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Patients' experiences of treatment and the scar management pathway during the Early Laser for Burn Scars (ELABS) trial: An embedded qualitative study

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ABSTRACT

Background: Due to improvements in acute burn management, burn injuries are a leading cause of morbidity globally. Alongside physical sequelae of burns, there are significant psychological implications. Limited qualitative research exists exploring quality of life (QoL) and delayed reintegration into society; the latter is argued as the greatest unmet challenge in burn rehabilitation. Furthermore, there is a lack of research into non-scar outcomes after pulse dye laser (PDL) treatment of burn scars. This qualitative study examines the patient's experience of early PDL treatment and its impact upon QoL and social reintegration.
Methods: This qualitative study is nested within a national, multicentre, parallel-arm randomised controlled trial (RCT) across seven National Health Service hospitals in the United Kingdom (Early Laser for Burn Scars (ELABS), Trial registration ISRCTN14392301). The Consolidated Criteria for Reporting Qualitative Studies were used. Of the 153 participants in the trial, 34 were approached across a range of demographic, burn and site criteria including: gender, age, burn location, depth, total body surface area (TBSA), skin type, site location, and treatment arm. Data was collected using semi-structured telephone interviews. reflexive thematic analysis was used to analyse the transcribed data.
Results: 20 participants were interviewed. Six themes were constructed: frustration with initial burns treatment, feeling disconnected, human costs (with three sub themes: having to adapt, it's changed how I feel about myself, and it doesn't just affect me), money worries, reflections on pulse dye laser treatment, and moving forwards.
Conclusion: The scar management journey is long and complex due to significant physical, psychological, financial, and psychosocial impacts. These can negatively affect QoL and reintegration into society. Use of early PDL treatment can ameliorate these challenges by positively impacting upon QoL and supporting individuals whilst they create their 'new normal' and adjust to reintegration into society.

1. Introduction

Burns are a global public health issue, with associated yearly mortality of 180,000 [1]. A systematic review of 46 studies identified that improved knowledge of the pathophysiology of burns paired with advancements in burn management have reduced mortality in middle, high and very high-income countries [2]. However, these reductions in mortality have led to non-fatal burn injuries being recognised as a leading cause of morbidity globally [1]. In the United Kingdom (UK) approximately 120,000 people per annum attend an emergency

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department due to a burn injury with 8000 of these being admitted to hospital [3]. Improvements in the management of burns have led to a reduction in hospital length of stay [2].

In terms of patient journey, discharge from hospital does not equate to completion of clinical care. Burns management has two aspects: 1) the initial acute phase of emergency treatment and wound management, and 2) the secondary phase, consisting of rehabilitation and aftercare [4]. In terms of morbidity, burn survivors are more prone to abnormal types of scarring such as hypertrophic scars, keloids and contractures, with up to 70 % of patients developing hypertrophic scars after burns [5]. Other associated physical experiences include itching, pain, tightness and limited joint mobility [6]. In addition to the physical consequences, there are psychological complications arising from scars. Gilboa asserts that the unique function of the skin is holding the different components of the body together into a composite entity [7]. This includes the psychosocial importance, as our skin is the tool that we use to interact with others, it is through our skin that we feel intimacy and connection, pleasure and pain.

The current standard of care for the management of hypertrophic burn scarring includes moisturisation, silicone gel, pressure therapy, corticosteroid injection, and splinting [8]. In addition, treatment of hypertrophic burn scarring can include laser modalities for example, pulsed dye laser (PDL) and ablative fractional laser (AFL) [9]. Whilst a randomised controlled trial (RCT) has noted the effectiveness of AFL in reducing scar thickness and texture [10], at the time of study conception, there were no RCTs exploring the use of PDL. The study design and protocol for the Early Laser for Burn Scars (ELABS) RCT including this nested qualitative study was previously published [11]. Systematic reviews have also postulated that the early use of any modality of laser may further improve its effectiveness. There is a need for better evidence regarding scar therapies such as PDL in burns aftercare [5,12,13]. A qualitative study identified key outcomes important to people during their burn scar management pathway, see Table 1 [14].

As seen in Table 1, these outcomes include a range of holistic domains beyond that of purely physical parameters. Yet a large internet survey study with 1267 participants identified that half of the respondents felt that they had not received adequate support from healthcare providers after discharge [15]. They called for more targeted qualitative research to explore the impact of scarring and the associated effects on quality of life of people living with scars. It has been mooted that the greatest unmet challenge in burn rehabilitation is the decreased quality of life and delayed reintegration into society [5]. This is exacerbated by the lack of discussion regarding the holistic assessment of the effects of scar management interventions [16]. The aim of this research was to explore patient's experiences of early PDL treatment and its impact upon QoL and social reintegration. This is, to our knowledge, the first qualitative study exploring the patient experience of PDL treatment in early scar management. Qualitative research in this area is important as it can capture the perspectives and experiences of people living with a burn injury. Thus, this study contributes to the body of knowledge, in particular, expanding on the holistic care required within a burns rehabilitation service [17].

Table 1
Key outcomes [14].

1) Scar characteristics and appearance
2) Movement and function
3) Scar sensation
4) Psychological distress
5) Adjustments and a sense of normality
6) Body image and confidence
7) Engagement in activities
8) Impact on relationships
9) Treatment burden

2. Materials and methods

2.1. Design

This nested qualitative study sat within a national, multicentre parallel arm RCT across seven National Health Service (NHS) hospitals in the United Kingdom. The hypothesis of ELABS was that early pulsed dye laser (PDL) treatment of hypertrophic burn scarring alongside standard of care (SOC) improves both scar quality and quality of life (QoL) more than SOC alone. Early treatment was defined as within 3 months of the wound healing. The intervention arm received a course of three PDL treatments, in addition to SOC, at intervals of 6 weeks whereas the control arm received standard of care (SOC) alone. The primary endpoint was at 6 months. Standard of Care treatment included moisturisation, massage, silicone gel, pressure therapy, corticosteroid injection, and splinting. The trial was registered with ISRCTN (UK Clinical Study Registry) (ISRCTN14392301) and the study protocol published [11]. This paper does not report on the clinical findings of the RCT as these have been reported elsewhere [9], rather it reports purely on the nested qualitative study using the Consolidated Criteria for Reporting Qualitative Research (COREQ) criteria [18].

