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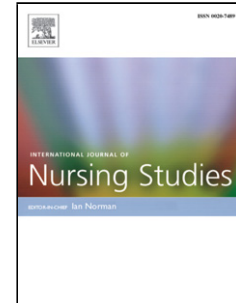
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## TITLE PAGE

## Title

Patients' perceptions and experiences of living with a surgical wound healing by secondary intention: a qualitative study

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## ABSTRACT

**Background:** Most surgical wounds heal by primary intention, that is to say, the edges of the wound are brought together with sutures, staples, adhesive glue or clips. However, some wounds may be left open to heal (if there is a risk of infection, or if there has been significant tissue loss), and are known as 'surgical wounds healing by secondary intention'. They are estimated to comprise approximately 28% of all surgical wounds and are frequently complex to manage. However, they are under researched and little is known of their impact on patients' lives.

**Objectives:** To explore patients' views and experiences of living with a surgical wound healing by secondary intention.

**Design:** A qualitative, descriptive approach.

**Settings:** Participants were recruited from acute and community nursing services in two locations in the North of England characterised by high levels of deprivation and diverse populations.

**Participants:** Participants were aged 18 years or older and had at least one surgical wound healing by secondary intention, which was slow to heal. Purposeful sampling was used to include patients of different gender, age, wound duration and type of surgery (general, vascular and orthopaedic). Twenty people were interviewed between January and July 2012.

**Methods:** Semi-structured interviews were conducted, guided by use of a topic guide developed with input from patient advisors. Data were thematically analysed using steps integral to the 'Framework' approach to analysis, including familiarisation with data; development of a coding scheme; coding, charting and cross comparison of data; interpretation of identified themes.

**Findings:** Alarm, shock and disbelief were frequently expressed initial reactions, particularly to "unexpected" surgical wounds healing by secondary intention. Wound associated factors almost universally had a profound negative impact on daily life, physical and psychosocial functioning, and wellbeing. Feelings of frustration, powerlessness and guilt were common and debilitating. Patients' hopes for healing were often unrealistic, posing challenges for the clinicians caring for them. Participants expressed dissatisfaction with a perceived lack of continuity and consistency of care in relation to wound management.

**Conclusions:** Surgical wounds healing by secondary intention can have a devastating effect on patients, both physical and psychosocial. Repercussions for patients' family members can also be extremely detrimental, including financial pressures. Health care professionals involved in the care of patients with these wounds face multiple, complex challenges, compounded by the limited evidence base regarding cost-effectiveness of different treatment regimens for these types of wounds.

## KEY WORDS

**Patient experience, Qualitative research, Surgical wounds, Secondary intention healing**

## MAIN TEXT

Patients' perceptions and experiences of living with a surgical wound healing by secondary intention: a qualitative study

### What is already known about the topic?

- Surgical wounds healing by secondary intention are open surgical wounds that are left to heal from the base up. They are often slow to heal and are prone to infection.
- There is relatively little information about these wounds, their management, and which treatments offer best value for money.
- No previous research had reported the perspectives of patients living with a surgical wound healing by secondary intention.

### What this paper adds

- This is the first study specifically designed to explore patients' views and experiences of living with a surgical wound healing by secondary intention.

- Having a surgical wound healing by secondary intention impacted substantially on daily living and this impact was particularly important for those patients with children or in employment, who constitute a younger demographic than seen in previous research associated with other complex wound types.
- The study findings promote and enhance understanding of the impact of a surgical wound healing by secondary intention on patients' and their family members' lives, as well as describing the challenges faced by clinicians in managing these wounds.

## 1. Introduction

More than six million surgical operations are performed annually in the United Kingdom (UK) National Health Service (NHS) (Department of Health, 2010). The majority result in a wound which heals by primary intention, that is to say, the incision is closed by fixing the edges together with sutures (stitches), staples, adhesive glue or clips. However, some wounds may be left open to heal if there is a risk of infection, or if there has been a significant tissue loss. Healing occurs through the growth of new tissue, from the base of the wound upwards, a process described as 'healing by secondary intention'. Types of wounds that might be left open to heal are those resulting from excision of a pilonidal sinus (chronic wounds arising from hair follicles in the buttock cleft) (AL-Khamis, 2010) and breast abscesses (Lewis et al., 2001). Wounds that were healing by primary intention may sometimes 'dehisce', resulting in full or partial separation of the wound edges, which may then be left to heal fully through secondary intention, or closed surgically after partial healing.

