profoundly traumatic experience. As in our study of current caregivers of patients with CTCL [5], bereaved family caregivers reported having been overwhelmed by the demands of care-giving and the impact of CTCL on their lives. Our findings support previous work highlighting multiple problems and responsibilities faced by family caregivers of cancer patients [9]. The sometimes distressing accounts of bereaved family caregivers suggest that this is a vulnerable group and this is consistent with previous work on bereaved spousal caregivers of patients with cancer [10, 11]. However, the extent to which caregivers were prepared for the death of their relative and supported in their bereavement was highly variable, indicating inconsistency in the services and care available.

Our findings have several clinical implications. Health care providers need to take a flexible, patient-centred approach to care, rather than relying on existing organisational systems to meet the needs of complex patients with the extensive skin breakdown present in advanced CTCL. As in other life-limiting conditions, caregivers also need to be recognised as separate from but integral to the care being delivered to the patient. CTCL raises specific challenges for caregivers given its initially benign appearance and rarity - adapting to the worsening symptoms and prognosis may require specific support. Given the varied roles taken on by family caregivers of patients with advanced CTCL, practical and emotional support and information tailored to their needs and preferences should be provided during the course of the disease. This should be accessible regardless of place of care and death and should continue into bereavement.

The complexity of care for patients with advanced CTCL highlights the value of good communication which was not always present in the experiences of participants in this study. This includes communication between health care providers and family caregivers (who will often have detailed understanding of the impact of advanced disease on their relative) and amongst health care providers supporting the patient across different settings (e.g. specialist centre, local hospital, hospice) over time. The extensive care needs in advanced CTCL also serve to highlight the importance of the role of clinical nurse specialists (CNSs) in the care of this patient group and indeed in liaison between care settings. CNSs are involved in looking after patients with CTCL in various

locations in the UK, and CNS involvement is specifically recommended in melanoma and non-melanoma skin cancers [12, 13]. We argue that CNSs are equally important in looking after patients with CTCL.

Turning to the challenging experiences of the approach of death in patients with advanced CTCL, families may have got used to a disease trajectory more typical of organ failure with long term limitations with intermittent serious episodes than of cancer [14] and find it hard to anticipate a final decline in the health of their relative. This highlights the value of sensitive conversations about what the patient and their family would find acceptable and unacceptable in terms of quality of life and medical intervention as life ends [15]. This could spare patients futile and distressing interventions which they would not wish to undergo and could spare their families potentially distressing memories. Following the death of the patient, letters of condolence from consultants are valued by bereaved relatives and this practice should be encouraged.

Our study has several limitations. It is possible that carers who participated had different (potentially worse) experiences than those who did not. Given the small population, we could not aim for a purposive sample across carer or patient characteristics. Though not all the patients were White British, our carer sample consisted of White British family members, However, our participants were diverse in terms of age and both men and women caregivers participated. We are also confident that we achieved sufficient information power to meet the exploratory aims of the study [16]

In conclusion, this study adds the bereaved family caregiver perspective to the evidence regarding the experiences of patients with CTCL and their families. Advanced disease places considerable demands on patients, their medical teams and family, regardless of care setting. Family caregivers should be considered part of the wider care team, acknowledging their multiple roles in caring for relatives with this rare disease, the impact of witnessing advanced disease and then experiencing bereavement from CTCL.

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## Abstract

**Background:** Cutaneous T-cell lymphomas (CTCL) are rare cancers which can be difficult to diagnose, are incurable and adversely affect quality of life, particularly in advanced disease. Families often provide care, but little is known about their experiences or needs while caring for their relative with advanced disease or in bereavement.

**Objectives:** To explore the experiences of bereaved family caregivers of patients with CTCL.

**Methods:** Single semi-structured qualitative interviews were conducted with bereaved family caregivers of patients with CTCL recruited via a supra-regional CTCL clinic. Transcribed interviews were analysed thematically, focusing on advanced disease, the approach of death and bereavement.

