



Orlowska, D., Selman, L., Beynon, T., Radcliffe, E., Whittaker, S., Childs, F., & Harding, R. (2018). '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. *British Journal of Dermatology*. Advance online publication. <https://doi.org/10.1111/bjd.16447>

Peer reviewed version

Link to published version (if available):
[10.1111/bjd.16447](https://doi.org/10.1111/bjd.16447)

[Link to publication record in Explore Bristol Research](#)
PDF-document

This is the author accepted manuscript (AAM). The final published version (version of record) is available online via Wiley at <https://onlinelibrary.wiley.com/doi/abs/10.1111/bjd.16447> . Please refer to any applicable terms of use of the publisher.

University of Bristol - Explore Bristol Research

General rights

This document is made available in accordance with publisher policies. Please cite only the published version using the reference above. Full terms of use are available: <http://www.bristol.ac.uk/red/research-policy/pure/user-guides/ebr-terms/>

TITLE “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

AUTHORS: Orłowska D [1], Selman LE [2], Beynon T [3], Radcliffe E [4], Whittaker S [1], Child F [1] and Harding R [4]

Affiliations:

[1] St. John’s Institute of Dermatology, Guy’s and St. Thomas’ NHS Foundation Trust

[2] Population Health Sciences, Bristol Medical School, University of Bristol

[3] Department of Palliative Care, Guy’s and St. Thomas’ NHS Foundation Trust

[4] King’s College London, Cicely Saunders Institute, Dept. Palliative Care, Policy & Rehabilitation

- **Funding sources**

This project was funded by Dimpleby Cancer Care. The funder had no role in the study design, data collection, data analysis, manuscript preparation or publication decisions

- **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

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 Table1. 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.

Acknowledgments

We would like to thank the staff at St. John's Institute of Dermatology, Guy's and St. Thomas' NHS Foundation Trust, for assistance with the study, and all the caregivers who participated. Also thanks are due to the project steering group and our colleague Cath Morgans, Clinical Nurse Specialist for comments on an earlier draft.

References

- [1] Bradford PT, Devesa SS, Anderson WF et al, Cutaneous lymphoma incidence patterns in the United States: a population based study of 3884 cases. *Blood*, 2009. **113**; 5064 – 73.
- [2] Agar NS, Wedgeworth E, Crichton S *et al.* Survival Outcomes and Prognostic Factors in Mycosis Fungoides/Sezary Syndrome: Validation of the Revised International Society for Cutaneous Lymphomas/European Organisation for Research and Treatment of Cancer Staging Proposal. *J. Clinical Oncology* 2010; **28**: 4730 – 9.
- [3] Beynon T, Radcliffe E, Child F *et al.* What are the supportive and palliative care needs of patients with cutaneous T-cell lymphoma and their caregivers? A systematic review of the evidence. *Br. J. Dermatol.* 2014; **170**: 599-608.
- [4] Beynon T, Selman L, Radcliffe E, Whittaker S, Child F, Orłowska D, Morgans C, Morris S and Harding, R 'We had to change to single beds because I itch in the night': a qualitative study of the experiences, attitudes and approaches to coping of patients with cutaneous T-cell lymphoma. *Br. J Dermatology*, 2015. **172(6)**:1581-92
- [5] Demierre MF, Gan S, Jones J *et al.* Significant impact of cutaneous T-cell lymphoma on patients' quality of life - Results of a 2005 National Cutaneous Lymphoma Foundation Survey. *Cancer* 2006; **107**: 2504-11.
- [6] Selman L, Beynon T, Radcliffe E, Whittaker S, Orłowska D, Child F and Harding R 'We're all carrying a burden that we're not sharing': a qualitative study of the impact of cutaneous T-cell lymphoma on the family. *Br. J Dermatology*, 2015. **172(6)**: 1581-92
- [7] National Bereavement Survey (VOICES) 2011 Office of National Statistics
- [8] Braun V and Clarke V Using thematic analysis in psychology. *Qualitative Research in Psychology*, 2006. **3**; 77 – 101.
- [9] Stenberg U, Ruland CM and Miaskowski C Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology*, 2010. **19**; 1013 – 1025.
- [10] Fasse L, Sultan S, Flahault C, MacKinnon CJ, Dolbeault S and Bredart A How do researchers conceive of spousal grief after cancer? A systematic review of models used by researchers to study spousal grief in the cancer context. *Psycho-Oncology*, 2014. **23**; 131 – 142.

- [11] Braun M, Mikulincer M, Rydall A, Walsh A and Rodin G Hidden morbidity in cancer: spouse caregivers. *J. Clinical Oncology*, 2007. **25(30)**; 4829 – 4834
- [12] NICE. Improving outcomes for people with skin tumours including melanoma. Cancer service guideline [CSG8] 2006. <https://www.nice.org.uk/guidance/csg8>
- [13] NICE. Skin cancer. Quality Standard. QS130. 2016. www.nice.org.uk/guidance/qs130
- [14] Murray SA, Kendall M, Boyd K and Sheikh A Illness trajectories and palliative care. *BMJ* 2005; **330**: 1007
- [15] Gawande A (2014) *Being Mortal*. Doubleday: Canada
- [16] Malterud, K, Siersma, VD and Guassora A D Sample Size in Qualitative Interview Studies. Guided by Information Power Qualitative Health Research. 2016, Vol. 26(13) 1753–1760

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