

The role of self-management in burns aftercare

Litchfield, Ian; Jones, Laura; Moiemmen, Naiem; Andrews, Nicole; Greenfield, Sheila; Mathers, Jonathan

DOI:

[10.1016/j.burns.2018.10.020](https://doi.org/10.1016/j.burns.2018.10.020)

License:

Creative Commons: Attribution-NonCommercial-NoDerivs (CC BY-NC-ND)

Document Version

Peer reviewed version

Citation for published version (Harvard):

Litchfield, I, Jones, L, Moiemmen, N, Andrews, N, Greenfield, S & Mathers, J 2018, 'The role of self-management in burns aftercare: a qualitative research study', *Burns*. <https://doi.org/10.1016/j.burns.2018.10.020>

[Link to publication on Research at Birmingham portal](#)

Publisher Rights Statement:

Checked for eligibility: 24/10/2018

General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.

The role of self-management in burns aftercare: a qualitative research study


Ian Litchfield¹, Laura L Jones¹, Naiem Moiemem², Nicole Andrews¹, Sheila Greenfield¹, Jonathan Mathers^{1§}

¹Institute of Applied Health Research, University of Birmingham, Birmingham, UK

²The Scar Free Foundation Centre for Burns Research, Queen Elizabeth Hospital, University Hospitals Birmingham NHS Foundation Trust, Birmingham, UK

E-mail addresses:



[§]*Corresponding author*
Room 235 Murray Learning Centre
Institute of Applied Health Research
University of Birmingham
Edgbaston
Birmingham
B15 2TT
Email: j.m.mathers@bham.ac.uk
Telephone: 

1 **Abstract**

2 Introduction

3 For severe burns patient care presents a considerable challenge, necessitating an integrated multi-
4 disciplinary approach that utilises a range of treatments. The period of care post-discharge can be
5 lengthy and complex, and include scar management, occupational and physiotherapies,
6 psychological support, and further surgery. How successfully the patient negotiates this complex
7 care regimen is critical to their long-term recovery and in doing so they would appear to employ
8 approaches recognised as “self-management” in other chronic conditions. However their exact
9 nature and how they are used has yet to be explicitly explored amongst chronic burn patients.

10

11 Methods

12 Semi-structured interviews were conducted with 24 patients to discuss their experiences of long-
13 term burn treatment as part of a broader mixed-methods feasibility study of the use of pressure
14 garment therapy in preventing hypertrophic scarring after burn injury. The topic guide included
15 questions on the patient experience of their care post discharge, including pressure garment therapy
16 and other scar management techniques; and their expectations and experiences of treatment and
17 recovery. The data were analysed using an established framework of self-management processes.

18

19 Results

20 Burns patients employ many of the same processes of self-management as those experiencing more
21 widely recognised chronic diseases or illnesses. This is despite the prospect of gradual improvement
22 amongst burns patients absent in those with incurable chronic conditions. The key processes of self-
23 management they share are the ability to focus on their illness needs, activate the appropriate
24 resources and coming to terms with the consequences of living with either the physical or
25 psychological consequences of their condition.

26

27 Conclusion

28 Modern burn care is technologically advanced and delivered by a highly trained, multi-disciplinary
29 team, yet the level of its success relies on the ability of the patient to independently fulfil a number
30 of health-related tasks and activities once leaving hospital. Considering the potential cost-savings to
31 health services and the prospect of improved outcomes for patients capable of self-management our
32 work is an important first step in more precisely understanding the use of self-management amongst
33 burns patients, and the level of implicit or explicit support currently offered by their care providers.

34

35 1. Introduction

36 Some 250,000 individuals sustain burns in the UK every year with the potential of lasting impact on
37 appearance, and psychological, social, and physical functioning [1]. For severe burns in particular,
38 patient care presents a considerable challenge, necessitating an integrated multi-disciplinary
39 approach and utilising a range of treatments [2]. Typically it consists of two distinct phases; the first
40 acute phase is when the patient is hospitalised where beyond their initial survival, the key requisite
41 is closing the wound [3]. The second phase consisting of rehabilitation and post-discharge
42 management is termed “aftercare” [4] and addresses aesthetic, functional and psychological
43 requirements [5]. This can last up to two years and is complex [6], using a combination of treatments
44 that include scar management modalities (e.g. massage, creaming, pressure garment therapy);
45 occupational and physiotherapies; psychological counselling, and further surgery [7]. Lack of
46 adherence to these treatments has implications for the degree of scarring, [8] functionality [9] and
47 psychosocial issues, [10] as well as cost implications for health care services [11]. Therefore, the
48 aftercare period is critical in terms of the overall success of the treatment and the degree to which a
49 functioning patient can rejoin society [12]. However despite its importance, patients and their
50 carers are expected to negotiate much of this lengthy and complex care regimen independently with
51 only intermittent contact with care providers.

52

53 Severe burns are technically defined as a chronic condition due to their effects lasting longer than
54 three months [13]. However, this chronicity is not always recognised [6] despite the lasting impact
55 on physical appearance and capability, and the psychological implications of long-term treatment,
56 being similar in nature to that experienced by those with more widely recognised chronic disease or
57 illness [14]. Similarly the obstacles burns patients face in maintaining their aftercare in the years
58 following the injury, that include depression, fatigue, dependence on family support, and financial
59 problems [15-18] are also comparable to those experienced by patients with other chronic

60 conditions [19]. However, for those with diseases such as type II diabetes or hypertension, there is
61 an understanding of how these obstacles can be mitigated by the use of “self-management” [20],
62 defined as “the ability of the individual in conjunction with family, community, and healthcare
63 professionals to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and
64 spiritual consequences of health conditions.” [21]. This self-management is frequently supported by
65 the training and education of patients that encourages problem solving, decision making, and
66 appropriate use of resources [20] and has led to improved patient engagement, adherence, and
67 efficiency of healthcare utilisation [22-24].