**Results:** Fifteen carers of eleven deceased patients participated. Experiences clustered under four themes:

1. Complexity of care and medical intervention
2. Carer roles in advanced CTCL
3. Person vs. organisation-centred care in advanced CTCL
4. Knowing and not knowing: reflections on dying, death and bereavement

Caregivers often had vivid recollections of the challenges of caring for their relative with advanced CTCL and some took on quasi-professional roles as a result. Advanced disease made high demands on both organisational flexibility and family resources. For many caregivers, seeing disease progression was a prolonged and profoundly traumatic experience. The extent to which they were prepared for their relative's death and supported in bereavement was highly variable.

Subthemes within each theme provide more detail about caregiver experiences.

**Conclusions:**

Family caregivers should be considered part of the wider healthcare team, acknowledging their multiple roles and the challenges they encounter in looking after their relative with CTCL as the disease progresses. Their experiences highlight the importance of organisational flexibility and of good communication between health care providers in advanced CTCL.

**Keywords:** Cutaneous lymphoma, CTCL, death, family, caregivers, bereavement, terminal care, advanced disease

**Appendix 1: Bereaved Carer Interview schedule**

**Section 1: Demographics**

How old are you (years)? How would you describe your ethnicity? Gender?

How would you describe your relationship status? Married/Cohabiting/Single/Divorced/Widowed

What was your relationship to X (patient)?

How would you describe your employment situation? Full time/part time/retired/unemployed

If employed – what kind of work do you do?

## **Section 2: History of illness**

Could you tell me about when X was diagnosed with CTCL? Where was it?

Do you know/remember how the diagnosis was made?

Was there any delay in the diagnosis being made?

Do you know what treatments he/she had for the CTCL?

Was he/she ever been hospitalised because of the CTCL?

If yes, do you know how many times? And for how long?

Did X tell you about the disease straight away?

How long is it since X died? (years)?

I realise this might be difficult to talk about but could you tell me a little about the last few weeks of X's life?

Was there anything that stands out for you as being particularly good or difficult about that time?

How do you describe the disease to other people if they ask?

## **Section 3: Living with CTCL**

When you look back on the period that X was ill, what were the issues that caused most difficulty for X?

### **1. Physical problems**

What physical problems are you aware of that have been caused by the CTCL?

*Prompts: Pain/Dressing changes/Other symptoms e.g. itch/Smell/Sleep*

Which seem to cause the most difficulty for X? Why?

### **2. Effect of treatment and any problems**

Depending on the treatments carer is aware of...

Did any of the treatments for CTCL seem to cause X any particular difficulties? Or were any particularly difficult from your point of view?

*Prompts: PUVA/chemotherapy (neutropaenia)/radiotherapy (skin soreness)/transplant*

*Travel/being away from home*

### **3. Lifestyle, social, relationships**

Could you tell me how the disease affected your life more generally?

*Prompts: Work (if applicable)/Leisure or social activities/Relationships/those around you/Finances/faith*

### **4. Communication and information**

Have you had any concerns about the way that people have communicated with you?

*Prompts: Who - health professionals or family?/Content or manner of conversations/Accessing people*

Were there any conversations you would have liked to have had that you haven't been able to?

Any conversations you would have preferred not to have? (Why?)

Did you have any concerns about the amount of information you were given?

*Prompts: Amount (Too much or little)/ Timing (too early or late)/too quickly*

### **5. Psychological**

Has the disease had any impact on how you feel? Or how you feel about yourself?

*Prompts: Low or anxious*

Was there any impact on the way you felt about your partner? Or in your physical relationship?

## **Section 4: The future and preferences for care**

### **The future**

What were you told about how the disease was likely to progress? Was it accurate?

Was there anything that you were told that made you particularly worried (or fearful)?

Was there anything you would have liked to have known about the disease that you weren't told or would have been too worried to ask at the time but would have liked to have known?

Is there anything you would like to say about where or how you would have liked X to have been cared for that was different to the way it happened?



