

“Negotiating a new normality” - a longitudinal qualitative exploration of the meaning of living with an open surgical wound

Ljubiša Pađen ^{a,b}, Jane Griffiths ^b and Nicky Cullum ^{b,c}

^aDepartment of Nursing, Faculty of Health Sciences, University of Ljubljana, Ljubljana, Slovenia; ^bDivision of Nursing, Midwifery and Social Work, the University of Manchester, Manchester, UK; ^cResearch & Innovation Division, Manchester University NHS Foundation Trust Research Office, Manchester, UK

ABSTRACT

Purpose: Little is known about the experiences of people living with open surgical wounds. These wounds are common and predominantly affect young and actively working people. The aim of this qualitative study was to explore the meaning of living with open surgical wounds.

Methods: A qualitative exploratory study was conducted. We collected data using two individual interviews with each of ten participants (aged between 18–73 years) who had open surgical wounds. Our analytical approach was based on qualitative content analysis. Methods are reported using COREQ guidelines.

Results: We found that the meaning of living with open surgical wounds is shaped by five subthemes: “enduring healing”, “life disruption”, “adapting to a new reality”, “striving for healing” and “returning to normal life;” all under an overarching theme of “negotiating a new normality”.

Conclusion: Participants’ well-being and everyday living are greatly impacted by open surgical wounds. Findings from this study emphasize that open surgical wounds are a long-term condition with a typical “chronicity” trajectory; this brings a new perspective to previous findings of studies on living with complex wounds. This study has also highlighted areas for further research, related to improving individuals’ experience of living with open surgical wounds.

ARTICLE HISTORY

Accepted 9 September 2022

KEYWORDS

Healing by secondary intention; complex wound; lived experience; suffering; adaptation; quality of life; complexity; body image; qualitative content analysis; nursing



Introduction

Complex wounds (also known as chronic wounds or hard to heal wounds) are wounds with superficial, partial or full thickness skin loss left open to heal by the growth of granulation tissue (referred to as healing by secondary intention; Cullum et al., 2016). They are a common and global health issue with an estimated prevalence of 1.64 per 1,000 (Gray et al., 2018). Complex wounds are managed across different levels of health services and a large amount of resources are allocated to their care (Gray et al., 2018; Urwin et al., 2022).


There are different subgroups of complex wounds, which differ in aetiology or underlying pathology (Cullum et al., 2016; Hall et al., 2014; Martinengo et al., 2019). Some complex wounds, such as arterial and venous ulcers, wounds related to diabetes and pressure injuries/ulcers have been extensively studied from the point of view of epidemiology (Cullum et al., 2016; Martinengo et al., 2019), interventions (Cochrane Wounds, n.d.) and impact on quality of life (Briggs & Fleming, 2007; Coffey et al., 2019;

Gorecki et al., 2009; Herber et al., 2007; Persoon et al., 2004; Phillips et al., 2018), whilst open surgical wounds (OSWs) have been less studied and only recently received research attention (Chetter et al., 2017, 2019; Liu et al., 2018; McCaughan et al., 2018; Norman et al., 2020; Pađen et al., 2019; Seidel et al., 2020; Shiroky et al., 2020; Thom et al., 2021).

Surgical wounds are usually sutured or clipped and heal by primary intention without complications (Harper et al., 2014; Walter et al., 2012; Young & McNaught, 2011). However some surgical wounds are open and heal by secondary intention, for a variety of reasons. Surgical wounds may be deliberately left open to heal because of a high risk of infection: open healing allows easy drainage (Chetter et al., 2017, 2019). Alternatively, surgical wounds may be left open to heal because of a large tissue deficit, after excision, where wound edges cannot be surgically approximated, or when a delayed primary closure technique is used (Siribumrungwong et al., 2014). OSW can also result from wound dehiscence e.g., partial or full separation of surgically closed wound

CONTACT Ljubiša Pađen  ljubisa.paden@zf.uni-lj.si  Department of Nursing, Faculty of Health Sciences, University of Ljubljana, Zdravstvena pot 5, Ljubljana 1000, Slovenia

This article has been corrected with minor changes. These changes do not impact the academic content of the article.

 Supplemental data for this article can be accessed online at <https://doi.org/10.1080/17482631.2022.2123932>

© 2022 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

with or without the exposure of underlying tissue or even organs (World Union of Wound Healing Societies, 2018). Surgical wound dehiscence occurs due to various reasons, such as: disruption in healing (impact of local and systemic factors, including patient comorbidities), or surgical technique, and can even occur due to excessive tension on wound edges, for example, when the patient is coughing (Casha et al., 2014; Listewnik et al., 2019; Sandy-Hodgetts et al., 2015).

Little is known about *living with* OSWs, despite their prevalence and potential for causing unpleasant symptoms and negative impact on well-being, compared to an ever-growing body of literature on living with other types of complex wounds (Alexander, 2010; Briggs & Flemming, 2007; Coffey et al., 2019; Gorecki et al., 2009; Herber et al., 2007; Lindahl et al., 2007; Lo et al., 2012, 2008; Persoon et al., 2004; Phillips et al., 2018; Probst et al., 2013a, 2013b). Findings from studies of other types of complex wounds have illustrated the negative effects they have on people's physical, psychological and social well-being (Briggs & Flemming, 2007; Coffey et al., 2019; Gorecki et al., 2009; Herber et al., 2007; Persoon et al., 2004; Phillips et al., 2018). For example, the wound itself is associated with negative emotions such as fear, frustration, anxiety and depression. Researchers reported that people with wounds often have restricted social lives, reduced social contact and experienced social isolation (Klein et al., 2021). Complex wounds also affect mobility and produce a cascade of even deeper impacts on people's well-being (Briggs & Flemming, 2007; Coffey et al., 2019; Gorecki et al., 2009; Herber et al., 2007; Persoon et al., 2004; Phillips et al., 2018).

While there is likely to be some overlap of the impact of open surgical wounds with other types of complex wounds, there may be important differences as yet unexplored. For example, people with open surgical wounds are more likely to be younger compared to people with other types of complex wounds (Chetter et al., 2017; Hall et al., 2014). Complex wounds such as leg ulcers or foot ulcers are often shallow, affecting skin and subcutaneous tissue, while surgical wounds can be deep and affect deep tissue and organs (Chetter et al., 2019). Furthermore, complex wound related symptoms are diverse in their intensity; some studies have suggested that people with pressure injuries/ulcers (Girouard et al., 2008) or wounds related to diabetes (Ribu et al., 2006) experience pain more frequently compared with people with leg ulcers (Persoon et al., 2004), while people with leg ulcers are reported to experience more frequent wound related pruritus (Paul, 2013) than people with open surgical wounds (Pađen et al., 2019).

A recent UK study by McCaughan et al. (2018) illustrated the experiences of people living with

OSWs. This qualitative interview study found that people suffer greatly due to their deep, odorous and moist wounds, with all domains of daily life being greatly impacted, especially for those who were young and still working. Importantly, the study by McCaughan et al. (2018) was cross-sectional and a longitudinal approach would capture people's experiences and the impact over time, as a recent quantitative study carried out by Chetter et al. (2019) has shown that health-related quality of life scores of individuals with an open surgical wound improves with time.

Apart from the qualitative study by McCaughan et al. (2018), the only study to our knowledge that has looked at unpleasant symptoms of OSWs was carried out by Pađen et al. (2019) as a part of an epidemiological survey across health and social care services in Ljubljana (Slovenia). One of the aims of that study was to explore the burden of unpleasant symptoms experienced by people with OSWs. 110 patients with OSWs were identified and found that they frequently experienced symptoms, such as pain and exudate (84% and 75% respectively), while malodour (32%) and pruritus were experienced less frequently (10%); (Pađen et al., 2019). The impact of these unpleasant symptoms which were prevalent in the OSWs population were explored in this subsequent study.

A relative lack of understanding of the impact of OSWs directed us towards the need for further exploration of how patients are affected by them. Furthermore, as existing quantitative data on OSW have suggested that impacts on quality of life change over time, and considering the possible limitation of the findings in the context of condition evolution in McCaughan et al. (2018) study, we designed a longitudinal, qualitative study, with the aim of understanding in depth the meaning of living with OSWs.

Methods

A qualitative, interview-based study sought to explore the meaning of living with open surgical wounds over time. The COREQ checklist guided reporting of this study (Supplementary File 1).

Procedures

After obtaining approval from the University of Manchester Research Ethics Committee 1 (Ref. 16,301) and Republic of Slovenia National Medical Ethics Committee (0120-451/2016-2 KME 32/09/16), and gaining the permission of the local primary services provider, we commenced our participant recruitment procedures.

Participants with OSW were sampled from Primary Care Services in Ljubljana (Slovenia), where adult patients generally have their own general practitioner

(some of the patients under 26 years old might still use school health services—medical doctors specializing in paediatric or school medicine). Patients with major surgical wound complications would generally be referred to a surgeon and then, according to the treatment plan, wound management would be provided by primary care teams (General practitioner and Registered nurse or Nursing assistant). Minor complications such as wound dehiscence would be managed by primary care teams.