68

69 Research exploring burns aftercare has described how patients need to adapt to the long-term
70 consequences of their injury (25). The ways in which patients may try to achieve this have been
71 conceptualised as self-management processes in other chronic conditions, but to date there has not
72 been an explicit focus on self-management processes in burns aftercare. It is possible that if
73 acknowledged and understood these processes can be better supported with the potential to
74 benefit burns patients and healthcare services. First, however there is the need for a better
75 appreciation of which if any self-management processes are being employed by patients with severe
76 burns and in which context. Here we present data from a comprehensive exploration of patient
77 perspectives of burn aftercare conducted as part of a feasibility study for a trial of scar management
78 regimes [26] with the aim of establishing whether burns patients describe the self-management
79 processes that are widely recognised in other chronic conditions.

80

81 **2. Methods**

82 **2.1. Study design**

83 This qualitative research was a part of a broader mixed-methods feasibility study of Pressure
84 Garment Therapy (PGT) for the prevention of hypertrophic scarring after burn injury in adults and
85 children (The PEGASUS Study) [26]. One aim of the qualitative research was to understand adult
86 patients' experiences of scar management therapies, and predominantly PGT.

87

88 **2.2. Sampling and recruitment**

89 The sample consists of adult patients who were participants in a pilot trial of PGT that formed part of
90 the PEGASUS study. Patients participating in the pilot trial were allocated to scar management with
91 or without PGT. Participants were recruited by occupational therapists (OTs) and/ or research
92 nurses (RNs) in 3 of the PEGASUS pilot trial sites in the West Midlands and South East Regions of
93 England. Clinical staff provided information sheets to potential interviewees and took written
94 consent to pass participant contact details on to the PEGASUS qualitative research team. A member
95 of the qualitative research team then contacted potential interviewees, provided further
96 information and answered questions as necessary, before arranging a suitable time, date and venue
97 for the interview. Written informed consent was received from all participants prior to the start of
98 data collection. Participants were interviewed at two time points, soon after consent to participate
99 in the trial and allocation to treatment, and then 9-12 months later. The data utilised here comes
100 from the later interviews, undertaken at a stage when participants had significant experience of
101 burns aftercare and scar management.

102

103 **2.3. Ethics**

104 Ethics approval for the PEGASUS study was received from the West Midlands: Coventry and
105 Warwickshire Research Ethics Committee (14/WM/0160).

106

107 **2.4. Data collection**

108 Semi-structured interviews were conducted by IL and JM who are experienced non-clinical
109 qualitative researchers who were independent of the participants' clinical care team. Interviews
110 were conducted in the patient's home, or via telephone. A semi-structured discussion guide was
111 developed based on the literature, discussions with our patient and public involvement (PPI) group,
112 and the wider PEGASUS research team. The semi-structured interviews were conducted in a
113 participant-focused manner allowing issues and perspectives important to participants to emerge
114 naturally. Topics discussed included: accounts of the accident and injury (where participants were
115 happy to talk about these in order to provide context for the remainder of the discussion); accounts
116 of subsequent treatment; the experience of PGT and other scar management techniques; hopes and
117 expectations for treatment, recovery and scar management; perspectives on the pilot trial of PGT
118 including trial processes and assessments, and patient-centred outcomes. The topic guide and
119 interview process was refined over the first 3 interviews. Following this, data collection and analysis
120 took place iteratively. At the end of each interview, participants were asked to complete a short
121 demographic questionnaire to facilitate maximum variation sampling and a description of the
122 sample characteristics. We attempted to include a range of patients according to sex, age, ethnicity,
123 type and severity of burn, and allocation to scar management with or without PGT.

124

125 **2.5. Data analysis**

126 Interviews were digitally audio-recorded and transcribed clean verbatim by a specialist company. In
127 order to establish whether burns patients describe the use of self-management processes that are
128 recognised in other conditions we applied a framework of self-management processes developed by
129 Schulman-Green et al (2012) to the interview data (27). This framework is based on a meta-
130 synthesis of 104 qualitative research papers that have explored self-management from the
131 perspective of chronically-ill patients. There are a number of other existing frameworks that have
132 been used to describe the processes of self-management [20, 28- 31]. However, the Schulman-
133 Green study was the first to define these processes solely from the perspective of patients living

134 with chronic illness. The three key processes they identified were; 1) **Focussing on illness needs**; 2)
135 **Activating resources**; and 3) **Living with a chronic condition** (Table 1).

136

137 A sample of interviews were analysed separately by two of the authors (IL & JM). Any discrepancies
138 were resolved via discussion and the overall interpretations presented here were discussed and
139 agreed with all authors. We do not claim to have reached data saturation in relation to participants'
140 use of self-management processes and techniques (32). The interviews were broad ranging and the
141 intention of this paper is to illustrate that patients are utilising processes conceptualised as self-
142 management in other disease areas, not to provide a comprehensive theory of self-management in
143 burns.