Some people consider making an advance directive to make it clear what their wishes are. Is this something you discussed with X or would have liked to discuss?

### **Support**

How satisfied were you with the care X is received? Very satisfied/Satisfied/Some concerns/Very dissatisfied

What did you find most helpful in supporting you through the disease

*Prompts: Medical/Nursing/Support group/Psychologist/Other*

Summary of needs

How would you like the services to work differently to the way they do now?

Do you feel you have had sufficient support following the death of X?

Is there anything else you would like to tell us about the service that we haven't covered?

### **The interview**

How have you found the interview? *Distressing /helpful/too long or short*

ID code	Carer Age	Carer sex	Relationship to patient	Patient's place of death
C1	56-66	Female	Wife	Home
C2	>66	Male	Husband	Home
C3	>66	Female	Wife	Hospital (for comorbid condition)
C4	42-55	Male	Son	Home
C5	>66	Male	Husband	
C6	42-55	Female	Wife	Hospital
C7	<42	Female	Daughter	
C8	<42	Male	Partner	Hospital
C9	56-66	Female	Wife	Home
C10	56-66	Female	Wife	Home
C11	42-55	Female	Wife	Hospital
C12	56-66	Female	Wife	Hospital
C13	<42	Female	Daughter	
C14	>66	Female	Wife	Hospice
C15	42-55	Male	Son	

**Table 1: Characteristics of bereaved carers**

Theme	Sub-theme	No.	Exemplifying quote [Q] with interviewee number
1. Complexity of care and medical intervention	1.1 Vivid descriptions of advanced disease	Q1	<i>C2 Husband: By that time [...] her face was grotesque really, and completely black and blue and she was in a terrible state.</i>
		Q2	<i>C10 Wife: It was becoming more widespread so it was on his face, his head, by then everywhere, you know, completely everywhere. The soles of his feet used to just be, oh, they looked like a desert that had, you know, been cracked. There was cracks everywhere. And his hands were the same.</i>
		Q3	<i>C8 Partner: I would say, eighty percent of your skin open, ulcerated, a lot of pain, huge amount of pain.</i>
		Q4	<i>C13 Daughter: It's just, you know, like blood everywhere and open sores every, all the time. They never seemed to really heal, like there was nothing that made it better really. You'd just cover them and eventually it might heal...</i>
		Q5	<i>C5 Husband: He [specialist doctor] couldn't believe it the way it [the disease] had gone, and he got all these, well I don't know, they were understudies, filled the room up, and he said "Do you still want to be doctors?" [...] I had to smile. But he was very nice to [patient].</i>
	1.2 The challenges of skin care & wound dressings	Q6	<i>C1 Wife: I mean it took them [district nurses] up to two hours to do the dressings, you can imagine the state that he was in at that time, and the pain</i>
		Q7	<i>C11 Wife: he got really bad skin disease, particularly, well all over, but it was very bad in his groin, and, and over his scrotum and so on, and trying to dress that was really difficult and he ended up, sounds silly, but he ended up covered in sanitary towels and maternity knickers because it was all we could [use]. Other dressings, when you took them off, would just simply tear the skin, and especially round there, you can imagine how painful that was.</i>
		Q8	<i>C11 Wife: Once he was on Ward X it was fine, cos we had a fixed team of nurses doing it and they were used to it and they knew exactly how to do it.</i>
	1.3 The impact of advanced CTCL & comorbidities on care options	Q9	<i>C8 Partner: in the last six months it was very difficult to actually touch anywhere.</i>
		Q10	<i>C10 Wife: And the problem was that, because of his skin, people couldn't help him, you couldn't lift him or, you know... You had to be very careful because his skin was so fragile and, and so painful. ...</i>
		Q11	<i>C10 Wife: Because of his skin he couldn't have things like syringe drivers and stuff like that to alleviate things, and um so they, they really mixed, I mean they're so specialised with their drug use there, and she instructed the district nurses on what to mix and so on.</i>
		Q12	<i>C11 Wife: We were left in a Catch-22 situation where he was getting, he started getting, more infections on top of the parainfluenza, so as they treated those and lightened up on his immuno-suppression then his graft versus host disease would get worse, so then they would give him more immuno-</i>