Inclusion criteria were: individuals with open surgical wounds, defined as “superficial-, partial-, or full-thickness skin loss wounds healing by secondary intention”, which had been clinically confirmed by an medical doctor or registered nurse; at least 18 years old; living at home and being treated in the community; able to understand and communicate in Slovene and able to give informed consent. Participants were excluded if they had impaired cognitive capacity (such as dementia) or had pre-existing, documented severe mental illness or had any other complex wounds besides a surgical wound healing by secondary intention, as this might influence people’s experiences of the observed phenomena. Participants who had terminal illness or were in emergency situations were also excluded.

Recruitment was carried out in two phases. First, the health professionals who were providing health-care services to eligible participants approached the potential participants and briefly informed them about the study. All eligible participants were given a Participant Information Sheet (written information) and asked if they were prepared to participate. In the second phase, i.e., 24 hours later, the researcher contacted each eligible participant who had signalled their willingness to participate, providing them with additional explanations about the study, and answering any questions, and then the participant was asked to sign the informed consent form for participating in the study. All participants were informed that participation in the study is voluntary and that they are free to withdraw at any time without giving a reason and without detriment to any treatment/service.

Participants

Ten people (five women, five men) with OSWs were recruited with a median age of 41.5 years (18–73 years). All were white and Slovenian. Participants represent a range of sociodemographic backgrounds, namely three participants have finished the lower level of secondary school, two the upper level of secondary school, three had bachelor’s degrees and two master’s degree. One participant was widowed, two were single, three were married and four lived with a partner. The majority of people were employed ($n = 7$), two were retired and one was a student.

People underwent different types of surgery (dupuytren contracture, pilonidal sinus excision, different abdominal surgeries, amputations, excision of abscesses, C-section) which resulted in open surgical wounds involving different body locations (finger/hand, gluteus, abdomen, leg, foot, armpits/upper extremities). Four people had their wound left open at the time of surgery and six had a wound which was closed and then dehisced.

Data collection

Data were collected at participants’ homes or the researcher’s office where privacy and confidentiality could be ensured between April 2017 and March 2018, through face-to-face semi-structured interviews using a topic guide. The researcher, male, registered nurse by his background and trained in qualitative methods at PhD level (L.P.) asked open-ended questions with follow-up questions to elicit participants’ experiences, for example: “Please describe your journey of having the wound”. In the interviews we addressed topics related to the journey of living with a wound, experiences of unpleasant symptoms, physical, psychological and social health, financial impacts, and coping strategies, and experiences related to treatments. Each participant took part in two interviews: the first when they were identified as eligible (usually at the beginning of their condition) and the second when they notified the researcher that the wound had almost or completely healed (between 4 and 16 weeks after first interview). The interview audio recordings lasted between 17 and 59 minutes. The researcher (L.P.) transcribed each interview immediately afterwards. After the first interview, participants were asked to answer a short demographic questionnaire.

Data analysis

Data were analysed using a qualitative content analysis (QCA) approach (Graneheim and Lundman (2004) and Graneheim et al. (2017)). During the analysis process, all the interviews were read as a whole to obtain a sense of them. The first reading helped the researcher (L.P.) to understand the ideas for further data analysis. In the next process in the analysis (Table 1) the transcribed text was divided into units of meaning (words, sentences or phrases associated with the context). Each meaning unit was then condensed (text and words which were not related to the context were removed from the meaning unit). The condensed meaning unit was abstracted and labelled with a code. Due to the rich nature of the data, the codes were grouped, based on similarity, into subthemes and one overall theme, which reflected the latent content (Graneheim et al., 2017; Graneheim & Lundman, 2004). The data analysis

Table 1. Example of process of data analysis.

Meaning unit	Condensed meaning unit	Code	Subtheme	Theme
When I looked at it, I understood that this is a part of me, that this looks as it looks; and then you start to think, to process it in your head; and I don't mean from a medical perspective—where is the infection and is there redness—but in your subconscious, this is on you, this is yours, this is you ... You start to be aware that this is really on you and that it will stay for some time, and that you have to accept it. This is how it is.	I understood that this is a part of me this is on you, this is yours, this is you ... You start to be aware that this is really on you and that it will stay for some time, and that you have to accept it. This is how it is.	Acceptance	Adapting to a new reality	Negotiating a new normality
At the beginning I needed and really appreciated help. My mother helped me a lot, especially by taking care for the older child. Husband helped also, but he was at work during the day.	I needed and appreciated help. My mother helped me a lot ... Husband helped also ...	Accepting outside support		
I looked at the Internet, as I needed information about this "condition". I am not a professional like you ... When you hear the word "gangrene" you are scared, and then you seek information.	I looked at the Internet, as I needed information about this "condition". ... When you hear the word "gangrene" you are scared, and then you seek information.	Seeking information		

was discussed and codes and subthemes agreed among all three researchers (L.P., J.G., N.C.).

Language consideration

The first two phases of analysis (developing meaning units and condensing) were carried out in the Slovene language. This decision was taken due to limited resources being available for translating complete interviews. The data were then coded directly in English and the analysis process was completed in English.

Confidentiality and ethical considerations

This study conformed to the ethical principles for medical research on human beings set out in the declaration of Helsinki (World Medical Association, 2013). Furthermore it has fulfilled the requirements of research: information, consent, confidentiality and safety of the participants and was guided by the ethical principles: autonomy, beneficence, non-maleficence, and justice. A strategy to ensure participants' privacy and confidentiality was developed in advance. Ethical considerations such as emotional distress, safety or even identification of poor or less than optimal practice during the interviews were taken into consideration and were specifically addressed in the ethics review application (protocols available upon request).

Results

The meaning of living with open surgical wounds is illustrated by a main theme, "negotiating a new normality", which reflects the complex disruption of life, perceived as long and emotionally harrowing. Helping people to live with OSWs involves provoking them into action and into having the aspiration to get through their wound related difficulties. The journey

through the experience of having open surgical wounds is then resolved on returning to normal, though a reconstructed life which reflects new challenges related to past experiences. The analysis resulted in five sub-themes: "Enduring healing", "Life disruption", "Adapting to a new reality", "Striving for healing" and "Returning to normal life" (Supplementary File 2). The sub-themes are presented in the sections that follow.

Enduring healing

Participants with open surgical wounds were enduring healing. The experience of living with a chronic, slow-healing wound was unexpected and unpleasant. Participants who experienced wound dehiscence were surprised by it and usually not aware of dehiscence as a possibility; the situation they found themselves in was previously unimaginable for them. On the other hand, for participants who were aware that their wound would be left open to heal during surgery, the "surprise" was associated with the time healing took to occur; for them it was unimaginable that they would be able to live with an open wound for such a long time.

Participants often used rich descriptors for their wound, such as: *nasty, smelly, ugly, horrible, disgusting, awful, dirty, unsightly and dreadful*, which reflected how unpleasant having a wound could be. Experiencing open surgical wounds and open healing provoked various reactions and feelings, including fears, worries and anger. The fears and worries were very much involved with the wound itself, wound-related symptoms, and the overall experience itself.

The wound was horrible – everything was, all the smell and pain. I was afraid of how it was going to end. At some point I was even scared that everything would fall out of my stomach. I didn't imagine this could happen. (P8)

Participants had fears and worries connected with the unpleasant symptoms associated with their wounds, such as pain, odour and exudate. They were worried that the symptom might be a sign of complications, perceiving exudate and odour as signs of a deterioration in healing. Often the symptoms increased their level of general uncertainty. Participants often reported fear of physical pain. It seemed that the experience of pain was initially more extreme, from their descriptions of their experience of open wounds, but later was accepted as part of the experience and they moved their focus away from it, or it seemed less important.

The wound is really painful; it's burning. It is unpleasant, and it really bothers me, also because everything is bandaged, and it really burns me inside. It's horrible, really horrible. (P1)

At the beginning it hurt a lot, but now it doesn't any more. My skin has become "deaf", which is logical, you know, if you have an open wound for weeks. (P3)

The worries, fears and uncertainty were closely associated with their overall experience of having a wound, or were due to the length of the healing. Participants also talked about their experience at a more abstract and holistic level, for example, that it would affect their life "experience". They perceived their wound as a very intrusive body/life experience.

Well, I always wanted a life, to make it nice, joyful, make something positive out of it, but now, I am losing it. I can't go to the mountains, I can't run, people are staring, and you either care about this or you don't. The "joy" has become ordinary life. The wound is now a barrier to the joy. (P5)

Life disruption

Open surgical wounds interfered with most aspects of participants' daily living, namely physical daily activities, work and their general social life. Open surgical wounds impacted on relationships with partners and provoked various reactions from loved ones. The wounds also impacted on participants' physical appearance; they evoked concerns about appearance and attractiveness in those affected and could cause embarrassment and shame.

Mobility was one of the activities most frequently referred to as being affected: the ability to move around in the home environment and in the outside environment. Participants described how their mobility was significantly reduced due to wounds and that they often needed assistance. The anatomical location of a wound influenced its impact on mobility. Sometimes treatment strategies and people's beliefs and fears caused reduced mobility, for example, a treatment such as negative pressure wound therapy, which can be bulky and requires electrical power.