This qualitative study is located within interpretivism and explores experiences of scar management through the eyes of the participants, while recognising the multiple perspectives of reality [19]. In addition, interpretivism embraces co-constructed meanings between participants and researchers [20], by embracing the researchers' values and recognising reflexivity as an integral part of the research process [21].

2.2. Ethical approval

ELABS was approved by the South-West Research Ethics Committee (REC reference 21/SW/0049). All participants were provided with an information sheet which detailed the purpose and activities of the trial to enable them to make an informed choice about participation. The patients that chose to participate signed a consent form. While consenting to the trial, participants were asked if they would like to take part in the qualitative aspect once their part in the main trial concluded. Additional consent was then given for the qualitative component.

2.3. Recruitment

All active ELABS trial participants were added to a trial database (REDCap Cloud) and those who agreed to participate in the qualitative component were flagged by the study coordinator. The qualitative researcher was sent, through a secure site, the trial reference number of the participant along with brief biographical, scar and site information, as seen in Table 3. If the participant was identified for interview, contact information was then provided in the form of an email address and/or telephone number. The qualitative researcher contacted the participant to confirm willingness to be interviewed (n = 34).

2.4. Participants

Patients with a burn > 1 % TBSA who had scars, or were at risk of developing scars, were eligible for ELABS, full details are published elsewhere [11]. Since they were already enrolled in the trial, all those who agreed to participate in the interviews were eligible. As the research sought to both explore participants' experiences of their burn scar management and establish patterns of meanings across their different experiences, the dataset needed to be large enough to ensure data saturation and justify the claims made [22]. A systematic review by Hennikink and Kaiser [23] noted between 9 and 17 interviews is usually sufficient to ensure depth of understanding. The study used a purposeful sampling strategy and aimed to recruit 20 participants: 10 who had received PDL and standard care, and 10 who had received standard care alone. Furthermore, it aimed to recruit a range of participants in terms of

gender, age, Fitzpatrick skin type, depth of burn, location of burn, total body surface area (TBSA) and treatment site (Table 3).

2.5. Data collection

Data were collected through semi-structured telephone interviews with a female professor of nursing with expertise in qualitative research. It is important in qualitative research to acknowledge the researchers' positionality through reflexivity [24]. Participants were made aware that the researcher was a nurse working on the ELABS trial but did not work at any of the sites where they experienced treatment. This was important so that participants could feel free to share any experiences without concerns about the impact that this may have had on their continuing clinical care. The fact that the researcher was a nurse, was felt to have been beneficial to the research due to the notion of trust associated with nursing as nurses are repeatedly identified as the most trusted profession [25]. This professional registration and research experience also enabled the researcher to examine sensitive issues such as sexual intimacy. However, time was spent building rapport with participants before the interview date, participants spoke to the researcher about the purpose of the study, to check they were still happy to participate, as well as to make practical arrangements such as setting the date and time of interview. During the interview, time was spent at the start getting to know participants before asking them to share their burn experience, to help them feel relaxed and comfortable during the interview.

Telephone interviews occurred at approximately 26 weeks after treatment began and arranged at a time to suit the participant that included during evening or weekends. The interview prompts (see Table 2) were developed in conjunction with the ELABS Patient and Public Involvement and Engagement (PPIE) Group, to ensure that any aspects deemed important by the PPIE were covered. Whilst the same interview prompts were used to ensure all areas were covered, these tended to occur in conversation with participants utilising the researcher's skills both in assessment as a nurse and in undertaking interviews as a skilled qualitative researcher. As participants were located across England, interviews occurred via telephone and were audio-recorded to enable an accurate recollection of the participant's experiences. At the start of the interview, there was clarification that there are no right or wrong answers, instead, the interview was seeking to understand their experience of the treatment and the scar management process. Transcripts were not returned to participants as this is not advocated in reflexive Thematic Analysis [24], however during the interviews clarification of interpretations were sought through repeating and paraphrasing participants' experiences and checking accuracy of interpretation as advocated by Gupta [26].

2.6. Data analysis

Interview recordings were transcribed *verbatim*. The anonymised transcripts were analysed thematically using a process of reflexive Thematic Analysis [24] to search for meanings and patterns across the data set. Throughout the analytical process it was important that the researcher (a nurse) remained grounded to the participants' experiences analysing the data inductively [24], rather than having a pre-determined framework, ensuring they remained focussed on the lived experiences of participants.

There were six stages to the analytical process [24]. Stage 1 included re-reading the transcripts to ensure data familiarisation. This was followed by stage 2 which included systematic data coding of each of the individual transcripts by highlighting segments in the text that provoked meanings linked to the research question and tagging an appropriate code. At Stage 3, the codes across the dataset were brought together and further analysed, moving away from the smaller meaning units (codes) to larger meaning patterns (themes). Stage 4 included reviewing the initial themes (identified in stage 3) to explore whether they adequately reflected the participants' experience (validity check) as well as examining the richness of presenting the participants experiences. In Stage 5, there was further reflection, questioning and imagining of what the participants were trying to express. This led to the refinement of developed themes. These were shared and reflected upon across the research team and PPIE to ensure both cognisance with raw data (interview transcripts) and for further reflexivity [22,24]. During the write-up of the study, or Stage 6, there was further reflexivity to ensure that the generated themes would speak to the reader in an embodied way. Data analysis was undertaken by a professor with expertise in undertaking qualitative research in conjunction with the principal investigator for the trial to ensure integrity and trustworthiness of the analytical process. Furthermore, the themes were shared with the PPIE group who noted the results resonated with their experiences of living with burns and their burn management journey.