			<i>suppression and then his infections would get worse, and we were stuck in this, this cycle basically.</i>
		Q13	<i>C8 Partner: Even though the two teams were in the same Trust, they didn't seem to communicate and, but because the dermatologists and, and haematologists were saying "You need to get [other medical issue] sorted" we'd go to the [other medical] department and they would delay and delay, and be stuck between the two.</i>
		Q14	<i>C6 Wife: For a long time I think he was doing well until he had to stop the Interferon because there was a problem with his heart. And even then they had him in the hospital for a while then sent him home, phoned up to get an appointment with the heart specialist here, that heart specialist appointment never happened.</i>
	1.4 Variations in health professionals' knowledge about CTCL	Q15	<i>C3 Wife: Up there [local hospital] when he went in on emergencies and I told them what he had, and they said they'd never heard of it, [...] "How do you spell that? What is it?"</i>
		Q16	<i>C14 Wife: Oh yes. it spread to his mouth. C15 Son: Mm, and was, it was really very, very painful, it was, you know, very hard to eat, and he had quite a large lesion in the back of his, the roof of his mouth [...] first of all he went to the GP, GP had a look. "Well I, you know, I can't see any, it's just an ulcer [...] Oh yeah, it's a dental thing, go and see the dentist [...] So he went to the dentist, the dentist looked at it, he said "No, it's something, this is not something I can do anything with. Go to the hospital." [...] C14 Wife: [...] But that, but then what happened is then from the hospital it came back, they said "Oh it's mouth ulcers." I said "Oh...You know, we've known that for three months" ... At Hospital X they didn't diagnose it. C15 Son: So then, so then he went, then he took it up with Hospital Y. They did a, a biopsy which took another six weeks and then the diagnosis came back. Well it is, it's cancerous.</i>
		Q17	<i>C7 Daughter: So he was a dark guy, but the skin colouring made him look, you know, white. So for people, when we tried to explain to them, they, they... C6 Wife: This is not the colour, yeah. C7 Daughter: This is not his skin colour, you know...: ...this isn't the skin colour he should be, but they didn't really seem to understand that.[...] I mean we took photos in some, sometimes to say "Look, this is what he, he should be like."</i>
2. Carer roles in advanced CTCL	2.1 Family caregivers as hands-on providers and care-co-	Q18	<i>C10 Wife: District nurses came in twice a day, and I managed him between times, if necessary, and they taught me how to do the slide sheet to change things and, you know, so I, I learnt a lot from them... [personal care] didn't worry me at all, I imagine for some people that would be quite hard. I think the barrier you need to get over is when you, you, you know, you go from being a wife to a carer ...."</i>
		Q19	<i>C9 Wife: But I did find it very difficult to do his dressings, when he couldn't cope any more to do them. Um, I'm not a very brave person with things like that. [...] I was ashamed to say really, 'cos it made me feel very weak.[...] The community nurses were coming in to do his dressings, because there, there was an awful one on his leg and I just, I couldn't handle that one. He thought I could, but I said "I can't, my love". So they came in and did that one.</i>