144 **Table 1. Key processes and sub-processes, including definitions (taken from Schulman-Green et al).**

145

146

147

148 **3. Results**

149 We interviewed a total of 24 patients, with equal numbers from each clinical site. The majority were
150 male and had experienced burns from direct contact with flames. The characteristics of patients are
151 summarised in Table 2 including their age group, the type of burn and total body surface area
152 burned.

153 **Table 2: Sample characteristics**

154

155 Not every sub-process identified by Schulman-Green was observed in our cohort but those shared by
156 the burns patients we spoke to are described below alongside exemplar quotes.

157

158 **3.1. Focussing On Illness Needs**

159 The first process of self-management requires patients understand the parameters of their disease
160 or condition and its treatment. They look to learn about their diagnosis, understand and assume
161 responsibility for the implications on their lifestyle, and undertake related health promotion
162 activities.

163

164 **3.1.1. Learning**

165 Patients successfully self-managing their chronic disease acquire information about their condition
166 and learn the requisite regimens and skills to manage their daily illness needs. Our participants
167 undergo a similar process as they learn to manage their condition and recovery. This includes
168 understanding the prognosis of their injury and the implications of their particular burn and how
169 these might be mitigated, for example, via additional surgical interventions. One patient described
170 the process of cording (feeling of tightening), which can occur following a skin graft when lymph
171 vessels become clotted, and how this necessitated further surgery to increase functionality:

172

173 *So that's like cording, so I don't know if you know about skin grafts?...Can*
174 *you see the way it pulls, like that?...This does that here, wearing the*
175 *garment on my torso won't help that but there, that needs some more Z-*
176 *plasties done, some more operations just to get that to stretch even more,*
177 *West Midlands, Male, (Participant ID) P16*

178

179

180 **3.1.2. Taking ownership of health needs**

181 Patients with chronic disease learn to manage their symptoms and body responses and the patients
182 we spoke to described how they monitored and managed symptoms of their burn injury and
183 adjusted their treatment accordingly. One example is how they applied moisturiser to their skin to
184 prevent the scar site from tightening. Patients also described the changes in sensitivity of the burn
185 site in terms of its tactile responses to different materials or its reaction to sunlight:

186 *Yes, it's just my fingertips I have to be careful how I touch things, different*
187 *materials, metals I have to be careful with, and it's the sun as well, I have*
188 *to really be careful in the sun, ever so sensitive to the sun, factor 50 all the*
189 *time. West Midlands, Male-P12*

190

191 As part of their care, patients with chronic disease are required to complete a number of related
192 health tasks including taking their medication. In the same way burns patients have to complete
193 certain activities as part of the recovery process including taking a specific combination of analgesics
194 or regularly administering moisturiser:

195 *Got up in the morning and washed it and creamed it. I made sure I did*
196 *that all the time, took their advice. West Midlands, Male-P15*

197 Failure to attend appointments is a common issue in the NHS and though it may appear to be a
198 straightforward process, organising and managing responsibilities in order to ensure attendance can

199 be complicated by a number of social or clinical factors. In the same way that those with chronic
200 conditions need to regularly attend clinical reviews as part of the ongoing management of their
201 condition, patients with serious burns also have to attend regular appointments at specialist clinics.
202 That there are only a handful of these burns units across the UK means that many patients are
203 required to travel long-distances and utilise considerable resource:

204

205 *So it does take a big chunk of my day out because I have to take the day*
206 *off from work,...it takes you half a morning just to get there and back and*
207 *have the treatment and sometimes it takes longer and you end up being*
208 *left two hours waiting or something. So it has cost me a lot of money in*
209 *terms of petrol and getting there and parking and stuff, but on saying*
210 *that...[the staff] have been brilliant. Sussex, Female-P01*

211

212 Over time the ability of patients with chronic illness to manage their condition improves as their
213 experience and expertise increases. A similar increase in expertise was demonstrated by the burns
214 patients we spoke to who described how they adjusted their treatment over time to achieve a
215 particular goal. The prescription for pressure garments is typically to wear them for 23 hours a day
216 however for patients with skin grafts sensitisation can be an issue exacerbated by these lengthy
217 periods wearing the garment. Desensitisation requires re-training the nervous system to accept
218 mild-touch and to facilitate this process nurses can encourage patients to reduce the time they are
219 wearing the garment at the patient's discretion. One patient described how they gradually
220 decreased the number of hours they would wear their pressure garment as they successfully
221 reduced sensitisation of their burn site:

222

223 *The garments are great, but I can't go for more than... well actually if you*
224 *had spoken to me about a month or so ago it would have been about an*

225 *hour but now I can actually go without them for maybe half a day. But*
226 *that's because I'm trying to desensitise the scars, so I actually sleep*
227 *without it now... Essex, Female-P02*

228

229 Another patient spoke of the issues they encountered with itching around the site of the healing
230 injury. Aware of the sensitivity of the area and the importance of not disturbing the scar by direct
231 contact a patient described how they learnt to manipulate the area through their pressure garment
232 using escalating degrees of force and ultimately resorting to cold water when the itch was at its most
233 relentless:

234 *Yes it does itch and I find a way around it, rub my hand over the actual*
235 *pressure garment itself, and then if it does become a bit too intense that*
236 *itchy sensation I just itch over on top of the actual pressure garment, so*
237 *I'm not actually impacting any of the skin underneath, and worse comes to*
238 *worse I'll run it under cold water, the cold water shocks the skin into*
239 *something else. Essex, Female-P01*

240

241 **3.1.3. Performing health promotion activities**

242 Chronically ill patients would be required to make alterations to even the most routine activities to
243 minimise the impact of their condition. The same was observed in our participants who reported
244 benefits from what appear quite minor changes. For example one patient slept with an additional
245 duvet to minimise the disruption to their sleep caused by aggravating the sensitive injury:

246

247 *I was sleeping in the same bed but he had the double duvet and I had a*
248 *single duvet on me, because him rolling over and moving the duvet would*
249 *wake me up and make me cry. Essex, Female-P02*

250

251 **3.2. Activating Resources**

252 To optimise any self-management regime resources associated with the healthcare system or
253 derived socially from friends and family must be accessed. These resources assist individuals in
254 managing both the medical and psychosocial aspects of their condition.