Evidence concerning the epidemiology of surgical wounds healing by secondary intention (referred to hereafter as open surgical wounds) in the UK has been limited until relatively recently. Two published audit studies from the North of England (Bradford, UK, (Vowden and Vowden, 2009)) and Hull, UK, (Srinivasaiah et al., 2007), estimated that open surgical wounds constitute approximately 28% of all prevalent acute (mainly surgical/ traumatic) wounds that were receiving wound care provision. More recently, Hall et al. (2014) evaluated the point prevalence of all types of complex wounds in a UK city (with a population of 751,485) and found a point prevalence of dehisced surgical wounds of 0.07 per 1000 population. A further evaluation of the prevalence of open surgical wounds (Chetter et al., 2016) over a two week period in primary, community and secondary care settings, found a prevalence of 0.41 per 1000 population in a total population of 590,585, almost half of which were planned to heal by secondary intention.

Open surgical wounds can be challenging to manage as the wounds can be large, deep, at risk of infection and produce copious amounts of exudate (Dumville et al., 2015).

Management of open surgical wounds requires intensive treatments that may involve prolonged periods of hospitalisation for patients and/or further surgical intervention (for example, wound debridement and skin grafting), with associated quality of life implications (Sandy-Hodgetts et al., 2013). Despite being relatively common, there is a lack of robust evidence concerning the effectiveness of treatment options for open surgical wounds (Vermeulen et al., 2005; National Institute for Health and Clinical Excellence (NICE), 2008; Dumville et al., 2015). Negative pressure wound therapy is a widely used intervention,

whereby negative pressure is applied to a wound via a gauze or foam dressing, and theoretically promotes wound healing by removing exudate and reducing infections; however, evidence of its effectiveness is limited (Dumville et al., 2015). Open surgical wounds are also managed through application of a variety of wound dressings, generally applied by hospital or community nurses, requiring patients to undergo frequent dressing changes, often including packing of the wound cavity.

While there is an expansive literature relating to patients' experiences of chronic wounds, such as leg ulcers (Briggs and Flemming, 2007; Faria et al., 2011; Finlayson et al., 2017; Green et al., 2013; Green et al., 2014; Hareendran et al., 2005; Herber et al., 2007; Persoon et al., 2004), evidence concerning the impact on patients of experiencing an open surgical wound is lacking. Our qualitative study, embedded within a large programme of research related to open surgical wounds, specifically aimed to explore patients' perspectives of living with an open surgical wound, and to elicit their views regarding healing of their wounds and their experiences of treatment.

## **2. Methods**

### **2.1 Design**

A qualitative, descriptive design was adopted, using semi-structured, individual interviews. Semi-structured interviews were selected because they offer flexibility in data collection and lead to rich narratives, which permit the researcher to analyse how the participants make sense of the topic under investigation (Pope and Mays, 2006). The study was designed in collaboration with three patient advisers, with personal experience of an open surgical wound, acting as 'key informants'. They were involved through face-to-face meetings in: design and piloting of the interview topic guide (Appendix 1); data analysis; interpretation of the study findings; and comments on early drafts of study findings.

### **2.2 Setting**

Participants were recruited from acute and community nursing services in two locations in the North of England, one a large conurbation with broad economic and ethnic diversity, and high levels of deprivation, the other a smaller sized city, also with high levels of deprivation, though less ethnically diverse.

### **2.3 Participants**

Patients were purposively sampled to include those with an open surgical wound which was slow to heal, according to gender, age, duration of wound and type of surgery (general, vascular, orthopaedic surgery). We aimed for ethnic diversity within the sample. Patients were identified and approached regarding study participation by a member of their usual healthcare team. Twenty patients with open surgical wounds, 11 women and nine men, median age 53 (range 19-76) years, were recruited between January 2012 and July 2012. Ethnicity was white British for all but one female (P15), who was Asian British. The surgical procedure preceding the open surgical wound was general abdominal surgery in 11 patients, vascular surgery in five patients, orthopaedic surgery in two patients, excision of pilonidal sinus in one patient and drainage of abscess in one patient. The median duration of healing of the open surgical wounds was 5.5 (range 1.5 – 60) months. Wound characteristics,

patient comorbidities (as recounted during interview), and socio-demographic details, are presented in Table 1.

**Table 1 Study participants' socio-demographic details**

<b>ID</b>	<b>Gender</b>	<b>Age</b>	<b>Employment status</b>	<b>Wound type</b>	<b>Wound duration (months)</b>	<b>Co-morbidities (self-reported)</b>
P1	Female	58	Unemployed Registered disabled	Dehisced abdominal wound; had had multiple operations	6	Diabetes Crohn's disease
P2	Female	73	Retired	Dehisced wound on upper thigh after bypass graft	2	Diabetes
P3	Female	19	Unemployed since surgery	Dehisced wound on leg after open fracture	3	
P4	Female	65	Retired	Open surgical wound following amputation of toes	12	Diabetes
P5	Male	30	Employed	Dehisced wound in groin after infection	3	
P6	Male	32	Unemployed since surgery	Open surgical wound after abdominal surgery	2	
P7	Female	44	Employed	Open surgical wound after	1.5	