3. Results

Of the 34 people approached, 20 participated in the qualitative component of the RCT (n = 11 female, n = 9 male). For this group, the duration of the telephone interview ranged from 38 to 101 min. Biographical, burn and burn management details are presented in Table 3. There were a range of burns both in terms of location, total body surface area (TBSA, %) and depth of burn across the seven sites included in the RCT. The duration of the participants initial hospital admission at a burns unit ranged from 1 to 2 days to three months, and some initially spent time in intensive care.

It was evident during the data collection and analysis that irrespective of whether the participants received SOC or SOC alongside PDL that they shared common experiences in their early burns management as well as the impact that burns had on their daily lives and those of their families (see Fig. 1). This is presented in the first four themes: Frustration with initial burns treatment, Feeling disconnected, Human costs (which included three sub themes: having to adapt, it's changed how I feel about myself, and it doesn't just affect me) and Money worries.

This shared context is important to note in order to understand any

Table 2
Interview prompts.

1. I am interested to hear your thoughts and feelings about how the scar management journey was for you.
2. Following up questions will explore:
   a. How did you find the treatment, did you feel comfortable, cared for, etc.?
   b. Did the treatment have any surprises or challenges for you?
   c. Did the treatment have any unexpected advantages or disadvantages as well as whether these thoughts and experiences changed over time?
   d. How did the treatment and/or your scarring affect your daily life (washing, dressing, cooking, sleeping) and whether this changed over time?
   e. How did the treatment and/or your scarring affect your family life?
   f. How did the treatment process and your scar make you feel psychologically and whether this affected your social engagement with others, and whether this changed over time?
   g. Can you tell me about any work or financial implications you experienced through the treatment process and whether your scar impacts upon your work life?
   h. Was there any aspect of your treatment/care that you wish was done differently and if so, how could this have been delivered.
   i. Would you recommend this treatment to others and why?
   j. What are your thoughts and plans moving forwards with regards to your burns and treatment?
3. Is there anything else you would like to tell me about the treatment you have received?

Table 3
Biographical, burn and burn management details.

Category	Fields					
Gender	Male (n = 11)			Female (n = 9)		
Age	16 – 24 (n = 4)		25 – 64 (n = 13)		65 + (n = 3)	
Treatment	PDL and Standard Care (n = 11)			Standard Care (n = 9)		
Skin Type (Fitzpatrick)	I (n = 2)	II (n = 8)	III (n = 5)	IV (n = 4)	V (n = 1)	VI (n = 0)
TBSA (%)	1 – 5 (n = 0)		5 – 30 (n = 6)		> 30 (n = 14)	
Depth of Burn	Superficial (n = 0)	Superficial Dermal (n = 8)	Deep Dermal (n = 4)	Full Thickness (n = 1)	Mixed (n = 7)	Unknown (n = 0)

* Total Body Surface Area (TBSA) is a measure of the extent of burn injury across the body surface; it magnitude is expressed as a percentage.

impact that early engagement with PDL could have.

3.1. Frustration with initial burns treatment

The participants would commence the interview by discussing their accident and the initial management. Most participants noted that initial treatment was often provided by their local emergency and/or routine healthcare services. Those who accessed the burns pathway through this route expressed that the knowledge of burn injury and its management in these services was limited, and they spoke of a desire for better links with specialist burns units and improved knowledge of initial burn management.

> *"So, an hour, an hour and a half had passed. I still hadn't seen anyone. I spoke to the lady on Reception … I said, "Can someone have some kind of look because the blisters are just getting bigger and bigger". So, then they got me to go in and I saw a doctor. Lovely doctor, a really nice man, but they obviously didn't understand what they were doing at ****[names hospital]" (F, SOC, ESX002).*

> *"…they made me wait about 11 h and then told me they don't do burns even though they saw my burns. They made me sit there and wait for the doctor to say, "No, you've got to go to **** [names burn unit]" (M, PDL, BRL001)*

3.2. Feeling disconnected

Many of the participants spoke about feeling disconnected from their skin where the scar was located. They were emoting that their skin did not feel like it belonged to them. Many of the participants reflected that, rather than feeling like skin, the skin felt like leather. One of the participants noted that she was unable to touch the skin through hand to skin contact and, at the start of her journey, had to wear a glove when touching her skin.

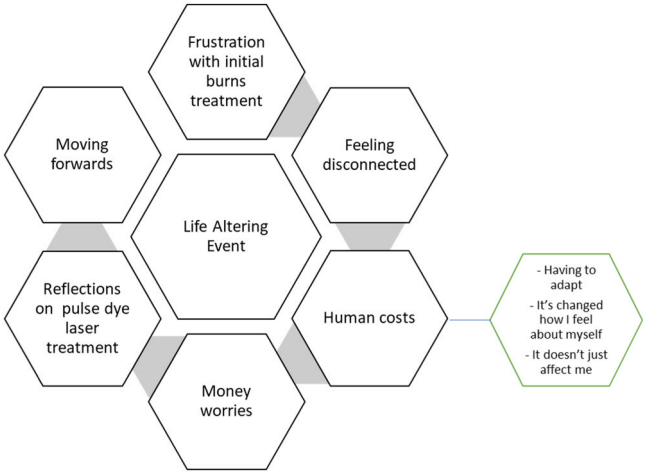

Fig. 1. Constructed themes.