255

256 **3.2.1. Healthcare resources**

257 The activation of healthcare resources can vary in intensity and complexity dependent upon the
258 individual and the severity of their illness or condition. One aspect of this, recognised in chronically
259 ill patients and also seen in burns patients, is the collaborative relationship developed with their care
260 providers. Our patients described how they would contribute to decisions affecting their care
261 regime. For example one patient spoke of working together with their occupational therapist in re-
262 designing a pressure garment so that it was more comfortable and delivered pressure more
263 effectively:

264 *Between me and the occupational therapist we devised one, ... that*
265 *actually is an all in one and does up under the crotch, and a) that gives me*
266 *better compression because it stays still, and b) it's more comfortable*
267 *because I'm not pulling it down all the time. Essex, Female-P02*

268

269 **3.2.2. Social resources**

270 The social resources activated are individual to each patient and can vary over time dependent on
271 availability and requirements, as their condition and needs change. There are a number of
272 recognised sources of such support activated by chronically ill patients, including family and friends.
273 Our participants also recalled how they relied on family members during their recovery for example
274 in transportation to the clinic during the early part of their recovery:

275

276 *I've got a really good support service with my family, and once I could*
277 *drive that was it. But I was being taken either by my daughter or by my*
278 *mum, and then once I was driving I would drive myself. Essex, Female-P02*

279

280 Participants also spoke of the psychological support derived from their family. The same patient
281 described the increased value attached to the feedback of trusted family members, perceived as
282 being unencumbered by the same social conventions that might moderate the responses of their
283 friends:

284

285 *I don't know if it's helped my scars but people that see them are my*
286 *friends, and of course they're going to say they look great. But my*
287 *children... my girls are a little bit more... they're 21 and 17 and they can't*
288 *hide their faces, and they actually say that it's all looking great and how*
289 *soft it is. Essex, Female-P02*

290

291 **3.2.3. Psychological resources**

292 Those with chronic diseases are sometimes required to draw on their psychological resources to
293 manage their condition. Participants also demonstrated this same ability to use their own resources
294 to remain positive and focus on their recovery:

295

296 *I always said when I was in hospital I'm going to control this whole*
297 *situation, I'm not going to let this situation control me.... Unfortunately*
298 *my stump has decided to take control, because it means it's going to grow*
299 *out, it's going to be awkward,... Once the operation is out of the way and*
300 *they've sorted that out then I'm back in control, I can start the physio, I*

301 *can start doing my walking, and I can nail it then ... I'll just bide my time a*
302 *bit more.* West Midlands, Male-P13

303

304 **3.3. Living With A Chronic Illness**

305 The final process of self-management describes how patients come to terms with their chronic
306 condition, learning to cope with their illness and integrating it into the context of their life. The burns
307 patients we spoke to appeared to undergo a similar transition and described how they came to
308 process their emotions, and adjust to and integrate their condition into their daily lives, ultimately
309 making meaning of what has happened to them.

310

311 **3.3.1. Processing emotions**

312 Dealing with the psychological consequences of their condition is an important part of self-
313 management in the chronically ill, part of which requires that patients explore and express various
314 emotions relating to their diagnosis, including grieving and loss. We observed this in our
315 interviewees who described the anguish of coming to terms with their scars as the long-term impact
316 of the injury became apparent. One patient described the length of time it took before they
317 addressed how they felt about their altered appearance:

318

319 *When I was in hospital I said to my wife and everybody 'I don't care what*
320 *it looks like, I don't care about the scars, it doesn't bother me.'* But it did!
321 *At the time it didn't...but then it wasn't until a couple of months*
322 *afterwards....I'm looking and I think 'I can't fucking believe this - what I*
323 *look like.'* and...it hit me ... *'I do care what it looks like, I really do!'* West
324 Midlands, Male-P16

325

326 **3.3.2. Adjusting**

327 In adjusting to a new-self patients often use coping strategies. In burns patients these can be
328 employed to help deal with the visual impact of their injuries. One patient used “self-talk” and
329 created nicknames for each of three burn sites based on their appearance or sensitivity:

330

331 *...the underarm one was called ‘The Camembert’, because that’s what it*
332 *looked like, it looked like soft cheese, and then the one right under my*
333 *forearm where it’s still sensitive is called ‘The Chevron of Hate’, and then*
334 *I’ve got a flash one on my shoulder, that’s ‘The Harry Potter’ [laughter]*

335 Essex, Female-P02

336

337

338 Those with chronic conditions have to deal with the stigma associated with either the condition itself
339 or its treatment. For our participants much of this stigma surrounded the change in appearance and
340 a patient described how they had come to terms with that:

341

342 *No, when I say it bothered me, it was more the look of them do you know*
343 *what I mean? Going out and about and stuff like that, the sun shining*
344 *walking round with a pair of bloody gloves on like, and you just look like a*
345 *plonker. But yes it doesn’t matter does it, it doesn’t matter. West*

346 Midlands, Male-P12

347

348 **3.3.3. Integrating illness into daily life**

349 The process of integrating their illness into their daily life and routines requires patients balance the
350 pursuit of meaningful activities with the needs of their illness. Modifying lifestyles for the chronically
351 ill frequently involves the creation of consistent health management routines. In the same way
352 burns patients would create routines to help them comply with their prescription. One patient

353 explained how they had learnt to dress in the morning in a specific order to ensure that they wore
354 their pressure garment for the specified period of time:

355

356 *Yes, it's just second nature now; I put the garment on before I put my*
357 *socks on. I think it will be strange not to have it now. Sussex, Female-P05*

358

359 The process of modification requires chronically ill patients exercise flexibility in their approach as
360 they resume usual activities. Study participants also understood that they needed to be flexible as
361 they sought to maintain patterns of behaviour followed before their injury. This type of adjustment
362 was also found in our cohort with one patient describing how their return to work was predicated on
363 amending the range and length of the tasks they performed:

364

365 *I started to sneak in about four weeks later just for an hour or two...and*
366 *then I think it was about four or five weeks, maybe five/six weeks after, I*
367 *said "I'm going to do a full day at work today and see how I get on", ...I*
368 *didn't stay off work again. I work in - did work - half my time in the*
369 *machine shop, half my time in the office, but it's been office more than*
370 *anything. I walk around the machine shop but I don't do any lay work or*
371 *anything now... West Midlands, Male-P15*

372

373 **3.3.4. Meaning making**

374 Ultimately chronically ill patients attempt to make sense of what has happened to them and gain
375 meaning as a way of moving forward with their lives. They can use their condition as a learning
376 process becoming empowered as they gain a greater understanding of their body and its responses
377 and the prospects that remain to live a fulfilling life. Participants spoke of their desire to return to
378 work even in a limited capacity or how alternative opportunities to those which existed prior to the

379 injury might be pursued. For example one patient we spoke who prior to the injury planned on
380 serving on the front line for the army discussed the possibilities that still remained to work for the
381 military albeit in a logistics role:

382

383 *Hopefully join up for something in the military if I can. My boss says,*
384 *“There will be hundreds of jobs for you, you could be logistics, driving, just*
385 *doing the driving and stuff like that...” I said, “Yes I don’t mind doing a bit*
386 *of that.” He said, “...anything, you won’t be frontline, you won’t be*
387 *jumping out of a DC130 behind enemy lines, not like you were going*
388 *to...but at the end of the day if you’re bringing home a good wage and*
389 *whatnot...don’t worry about it.” ... So I would be happy West Midlands,*
390 *Male-P13*

391

392 Another patient we spoke to appeared philosophical after their injury and described how they felt
393 lucky their situation wasn’t worse. Instead they used the memory of their accident to remind them
394 to treat fire with respect, content in the knowledge that they were still alive.

395

396 *At first you don’t realise, but then you think to yourself “Jesus Christ it*
397 *could have been right worse!”. But luckily it wasn’t, and we live another*
398 *day, and put it behind you. But say put it behind you, I always keep it, I*
399 *don’t walk about 24/7 thinking about it, but I respect fire and everything.*
400 *West Midlands, Male-P16*

401

402 **4. Discussion**

403 Modern burn care is technologically advanced and delivered by a highly trained, multi-disciplinary
404 team yet the level of its success ultimately relies on the ability of the patient to independently fulfil a

405 number of health related tasks and activities once leaving hospital [2]. That this recovery can take in
406 excess of three months means severe burns are defined as a chronic condition [13]. Self-
407 management is an important concept in the current care model for many patients with similar long-
408 term conditions [33]. It can provide them with the self-confidence to achieve the outcomes
409 important to them [34], to experience better clinical outcomes [35], and allow care providers to
410 have more meaningful conversations with their patients [36]. For the first time our thematic
411 analysis has drawn attention to how burns patients employ many of the same processes of self-
412 management as those experiencing more widely recognised chronic diseases or illnesses [27]. Our
413 participants used examples of all three key self-management techniques namely they focused on
414 their illness needs, activated the appropriate resources and began to come to terms with the
415 consequences of living with the physical and psychological consequences of their condition.

416

417 **4.1. Strengths/limitations**

418 We offer a novel perspective on burns care, describing the similarities between the self-
419 management processes used by those with more widely recognised chronic disease and those
420 employed by patients with severe burns. The qualitative dataset we analyse here is drawn from one
421 of the largest exploration of burns aftercare yet conducted in the UK. During the primary analysis of
422 this data, collected as part of the final phase of the Pegasus study [26], it appeared burns patients
423 were employing some of the self-management strategies described by patients experiencing chronic
424 disease. The secondary analysis we present here is not intended to be exhaustive and the topic
425 guide was not designed to explore self-management processes. Nevertheless these processes were
426 evident and drawn from patients with a range of characteristics and burn types that we would
427 suggest are potentially reflective of the broader population of burns patients.

