



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/>

| 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-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 | 2.1 Family caregivers | 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 caregiver | 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>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 caregivers as contributors to medical knowledge | 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 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... C14 Wife: Oh his mouth, yeah, that's right, poor thing. 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? 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 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 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 Admissions and interventions at end of life | 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 drivers, 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 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> |