				drainage of abscess in axilla		
P8	Male	52	Unemployed since surgery	Dehisced abdominal wound	24	
P9	Male	76	Retired	Non-healing abdominal wound following surgery for bowel cancer	60	
P10	Male	64	Early retirement due to work injury	Open surgical wound following amputation of toes; had had skin graft	5	
P11	Male	45	Unemployed since surgery	Dehisced wound due to infection after surgery for Crohn's disease	3	Crohn's disease Necrotising fasciitis Pyoderma
P12	Female	72	Retired	Dehisced abdominal wound	8	
P13	Female	54	Employed	Dehisced abdominal wound	1.5	
P14	Female	47	Unemployed since surgery	Dehisced abdominal wound	4	
P15	Female	46	Unemployed since surgery	Dehisced abdominal wound	9	Crohn's disease
P16	Female	76	Retired	Dehisced abdominal wound	10	
P17	Male	44	Unemployed	Open surgical wound following	24	Diabetes



				partial amputation of foot		
P18	Male	65	Employed	Non-healing abdominal wound	2	
P19	Male	25	Employed	Slow to heal wound following treatment for pilonidal sinus	30	
P20	Female	71	Retired	Dehisced wound following spinal surgery	9	Rheumatoid arthritis

## 2.4 Interviews

Interviews were semi-structured, using the topic guide developed and piloted with input from three patient advisors. Two researchers (DM and LS) carried out the interviews. DM is a registered nurse with previous experience of research into wound care. LS has a background in sociology. Interviews took place in patients' homes and lasted approximately one hour, were audio-taped and fully transcribed. Interviews continued until no further pertinent information was forthcoming (20 interviews); Hennink et al. (2017) suggest that meaning saturation may be obtained with 16-24 interviews. Data were analysed using 'Framework' approach, as described by Green and Thorogood (Green and Thorogood, 2014, pp 218-222). The recommended sequential steps were followed: familiarization with the data; development of a coding scheme, based on identification of recurrent and important themes; coding of transcripts, through systematic application of the coding scheme; summarising and charting data (using Microsoft Excel (Microsoft, 2010)), to enable comparison within and between cases; and, finally, comparison of themes across the data set, to allow for synthesis and interpretation of the data (see Appendix 2). To enhance rigour, the two researchers wrote reflective notes to help clarify established and new themes and differences of opinion were discussed until consensus was reached. The researchers met regularly to discuss expansion and modification of the coding framework as it evolved during the initial phases of data analysis. Contributions from patient advisors (each of whom had experience of an open surgical wound) were crucial to reflection on the meaning of the interview data and its interpretation.

## 3. Ethics approval

The study received research ethics (REC reference: 11/YH/0313) and governance approval. All study participants were given verbal and written information relating to the study aims and their involvement. Written consent was obtained and participants were given assurances

concerning confidentiality and anonymity of their responses. Participants were also reassured that their care would not be affected in any way, whether or not they decided to take part in an interview, and it was made clear that they could withdraw from the study at any time.

#### 4. Findings

A description of the main themes is presented below.

##### 4.1 Initial reactions

Alarm, shock and disbelief were commonly reported feelings following an “unexpected” open surgical wound, that is to say, following emergency surgery or a dehisced wound. Extensive open surgical wounds, or those associated with exposed internal organs were particularly associated with such feelings: “.....it [the wound] was *left absolutely open, quite deep and wide... it's been a massive shock to me.....*” (Patient 13). Frequently, participants would produce photographs of their wounds, intimating that words alone could not sufficiently convey the true extent and nature of the wound that had suddenly been ‘inflicted’ on their body. The sudden, unanticipated extensive wounds often provoked feelings of distress, disbelief and disgust: “.....a few days after my surgery, all of a sudden ‘whoosh’ my wound [dehisced]...it frightened me to death, obviously when you see your own innards, clots all over, I was so alarmed, I couldn’t believe it, they put their hands in, and I thought, am I dying?.....” (Patient 12).

In contrast, an “elective” open surgical wound (for example, from an elective partial foot amputation in a patient with diabetes) tended to produce equanimity concerning the initial appearance and immediate impact of the wound. Preoperative discussion with clinicians concerning the likely nature of their post-operative surgical wound was more common in this group of patients. Moreover, these patients frequently viewed surgical intervention as a means of respite from intractable pain, as well as offering a reduced risk of more proximal limb loss: “....it was the best thing I ever did having my toes off...the pain before had been so bad, it was excruciating...if it wasn’t the toe, it could have been the foot...I never felt it was such a major thing once I got used to the idea they were going to take my toes off” (Patient 3).