428

429 **4.2. Specific findings**

430 *4.2.1. Focusing on illness needs*

431 Patients with chronic disease focus on their illness needs and develop expertise in managing their
432 condition as they learn how to recognise and ameliorate their symptoms by making independent yet
433 informed decisions on their care regimen as seen in patients with psoriasis [37] or type 1 diabetes
434 [38]. For burn care to be successful patients need to assume a degree of responsibility for managing
435 their wound and their physical and mental health once leaving the hospital. This begins with
436 understanding more about their condition. Some of those we interviewed described how they had
437 learnt to adjust their treatment as their recovery proceeded. For example, one common yet
438 fluctuating side-effect of burn recovery are multiple episodes of acute pruritis [39] and patients in
439 our study described how they developed strategies to reduce its impact.

440

441 *4.2.2. Activating resources*

442 Self-management of chronic disease requires the establishment and maintenance of relationships
443 with care providers as patients navigate the healthcare system and access appropriate resource [27].
444 This behaviour previously observed in patients with chronic disease such as type II diabetes [40,41]
445 was also described by our interviewees who attended appointments throughout their aftercare with
446 a range of consultants, nurses, and therapists. In line with previous research with burns patients
447 [40] our participants also reported the benefits of developing rapport with their healthcare provider
448 over the course of their treatment.

449

450 As well as effectively accessing health care resources the utilisation of social resource also plays an
451 important role in the self-management of a variety of chronic diseases [42] and conditions [43]. Our
452 participants also spoke of the value of the support gained from friends and family, particularly in the

453 early stages of their recovery. Previous work with burns patients has described how support of this
454 nature improved their quality of life [44], and provided motivation to recover [45] and it is perhaps
455 worth noting that this support may be particularly salient for burns patients, a group vulnerable to
456 depression and mental ill-health [46,47].

457

458 4.2.3. *Living with a chronic condition*

459 Ultimately successful self-management requires chronically ill patients learn to live with their
460 condition or disease, developing strategies to help them cope and ultimately integrate the
461 management of their disease into their everyday life. Such strategies observed in patients with
462 chronic heart failure [48] or white lymphedema [32] may be equally influential in the rehabilitation
463 journey of burns patients [45,34] though have not previously been explicitly recognised as a self-
464 management process. For example one of our participants described how they enabled their
465 prompt return to work by adjusting the parameters of their role to account for their physical
466 limitations. This modification of activity has not only been observed in other burns patients [25] but
467 also in patients with chronic obstructive pulmonary disease [49] and multiple sclerosis [50].

468

469 For those left disfigured or functionally limited by serious burns, acknowledgement and acceptance
470 play an important part in their recovery [25]. The process of acceptance is equally important for
471 those diagnosed with long-term conditions such as chronic heart failure [48]. Humour and self-
472 awareness evident in “Self-talk” contributes to this [48] and was evidenced in our patients with one
473 patient creating nicknames for each of their scars.

474

475 4.2.4. *Support of self-management*

476 The adoption of self-management is not uniform across all patient groups and is influenced by
477 factors including the severity of the disease or condition [51,52], the ability of patients to embed
478 solutions into everyday practice [53,54], and the available support of family and healthcare
479 providers [55,56]. Frequently in other long-term conditions or illnesses structured support is
480 provided to help sustain self-management and is a central part of many of the health and social care
481 policies being employed across the UK [35; 57-59]. This support incorporates training not only for
482 patients and carers but also health care professionals, and involves peers and community groups
483 and the organisational systems necessary to underpin patient self-management [60]. Where
484 appropriate support is in place and embedded in commissioning and planning it has been
485 demonstrated to improve levels of self-management for those with chronic disease [61,62].

486

487 **4.3. Conclusions**

488 Before targeted self-management support can be considered for burns patients further work is
489 needed to understand more accurately its prevalence amongst burns patients, the level of implicit
490 or explicit support currently offered by their care providers and the suitability of existing systems to
491 underpin it. Ultimately interventions might be usefully introduced to bolster these processes; in the
492 meantime our findings at least begin to raise awareness of the *ad hoc* self-management processes
493 currently used by patients with severe burns and will encourage discussion on the level of existing
494 support offered to patients post-discharge.

495

496 **Conflict of interest statement**

497 All named authors declare that there are no known conflicts of interest relating to this manuscript.

498

499 **Funding**

500 This project was funded by the National Institute for Health Research (NIHR) Health Technology
501 Assessment (HTA) Programme (project number 12/145/04) and will be published in full in the HTA
502 journal series.

503 This report presents independent research commissioned by the NIHR. The views and opinions
504 expressed by authors in this publication are those of the authors and do not necessarily reflect those
505 of the NHS, the NIHR, MRC, CCF, NETSCC, the HTA programme or the Department of Health.

506 The views and opinions expressed by the interviewees in this publication are those of the
507 interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, MRC,
508 CCF, NETSCC, the HTA programme or the Department of Health.

509 **Acknowledgements**

510 We would like to thank the patients who kindly participated in the research interviews that form the
511 basis of this work. We would also like to acknowledge the contribution of the clinical staff who
512 helped recruit participants to the Pegasus study.