You always have to take a care of those ropes [cable and drainage system] from the machine [NPWT]. You have to take care so you don't get stuck in the chair or on the door hook. You can't shower; you just use a cloth to wash yourself. You always have to look at that [NPWT]. I've started to cook a bit, now, but you have to take care. (P3)

Reduced mobility due to the wound often affected daily activities such as participation in family and leisure activities, shopping and buying food. The wounds interfered with individuals' ability to take care of their personal hygiene whilst simultaneously heightening the need for hygiene as they induced feelings of being dirty and smelly due to odour and exudate. Participants often noticed reduced appetite due to wound-associated symptoms such as pain or odour. Furthermore, they often had physical limitations, which often prevented them preparing meals or left them unable to lift heavy things due to the wound.

Firstly, you have to take care of the wound, change your dressings. It starts to impact you; I can't hang clothes up to dry ... I can't lift heavy things ... which bothers me as I can't bring groceries from the shop. It also bothers me as I can't take care of my child [new-born], it's hard to lift him. It is so unpleasant (P8).

Participants described disruption of work life due to the wounds, as they had to stay home on sick leave. Long periods of sick leave decreased financial stability and participants were often in need of support from others. Furthermore, they often perceived work in a wider context of satisfying their needs, both social and professional, and were pushed to make hard decisions which could affect them in later life; for example, one male patient said:

I had to leave school. I felt a lot of pressure; I was getting more and more F(s) [School grade]. It didn't work as I was missing too much. My parents supported this choice and I felt relieved. (P2).

Wounds and related symptoms also challenged participants' social lives. Participants often considered whether they would have social interaction, or were worried that others would notice the wound. In general they reduced physical social contact with others or started to avoid them despite their expressed need to meet them.

Individuals with open surgical wounds reported the impact on their relationships with their partners, and their reactions. Younger people described how their relationships were affected by reduced sexuality due to their changed physical appearance. Thoughts and feelings of being dirty (i.e., having wounds and wound symptoms) and fear of rejection produced feelings of low self-esteem, and people lost interest in sexuality or close physical contact. On the other hand they sought signs of acceptance from their partners, which evoked feelings of being still desired.

I am quite emotional, my partner is an important part of my life - a special part, I would say; and this was additional pressure on me. All this smell and exudate, you don't really have sex. ... It felt good, when she kissed me, and that she was there for me. (P9)

Female participants more frequently reported the reactions of their loved ones. Male partners' initial responses to the wounds were described as practical and solution-focused.

I can't describe how scared I was; my brains didn't work. I talked with my husband, he was also scared, but he just said, we need to go to doctor. For him it felt natural what to do, but I was completely lost. (P8)

It seems that partners and significant ones (parents, children) suffered along with the people with wounds. Like the people with wounds, partners also experienced fear and worries, and felt an imbalance in the harmony of their family and relationship. This created an emotional spin-off for the participants, as they were worried for their life partners' and important ones' feelings. Participants greatly appreciated their partners' support. Acceptance, non-judgement and not holding back boosted their morale.

She accepted the wound. You know she has a "stubborn cancer", and when she is ill, she doesn't have any energy, but she is very supportive of me, she pushes me onward and motivates me to continue. (P5)

Physical appearance and concerns related to attractiveness featured in individuals' descriptions (mostly younger, female and male). Bodily disfigurement was an important factor for participants. They were concerned about their body image; they were often afraid of exposing their bodies in front of others. They were worried about their attractiveness and felt undesirable. A person's perceived personal attractiveness and physique were often attributed to society-wide interaction related to physical appearance. Women described feeling less feminine.

Wounds, wound-associated symptoms and scarring produced feelings of embarrassment and shame. Most of the descriptions concentrated on participant's beliefs about themselves (for example, being dirty or smelly) and perceived societal prejudices. Participants described issues with the visibility of their condition, i.e., they were worried about how they were or would be perceived by others due to the malodour and extensive leaking from the wound. Although in reality most of the participants' wounds were hidden under clothes, they were still concerned about stigma. Some were worried about others noticing their condition, due to wound odour:

I am always scared that someone might smell the wound odour. Maybe this is my issue, I don't know, but I am worried. The majority of people only see my child anyway and I didn't tell everyone about the

wound. They can't see it, but I know that I have it. (P10)

Furthermore, a major issue for people was future scars after healing, which for them could be seen as marks which could provoke "labelling".

People look at scars and just see a "scar-face. How should I describe ... let's say that people are looking at you with some scorn ... (P9)

Adapting to a new reality

In the process of adaptation, participants became aware of the negative impacts of the wound, and their personal frailty, and started to accept a new reality. Acceptance was related to changed thoughts and rationalization. Participants reported that they had to accept the situation, as it was expected that it would take great amount of time to achieve complete healing. Participants started to understand that they would have to live with the wound and they would have to adapt to a new way of living for some time.

When I looked at it, I understood that this is a part of me, that this looks as it looks; and then you start to think, to process it in your head; and I don't mean from a medical perspective - where is the infection and is there redness - but in your subconscious, this is on you, this is yours, this is you ... You start to be aware that this is really on you and that it will stay for some time, and that you have to accept it. This is how it is. (P6)

Acceptance and setting new priorities were later resolved in actions such as seeking information about the wound, causes of the wound, treatments, and instructions for care. Participants often sought information on the Internet—various forums and online patient support groups—and information from nurses and physicians. However, information from different sources was often contradictory or wrong, which caused concern and uncertainty. The actions of seeking information and instructions for care often illustrated that participants were aware that they lacked information or that they had poor information about their treatment or their condition.

I looked at the Internet, as I needed information about this "condition". I am not a professional like you ... When you hear the word "gangrene" you are scared, and then you seek information. (P7)

I was reading information on the Internet about the condition. But then, when you start to read you can find almost anything. There are a lot of stupid things written which can even lead to harm. (P9)

A sense of empowerment encouraged people to adopt new behaviour. Actions related to taking care of the wound were described at an abstract level, such as being aware of and alert to the need for

action, or were described more specifically, for example, physical actions such as changing dressings, or providing time for care, and taking control of the wound and themselves. Changes in the physical performing of daily activities were noted and constructed patterns of protective behaviour. Participants reported that they protected their wounds with long periods of rest, reducing physical forces on the wound and being careful with it.

Participants also narrated a range of intersected coping strategies related to themselves and their state of the mind. There was a need to boost optimism and morale in order to live with a wound in everyday life. They described encouraging themselves to live, by staying positive and insisting on continuing with everything. They were self-motivating to cope with a life which was different for them. Participants also comforted themselves by minimizing their experience or by comparing their condition to something far worse:

It is just a period of time which has to be got through, with surgery and antibiotics, and then I hope that everything will be ok. It is not like I have only three months of life left. (P9)

Seeking and accepting outside support, especially at the beginning of the journey, was often perceived as needed; participants were content, and felt pleasant, relieved and encouraged. Participants sought support and gave importance to having support. On the other hand, support became a burden to them. Later, support was perceived as an intrusion into their life; individuals felt controlled, and under pressure due to questions and expectations.

It was all about the finger: my wound was the most important topic of each encounter. No one was interested in me, and I was fed up with people. It is nice to have people around you, but enough is enough. I said, "You have your life, leave me; I will manage; my finger is ok." (P1)

Participants also developed maladaptive coping strategies, such as self-isolation and withholding information. They withdrew and started to avoid the people supporting them, often due to the perceived invasiveness of the support.

I needed my time. There were always calls asking how I felt and if I needed something. I started to turn them down, as I needed my peace. I remember, later, once my brother said that I am making it too complicated. (P10)

Furthermore, participants started to withhold information about their condition. The reasons for information reticence were related to the nature of condition, perceived self-image, rumours, keeping their privacy and not raising concerns.

People are, by their nature very interested in other people's business. Everyone wants to know what,

how and why. One even asked me if I had stepped on a bomb, and this [comments from others] became unpleasant. All those questions and advice – I started to tell them that it was getting better so they would leave me alone. (P7)

Striving for healing

Participants with wounds strove for healing. They exerted themselves to recover and were willing to do or try anything to achieve it. Individuals were willing to accept invasive treatments regardless of potential complications, side-effects or risks associated with treatment, as treatments were often perceived as a hope to end the suffering.

I had seven operations. The wound didn't heal and they [surgeons] proposed plastic surgery. I was willing to undergo it regardless of whether I would suffer from long lasting aesthetic deformation – my buttocks would be deformed. I was not happy about it, but I would go for it, so the wound would heal better. (P2)

Participants made an effort to go through this experience. They struggled, often perceiving their actions as a "fight", and hope for healing. Striving for healing was related to people's treatment adherence, treatment experiences and relationship with the nurse or physician. Individuals said that they adhered to the advice and simple treatment interventions by following nurses'/physicians' orders; however when they felt that the treatment was not working as they expected, some patients took matters into their own hands, and others did not follow advice.