> *"It does just make it almost feel like this separate thing. Even though it is part of your body, it does feel a bit disconnected" (F, SOC, BRL005)*

> *"… both wrists are like what I would call thick leather. They are thick leather scars. A couple of months back they were like chunky plastic. Now they're like thick leather" (F, SOC, ESX048)*

> *"It was easier to use the gloves than it was the skin-to-skin touch… whether it was psychologically me feeling the skin and the damage, where the gloves didn't give me that" (F, SOC, ESX002)*

This feeling of disconnectedness from their skin was perpetuated by a lack of feeling within their skin, as well as the colour and texture of their skin.

> *"It was redder than the rest of it, whereas the other, sometimes it looked almost like… You know how pig skin is white… It was, sort of, like that until it went purple and everything else, but just touching it, it just felt like nothing, really. You couldn't. Even if I pressed it in, I had to press really, really far down in order to feel like I could actually get any feeling at all, if that makes any sense…. it's almost like someone has strapped some sort of steak or something on my side and stitched it on… It didn't belong to me" (F, SOC, SAL001)*

> *"And there's, like, this tide line, so you can see where my normal skin tone is, and then the skin that only was, like, gently burned is white, like White people white, and then it's kind of spackled where there's bits of the melanin where it's kind of patchy. It kind of looks like when you flick paint. And then there's really dark patches where it's properly scarred…I say, "You can tell I'm mixed race now", because I was like, "This is my brown side, this is my white side" (F, SOC, SAL008)*

Not only did the colour and texture of the scar lead to a feeling of disconnection from their skin, but this was perpetuated by the fact that the skin no longer served them as it used to do. Many of the participants expressed tightness in their skin and this affected their day-to-day activities. Furthermore, the tightness resulted in pain and was something, prior to their injury, they would not have experienced from their skin, which perpetuated a feeling of disconnection. In addition to the pain, there was an irritating itchiness.

> *"It was more just tightness… That was mostly the pain, just trying to straighten my arm" (F, SOC, NMC001)*

> *"[lifting the arm] … that, I do remember, was painful, but tight. Because I was moving the skin. Anything that meant twisting or bending was tight. It was agony just being still but moving and twisting was very tight indeed" (F, PDL, SAL006)*

> *"… it gets itchy. That's the worst thing. It's itchy around the edges, yes, just from where the burn is" (F, PDL, SAL013)*

> *"… the itching drove me potty, absolutely potty" (F, PDL, BRL008)*

3.3. Human costs

For the participants, their injuries were life-changing and impacted them physically, psychologically and socially. This impact went beyond the individual and was extended to their families and partners.

3.3.1. Having to adapt

Many of the participants struggled physically in the early days of their scar management across many of the activities of daily living (ADL) such as cooking, sleeping, walking, washing and dressing. This resulted in adaptations such as changing types of clothes, work and having assistance from a partner or family member. For many of the participants, this continued for a period of months before they were able to be independent again and for others the physical damage was permanent.

"So I was quite lucky my mother-in-law's quite good and she came and she helped at home with my other half. So do all the cleaning and washing, and stuff like that. And I just sort of laid in bed, and I had a recliner chair as well so I used that. And then she would help me with personal care, and my mum would help me with personal care as well" (F, SOC, ESX002)

"…my mum had to wash my hair and everything for me. I couldn't actually physically do anything …. So, my mum just helped me with everything" (F, SOC, NMC001)

"My left hand, the digits on my left hand have all been removed as a consequence of the injury. My left thumb wasn't able to stretch and make a grip. That was quite tight. The inside of my elbow was quite tight, and I wasn't able to stretch it out. It was still retracted skin. The same for my stomach. I couldn't stretch and do things [when asked how he managed. he noted]… a lot of times, my daughter at the time, when I came back was doing it*" (M, PDL, SAL005)*

3.3.2. It's changed how I feel about myself

For many of the participants, there was an appreciable psychological impact. Whilst there was a sense that the participants knew they had to just accept the accident, move on with their lives, and adapt to a 'new normal', the reality was that many of them were struggling to come to terms with their scarring. This seemed to be influenced by numerous factors including their age and gender. Older participants seemed more philosophical about the appearance of their scars, whilst the young, particularly younger women, found they were very self-conscious of their scars and would adapt clothing to avoid them being seen.

"…my age has been an advantage for me, I think, that things don't bother me like maybe if I'd been a lot younger (F, SOC, SHK-008)

"… It just makes you feel a bit ugly" (F, SOC, NMC001)

"… all my friends, wearing nice bikinis and stuff, and I'm having to hide that part of my body. I just felt a bit uncomfortable as to what people are thinking, are they wondering why and stuff like that? … It's all a bit depressing. But it's just, again, I try not to really think about it, I just sort of get on with it now" (F, SOC, NMC001)

"This is existing" (F, PDL, SAL006)

"The phrase, "My new normal," I don't think I'm there yet. Quite interesting hearing that out loud, because I'm not even a year in. I think for me it's like I'm just assessing it day by day, year by year, how I look, … But I definitely know that potentially there comes a time where I have to just say, "Oh, I look like this now." I'm not sure I'm there yet" (F, PDL, CHW009)

"Yes, you have bad days, and you can think, "Oh, gosh. Am I ever going to repair or be normal?" (F, SOC, ESX048)

This increased self-consciousness about their bodies influenced their ability to feel connected and intimate with partners. This typically affected the women in the study more than the men who did not report issues of intimacy after the accident. For the women, some of whom were in established relationships before the accident, whilst they initially struggled with intimacy, as time went on, they were able to resume this closeness with their partners. However, other women in established relationships, and those who had new partners, found this aspect of closeness difficult. This was due to a range of factors such as their partners feeling wary, their skin being irritable or a lack of confidence in their body image.