	Q20	<i>C3 Wife: They kept sending him home [from hospital], and then in the end I got his own doctor to come out and look at him, and I said "I just can't cope with it any more." And he [GP] got these two people in and they got him into this [...] unit place, but of course it was too late then [he died soon after].</i>
	Q21	<i>C6 Wife: Nurse [name] would phone the hospital and say "He has his creams on at least three times a day, you know, there's certain things you've got to" and they just didn't do it. You know, I would go in, we would go in... [...]...and we'd cream him, I'd cream him C7 Daughter She'd take his creams in to hospital C6 Wife: I'd shower him, how important it was for him to have a shower, but there was no communication at all, there really wasn't, and it was, it was hard, it was really hard</i>
	Q22	<i>C1 Wife: When I left hospital, they said "If that's the route you're going to take [family chose home as preferred place of death], consider yourself the sister of the ward because you'll be organising so many things" and that was absolutely true. 'Cos there was a constant stream of people coming in and going out.</i>
2.2 Family caregivers as advocates	Q23	<i>C2 Husband: I'm one of those people I like to know all the ins and outs and I kept on at Doctor X and the other doctor, the oncologist saying, you know, what, if this doesn't work, what are you going to do, and, and what happens, what's, what's the bottom line, sort of thing, and of course they put me off all the time, which I don't know that that is a good thing to do..</i>
	Q24	<i>C8 Partner: Me having to tell people that he's had his painkillers, he needs his dressing doing, moaning at the nurses [...] What would happen if, if I wasn't [...] someone who was able to stand up?</i>
	Q25	<i>C5 Husband: She phones him up one night when I'm...[...] and she says "I've been laying in this bed all day" [...] " I'm soaking wet with these dressings and I've asked the nurse a hundred times" she said "there's no" she says... C4 Son: Yeah, there was a shortage of nurses at the time C5 Husband: "I want to come out." So... [...] He got hold of me... C4 Son: [...] this was in the middle of the night wasn't it basically? So we went down there and er, we got her out.[...]: I think they were a bit surprised, the staff there they were really taken back by what we did. But, as I say, I've never really heard her this sort of desperate and this upset before...</i>
2.3 Family caregivers as decision-makers	Q26	<i>C11 Wife: About a month before he died, where we were feeling very much like things weren't going to work and we wanted to pull out, and all (laughs) three consultants were adamant that [...] um we ought to, we ought to continue, and um in the end we sort of bowed to their expertise [...] but I, I, I think we were right. But at least by having done what they wanted, we felt in the end that we really had tried everything.</i>
	Q27	<i>C1 Wife: Much later on in the disease when very serious types of um treatments were on offer and, you know, although we're not daft and although we can use a computer and, and research, um we didn't have enough experience or enough data to be able to make informed choices. And it got to the stage where um very hefty treatments were proposed and two different consultants [at Hospital X] each thought their own particular treatment would be more effective, um so we had to arbitrate between the, the two or three things on offer, which was an impossible situation.</i>
2.4 Family	Q28	<i>C4 Son: Seeing that she's sort of been treated in so many different hospitals by so many different consultants, by so many different doctors, and</i>

		<i>you've got to keep some sort of records really for yourself in order to sort of explain, you know, the situation</i>
	Q29	<i>C10 Wife: And I rang [specialist nurse] [...] And I, I said, you know, about would they want to do a post mortem. [Nurse] said "Well obviously, with your permission, yes, of course we would." Because so many teams were involved with [name], when they were trying to find out what was going wrong with him [...] and they just used to come and see him all the time in Hospital X cos they really couldn't (laughs) puzzle him out, to be honest. So I thought yeah, we need to do this, but the problem was, of course, because he was here, it needed to be arranged before he died. So that was really, really difficult...[...] thinking 'oh this is dreadful, you know, my husband's still alive and I'm arranging his autopsy, horrible thing to do'. But I thought I've got to do it because otherwise how will we know?</i>
	Q30	<i>C3 Wife: Well I asked for the cheques [from donations at the funeral] to go to um, the funeral people, and they dealt with it, that it went to um Sezary Syndrome research only. I didn't want it to go to anywhere else, the charity, just to that alone.</i>