513

REFERENCES

1. Falder S, Browne A, Edgar D, et al. Core outcomes for adult burn survivors: a clinical overview. *Burns*. 2009;35(5):618-41.
2. Al-Mousawi AM, Mecott-Rivera GA, Jeschke MG, et al. Burn teams and burn centers: the importance of a comprehensive team approach to burn care. *Clin Plast Surg*. 2009;36(4):547-54.
3. International Best Practice Guidelines: Effective skin and wound management of non-complex burns. *Wounds International* 2014
4. Van Loey NE1, Faber AW, Taal LA. Do burn patients need burn specific multidisciplinary outpatient aftercare: research results. *Burns*. 2001 Mar;27(2):103-10.
5. S. Rea, F. Wood Minor burn injuries in adults presenting to the regional burns unit in Western Australia: a prospective descriptive study *Burns*, 31 (2005), pp. 1035-1040
6. Christiaens W, Van de Walle E, Devresse S, et al. The view of severely burned patients and healthcare professionals on the blind spots in the aftercare process: a qualitative study. *BMC Health Serv Res*. 2015;15:302.
7. Anthonissen M, Daly D, Janssens T, et al. The effects of conservative treatments on burn scars: A systematic review. *Burns*. 2016;42:508-18.
8. So K, Umraw N, Scott J, Campbell K, Musgrave M, Cartotto R Effects of enhanced patient education on compliance with silicone gel sheeting and burn scar outcome: a randomized prospective study. *J Burn Care Rehabil*. 2003;24(6):411-7;
9. Esselman PC Burn rehabilitation: an overview *Arch Phys Med Rehabil*. 2007;88(12 Suppl 2):S3-6
10. Hop MJ1, Polinder S, van der Vlies CH, Middelkoop E, van Baar ME Costs of burn care: a systematic review. *Wound Repair Regen*. 2014;22(4):436-50. doi: 10.1111/wrr.12189.
11. Fletchall S1, Hickerson WL. Fletchall and Hickerson Quality burn rehabilitation: cost-effective approach. *J Burn Care Rehabil*. 1995;16(5):539-42.
12. Takayanagi K, Kawai S, Aoki R. The cost of burn care and implications for efficient care. *Clin Perform Qual Health Care* 1999;7(2):70-3.
13. National Center for Health Statistics, Centers for Disease Control and Prevention. (2013) Summary Health Statistics for the U.S. Population: National Health Interview Survey, 2012.
14. Goodman RA, Posner SF, Huang ES, Parekh AK, Koh HK. Defining and Measuring Chronic Conditions: Imperatives for Research, Policy, Program, and Practice. *Prev Chronic Dis* 2013;10

15. Jerant AF, von Friederichs-Fitzwater MM, Moore M. Patients' perceived barriers to active self management of chronic conditions. *Patient Educ Couns* 2005;57:300-307.
16. Oster C, Kildal M, Ekselius L. Return to work after burn injury: burn-injured individuals' perception of barriers and facilitators. *J Burn Care Res.* 2010;31:540-550.
17. Ripper S, Renneberg B, Landmann C, Weigel G, Germann G. Adherence to pressure garment therapy in adult burn patients. *Burns.* 2009;35:657–664.
18. Gonçalves N, Echevarría-Guanilo ME, de Carvalho FE, Miasso AI, Rossi LA. Biopsychosocial factors that interfere in the rehabilitation of burn victims: integrative literature review. *Fatores biopsicossociais que interferem na reabilitação de vítimas de queimaduras: Revisão integrativa da literatura* 2011;19:622–630.
19. Larsen p. Chronicity. In: Lubkin IM, Larsen PD, editors. *Chronic Illness: Impact and Intervention.* 7th ed. Jones and Bartlett; Boston, MA: 2009. pp. 3–24
20. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms *Ann Behav Med* 2003;26:1-7.
21. Richard AA, Shea K J Delineation of self-care and associated concepts. *Nurs Scholarsh.* 2011 Sep; 43(3):255-64. p261
22. Horwitz RI, Horwitz SM. Adherence to treatment and health outcomes. *Arch Intern Med* 1993;153:1863-1868.
23. Horwitz RI, Viscoli CM, Berkman L, et al. Treatment adherence and risk of death after a myocardial infarction. *Lancet* 1990;336:542-545.
24. S. Nolte, G. Elsworth, A. Sinclair, R.H. Osborne The extent and breadth of benefits from participating in chronic disease self-management courses: a national patient-reported outcomes survey *Patient Educ Counsel*, 2007; ;65(3):351-60.
25. Kornhaber RA, Wilson A, Abu-Qamar MZ. Coming to terms with it all: adult burn survivors' 'lived experience' of acknowledgement and acceptance during rehabilitation. *Burns.* 2014;40(4):589-97.
26. National Institute for Health Research (2013) HTA – 12/145/04: a feasibility study and open pilot two-arm randomised controlled trial comparing Pressure Garment Therapy with no Pressure Garment Therapy for the prevention of abnormal scarring after burn injury (PEGASUS).
27. Schulman-Green D, Jaser S, Martin F, Alonzo A, Grey M, McCorkle R, et al. Processes of self-management in chronic illness. *J Nurs Scholarship* 2012;44(2):136-44.
28. Corbin JM, Strauss A. *Unending work and care: Managing chronic illness at home.* San Francisco, CA: Jossey-Bass; 1998.
29. Dunbar SB, Clark PC, Quinn C, Gary RA, Kaslow NJ. Family influences on heart failure self-care and outcomes. *J Cardiovasc Nurs* 2008;23(3):258-265.