"Probably no impact, to be honest" (M, PDL, BRL004)

"It did at the beginning, for a good, probably, three months, if not longer. Yes, it was definitely challenging there, but now it's okay" (F, PDL, SAL013)

"Well, I haven't felt comfortable…. It's not him. It's more me than it is him" (F, SOC, ESX002)

"I don't know, it's weird. If it's a real in the moment thing, I probably don't really think about it if I'm naked or something. I think if it's not that situation and even if I'm getting dressed to go out on a date or whatever, then I do feel that it has knocked my confidence and I don't feel as sexy" (F, SOC, BRL005)

"It's had an impact. Erm… Like, just, yeah, I mean…The skin on the top of my leg, where it was one of the worst places it got burnt, that can still be quite sensitive sometimes… So, it can be uncomfortable sometimes" (F, SOC, SAL008)

"I think where it doesn't work for me, and still, I would say now is the case…it's with strangers or dating someone that I don't know" (F, PDL, CHW009)

For some of the participants, this affected their mental health resulting in low mood and depression. Participants also reflected experiencing Post Traumatic Stress Disorder (PTSD). These symptoms included flashbacks and avoidance techniques, as well as a more conscious awareness when dealing with the cause of their injury, such as flames or hot water. It is important to note that this not only affected the participants but sometimes affected family members who either witnessed the accident or saw the resultant scarring.

"…my son, like I say he struggles with the burns. He doesn't want to talk about it. He just blocks it" (F, SOC, ESX002)

"There are certain things that trigger me, and I don't always know when that's going to happen. It can be so random. Because sometimes I can watch fire on television or there's candles or there's a fire in a house, whatever, and I'm absolutely fine. Other times I'm actually a little bit more apprehensive" (F, PDL, CHW009)

"I don't know if PTSD's the right word for it, but there's definitely trauma responses to some stuff… You know, I still don't particularly like cooking, I don't like being around any kind of heat source or things that are hot. It can still be a bit triggering" (F, SOC, SAL008)

"… But I struggle sometimes, still now even really, it's just a mental thing, getting oven dishes out of the oven. That's not how I burnt myself. It was with fire. But I just get a bit scared. And sometimes if I am a bit uncomfortable I ask someone else to do it. But that's purely a psychological thing" (F, PDL, CHW009)

3.3.3. It doesn't just affect me

The majority of the participants lived with family, either spouse, children, or parents, where only a couple of them lived alone. All the participants significantly relied upon family or friends, especially at the beginning, for assistance with ADL. However, for those with caring responsibilities, there was a sense that they needed to be strong as other people may be reliant on them. This caused additional pressure in adjusting to their new life.

"…my mum had to wash my hair and everything for me. I couldn't actually physically do anything because I had to keep it out of the water [arm] for a few weeks" (F, SOC, NMC001)

"It was hard with the kids because they, "Come on, Gramps, you can get down and do this." They wanted me to play with their toys on the floor and stuff like that, and that is where I had to say, "Look, I can't do it."

Then my son or my daughter would say, "No, leave Gramps alone. He is not able to do that sort of stuff at the minute," (M, PDL, BRL001)

*"*** [names partner] was my main person. And then my friend, who drove me to the hospital, and then my other friend came and looked after me when *** [names partner] had to go, she had to be at work all day" (F, SOC, SAL008)*

"I said I've got a family to support, and I run a service for the Health Service so I can't break down. I haven't got time to break down, if you see what I mean. They rely on me" (F, SOC, ESX002)

3.4. Money worries

The participant's accident and associated treatment led to increased financial costs as their expenditure increased whilst their income decreased. Increased expenditure included large expenditure for example one participant lost everything in the fire (F, PDL, BRL008) while another had to change her car to an automatic in order to be able to drive (F, SOC, ESX048). Other expenditure was linked to purchasing additional items such as pre-cooked meals during the initial recovery and purchasing different clothes to adapt to their injuries. In the long-term, there are still associated costs related to purchasing creams, many of which are not on prescription, such as high factor suntan lotion.

"That's twenty-odd quid for one pump [cream]. It lasted me a couple or three weeks, and then as time went on it lasted one month" (F, SOC, ESX002)

"…I had to buy… It was more about the textures really than the actual clothes. I couldn't wear jeans for ages and normally that's all I wear every day. I had such bad hypersensitivity, and I still do, that I probably opt for looser and softer things" (F, SOC, BRL 005)

"I'm going to a festival next week, so I've had to get the majority of my dresses handmade. With it being long-sleeved, there's not really much out there that I could wear, so I've had to get everything made" (F, SOC, NMC001)

Travel to ongoing medical reviews and associated treatment was an additional cost as many of the participants lived some distance away from the specialist burns unit. This often required extensive travel with the closest participant living 45 min away and the furthest participant requiring an hour plane journey away followed by an hour drive. For the majority of the participants, the journey was between 1.5 and 2 h each way. This cost was also experienced by the participants' family and partners who had to take them. Often, this meant that they had to take unpaid leave from work.

"[talking about a hospital car] You have to phone up and book a car. But sometimes I was over five hours in the car, so that was very draining" (F, SOC, ESX048)

"… once I left the hospital was just having to take the unpaid time off of work to go. Then the parking at the hospital, but it was only £ 3.50. Then the petrol to and from" (F, SOC, BRL005)

"… to be honest with you, just it never really entered my mind. Like, in terms of how far it was, I was just like, "They're the best, but I just need to get there." But in terms of the petrol side of it, yes, it was stressful, but my mum, she was very good. She didn't ask for any money when she did it" (F, PDL, SAL013)

This distance led to one participant requesting to be sent to a different specialist unit which for her had better transport links. Another participant expressed feeling relieved when she could use digital technology rather than having to conduct face-to-face consultations.