### 3. Patient vs. organisation-centred care

#### 3.1 Impact of time pressure on care

Q31	<i>C8 Partner: You know you're going to get patients with that condition that have, have, are quite highly intensive in terms of dressings. But what the consequences of them, them not having the staff on, was he would be given analgesia and by the time they started doing the dressing, the analgesia would have worn off.</i>
Q32	<i>C1 Wife: There was more than one occasion when there were certain plaques that were desperate to be treated but the consultant didn't have time to mark them up. So he would mark up three, but would say the next ones would have to wait, and that might be six weeks, during which time they got considerably worse, and I'm talking sort of, you know, the last stages, the last six months, um which meant that my husband suffered enormously with things that were not treated</i>
Q33	<i>C15 Son: Oh that's right, dad had to take pills and um he'd, he'd been given um soluble Paracetamol um, to take. I'm not quite sure why [laughs] they were giving him Paracetamol anyway, and a nurse came with this pot of pills to swallow and his mouth was just sore...</i> <i>C14 Wife: Oh his mouth, yeah, that's right, poor thing.</i> <i>C15 Son: ...and so he was struggling to do these, and she was saying "Come on, get a move on, I haven't got all day." You know, and just being really, you know "What's wrong with you?"</i> <i>C14 Wife [...] Well it's just unawareness of, er [...] of his condition</i>

#### 3.2 Organisational challenges to patient-centred care

Q34	<i>C8 Partner: He needed regular sort of [-----] exams and so he'd be taken down to the [-----] department, or wherever it was.[...] There was one [...] of the [-----] registrars who used to bring the examination equipment up [...] It was on wheels and she just brought it up and came to the ward, came to the room, and she was the only one that did that. I didn't understand why that didn't happen, why that couldn't happen any other, every other time. Because you're inflicting pain on someone by moving them when it's not necessary.</i>
Q35	<i>C11 Wife: In fact he told one poor unsuspecting registrar, and subsequently a consultant, that, that they just had no idea and that as haematologists all they did was look at blood results and they forgot that there was a, a patient behind there, a real human being with feelings and their own views and so on [...] But they took it very well and they subsequently admitted that actually he was probably right.</i>
Q36	<i>C15 Son: At first when he was doing, you know, quite well there [hospice] and I remember the, the nurse or the sister, she, she was saying, she was worried about Where they, where they could send him 'cos they can't, they can't keep them, you know, forever in, in the hospice. Where they could possibly send him? Where he would get all this care, all this nursing care? 'Cos even in a, even in a nursing home it would have been a lot for them to</i>

			<i>cope with wouldn't it?</i>
		Q37	<i>C9 Wife: When the carer called me and I came and saw him I really said, was upset, I said "Why didn't you call me?" So she said "Oh he's been like this for a while but" she said "I don't think you would want to see this". I said "What, to see him in this condition? What does it, this condition mean, you know?" And she said "Well I thought it was best you rested". I was furious cos I'd been with him for so long, always with him through everything. He'd call and I'd run, and not to be there those last three hours, I could have called the children, we could have spoken to him more, eased it for him. [...] I was absolutely beside myself, I was so upset.</i>
4. Knowing and not knowing: reflections on death, dying and bereavement	4.1 Variations in understanding the prognosis and approach of death	Q38	<i>C14 Wife: We didn't really know it was that</i>  <i>C15 Son:: ...these were secondaries, yeah we had no idea that it would, because all the information we'd had up to that time was that it's just a, you know, a, remained as a skin condition [...] so I think if we'd had some idea beforehand that it could progress in that way, um he, he would have, we would have asked more questions earlier on about the mouth ulcers. Um, and it was only then that Dr X said "Well it's, you know, it's reached stage three, um, there's no evidence that it's reached other parts of his body but it, it is serious and on average patients will survive for a year"</i>
		Q39	<i>C11: [The Consultant] was very categorical, I mean right from the start, when we first met [...] survival was going to be anywhere from six months to ten years but not longer, and she was very clear about what we needed to do in terms of life/work, all that sort of stuff [...] So, so actually, though obviously we were very shocked by the news, we were very grateful that she was so clear cut and categorical about it.</i>
		Q40	<i>C2 Husband: I know it's hard from their [doctors'] point of view, but I suppose you do have to use your judgement with who you're dealing with, and in my particular case I would much rather they had been upfront right from the beginning with me.</i>
		Q41	<i>C1 Wife: So knowing that it wasn't going to go away was helpful in a sense. Thinking that it wouldn't kill him was hugely helpful.</i>
	4.2 Admission and interventions	Q42	<i>C6 Wife: even at the end, truthfully, when he went in here in the Hospital X, he had been in so many times before with an infection of some sort and we honestly had no... You know, you just think 'he's gone in there and he'll be home again in a couple of weeks as per normal', you know, it was a complete and utter shock.</i>