30. Grey M, Knafk K, McCorkle R. A framework for the study of self and family management of chronic conditions. *Nurs Outlook* 2006;54(5):278-286.
31. Ryan P, Sawin KJ. The Individual and Family Self-Management Theory: Background and perspectives on context, process, and outcomes. *Nurs Outlook* 2009;57(4):217-225.
32. Saunders, B., Sim, J., Kingstone, T., Baker S, Waterfield J, Bartlam B, Burroughs H, Jinks C. *Qual Quant* (2018) 52: 1893. <https://doi.org/10.1007/s11135-017-0574-8>
33. Bogan LK, Powell JM, Dudgeon B J. Experiences of living with non-cancer-related lymphedema: Implications for clinical practice. *Qual Health Res* 2007;17:213-224.
34. Dahl O, Wickman M, Wengstrom Y. Adapting to life after burn injury-reflections on care. *J Burn Care Res* 2012;33:595–605.
35. National voices, prioritising person-centre care supporting self-management 2014]
36. Kidd L, Lawrence M, Booth J, Rowat A and Russell S (2015) Development and evaluation of a nurse-led,tailored stroke self-management intervention. *BMC Health Serv Res* 15, 359
37. Ersser SJ, Cowdell FC, Latter SM, Healy E. Self-management experiences in adults with mild-moderate psoriasis: An exploratory study and implications for improved support. *Br J Dermatol* 2010;163:1044-1049. (5): 347–50.
38. Paterson B, Thorne S. Developmental evolution of expertise in diabetes self-management. *Clin Nurs Res* 2000;9(4):402-419.
39. Ahee AM, Smith SJ, Pliska-Matyshak G, Cullen ML. When does itching start and stop post-burn? *J Burns Care Rehabil* 1999;20:S187.
40. Furler J, Walker C, Blackberry I, et al. The emotional context of self-management in chronic illness: A qualitative study of the role of health professional support in the self-management of type 2 diabetes. *BMC Health Serv Res* 2008;8:1-9.
41. Esselman PC. Burn rehabilitation: an overview. *Arch Phys Med Rehabil* 2007 Dec;88(12 Suppl 2):S3-6.
42. Hwang EJ, Kim YH, Jun SS. Lived experience of Korean women suffering from rheumatoid arthritis: a phenomenological study. *Int J Nurs Stud* 2004;41:239-246.
43. Lee AM, Poole G. An application of the transactional model to the analysis of chronic illness narratives. *Qual Health Res* 2005;15:346-364.
44. Rossi L, Silva Costa M, Dantas R, Ciofi-Silva C, Lopes L. Cultural meaning of quality of life: perspectives of Brazilian burn patients. *Disabil Rehabil: Int Multidis J* 2009;31:712-719.
45. Moi A, Gjengedal E. Life after burn injury: striving for regained freedom. *Qual Health Res* 2008;18:1621-1630.

46. Wiechman SA. Psychosocial recovery, pain, and itch after burn injuries. *Phys Med Rehabil Clin N Am* 2011;22(2):327-45.
47. Sheridan RL. Burn rehabilitation. Medscape. 2016. Available at: <http://emedicine.medscape.com/article/318436-overview> (accessed March 2017).
48. Bennett SJ, Cordes DK, Westmoreland G, Castro R, Donnelly E. Self-care strategies for symptom management in patients with chronic heart failure. *Nurs Res* 2000;49:139-145.
49. Cicutto L, Brooks D, Henderson K. Self-care issues from the perspective of individuals with COPD. *Patient Educ Couns* 2004;55:168-176.
50. Courts NF, Buchanan EM, Werstlein PO. Focus groups: The lived experience of participants with multiple sclerosis. *J Neurosci Nurs* 2004;36:42-47.
51. Riley JP, Gabe JP, Cowie MR. Does telemonitoring in heart failure empower patients for self-care? A qualitative study. *J Clin Nurs* 2013;22(17-18):2444–55.
52. Or CK, Karsh BT, Severtson DJ, Burke LJ, Brown RL, Brennan PF. Factors affecting home care patients' acceptance of a web-based interactive self-management technology. *J Am Med Inform Assoc* 2011;18(1):51-9.
53. Taylor DM, Stone SD, Huijbregts MP. Remote participants' experiences with a group-based stroke self-management program using videoconference technology. *Rural Remote Health* 2012;12:1947.
54. Fex A, Flensner G, Ek AC, Soderhamn O. Self-care agency and perceived health among people using advanced medical technology at home. *J Adv Nurs*. 2012;68(4):806-815.
55. Austin SA, Claiborne N. Faith wellness collaboration: a community-based approach to address type II diabetes disparities in an African-American community. *Soc Work Health Care*. 2011;50(5):360–75. doi:10.1080/00981389.2011.567128.
56. Shaw SJ, Armin J, Torres CH, Orzech KM, Vivian J. Chronic disease self-management and health literacy in four ethnic groups. *J Health Commun*. 2012;17 Suppl 3:67–81. doi:10.1080/10810730.2012.712623.
57. Gaun Yersel; Scotland <http://www.gov.scot/Resource/0042/00422988.pdf> accessed July 2017
58. Living with long-term conditions in Northern Ireland <https://www.health-ni.gov.uk/publications/living-long-term-conditions-policy-framework> accessed August 2017
59. Designed to Improve Health and the Management of Chronic Conditions in Wales http://www.wales.nhs.uk/documents/Chronic_Conditions_English.pdf accessed August 2017
60. The coalition for collaborative care NHS England <http://coalitionforcollaborativecare.org.uk/> accessed August 2017

61. Dwarswaard J, Bakker EJ, van Staa A, Boeije HR. Self-management support from the perspective of patients with a chronic condition: a thematic synthesis of qualitative studies. *Health Expect* 2016;19(2):194-208.
62. Kennedy A, Rogers A, Bower P. Support for self care for patients with chronic disease *BMJ* 2007; 335 :968