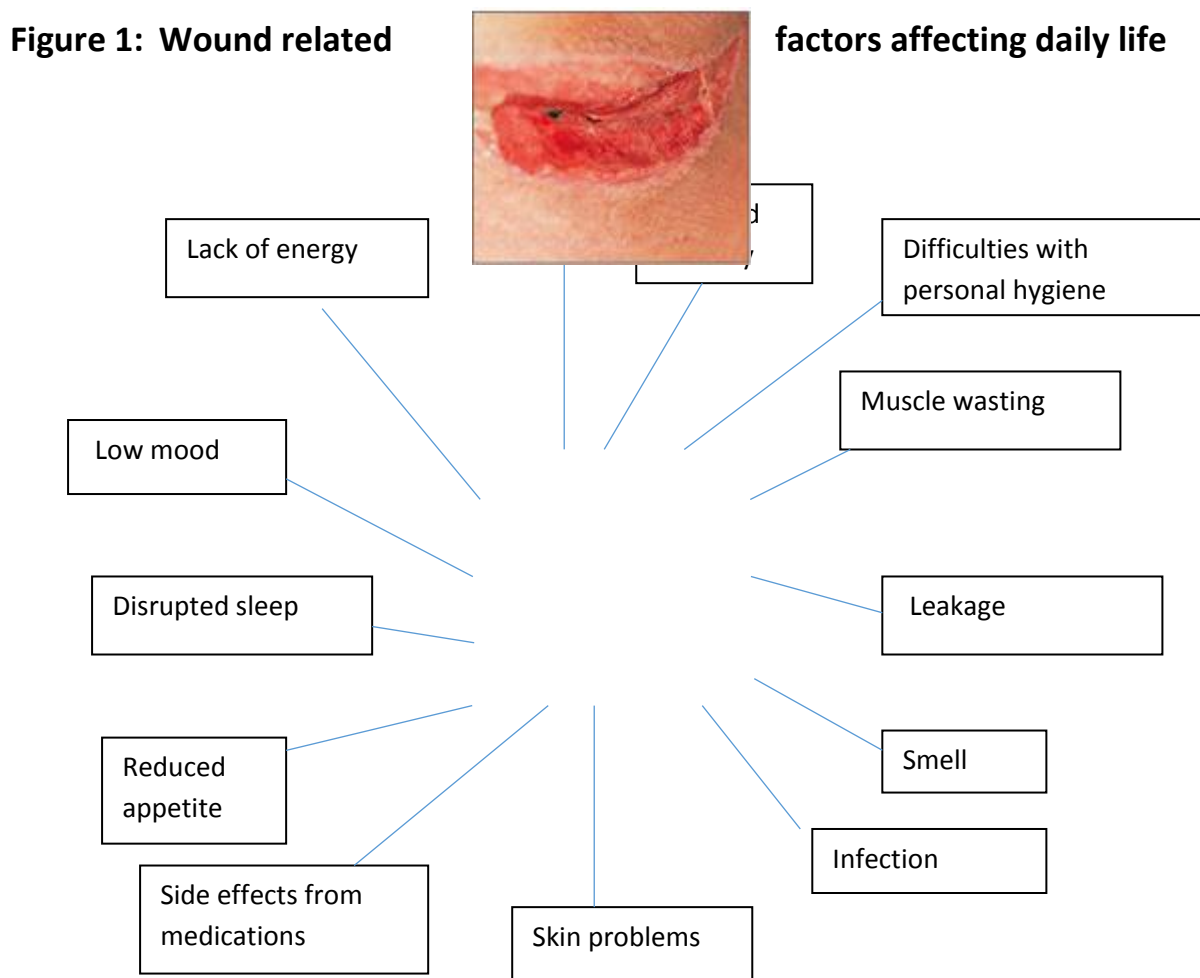
##### 4.2 Wound related factors

A range of wound associated factors were reported to have a negative impact on daily life, physical and psychosocial functioning and sense of wellbeing. Frequently reported symptoms included pain and reduced mobility: “....I can’t stretch and I can’t stand up straight because of the wound, because it’s right in the middle of my stomach...when I’m stood up it hurts...” (Patient 15); leakage, smell and difficulties with personal hygiene: “.....all the wound had leaked, it ran down my legs. It was all slimy, it was all green, it smelt horrible...” (Patient 16); reduced appetite: “.....I just couldn’t eat, just didn’t have any appetite....” (Patient 3); weakness and muscle wasting: “....I’ve been so poorly, I’ve been in bed because I’ve been really weak...my muscles have just given up.” (Patient 15); disrupted sleep: “....I wasn’t getting a good night’s sleep, my bag [exudates container] was filling up and I was getting up seven to twelve times a night.....” (Patient 6); lack of energy and low mood: “.....I didn’t have the energy to do anything... you’re in your nightie all the time ...you haven’t got the strength,

*you haven't got the inclination [to socialise]" (Patient 1); skin problems; and side-effects from medication.*

Patients' disabling, limited physical mobility (and particularly being unable to drive), was frustrating and disruptive of normal activities. In addition, patients regarded themselves unfit to socialise because they felt tainted by the smell and exudate from their wounds, which they thought others might find offensive: *".....it's a nasty smell...I daren't go on a bus because I thought, anybody could smell me..." (Patient 2).*