	Q43	<i>C13 Daughter: It went on for so long it was like well “was he dying?”, like 'cos at first it was like you only had this long to live and then it went on well past that and so it was like you never really, really knew...</i>
	Q44	<i>C8 Partner: I never heard them say that, if this doesn't work there is nothing else and you will die. I suppose it would have helped me in that I would have been able to say to [name] “You need to start planning about a funeral, about what you want to do with your, your money” all that stuff.</i>
	Q45	<i>C10 Wife: [reading from notes made during husband's illness] to have echo-cardiogram, tube down the stomach. I mean this is (laughs) within weeks of him going [dying] you know.</i>
4.3 Reflections on death with CTCL	Q46	<i>C8 Partner: It's a traumatic illness, traumatic, traumatic to witness.</i>
	Q47	<i>C4 Son: What you've got to realise is it's a very, very painful thing to have... Yeah, she had two morphine drippers, and it really is a slow lingering death, you wouldn't, you wouldn't really want to wish it on your worst, worst enemy.</i>
	Q48	<i>C11 Wife: He had a month of absolute hell towards the end, but at least I do feel that, that they tried everything. [...] actually he had a very good death [in hospital]</i>
	Q49	<i>C2: Husband: I mean I'd got to a point where if I had the means I would, I would happily have, you know, put my wife to sleep, I can't see how they can allow a human being to suffer like that.</i>
4.4 Bereavement support	Q50	<i>C1 Wife: Dr X wrote to me after he'd died um, a very kind letter, which was very important to me. I mean I wrote to both him and Dr Y to let them know, and to thank them for all they'd done, um and I got a response from Dr X, which was for whatever reason, was very important to me [...] made my husband human, and made the whole, you know, the whole miserable cycle personal [carer getting upset] and that's very valuable. And I think perhaps</i>

	<i>it's worth doctors knowing how important their relationship with a patient or a patient's family is, not to underestimate it, you know. It's not, it's not just the treatment and organising what medication, it's not that, not only that, but that personal aspect is extremely important for how somebody feels.</i>
Q51	<i>C9 Wife: When he did pass away, Dr X wrote to me to say what a stoic man he was. It was lovely he wrote to me, it really touched me actually</i>
Q52	<i>C14 Wife: There was a lot of support offered, offered by the hospice, wasn't there? I've had several letters from them [...] saying you know, that we have a bereavement team, you know, and if you, if you need them, just ring.</i>
Q53	<i>C8 Partner: I saw a psychotherapist. [...] Um I think it, it probably, it probably would have helped, because it's quite a traumatic, it's a traumatic illness, traumatic, traumatic to witness. [...] I was referred to them by, I, out the blue, I didn't know it was coming, no. Interviewer: And did you find it helpful? Yes, yeah, I, I, I needed it, so yeah.</i>
Q54	<i>C7 Daughter: I still feel upset, and we all do [...] And bitter, and my [relative] had a really hard time [...] cos she's not been sleeping they've given her tablets, put her on antidepressants and, and sent her for a few counselling [sessions], but we were never offered anything [...] And I, I sort of went to the doctor and asked and they give me a phone number for Cruse [bereavement support charity], but I just never got, was ready to call, you know, and I do feel like we should. But that was months after, [...] that was never offered to me, that was like I asked for it.</i>
Q55	<i>C13 Daughter: So much has happened, all sort of, this huge time, it all sort of gets smaller and smaller and smaller doesn't it, and you forget. But luckily we, we forget.</i>