*"And so, having been told that I would obviously have to have follow-ups, I'm afraid I refused, and said, "Why can't I go to **** [names unit] I know there's a burns unit in ***" (F, PDL SAL006)*

"…I was able, to email some photos and stuff, which was brilliant because that saved my travel" (F, PDL, SAL013)

"… but the last couple of times I went there, they could've probably just said it on a phone call, like this, and it would save me from having the day off work and driving two hours" (M, SOC, ESX003)

This increased expenditure came at a time where many of the participants had to take significant time off sick from three weeks to three months. During this time, many received statutory sick pay which meant their income was significantly reduced from the normal level. Some participants were still not working due to their accident. For those who had returned to work, very few of the participants were provided time off to attend follow-up appointments. This meant that many of them had to use annual or unpaid leave.

"I couldn't live on that [statutory sick pay], that is for sure" (M, PDL, BRL001)

"But yes, I need to budget. If I've got an appointment, I'll budget around it" (M, PDL, SAL005)

"… it's messed me up financially. Every time I go to hospital to have an appointment or whatever I have to take that time now as unpaid leave" (F, SOC, BRL005).

Some of the participants were not entitled to statutory sick pay as they had either just left a job or were waiting to start a new job. Another participant claimed industrial injury benefit as they were injured at work, as well as other benefits (F, PDL, SAL013). The additional expenses and reduced income made many of the participants worried about financial security.

"It was crazy. We had to borrow money from everywhere. It was really tough" (F, PDL, SAL013)

"I'm still employed but I've been so sick for so long, there has to be a time where they'll turn around, and make me redundant, which will affect, therefore, my benefits, and blah, blah, blah. Your whole mind goes into turmoil of the fear" (F, PDL SAL006).

Whilst the above four themes (frustration with initial burns treatment, feeling disconnected, human costs and money worries) were common experiences across participants in both the SOC/PDL and SOC groups. Participants in the PDL/SOC also had additional experience related to their PDL treatment (theme 5 Reflections on pulse dye laser treatment), see Fig. 1.

3.5. Reflections on pulse dye laser treatment

Many of the participants allocated to the standard care arm of the trial felt disappointed as they wanted to receive the laser treatment earlier in their scar management journey (NMC001, SAL006, ESX002, ESX003, ESX048, ESX066). Only one participant (F, SOC, SK008) expressed they were not bothered that they were allocated to standard care, in contrast, participants in the PDL/SOC arm were pleased to be receiving PDL early in their scar journey.

Participants noted that having PDL treatment was associated with additional human and financial costs. These linked to the additional appointments required for the PDL treatments such as taking time off work for both the individual and often their family member/partner the cost of travel to the centre which was often some distance away from the participants homes. In response to this one participant suggested that either evening or weekend laser clinics would help to reduce the financial burden on the individual and their family.

"Probably the biggest disadvantage was the fact that I had to travel two hours to have it done" *(M, PDL, BRL004)*

"… if it could run a bit in the evenings, or something else like that, or even on a Saturday" (M, PDL, BRL004)

In addition, many participants experienced some pain associated with the treatment (SAL005, SAL006, SAL013, ESX001, ESX009, BRL004, CHW009). Having laser treatment is often described as having an elastic band flicked against your skin. However, the participants expressed a range of definitions of pain from no pain at all to significant pain during the PDL treatment.

"I'm a pretty tough girl, so I said, "Do what needs to be done," (Laughter) kind of thing, but I did find that it was quite painful after having the treatment. On two of the occasions, I found I couldn't use my arm for a couple of days, because it was quite painful" (F, PDL, SAL013)

"Laser feels like tattoo removal, skin goes numb after a while" (M, PDL, SAL005)

"It only felt like someone was flicking it [with an elastic band] when they were using the laser. When the laser was switched off, I didn't feel anything…. It hurt the second time… but it wasn't stopping me from doing anything. It was just all bruised" (M, PDL, BRL004)

Many of the participants who had the PDL expressed that the treatment was positive, identifying that it made a difference to the visual appearance, itch and tightness of the scar.

"I've also got better movement with it, as well, like particularly around my wrist. Where I found, before, it was restrictive around there, it's better. It's a lot softer, as well. It's not quite so leathery, like it was" (F, PDL, SAL013)

"I mean it looks smashing really, the skin graft, because they did half and half, I don't know if you know that, but they lasered half of the skin graft and half of what is good skin, if you know what I mean? [interviewer… You say it looks smashing?] …Well compared to what it was, it's nice and smooth" (M, PDL, BRL006)

"No, that's improved a lot, it's flat, there's hardly anything there" (F, PDL, BRL008)

"…It's given me a lot more freedom of movement in my arm and my stomach and my chest area" (M, PDL, SAL005)

"All I know is that I have effectively got remarkably better [itching] in the six months of having the laser treatment, than I was at the beginning" (F, PDL, SAL006)

Having the laser earlier in their treatment not only had an impact on the look and feel of the scar but participants also expressed psychological benefits.

"I would say it's probably positive, because I've just managed to deal with it faster, like, the scars and not really worrying about it now. If people are looking at it, I think that's probably helped, because it's sped it up. Yes, because it made it look a bit more normal, faster, if that makes sense. I think that helped me in respect of it looking more normal. Okay, it looks a different colour, but it doesn't look really bad anymore" (M, PDL, BRL004)

"That's a good question really. I don't think I would be where I was without it (PDL)… I wouldn't be where I was without the scar management and the laser treatment. All the tightness has gone from my stomach. I can, obviously, see it healing quite well" (M, PDL, SAL005)

Of the four participants who had the PDL with a TBSA ($\geq$ 22), three identified that they did not feel the laser made any real difference (BRL001; BRL006; SK002); all of these were full thickness burns and two of them had a larger TBSA (28 % and 50 %).