Figure 1 illustrates wound related factors affecting daily life



#### 4.3 Expectations of wound healing

A lack of understanding regarding the process of wound healing by secondary intention and fear and anxiety that healing of their open surgical wound would never occur were common: *".....it was big and it was deep and I couldn't believe that it was going to heal..." (Patient 15).*

Disappointment, dismay and frustration with the slow healing process were also common, exemplified in phrases such as *“it drags on and on”* (Patient 13) and *“it is taking for ever”* (Patient 15). These feelings were intensified by setbacks to healing, such as episodes of infection or the need for further surgery.

The aspiration for complete wound healing was a major focus of all those interviewed and achieving this equated with *“.....getting your life back...”* (Patient 16), a return to some semblance of life prior to surgery, and a sign that the body was returning to ‘normality’. Unrealistic expectations of rate of healing amongst patients, frequently at odds with clinicians’ expectations, were common. Comments from health care professionals regarding healing and the condition of their wound had profound implications for patients. Positive feedback was a boost for morale, and sustained the patient’s hope for healing, while negative remarks adversely affected the patient’s general outlook. Conflicting information led to feelings of confusion and consternation in patients. Even quite casual remarks from health care professionals could have a profound impact.

Participants were ever-hopeful that a new or untried treatment might accelerate or achieve healing of the wound, and they often looked to tissue viability nurses, regarded as experts in their field, to provide a solution for their unhealed wound, as though these nurses would somehow be able to *“.....wave a magic wand.”* (Patient 8). There was a willingness amongst participants to undergo any procedure or treatment, no matter how unpleasant, if it promoted healing. The possibility of wound infection was viewed as a constant and insidious threat, representing a major setback to healing.

#### 4.4 Psychosocial impact

Open surgical wounds were frequently found to have a devastating effect on the lives of patients and their close family, especially following emergency surgery or if associated with a large cavity: *“.....it’s ruined our lives really...this [the wound] is our life now...it’s something that devastates your life as it was”* (wife of Patient 9).

Withdrawal from engagement with the wider world, into the confines of their own home, resulting in social isolation, was common: *“you’re like a prisoner...you feel shut in ...you don’t go out, you lose your days”* (Patient 2). This isolation often led to lives devoid of every-day pleasures and the small instances of happiness previously occasioned through the company of others.

The normal course of patients’ lives, and those of their families, were disrupted and overturned by their unanticipated need for surgery, engendering feelings of powerlessness. After their operation, patients described living in a state of limbo, dominated by multiple uncertainties, most prominently the uncertainty associated with healing of their wound. Anxieties concerning general physical health and their (sometimes rapidly worsening) financial situation impacted on the patient’s mental state and their relationships with others. Patients’ enforced dependency served to undermine or overturn established family roles and responsibilities, with consequences for everyone involved. Patients reported feeling disconnected from many aspects of their normal lives; unable to work or to drive, unwilling or unable to engage in day-to-day family activities and events, and subject to a seemingly never ending cycle of wound care and management, they felt bored, isolated, lonely and dependent, and reported emotional volatility, low mood or depression: *“.....sometimes I just*

*sit here and start crying, that's what it does do you, and there's nothing my wife can do and there's now't I can do...I do get depressed, very depressed....."* (Patient 2). Additionally, patients reported feelings of guilt due to perceptions that they were a burden to their partners and families.

#### 4.5 Financial repercussions

Financial repercussions associated with the wound were severe for some patients and their families, causing high levels of stress, especially where partners were torn between working longer hours to maintain the household income, and acting as an informal carer for the patient. Younger male patients, normally the main earners for their family, and who had young children to care for and support, appeared particularly hard hit by the uncertainties and restrictions that living with an open surgical wound imposed on them. A series of excerpts from the transcription of the interview with one such patient, unemployed since emergency abdominal surgery, illustrate how the effects of his surgery and subsequent non-healing wound had permeated all aspects of his life, causing him to feel worried and guilty because he was not fulfilling his roles as breadwinner and 'hands-on' father.