Well, I have to have those dressings every day, and I shower twice a day as instructed. But these dressings don't work, so I started to use dressings with silver instead. I read that silver kills bacteria, so wounds heal more quickly. (P2)

I knew that I had to rest, but I went to the birthday celebration. Later I bled from the wound ... A nurse came to change the dressing, but I had to go to the toilet, and probably I put too much weight on my foot and it started to bleed even more. (P5)

In their willingness to do anything, participants accepted various treatments which were offered to them, namely wound dressings, negative pressure wound treatment (NPWT), hyperbaric oxygen treatment (HBOT), light therapy, orthosis, various medicines such as antibiotics, anti-inflammatory drugs, biological treatment and analgesics, and surgical debridement and additional surgery. Participants were uncertain about their treatment plans; they were scared, had unanswered questions and were worried about or even unaware of potential side effects or complications. They often felt frustrated by their experience; often the treatment interventions raised concerns for them because they felt disempowered.

They propose different things to you and you try different things. I tried various dressings, including with silver to reduce the smell, and I got an allergic reaction. No one told me about this ... I also tried laser light therapy, which helped a bit, I think, but then the healing didn't make progress ... I was on antibiotics, and then at least the smell reduced a bit. ... I used pain medication to control the pain; I took one pill every two hours. (P6)

Over the weeks or months of treatment, participants and their health professionals built a relationship. According to the narratives, a good and trusting relationship was a requirement for treatment success. Individuals experienced a variety of behaviour from nurses/physicians, which was mostly positive. They said that they had often been reassured and comforted, and that they trusted and believed in the health professionals, which helped them to get through the experience. However on their journey they also had negative experiences, where, due to a lack of information, lack of empathy, or perceived incompetence, they reacted with mistrust and fear, and sought information and treatment elsewhere.

The worst thing is that nurses and doctors don't know a lot about this. I lost trust in the local GP and emergency services: they didn't know anything and I didn't want to go back there. When I first had surgery I had a hole 10 cm wide and 3 cm deep in my foot. I only trust the surgeon. She is really professional and I also go to the department [surgical department] to get my dressing changed. (P7)

Participants were patient and persistent in using health care services. Waiting times were of concern, however, they were willing to wait for additional check-ups, consultations with physicians from other specialities, and for other treatment to be provided.

Participants expected healing. Their expectations at the beginning were often not realistic and they were also burdened with healing-related uncertainty; however, their expectations changed over time. Healing was of particular interest for them; they were very glad when any progress was observed. Participants cherished feedback from healthcare professionals, and often asked them to take a photo, especially those individuals who could not see the wound due to its location. Photographs and feedback lifted their morale.

I look at my wound. I don't know a lot about the treatments, but I look when she [community nurse] changes the dressings and nicely washes the wound, and I look to see the progress in healing. This means a lot to me, and I do observe progress. (P5)

Returning to normal life

Finally, once healing occurred participants started to slowly return to their normal lives, and many said that their life was back in balance. They experienced

positive emotions and their self-esteem began to improve; they felt free again, were able to move freely and enjoyed life again. Participants started to perform daily activities in their old routine, and feel content with the normality of their lives. Their physical and mental performance started to improve greatly; they socialized with others again and were happy that attention had shifted away from them and their condition.

It was really hard experience. I can't really describe how it was. I was in fear, scared until the wound started to heal. I was scared that I would lose my leg. But when the healing occurred I almost immediately felt well, and the community nurse was also happy; we all were. And now that the wound is almost healed I feel great. I was really down, but now I feel completely different, really! (P4)

Individuals who were still working were happy to return to work, felt positive, changed their daily routine, were accepted at work, improved the social-professional domain of life, and improved their finances. Participants started to make plans for the future again.

When you are at home so much, you say to yourself that it's time to go to work. You also get tired of being at home all the time. I am doing well at work and I am quite happy. My routine has changed, and now that I am back, I can see how I was under pressure due to the wound. (P6)

Participants said, however, that the experience was stressful and unpleasant and had marked them for life. They kept remembering the experience, and the memories, for them, triggered fears. They described how they developed subconscious fears about the potential recurrence of the wound and about possible future experiences.

The doctor said, that this could repeat in future. When I think about it I can just feel all the chills and being, I don't know ... scared. It is not easy. (P9)

Although they were content that the wound had healed, a scar was not perceived as the end of their experience. Scars evoked memories and thoughts about the experience. A scar was often perceived as an eternal mark of experience.

Well it may sound strange, but the scar will stay forever; it'll remind me every day of this experience. For example, when I take shower, I see it, or when I scratch my belly, I feel a hard scar and kind of everything returns. (P10)

Discussion

Main results

The aim of this study was to explore the meaning of living with open surgical wounds over time. By

looking at the trajectory of meanings of living with OSW reflected in subthemes and the main theme, *"negotiating a new normality"*, it became apparent that the findings mirror the discourse in the chronicity literature (Bury, 1982; Charmaz, 1997; Corbin & Strauss, 1991). Chronicity is the process of becoming chronically ill, going on the journey of living with chronic illness, where one's person (oneself) and one's life is affected and disrupted, and where a reconstruction of self (identity) and life through coping mechanisms is accomplished (Smith-Morris, 2010). The subthemes and overarching theme reflect that people went through a process (stages) when living with OSW. Although we did not aim to explore the process or understand the links between concepts in processes related to chronicity, the longitudinal nature of this study with time windows between interviews brought to the light the changes in the experience of OSWs that happened over time.

The subthemes *"enduring healing"* and *"life disruption"* describe in depth the phenomenon of having a wound, from the perspective of the patients' initial reactions to the descriptions of profound impacts on well-being. This is coherent with the work of McCaughan et al. (2018) on patient perspectives of OSW and findings from many studies of people with other types of complex wound (Briggs & Flemming, 2007; Coffey et al., 2019; Gorecki et al., 2009; Herber et al., 2007; Persoon et al., 2004; Phillips et al., 2018). Findings attributed to both sub-themes mirror Bury's (1982) concept of biographical disruption, described as the impact of a chronic condition on individuals' biographies (lives), where peoples' known lives change and social relationships with others are impacted or might change.

Apart from descriptions of radiating impact on people's wellbeing, attention must be given to the impact on relationships (including sexuality). Concerns over perceived appearance, including stigma, were more prominent in participants' narratives in our study compared with that of McCaughan et al. (2018) and other complex wound research (Phillips et al., 2018). Our study yielded that people's relationships with their loved ones (life partners) or other significant were affected, especially in terms of sexuality and feelings of attractiveness. A possible reason for the extensive discussion of sexuality from both males and females is that our study sample consisted of young participants with OSW (average 40.5 years), which is different from the overall population with complex wounds, who are typically older (Chetter et al., 2017; Hall et al., 2014) or the population in McCaughan et al. (2018) study, where the median age was 53 years. Intimate relationships can break down due to change of self-perceived identity (in our study, perceived feelings of attractiveness and physical appearance) during (Bury, 1982; Charmaz,

1997; Karraker & Latham, 2015). Furthermore, other social relationships can be impacted due to the strain, demands and expectations that a person with such a condition might place on another (Eriksson & Svedlund, 2006; Eriksson et al., 2019; Sautter et al., 2014).

Participants also expressed concerns with their physical appearance: they were often concerned about public stigma due to their wounds and wound-related symptoms, which confirms the findings from previous wound research (Lindahl et al., 2007; McCaughan et al., 2018; Probst et al., 2013a, 2013b; Taverner et al., 2011). Fears that wounds and symptoms such as malodour or exudate could be observed by others, are disgusting and have impacts on everyday living could be attributed to an underlying cause: to individuals internalizing public stigma and developing self-stigma. Self-stigmatizing behaviour has been substantially theorized in other areas of chronic disease research (Corrigan & Watson, 2002; Scambler, 2009, 2006; Van Brakel, 2006) and is related to social withdrawal, social isolation and social alienation, which lead to deterioration of mental health, and development of anxiety and depression (Leigh-Hunt et al., 2017).

The subtheme *"Adapting to a new reality"* reflects participants' reactions, which are similar to the psychological adjustments described in the healthcare and chronicity literature (Bury, 1982; Charmaz, 1995, 1997; Dekker & de Groot, 2018; Gagliardi et al., 2002; De Ridder et al., 2008; Stanton et al., 2007; Vann-Ward et al., 2017). Living a long time with a wound results in developing adaptation behaviour to the "new", and can be interlaced with a high level of uncertainty, as previously described in other complex wounds studies (McCaughan et al., 2018; Persoon et al., 2004). Charmaz (1997) describes how individuals learn how to live with chronic conditions by normalizing their experience with adaptations that contain the unpleasant symptoms and make daily life ordinary. Furthermore, individuals react to new circumstances by seeking knowledge (Vann-Ward et al., 2017), and needing to be informed and empowered by information (Etkind et al., 2017). In our study, participants emphasized that they received conflicting information about their conditions and treatments. Conflicting information in healthcare is not a novelty; there have been many studies reporting that at some point up to 80% of patients receive conflicting information (often from various sources), which can affect their adherence to treatment and expected treatment outcomes (Carpenter et al., 2014, 2016; Elstad et al., 2012). Nurses and physicians should support individuals with information based on reliable and high quality evidence, and furthermore they should inform them about the credibility of health information sources, such as Google, and potential threats;

however this could be challenging, as there are many existing uncertainties related to effective wound care interventions (Gray et al., 2017).