"…they did a patch that I'd say is 50 by 50, so I've got a square patch they did. So, before the laser treatment the scarring was quite raised in that area, and now after it, it's a lot flatter… and the colour isn't as red. It's more toned down, the colour. but I don't think the laser treatment- the treated area has been big enough, so it hasn't been a big enough area for it to have an impact on my life, so it hasn't made it better or it hasn't made it worse" (M, PDL, SK002)

Furthermore, one of the participants (F, PDL, CHW009) experienced a skin breakdown after receiving the laser and this had a significant negative impact upon her mental health.

"No-one really knows if it was to do with the laser or just breakdown of my skin… once I'd started the laser, I did have a severe breakdown in my skin and my arm and had to go back to hospital, get it redressed. It was bleeding. I was scratching and itching it at night. And that really took a hit. Like mentally I would say more than anything. Kind of brought me straight back to when I burnt myself. So that was really tough" (F, PDL, CHW009)

Overwhelmingly, there was a sense from seven participants that received the PDL that they would recommend it to others (ESX001; SAL006; SAL005; BRL004; SAL013; CHW009; SK002).

Lastly, participants in both the PDL/SOC and the SOC groups reflected on their future, in terms of continued scar management and readjusting their lives to living with their scars. These are reflected in the fifth theme 'Moving Forwards' (see Fig. 1).

3.6. Moving forwards

Many of the participants had not reached the end of their scar management journey at the time of the telephone interview. Many had plans for further laser treatment to improve the colour and texture of the scars and felt that this was important in terms of their confidence. However, it is important to note that, for some participants, their scar was only one part of their journey following their accident. Some were facing additional surgery to improve function and quality of life. One participant with extensive burns (TBSA 50) was unable to use their left hand, used a walking boot due to having their ankle fused, both of which significantly had a negative impact on their mobility, and was considering requesting an amputation.

"Just hopefully I can get the laser treatment to reduce the scar and the redness. Hopefully I do get offered that. I'm just waiting to hear. [considering the future] I'm just hoping eventually you won't be able notice that it's there, just so I can get my confidence back" (F, SOC, NMC001)

"I'm still questioning a few things myself, like do I want my right leg amputated? Just because of the- well, how it's left me now is not how I want to be, I want to be able to run and go tracks and do events and stuff like that. So, for me, in my head, it would make more sense to me is to have it amputated because then it gives me a bit more mobility" (M, PDL, SK002)

4. Discussion

It is evident that a burn injury is traumatic for those with associated hypertrophic scarring. This can have life-changing impacts upon the individual concerned. The findings from this research identify that it is not sufficient to focus singularly on the scar management process. This needs to be considered as part of a wider, more holistic exploration of the recovery process. That said, ensuring early management of the scar, such as PDL treatment, can have positive impacts both physically [6] and psychologically [7] for individuals, particularly those with a TBSA $\leq$ 21.

To understand the wider life-changing impacts following a traumatic burn, the Life Thread Model [27] was used (see Fig. 2). This model was developed to understand the rehabilitation processes required following an acute stroke but as will be argued here, could also be utilised to understand the life rebuilding process undertaken by those who have experienced a traumatic burn.

The Life Thread Model uses the metaphor of life threads representing

the strands of the individuals that are created and re-created throughout their lives [27]. The complete life thread represents the variety of perceptions and stories that we can tell about ourselves. This includes both a reflection of our past lives through our memories but also our future lives through our future plans [27]. Some aspects of our life threads remain throughout our life, such as being a daughter/son, wife/-husband, and these connections provide stability and are known as parallel life threads. It is our life threads that create our sense of identity, and of who we are. However, a traumatic event, which in this case a burn injury, can lead to the unravelling of these life threads. Here, the 'predictability of usual life is suddenly lost, and the life threads are broken and frayed' [27] page 8. This can lead to a lack of coherence and control. As part of the last process in the model, the individual must find 'the new me' [27] page 9. In this Ellis-Hill et al. [27] argues that the Life Thread Model suggests that rehabilitation journey includes psychological and social processes, alongside the physical.

In the context of burns management, this study clearly articulates the process of un-ravelling of the Life Threads following a burn injury and the impact that this has not only upon themselves but their wider family as evident in both cohorts (SOC and PDL). It highlights the importance of family members, or parallel life threads, not only in the immediate rehabilitation process, but also supporting people to manage the wider ADL. However, the predominant focus of clinical care is on the individual with little consideration of the impact upon the wider family dynamics. This study highlights the importance of the wider family support on the scar management journey not only in terms of the initial adjustment such as supporting ADL but also ongoing access to care. This study asserts that, in terms of burns scar management, there needs to be a shift towards family-centred care akin to that of children's services. Here, a greater emphasis is put on recognising the importance of wider family in promoting high quality care [28]. However, a review by Park et al., [29] noted a lack of research examining the impact of family-centred care in the acute setting and, as such, more targeted research is required here.

Furthermore, this research highlights the importance of considering the wider psychological, social and physical implications as part of the burns scar management journey, which has been reported elsewhere [14,30]. It was evident in this study that many participants in both cohorts (SOC and PDL) were still experiencing trauma sometime after their initial injury, and this was impacting upon their day-to-day lives. A review by Lodha et al., [31] identified the prevalence of Post Traumatic Stress Disorder (PTSD) among burn patients ranged between 3 % and 58 % yet there are few centres providing specialist support to reduce the likelihood of developing symptoms [32]. Brewin and Horner [15] assert that routine screening for psychological distress should be an 'element of care for every patient' and this concept needs addressing urgently.