*"I feel like I've lost my career...because I was self-employed, I'm not entitled to any benefits...it is stressful... you know, I've got three kids...I'm struggling...I've gone from having £500 a week to having nothing and it's like there's not a lot I can do about it."*

*"It comes to a point where you can't borrow off your family and friends anymore... the financial implications are massive...as much as we try and put a brave smile on it, we know it's going to pretty much hurt and cripple us. I mean, my partner she's had to take shorter hours anyway to try and help me at home and she's even considering shorter hours because of the amount of help I need..."*

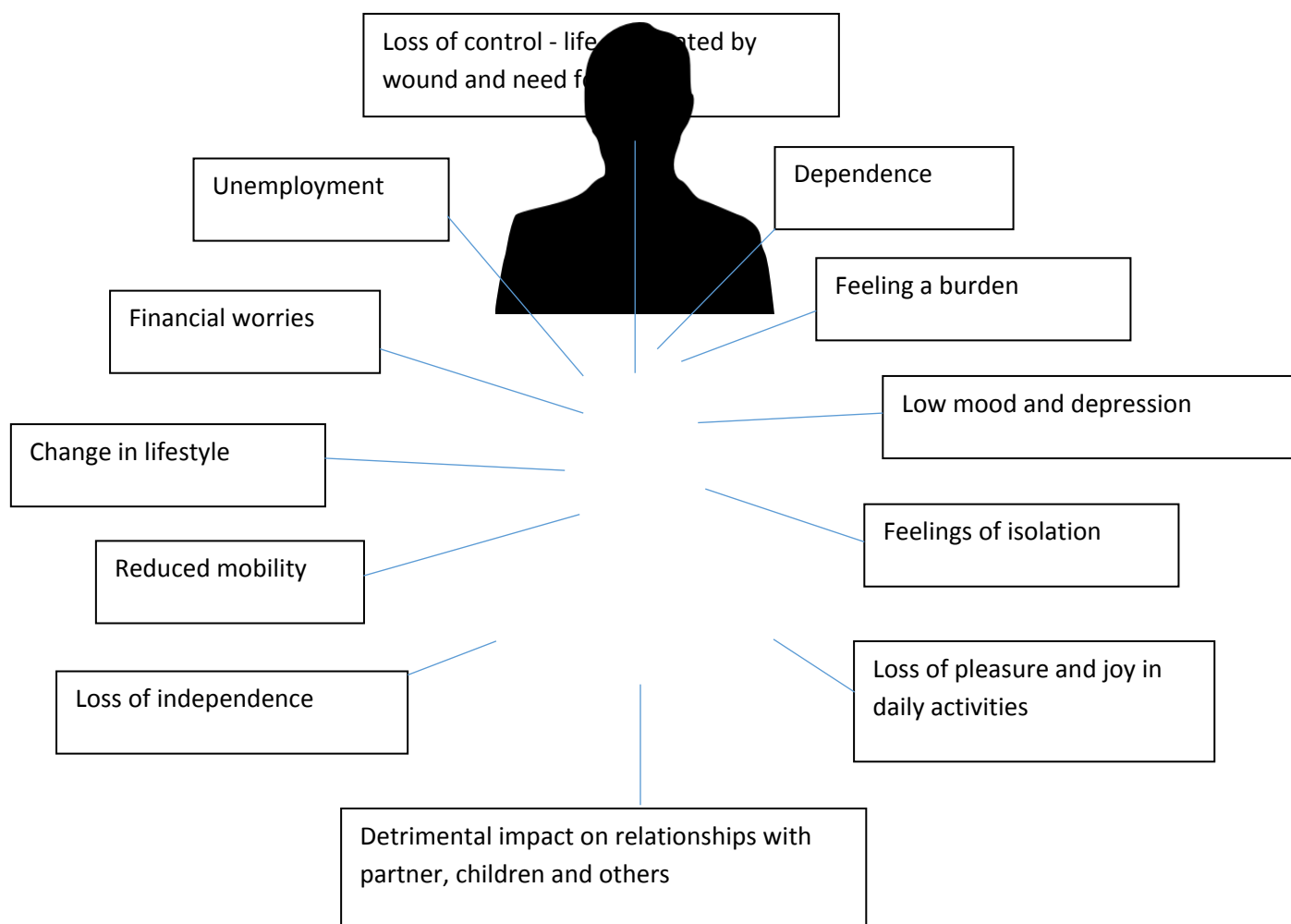
*"It affects your relationship with your kids in my opinion, massively. I mean my lad does rugby and I can't take him to his rugby games. I can't take him to his training. Luckily, his granddad, is doing all that for him anyway, so I mean he isn't missing out, but the relationship between me and him is missing out, if you know what I mean, because rugby was our thing... I've always been there at every game, every training session pretty much and, you know, the quicker I heal, the quicker I can get better and the quicker I can get back to a normality and somewhere near a normal life again..."* (Patient 6).

#### 4.6 Supportive role of others

The supportive role of partners, family members, friends and neighbours was described by most patients as crucial, providing practical and emotional support, and helping them to adapt and adjust to living with their wound. Practical assistance included providing transport, offering to accompany patients to medical appointments, help with food shopping, preparation of meals and basic household chores: *".....I did rely on neighbours, for shopping and things like that...I mean if you didn't have that support, I don't know what you would do, I suppose I'm lucky in the fact that my friends are prepared to do it"* (Patient 4). Some older patients were reluctant to ask for their adult children for assistance, preferring to try to manage independently. Patient 2 commented that her grown children *"... are working and they have their own lives to live without me all the time"*.