Coping strategies were also verbalized and noted in this study, which is similar to previous complex wound studies (Briggs & Flemming, 2007; Coffey et al., 2019; Herber et al., 2007; Persoon et al., 2004; Phillips et al., 2018); however, in this study we also observed maladaptive strategies such as the emotional over-involvement of loved ones; which has not been well reported in the wound literature (Upton et al., 2021), in contrast to other chronic condition research, such as mental health (Butzlaff & Hooley, 1998; Izon et al., 2018). Individuals, after having a wound for some time, withdrew from loved ones and often perceived their support as intrusive, implying that relatives were an overly intense source of support and often did not respect the patients' autonomy. Furthermore, individuals often concealed information from others; an issue that has also been discussed in other chronicity literature, where it has been suggested that people withhold information due to potentially negative perceptions of others and the need to appear healthy (Charmaz, 1997; Joachim & Acorn, 2000; Kaushansky et al., 2017; Munir et al., 2005).

In the subtheme "*striving for healing*", willingness to do anything to achieve complete healing was one of the central features. "*Striving for*" is similar to Charmaz's (1997) conceptualization of the struggle for control in chronic illness. In their struggles, people aim to preserve their "self" (Vann-Ward et al., 2017). On the other hand, in the chronicity literature, the phenomenon of "*surrendering*" has also been described, which relates to a discontinuance of struggling against both unpleasant symptoms and the condition itself (Charmaz, 1995). The difference—why participants in our study were motivated to seek resolution and were trying to achieve it—might be the fact that open surgical wounds, in contrast to chronic conditions, are expected to heal, or the fact that participants' narratives related to their striving for healing were shaped by their age and their "old lives". Findings from our study also suggested that compliance and adherence, and trusting relationships with health-care professionals, intersected with their "*willingness*". In some cases, participants became non-adherent due to mistrust, based on their belief that the treatment was ineffective, or because they had received conflicting information or had mistrust in the nurse or GP-patient relationship (interaction); common reasons described in the chronic wound literature (Phillips et al., 2018) and chronic illness studies (Kyngäs, 2000; Kyngäs et al., 2000; Shahin et al., 2019; Van Hecke et al., 2011, 2009). It is well documented that non-adherence can lead to negative outcomes for patients (Currie et al., 2012; Gosmanova et al., 2014; Guerci et al., 2019; Ho et al., 2006), and therefore nurses and physicians should build professional and trusting relationships with patients and

deliver tailored interventions to enhance their adherence (Hallett et al., 2000; Kyngäs, 2000; Van Hecke et al., 2011; Weller et al., 2013). Some participants, in their striving for healing, were motivated to believe that treatments such as dressings containing silver would be effective, despite a lack of evidence that silver-containing dressings heal wounds more quickly (Vermeulen et al., 2007). Overall, there is a lack of reliable and valid evidence about the effectiveness of topical treatments on OSWs (Dumville et al., 2016; Jull et al., 2015; Norman et al., 2016; S. R. Smith et al., 2016; F. Smith et al., 2013; Vermeulen et al., 2004, 2007).

"*Returning to normal life*" is a sub-theme reflecting people's experience of achieving healing, which involves liberation, fears and memories. The sub-theme "*Returning to normal life*" departs from traditional chronicity descriptions of "*resolution*" (Bury, 1982; Charmaz, 1997), as the wounds had healed and participants were able to continue with their "*known*" life, in contrast to other chronic conditions. However, findings from our study have shown that scars often became the vehicle for negative emotions. This phenomenon is often reported in patients with burns and other conditions (Ngaage & Agius, 2018). The possible explanation for this might be, as previously mentioned, that our study sample was younger in age and this was due to possible wider societal constructs on appearance. Another is that the interviews took place soon after the patients' wounds first healed and it was easy to be reminded of the event, or that participants were traumatized by the experience of having wounds (Tedstone & Tarrier, 1997).

Conceptual similarities to the chronicity literature signal that experiencing OSW might be as devastating in terms of suffering as experiencing other chronic conditions which in lay understanding might be considered "*more serious*". We were surprised to find such similarities with the chronicity literature, as the usual experience of OSWs is that it is expected to end (i.e., the OSW is expected to heal completely). Furthermore, complete healing is achieved in a shorter time frame (Chetter et al., 2019) compared with other complex wounds (Hall et al., 2014). Understanding and being aware that individuals with OSWs—a relatively short-term condition—respond in the same way as those with more typically long term conditions leads to the conclusion that people, regardless of the duration of their condition, might both suffer and find resolution in a similar ways (experiencing disruption and developing adaptations and coping mechanisms). Secondly, the findings signal health care professionals to be attentive when providing care: the care model for individuals with OSW should be adjusted in such a way as to promote addressing the whole range of their needs and suffering, which are related to the physical, psychological, social and vocational domains of people's well-being.

Trustworthiness

This study has a number of strengths. It is one of the first studies to provide in-depth insight into experiences of having OSWs globally. A particular contribution of this study is that it has illuminated that the experience of having OSWs changes over time, which is probably a result of the longitudinal nature of this study. It has identified significant findings related to the impacts on participants' wellbeing; furthermore it has revealed participants' adapting and coping strategies, which enable them to normalize their lives; these (e.g., subthemes *adapting to a new reality*, *striving for healing* and *returning to normal life*) were not comprehensively described or described at all in previous studies (e.g., McCaughan et al., 2018). Another strength related to the findings is that the study has shed light on how experiences of OSWs are similar to those described in chronicity literature, which indicates the need to consider using a longitudinal design when exploring people's experiences with complex wounds.

There are also a few methodological considerations related to credibility, dependability and transferability. One limitation is that we recruited only ten participants for this study; however we believe that the variety in the sample and conducting two in-depth interviews have none the less contributed to variation in perspectives, depth and richness of findings which promotes credibility. We have noted that descriptions of impacts on participants might be different based on wound location; however we have aimed to describe and interpret the meaning of living with an open surgical wound as a phenomenon rather than to report specifics of experience based on wound location. Though the analysis, up to the phase of development of sub-themes, was carried out by one researcher (L.P.), we believe that credibility is not affected, as we have described the approach in a logical and structured manner. Secondly, we have supported our findings (in terms of subthemes and a theme) with rich descriptions and quotes. Furthermore, all aspects of data collection and analysis were discussed with co-researchers (J.G. and N.C.) in order to obtain the most plausible interpretation of findings. A possible critical issue in the data analysis is in fact that it was carried out partially in Slovene and was later continued in English; however we believe that this has not affected the credibility of findings to a great degree, as the primary researcher (L.P.) is proficient in both languages, and furthermore, the interviews (as a whole) and data analysis were discussed by all three researchers. Interviews as a data collecting technique can be seen as a possible threat to dependability (Graneheim & Lundman, 2004); however, due to the longitudinal nature of the study and through using a topic guide, we were able to return to the topics

which were addressed only superficially (or were later revealed to be relevant in interviews with other participants) in the follow-up interviews. When considering transferability, we believe that findings from our study to be transferable to other individuals with OSWs as our sample reflects a similar population (in terms of gender and age) to those reported in epidemiological studies (Chetter et al., 2017, 2019; Hall et al., 2014; Pađen et al., 2019); however this population was homogeneous by race (all white Slovene). Users of this research must take into account the specific context related to this study.

Conclusions

This study is one of the first to provide in-depth insight into people's experiences of having OSWs. A particular contribution of this study is that it has highlighted that the experience of having OSWs changes over time. The longitudinal nature of this study allowed us to explore this aspect of living with a wound. It has identified significant findings related to the impact on participant's wellbeing; furthermore it has revealed people's adapting and coping strategies, which enable them to normalize their lives. While they are in the process of doing so, health care professionals should respond by providing effective treatments and support to people. However, this might be a challenge as there is an overall lack of relevant evidence for such interventions. The findings have also shed light on how experiences of OSWs are similar to those described in the chronicity literature, which indicates the importance of using a longitudinal design when exploring individuals' experiences with complex wounds.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

Funded by L.P. as a self-funded PhD.

Notes on contributors

Ljubiša Pađen, PhD, RN, is a Senior lecturer in nursing and applied health researcher at the University of Ljubljana. His background in is nursing (Bachelor of nursing at the University of Ljubljana in 2009). He completed his PhD at the University of Manchester in 2021. His research address topics such as complex wound prevalence and exploring people's experience of living with complex wounds.

Jane Griffiths, PhD, BNurs, RGN, NDNCert is a Senior lecturer in nursing and researcher at the University of Manchester. Her background is in nursing (Bachelor of Nursing degree at Manchester University in 1988 & PhD at Liverpool University

in 1996). Jane's research involves topics related to community nursing, long term conditions and palliative care. More specifically, she is interested in improving staff patient communication in long term conditions and palliative care, prognostication at the end of life for patients with cancer and treatment decisions of older women with breast cancer.

Nicky Cullum, DBE, PhD, RGN, FMedSci, is Professor of Nursing at the University of Manchester & Director of the NIHR Applied Research Collaboration for Greater Manchester. Nicky was also a founding member of the Cochrane Collaboration and has served as Coordinating Editor of the Cochrane Wounds Group since 1995. Most of her research has been in wound care where her goal is to work with patients and clinicians to answer important questions about the causes of wounds and effective treatments and ultimately to enhance health outcomes.