Other psychological experiences identified in this research included that many participants from both cohorts (SOC and PDL) felt disconnected from their skin, due to the texture, colour and lack of sensation in their burn scar which negatively impacted on their ability to socialise with others resulting in a detrimental impact on their mental health and well-being. The significance of the psychosocial aspect of skin cannot be underestimated, it enables people to feel pleasure, and connection with others [7]. This study highlights the importance from a patient perspective of the early inclusion of Pulse Dye Laser as part of the scar management journey. The early adoption of Pulse Dye Laser promoted physical benefits in terms of the visual appearance, texture and itch of the scar. Improvements, particularly in the colour and texture of the skin, also provided psychological benefits as it enabled participants to re-establish their social connections (life threads) as they felt less conscious about their scars.

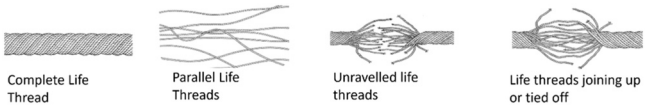

Fig. 2. Life thread model (Ellis-Hill 2008).

> *"I am pleased, because I think it has just sped it up faster, the healing, because it made it look more normal, well, as normal as it could look, quicker. So, I could get on with not worrying so much from people looking at it, and stuff like that" (M, PDL, BRL004)*

Thus, early PDL enabled the start of a reconnection process between their skin and body, which was disrupted following their burns injury and the early scar management process. This is vital to enable participants to rebuild their lives following their accident.

Other benefits to the early adoption of PDL in the scar management journey included a sense of control for participants which also gave them hope for the future, both of which are really important in the rehabilitation process, best described below

> *[when asked her thoughts on early PDL] "Massively. Massively. And if I had my life again, apart from not having the burn, I would be massively pleased that I did it, and I'd be distraught if I was put off for another few months because I do think that although initially, it was pretty bloody painful, and it still is… I do definitely think it has benefitted me beyond measure" (F, PDL, SAL006)*

In terms of the life thread model, early PDL enabled the reconnection of the broken, frayed life threads following their accident. However, participants with a TBSA ($\geq$ 22) felt that early PDL did little to impact their day-to-day quality of life and this may be due to the extensive nature of their burns, and the small PDL treatment area and further research is required here to explore which types of burns patients would benefit from routine early PDL. People who have experienced a burn desire to "return to normal" [14], yet this research has highlighted that, for many participants, this is an unrealistic goal. This study proposes that there needs to be a transition to a "new normal" in which they accept their scars and incorporate them into their Life Thread in order to move forwards.

Whilst the Life Thread Model [27] highlights the importance of psychological, social and physical processes, this research identified that financial processes must also be considered for burns patients. Participants in both SOC and PDL cohorts identified the financial aspects of the scar management journey is significant, not only for themselves but also their wider family networks. The initial treatment is often intensive, and many participants in this research had significant time off work. Yet, within the UK, statutory sick pay equates to £ 116.75 per week for a total of 28 weeks [33]. This is insufficient to meet normal living costs (mortgage, rent, bills etc) without considering additional costs of the scar management process (dressings, cream), as well as additional purchases required (clothing etc) in order to meet ADL. Not only is financial security required in order to be able to access and comply with treatment, moreover, this research identifies the psychological ramifications of financial insecurity perpetuates anxiety and mental health worries. A further corollary is the current financial climate, which may affect patients' ability to attend follow-up treatment (such as PDL) due to workplace pressures and concerns re job security which may have the potential to worsen scar outcomes. This is particularly true for those with significant burns where the entire patient journey may take years before they reach an acceptable level of functioning. Furthermore, even after a return to work, this research has highlighted many participants and their families have to take annual leave or additional sickness days to attend follow up or laser treatment, and this is an areas which requires further consideration by clinical and burns services to consider a more flexible approach of delivery such as weekend appointments, satellite clinics, remote monitoring using digital technologies which could ameliorate this burden.

4.1. Limitations

Whilst the study incorporated a range of people with different scar

experiences, there was a limited engagement of those with Fitzpatrick Skin Type V and VI in the main trial. This resulted in a limited number of people from these skin types in the qualitative component. Further work is required to specifically explore scar management experiences within darker skin tones. Furthermore, the qualitative component did not recruit anyone with a head or neck burn. As these scars are highly visible, their experiences may have been more profound and as such further research is required here. It also has to be noted that three quarters of the participants in the qualitative study came from three site locations, although this was also mirrored in the main trial. Lastly, the study only undertook interviews 26 weeks after initial treatment and as such can only been seen as a snapshot of their scar management journey. However, as noted burns scar management journey is a long one and further research is required to explore the nature of changes over time.

5. Conclusions

This research identifies that the scar management journey is long and complex with significant physical, psychological, financial, and social impacts on the individual, which negatively affect quality of life and delay reintegration into society. As such, any burns rehabilitation process must include a holistic focus on the lives of the individual and their wider family. This research highlighted that early use of PDL is important in patients with TBSA ≤ 21 in ameliorating these physical and psychological needs. It positively impacts upon quality of life and ADL, supporting individuals whilst they create their 'new normal' and engineer their readjustment into their lives and wider society. This study highlighted minimal impact of use of PDL in patient with TBSA ≥ 22, and in part this may have been due to the small area treated; therefore, further research is required to explore the impact of early PDL in patients with greater TBSA.

Author contributions

Vanessa Heaslip: conception and design of the study, acquisition of data, Data analysis, interpretation of data, drafting the article or revising it critically for important intellectual content, final approval of the version to be submitted

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Shelley Rhodes: conception and design of the study, interpretation of data, drafting the article or revising it critically for important intellectual content, final approval of the version to be submitted

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Katie Breheny: conception and design of the study, drafting the article or revising it critically for important intellectual content, final approval of the version to be submitted

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Declaration of Competing Interest

None.

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