Figure 2 illustrates psychosocial impacts of experiencing an open surgical wound

**Figure 2 Psychosocial impacts of experiencing an open surgical wound**



#### 4.7 Service provision

Findings reported here relate to (i) care in hospital and (ii) district nursing services.

##### (i) Hospital care

Prolonged admissions and multiple operations were not uncommon. Duration of hospital admission ranged from an overnight stay (following drainage of an axillary abscess) to nine months (following complex spinal surgery). Important factors during this period included feeling listened to and timely provision of information and explanations. Regular contact with the surgeon who had performed the procedure was particularly valued and preferred. During interactions, patients expected the surgeon to inspect the wound, in order to monitor progress, and disappointment ensued if this did not happen: *“Post-surgery, I would have thought more attention should be given by the surgeons to the actual wound...I think it’s important the actual surgeon reviews the wound”* (Patient 18). Verbal comments from surgeons concerning patients’ general progress and healing of their surgical wound appeared highly important to patients. Positive comments generated reassurance whilst brusque or uncaring interactions led to patients feeling unheard, dismissed and angry.

Patients often reported that their wound dressings had not been changed as frequently as necessary while they were in hospital and many participants reported dissatisfaction with hospital discharge procedures. Patients felt unsupported at the point of discharge, due to receiving insufficient information relating to the nature of their operation and the resultant open surgical wound. Details regarding required follow up care were frequently lacking and information regarding the risks, symptoms and management of potential wound infection deficient *“.....they never really told me the risk of infection is high...they could have gone more in-depth, look, you can get this infection, you could do this, and you could be off work...”* (Patient 5).

##### (ii) District nursing services

Almost all patients had had experience of home visits by district nurses, though they said they had been encouraged to attend GP surgery practice nurses once their general condition improved.

Patients perceived district nurses as usually pressed for time, due to staff shortages, so that their visits felt rushed: *“...I know they are short staffed because they keep saying to me that they are short staffed...”* (Patient 1).

Lack of continuity of care due to variation in nurses was a common concern: *“...there’s really not much consistency with the district nurses because everybody does it [dressing change] in a different way...”* (P19)

Unpredictable visit timings were particularly frustrating, leaving patients feeling ‘trapped’ in their homes, waiting for the nurses to visit *“.....you are stuck in the house waiting for the nurse...it’s not their fault, they don’t know when they are going to get here”* (Patient 6). Conversely, consistency regarding nursing staff and visit timings were associated with patient satisfaction.

Conflicting information from different nurses regarding the condition of their wound, or its management, was particularly troubling for patients, even more so if differed from information given by their surgeon (for example, concerning the need for debridement): *“when I went to the hospital the surgeon said that the nurses weren’t cleaning off the scab and the slough...they haven’t even wiped it off. They’ve just taken it [the dressing off] and put water on it which he [the surgeon] said they are not supposed to do, they are not supposed to get it wet...”* (Patient 3). Patients also felt confused and concerned when apparently spontaneous and unexplained changes were made to dressing or wound management regimens.

#### 4.8 Treatments for open surgical wounds

The main wound treatments experienced by study participants were (i) negative pressure wound therapy; (ii) debridement; (iii) skin grafting; (iv) dressings.

##### (i) Negative pressure wound therapy

Eleven participants had received negative pressure wound therapy, which they generally viewed as an effective treatment. Perceived advantages included a reduction in the need for dressing changes in comparison with ‘traditional’ dressings, and a reduced risk of wound infection: *“.....it’s much better for your healing, there’s much less risk of infection because they [the nurses] are only opening it up twice a week where they would have been doing it twice a day”* (Patient 13). However, negative pressure wound therapy dressing changes were described as painful when sponge or foam, rather than gauze, was used. Patients with prior experience of negative pressure wound therapy reported that some district nurses lacked appropriate knowledge, experience and expertise in its application, commenting that they needed guidance from the patient. Several participants reported that they were disinclined to mobilise outside the home with negative pressure wound therapy in situ, because the equipment was cumbersome, and/or they felt embarrassed due to the appearance, perceived associated smell, or constant ‘bleeping’ of the equipment: *“I don’t want to go anywhere too far...it’s a bit embarrassing carrying this long pipe behind you and you are always worried that it’s going to start beeping... yesterday I had to go to the dentist and I was sitting in the waiting room thinking, please don’t go ‘bleep, bleep, bleep”* (Patient 20).

##### (ii) Wound debridement

Some of the participants who had undergone wound debridement reported that it was extremely painful: *“.....there was some black in it, like dried blood, and they had to cut it...no anaesthetic, no nothing, I screamed, I really screamed...they had to do it every two days...I said, ‘you’re really hurting me’, I wanted to die...”* (Patient 16). The rationale for, and potential effectiveness of debridement, was apparently frequently poorly communicated to patients: *“when somebody is told that they are doing to debride it [their wound] they need more information about it...at that point I was thinking, what the hell is debriding?”* (Patient 17).