Data availability statement

The data sets for this study is not open access due to restrictions e.g., their containing information that could compromise the privacy of research participants, but can be made available upon reasonable request to the corresponding author (L.P.) and after the additional ethical approval.

ORCID

Ljubiša Pađen  <http://orcid.org/0000-0003-1701-3070>

Jane Griffiths  <http://orcid.org/0000-0002-6674-6361>

Nicky Cullum  <http://orcid.org/0000-0003-2631-123X>

References

- Alexander, S. J. (2010). An intense and unforgettable experience: The lived experience of malignant wounds from the perspectives of patients, caregivers and nurses. *International Wound Journal*, 7(6), 456–465. <https://doi.org/10.1111/j.1742-481X.2010.00715.x>
- Briggs, M., & Fleming, K. (2007). Living with leg ulceration: A synthesis of qualitative research. *Journal of Advanced Nursing*, 59(4), 319–328. <https://doi.org/10.1111/j.1365-2648.2007.04348.x>
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), 167–182. <https://doi.org/10.1111/1467-9566.ep11339939>
- Butzlaff, R. L., & Hooley, J. M. (1998). Expressed emotion and psychiatric relapse: A meta-analysis. *Archives of General Psychiatry*, 55(6), 547–552. <https://doi.org/10.1001/archpsyc.55.6.547>
- Carpenter, D. M., Elstad, E. A., Blalock, S. J., & DeVellis, R. F. (2014). Conflicting medication information: Prevalence, sources, and relationship to medication adherence. *Journal of Health Communication*, 19(1), 67–81. <https://doi.org/10.1080/10810730.2013.798380>
- Carpenter, D. M., Geryk, L. L., Chen, A. T., Nagler, R. H., Dieckmann, N. F., & Han, P. K. J. (2016). Conflicting health information: A critical research need. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 19(6), 1173–1182. <https://doi.org/10.1111/hex.12438>
- Casha, A. R., Manché, A., Gatt, R., Duca, E., Gauci, M., Schembri-Wismayer, P., Camilleri-Podesta, M.-T., & Grima, J. N. (2014). Mechanism of sternotomy dehiscence. *Interactive Cardiovascular and Thoracic Surgery*, 19(4), 617–621. <https://doi.org/10.1093/icvts/ivu184>
- Charmaz, K. (1995). The Body, Identity, and Self: Adapting To Impairment. *The Sociological Quarterly*, 36(4), 657–680. <https://doi.org/10.1111/j.1533-8525.1995.tb00459.x>
- Charmaz, K. (1997). *Good days, bad days: The self in chronic illness and time* (2nd ed.). Rutgers University Press.
- Chetter, I. C., Oswald, A. V., Fletcher, M., Dumville, J. C., & Cullum, N. A. (2017). A survey of patients with surgical wounds healing by secondary intention; an assessment of prevalence, aetiology, duration and management. *Journal of Tissue Viability*, 26(2), 103–107. <https://doi.org/10.1016/j.jtv.2016.12.004>
- Chetter, I. C., Oswald, A. V., McGinnis, E., Stubbs, N., Arundel, C., Buckley, H., Bell, K., Dumville, J. C., Cullum, N. A., Soares, M. O., & Saramago, P. (2019). Patients with surgical wounds healing by secondary intention: A prospective, cohort study. *International Journal of Nursing Studies*, 891, 62–71. <https://doi.org/10.1016/j.ijnurstu.2018.09.011>
- Cochrane Wounds. (n.d.). *Cochrane Wounds*. Retrieved 8 May 2020, from /home
- Coffey, L., Mahon, C., & Gallagher, P. (2019). Perceptions and experiences of diabetic foot ulceration and foot care in people with diabetes: A qualitative meta-synthesis. *International Wound Journal*, 16(1), 183–210. <https://doi.org/10.1111/iwj.13010>
- Corbin, J. M., & Strauss, A. (1991). A nursing model for chronic illness management based upon the Trajectory Framework. *Scholarly Inquiry for Nursing Practice*, 5(3), 155–174.
- Corrigan, P. W., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry: Official Journal of the World Psychiatric Association (WPA)*, 1(1), 16–20.
- Cullum, N., Buckley, H., Dumville, J., Hall, J., Lamb, K., Madden, M., Morley, R., O'Meara, S., Goncalves, P. S., Soares, M., & Stubbs, N. (2016). *Wounds research for patient benefit: A 5-year programme of research*. NIHR Journals Library. <http://www.ncbi.nlm.nih.gov/books/NBK379923/>
- Currie, C. J., Peyrot, M., Morgan, C. L., Poole, C. D., Jenkins-Jones, S., Rubin, R. R., Burton, C. M., & Evans, M. (2012). The Impact of Treatment Noncompliance on Mortality in People With Type 2 Diabetes. *Diabetes Care*, 35(6), 1279–1284. <https://doi.org/10.2337/dc11-1277>
- Dekker, J., & de Groot, V. (2018). Psychological adjustment to chronic disease and rehabilitation—An exploration. *Disability and Rehabilitation*, 40(1), 116–120. <https://doi.org/10.1080/09638288.2016.1247469>
- de Ridder, D., Geenen, R., Kuijjer, R., & van Middendorp, H. (2008). Psychological adjustment to chronic disease. *The Lancet*, 372(9634), 246–255. [https://doi.org/10.1016/S0140-6736\(08\)61078-8](https://doi.org/10.1016/S0140-6736(08)61078-8)
- Dumville, J. C., Gray, T. A., Walter, C. J., Sharp, C. A., Page, T., Macefield, R., Blencowe, N., Milne, T. K., Reeves, B. C., & Blazeby, J. (2016). Dressings for the prevention of surgical site infection. *Cochrane Database of Systematic Reviews*, 12. <https://doi.org/10.1002/14651858.CD003091.pub4>
- Elstad, E., Carpenter, D. M., DeVellis, R. F., & Blalock, S. J. (2012). Patient decision making in the face of conflicting medication information. *International Journal of Qualitative Studies on Health and Well-Being*, 7. <https://doi.org/10.3402/qhw.v7i0.18523>
- Eriksson, M., & Svedlund, M. (2006). 'The intruder': Spouses' narratives about life with a chronically ill partner. *Journal*

- of *Clinical Nursing*, 15(3), 324–333. <https://doi.org/10.1111/j.1365-2702.2006.01290.x>
- Eriksson, E., Wejåker, M., Danhard, A., Nilsson, A., & Kristofferzon, M.-L. (2019). Living with a spouse with chronic illness – The challenge of balancing demands and resources. *BMC Public Health*, 19, 19. <https://doi.org/10.1186/s12889-019-6800-7>
- Etkind, S. N., Bristowe, K., Bailey, K., Selman, L. E., & Murtagh, F. E. (2017). How does uncertainty shape patient experience in advanced illness? A secondary analysis of qualitative data. *Palliative Medicine*, 31(2), 171–180. <https://doi.org/10.1177/0269216316647610>
- Gagliardi, B. A., Frederickson, K., & Shanley, D. A. (2002). Living with multiple sclerosis: A Roy adaptation model-based study. *Nursing Science Quarterly*, 15(3), 230–236. <https://doi.org/10.1177/08918402015003009>
- Girouard, K., Harrison, M. B., & VanDenKerkof, E. (2008). The symptom of pain with pressure ulcers: A review of the literature. *Ostomy/Wound Management*, 54(5), 30–40, 42.
- Gorecki, C., Brown, J., Nelson, A., Briggs, M., Schoonhoven, L., Dealey, C., Defloor, T., & Nixon, J. (2009). Impact of pressure ulcers on quality of life in older patients: A systematic review. *Journal of the American Geriatrics Society*, 57(7), 1175–1183. <https://doi.org/10.1111/j.1532-5415.2009.02307.x>
- Gosmanova, E. O., Lu, J. L., Streja, E., Cushman, W. C., Kalantar-Zadeh, K., & Kovesdy, C. P. (2014). Association of medical treatment nonadherence with all-cause mortality in newly treated hypertensive US Veterans. *Hypertension*, 64(5), 951–957. <https://doi.org/10.1161/HYPERTENSIONAHA.114.03805>
- Graneheim, U. H., Lindgren, B.-M., & Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Education Today*, 56(9), 29–34. <https://doi.org/10.1016/j.nedt.2017.06.002>
- Graneheim, U. H., & Lundman, B. M. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105–112. <https://doi.org/10.1016/j.nedt.2003.10.001>
- Gray, T. A., Dumville, J. C., Christie, J., & Cullum, N. A. (2017). Rapid research and implementation priority setting for wound care uncertainties. *PloS One*, 12(12), e0188958. <https://doi.org/10.1371/journal.pone.0188958>
- Gray, T. A., Rhodes, S., Atkinson, R. A., Rothwell, K., Wilson, P., Dumville, J. C., & Cullum, N. A. (2018). Opportunities for better value wound care: A multiservice, cross-sectional survey of complex wounds and their care in a UK community population. *BMJ Open*, 8(3), e019440. <https://doi.org/10.1136/bmjopen-2017-019440>
- Guerci, B., Chanan, N., Kaur, S., Jasso-Mosqueda, J. G., & Lew, E. (2019). Lack of treatment persistence and treatment nonadherence as barriers to glycaemic control in patients with type 2 diabetes. *Diabetes Therapy: Research, Treatment and Education of Diabetes and Related Disorders*, 10(2), 437–449. <https://doi.org/10.1007/s13300-019-0590-x>
- Hall, J., Buckley, H. L., Lamb, K. A., Stubbs, N., Saramago, P., Dumville, J. C., & Cullum, N. A. (2014). Point prevalence of complex wounds in a defined UK population. *Wound Repair and Regeneration: Official Publication of the Wound Healing Society [And] the European Tissue Repair Society*, 22(6), 694–700. <https://doi.org/10.1111/wrr.12230>
- Hallett, C. E., Austin, L., Caress, A., & Luker, K. A. (2000). Community nurses' perceptions of patient 'compliance' in wound care: A discourse analysis. *Journal of Advanced Nursing*, 32(1), 115–123. <https://doi.org/10.1046/j.1365-2648.2000.01407.x>
- Harper, D., Young, A., & McNaught, C.-E. (2014). The physiology of wound healing. *Surgery (Oxford)*, 32(9), 445–450. <https://doi.org/10.1016/j.mpsur.2014.06.010>
- Herber, O. R., Schnepf, W., & Rieger, M. A. (2007). A systematic review on the impact of leg ulceration on patients' quality of life. *Health and Quality of Life Outcomes*, 5(1), 44. <https://doi.org/10.1186/1477-7525-5-44>
- Ho, P. M., Rumsfeld, J. S., Masoudi, F. A., McClure, D. L., Plomondon, M. E., Steiner, J. F., & Magid, D. J. (2006). Effect of medication nonadherence on hospitalization and mortality among patients with diabetes mellitus. *Archives of Internal Medicine*, 166(17), 1836–1841. <https://doi.org/10.1001/archinte.166.17.1836>
- Izon, E., Berry, K., Law, H., & French, P. (2018). Expressed emotion (EE) in families of individuals at-risk of developing psychosis: A systematic review. *Psychiatry Research*, 270(12), 661–672. <https://doi.org/10.1016/j.psychres.2018.10.065>
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, 32(1), 243–248. <https://doi.org/10.1046/j.1365-2648.2000.01466.x>
- Jull, A. B., Cullum, N., Dumville, J. C., Westby, M. J., Deshpande, S., & Walker, N. (2015). Honey as a topical treatment for wounds. *Cochrane Database of Systematic Reviews*, 3. <https://doi.org/10.1002/14651858.CD005083.pub4>
- Karraker, A., & Latham, K. (2015). In sickness and in health? Physical illness as a risk factor for marital dissolution in later life. *Journal of Health and Social Behavior*, 56(3), 420–435. <https://doi.org/10.1177/0022146515596354>
- Kaushansky, D., Cox, J., Dodson, C., McNeeley, M., Kumar, S., & Iverson, E. (2017). Living a secret: Disclosure among adolescents and young adults with chronic illnesses. *Chronic Illness*, 13(1), 49–61. <https://doi.org/10.1177/1742395316655855>
- Klein, T. M., Andrees, V., Kirsten, N., Protz, K., Augustin, M., & Blome, C. (2021). Social participation of people with chronic wounds: A systematic review. *International Wound Journal*, 18(3), 287–311. <https://doi.org/10.1111/iwj.13533>
- Kyngäs, H. (2000). Compliance of adolescents with chronic disease. *Journal of Clinical Nursing*, 9(4), 549–556. <https://doi.org/10.1046/j.1365-2702.2000.00368.x>
- Kyngäs, H., Duffy, M. E., & Kroll, T. (2000). Conceptual analysis of compliance. *Journal of Clinical Nursing*, 9(1), 5–12. <https://doi.org/10.1046/j.1365-2702.2000.00309.x>
- Leigh-Hunt, N., Bagguley, D., Bash, K., Turner, V., Turnbull, S., Valtorta, N., & Caan, W. (2017). An overview of systematic reviews on the public health consequences of social isolation and loneliness. *Public Health*, 152(11), 157–171. <https://doi.org/10.1016/j.puhe.2017.07.035>
- Lindahl, E., Norberg, A., & Söderberg, A. (2007). The meaning of living with malodorous exuding ulcers. *Journal of Clinical Nursing*, 16(3A), 68–75. <https://doi.org/10.1111/j.1365-2702.2005.01550.x>
- Listewnik, M. J., Jędrzejczak, T., Majer, K., Szylińska, A., Mikołajczyk, A., Mokrzycki, K., Górka, E., & Brykczynski, M. (2019). Complications in cardiac surgery: An analysis of factors contributing to sternal dehiscence in patients who underwent surgery between 2010 and 2014 and a comparison with the 1990-2009 cohort. *Advances in Clinical and Experimental Medicine: Official Organ Wrocław Medical University*, 28(7), 913–922. <https://doi.org/10.17219/acem/94154>

- Liu, Z., Dumville, J. C., Norman, G., Westby, M. J., Blazeby, J., McFarlane, E., Welton, N. J., O'Connor, L., Cawthorne, J., George, R. P., Crosbie, E. J., Rithalia, A. D., & Cheng, H.-Y. (2018). Intraoperative interventions for preventing surgical site infection: An overview of Cochrane Reviews. *The Cochrane Database of Systematic Reviews*, 2, CD012653. <https://doi.org/10.1002/14651858.CD012653.pub2>
- Lo, S.-F., Hayter, M., Hu, W.-Y., Tai, C.-Y., Hsu, M.-Y., & Li, Y.-F. (2012). Symptom burden and quality of life in patients with malignant fungating wounds. *Journal of Advanced Nursing*, 68(6), 1312–1321. <https://doi.org/10.1111/j.1365-2648.2011.05839.x>
- Lo, S.-F., Hu, W.-Y., Hayter, M., Chang, S.-C., Hsu, M.-Y., & Wu, L.-Y. (2008). Experiences of living with a malignant fungating wound: A qualitative study. *Journal of Clinical Nursing*, 17(20), 2699–2708. <https://doi.org/10.1111/j.1365-2702.2008.02482.x>
- Martinengo, L., Olsson, M., Bajpai, R., Soljak, M., Upton, Z., Schmidtchen, A., Car, J., & Järbrink, K. (2019). Prevalence of chronic wounds in the general population: Systematic review and meta-analysis of observational studies. *Annals of Epidemiology*, 29(1), 8–15. <https://doi.org/10.1016/j.annepidem.2018.10.005>
- McCaughan, D., Sheard, L., Cullum, N., Dumville, J., & Chetter, I. (2018). Patients' perceptions and experiences of living with a surgical wound healing by secondary intention: A qualitative study. *International Journal of Nursing Studies*, 77(1), 29–38. <https://doi.org/10.1016/j.ijnurstu.2017.09.015>
- Munir, F., Leka, S., & Griffiths, A. (2005). Dealing with self-management of chronic illness at work: Predictors for self-disclosure. *Social Science & Medicine* (1982), 60(6), 1397–1407. <https://doi.org/10.1016/j.socscimed.2004.07.012>
- Ngaage, M., & Agius, M. (2018). The psychology of scars: A mini-review. *Psychiatria Danubina*, 30(Suppl 7), 633–638. https://www.psychiatria-danubina.com/UserDocsImages/pdf/dnb_vol30_noSuppl%207/dnb_vol30_noSuppl%20_633.pdf
- Norman, G., Dumville, J. C., Mohapatra, D. P., Owens, G. L., & Crosbie, E. J. (2016). Antibiotics and antiseptics for surgical wounds healing by secondary intention. *The Cochrane Database of Systematic Reviews*, 3, CD011712. <https://doi.org/10.1002/14651858.CD011712.pub2>
- Norman, G., Goh, E. L., Dumville, J. C., Shi, C., Liu, Z., Chiverton, L., Stankiewicz, M., & Reid, A. (2020). Negative pressure wound therapy for surgical wounds healing by primary closure. *Cochrane Database of Systematic Reviews*, 5. <https://doi.org/10.1002/14651858.CD009261.pub5>
- Paden, L., Griffiths, J., & Cullum, N. (2019). A cross-sectional survey of patients with open surgical wounds in Slovenia. *Health & Social Care in the Community*, 27(4), e213–e222. <https://doi.org/10.1111/hsc.12700>
- Paul, J. (2013). A cross-sectional study of chronic wound-related pain and itching. *Ostomy/Wound Management*, 59(7), 28–34. <https://www.hmpgloballearningnetwork.com/site/wmp/article/cross-sectional-study-chronic-wound-related-pain-and-itching>
- Persoon, A., Heinen, M. M., Van Der Vleuten, C. J. M., De Rooij, M. J., Van De Kerkhof, P. C. M., & Van Achterberg, T. (2004). Leg ulcers: A review of their impact on daily life. *Journal of Clinical Nursing*, 13(3), 341–354. <https://doi.org/10.1046/j.1365-2702.2003.00859.x>
- Phillips, P., Lumley, E., Duncan, R., Aber, A., Woods, H. B., Jones, G. L., & Michaels, J. (2018). A systematic review of qualitative research into people's experiences of living with venous leg ulcers. *Journal of Advanced Nursing*, 74(3), 550–563. <https://doi.org/10.1111/jan.13465>
- Probst, S., Arber, A., & Faithfull, S. (2013a). Malignant fungating wounds – The meaning of living in an unbounded body. *European Journal of Oncology Nursing*, 17(1), 38–45. <https://doi.org/10.1016/j.ejon.2012.02.001>
- Probst, S., Arber, A., & Faithfull, S. (2013b). Coping with an exulcerated breast carcinoma: An interpretative phenomenological study. *Journal of Wound Care*, 22(7), 352–354, 356–358, 360. <https://doi.org/10.12968/jowc.2013.22.7.352>
- Ribu, L., Rustøen, T., Birkeland, K., Hanestad, B. R., Paul, S. M., & Miaskowski, C. (2006). The prevalence and occurrence of diabetic foot ulcer pain and its impact on health-related quality of life. *The Journal of Pain*, 7(4), 290–299. <https://doi.org/10.1016/j.jpain.2005.12.002>
- Sandy-Hodgetts, K., Carville, K., & Leslie, G. D. (2015). Determining risk factors for surgical wound dehiscence: A literature review. *International Wound Journal*, 12(3), 265–275. <https://doi.org/10.1111/iwj.12088>
- Sautter, J. M., Tulskey, J. A., Johnson, K. S., Olsen, M. K., Burton-Chase, A. M., Lindquist, J. H., Zimmerman, S., & Steinhäuser, K. E. (2014). Caregiver experience during patients' advanced chronic illness and last year of life. *Journal of the American Geriatrics Society*, 62(6), 1082–1090. <https://doi.org/10.1111/jgs.12841>
- Scambler, G. (2006). Sociology, social structure and health-related stigma. *Psychology, Health & Medicine*, 11(3), 288–295. <https://doi.org/10.1080/13548500600595103>
- Scambler, G. (2009). Health-related stigma. *Sociology of Health & Illness*, 31(3), 441–455. <https://doi.org/10.1111/j.1467-9566.2009.01161.x>
- Seidel, D., Diedrich, S., Herrle, F., Thielemann, H., Marusch, F., Schirren, R., Talaulicar, R., Gehrig, T., Lehwald-Tywuschik, N., Glanemann, M., Bunse, J., Hüttemann, M., Braumann, C., Heizman, O., Miserez, M., Krönert, T., Gretschel, S., & Lefering, R. (2020). Negative pressure wound therapy vs conventional wound treatment in subcutaneous abdominal wound healing impairment: The SAWHI randomized clinical trial. *JAMA Surgery*, 155(6), 469. <https://doi.org/10.1001/jamasurg.2020.0414>
- Shahin, W., Kennedy, G. A., & Stupans, I. (2019). The impact of personal and cultural beliefs on medication adherence of patients with chronic illnesses: A systematic review. *Patient Preference and Adherence*, 13, 1019–1035. <https://doi.org/10.2147/PPA.S212046>
- Shiroky, J., Lillie, E., Muaddi, H., Sevigny, M., Choi, W. J., & Karanicolas, P. J. (2020). The impact of negative pressure wound therapy for closed surgical incisions on surgical site infection: A systematic review and meta-analysis. *Surgery*, 167(6), 1001–1009. <https://doi.org/10.1016/j.surg.2020.01.018>
- Siribumrungwong, B., Noorit, P., Wilasrusmee, C., & Thakkinian, A. (2014). A systematic review and meta-analysis of randomised controlled trials of delayed primary wound closure in contaminated abdominal wounds. *World Journal of Emergency Surgery*, 9(1), 49. <https://doi.org/10.1186/1749-7922-9-49>
- Smith, F., Dryburgh, N., Donaldson, J., & Mitchell, M. (2013). Debridement for surgical wounds. *Cochrane Database of Systematic Reviews*, 9. <https://doi.org/10.1002/14651858.CD006214.pub4>
- Smith-Morris, C. (2010). The chronicity of life, the acuteness of diagnosis. In L. Manderson & C. Smith-Morris (Eds.), *Chronic conditions, fluid states: Chronicity and the anthropology of illness*. Rutgers University Press. 21–36.
- Smith, S. R., Newton, K., Smith, J. A., Dumville, J. C., Iheozor-Ejiofor, Z., Pearce, L. E., Barrow, P. J., Hancock, L., & Hill, J.

- (2016). Internal dressings for healing perianal abscess cavities. *The Cochrane Database of Systematic Reviews*, 8, CD011193. <https://doi.org/10.1002/14651858.CD011193.pub2>
- Stanton, A. L., Revenson, T. A., & Tennen, H. (2007). Health psychology: Psychological adjustment to chronic disease. *Annual Review of Psychology*, 58(1), 565–592. <https://doi.org/10.1146/annurev.psych.58.110405.085615>
- Taverner, T., Closs, J., & Briggs, M. (2011). A meta-synthesis of research on leg ulceration and neuropathic pain. *British Journal of Nursing*, 20(Sup12), S18–27. <https://doi.org/10.12968/bjon.2011.20.Sup12.S18>
- Tedstone, J. E., & Tarrier, N. (1997). An investigation of the prevalence of psychological morbidity in burn-injured patients. *Burns: Journal of the International Society for Burn Injuries*, 23(7–8), 550–554. [https://doi.org/10.1016/S0305-4179\(97\)00083-1](https://doi.org/10.1016/S0305-4179(97)00083-1)
- Thom, H., Norman, G., Welton, N. J., Crosbie, E. J., Blazeby, J., & Dumville, J. C. (2021). Intra-Cavity lavage and wound irrigation for prevention of surgical site infection: systematic review and network meta-analysis. *Surgical Infections*, 22(2), 144–167. <https://doi.org/10.1089/sur.2019.318>
- Upton, P., Cartwright, M., & Upton, D. (2021). Living with chronic wounds: An exploration of adaptive and maladaptive coping strategies and their association with wellbeing. *Wounds International*, 12(1), 12–17. <https://www.woundsinternational.com/resources/details/living-with-chronic-wounds-an-exploration-of-adaptive-and-maladaptive-coping-strategies-and-their-association-with-wellbeing>
- Urwin, S., Dumville, J. C., Sutton, M., & Cullum, N. (2022). Health service costs of treating venous leg ulcers in the UK: Evidence from a cross-sectional survey based in the north west of England. *BMJ Open*, 12(1), e056790. <https://doi.org/10.1136/bmjopen-2021-056790>
- Van Brakel, W. H. (2006). Measuring health-related stigma—A literature review. *Psychology, Health & Medicine*, 11(3), 307–334. <https://doi.org/10.1080/13548500600595160>
- Van Hecke, A., Grypdonck, M., Beele, H., Vanderwee, K., & Defloor, T. (2011). Adherence to leg ulcer lifestyle advice: Qualitative and quantitative outcomes associated with a nurse-led intervention. *Journal of Clinical Nursing*, 20(3–4), 429–443. <https://doi.org/10.1111/j.1365-2702.2010.03546.x>
- Van Hecke, A., Grypdonck, M., & Defloor, T. (2009). A review of why patients with leg ulcers do not adhere to treatment. *Journal of Clinical Nursing*, 18(3), 337–349. <https://doi.org/10.1111/j.1365-2702.2008.02575.x>
- Vann-Ward, T., Morse, J. M., & Charmaz, K. (2017). Preserving self: Theorizing the social and psychological processes of living with Parkinson disease. *Qualitative Health Research*, 27(7), 964–982. <https://doi.org/10.1177/1049732317707494>
- Vermeulen, H., Ubbink, D., Goossens, A., de Vos, R., & Legemate, D. (2004). Dressings and topical agents for surgical wounds healing by secondary intention. *The Cochrane Database of Systematic Reviews*, 2, CD003554. <https://doi.org/10.1002/14651858.CD003554.pub2>
- Vermeulen, H., van Hattem, J. M., Storm-Versloot, M. N., & Ubbink, D. T. (2007). Topical silver for treating infected wounds. *The Cochrane Database of Systematic Reviews*, 1, CD005486. <https://doi.org/10.1002/14651858.CD005486.pub2>
- Walter, C. J., Dumville, J. C., Sharp, C. A., & Page, T. (2012). Systematic review and meta-analysis of wound dressings in the prevention of surgical-site infections in surgical wounds healing by primary intention. *British Journal of Surgery*, 99(9), 1185–1194. <https://doi.org/10.1002/bjs.8812>
- Weller, C. D., Buchbinder, R., & Johnston, R. V. (2013). Interventions for helping people adhere to compression treatments for venous leg ulceration. *The Cochrane Database of Systematic Reviews*, 9, CD008378. <https://doi.org/10.1002/14651858.CD008378.pub2>
- World Medical Association (2013). World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. *JAMA*, 310(20), 2191–2194. <https://doi.org/10.1001/jama.2013.281053>
- World Union of Wound Healing Societies. (2018). *Consensus Document. Surgical wound dehiscence: Improving prevention and outcomes*. Wounds International.
- Young, A., & McNaught, C.-E. (2011). The physiology of wound healing. *Surgery (Oxford)*, 29(10), 475–479. <https://doi.org/10.1016/j.mpsur.2011.06.011>