##### (iii) Skin grafting



Three participants (patients 10, 11 and 20) had undergone skin grafting, and a further two participants (patients 3 and 9) had discussed the possibility of a skin graft for their open surgical wound. Views regarding the desirability of skin grafting were mixed, due to fears of infection and/or graft failure which would delay healing. Two participants (patients 3 and 9) were reluctant to undergo further surgery. Participant 3 stated that “...*I don't want to be opened up again...*”, while participant 9 said that he didn't ‘*want to start another operation*’, and his wife explained that when the tissue viability nurse had asked him whether he might like to consider the option of a skin graft, he had refused outright. Patient 11 expressed disappointment that his skin graft had been unsuccessful: “...*they did a skin graft but the skin graft didn't take...it seems like every time they try to do something, something spoils it along the way...*” (Patient 11).

#### (iv) Wound dressings and techniques

Participants' comments in relation to dressing of their wounds related to four main concerns, which overlapped to a large extent with their views of district nursing services: the possibility of developing an infection; lack of continuity in the district nurses carrying out dressing changes; receiving conflicting information; frustration with timing of dressing changes.

Participant 3 suggested a nurse had breached the principles of aseptic technique when changing the dressing that was being applied to the open surgical wound on her leg. She compared this nurse's dressing technique to that of other nurses she had observed: “...*they [the district nurses] usually put the gloves on after they've got everything laid out and put the gloves on so they are sterile. The one [nurse] today put her gloves on and was then walking all around and picking up bits of paper, probably getting all sorts on her gloves and then going into her bag, opening it and shutting it and touching all the zips...you are really not supposed to do that...I thought, if she touches that and I get an infection...it has been the infection that has worried me...*”. (Patient 3).

Participants wanted more information regarding individual clinicians' rationale for using different approaches, including different dressing products, in treating their open surgical wound. They commented that nurses rarely seemed to “...*sing from the same hymn sheet*” (Patient 19) regarding dressing choice, which raised patient anxiety. Most patients linked lack of continuity of care through the district nursing service to inconsistency in wound management: “...*I kept seeing different people all the time and they would look at it and be really worried...and that would get me all worried...it was somebody saying something different every time...that was hard...*” (Patient 3); “...*two weeks later you are seeing a new nurse and she says 'oh, no, it shouldn't be managed this way, it should be that way...sometimes it should be explained why they are doing that...*” (Patient 17).

## 5. Discussion

### 5.1 Patients' initial reactions to their open surgical wound

Patients' initial reactions to their open surgical wound encompassed feelings of shock, fear and anxiety, especially following emergency surgery; these feelings are akin to those reported by people who have undergone severe, life-changing trauma (Wiseman et al., 2013). The realisation of a changed body was immediately visually obvious post-operatively to patients in our study, many of whom reported initial disbelief at the extent of their wound,

particularly those with large abdominal cavity wounds that revealed 'inner' organs and the workings of bodily functions, *'things that never should be seen'* (Mantel, 1995). Kelly (1992) suggests that most sensate experiences of the body are background to everyday life, and it is usually only when there is an alteration in physical experience or sensations, being in pain or suffering trauma, that this aspect of self becomes salient. For patients in our study, every time a dressing was changed, the confrontation with the open wound recurred. Patients' open surgical wound acted as a constant visual reminder of a changed body, marking the differentiation between the former and present 'self', differences which may be viewed as undesirable by both the patient and others. Alterations to body image occur when there is a discrepancy between the way someone formerly perceived themselves and how they see themselves now (Cash, 2011). Some of the patients in our study perceived their open surgical wound as a bodily violation that threatened identity and diminished functionality in many domains of their lives. Fingeret et al. (2014) have shown that unpredictable or unavoidable changes to body image, such as those that occur due to the trauma of surgery, can potentially precipitate longer term consequences associated with psychosocial outcomes and reduced quality of life.

## 5.2 Impact of wound related factors

Common features of chronic wounds (leg and pressure ulcers, fungating wounds), are that they are painful, malodorous, prone to infection, slow to heal and complex to manage, and significantly adversely affect patients' quality of life (Adderley et al., 2014; Gibson and Green, 2013; Green et al., 2014). Similar to patients living with other types of chronic wounds, participants in our study reported reduced physical mobility, interrupted sleep, loss of appetite, difficulties with personal hygiene, skin problems, social isolation, dependence, financial pressures, low mood and depression in connection with their non-healing open surgical wound. Wound-related pain is frequently identified as the central concern of patients living with leg and pressure ulcers (Briggs and Flemming, 2007; Edwards et al., 2014; Gorecki et al., 2009; Green et al., 2014; Hopkins et al., 2006). However, participants in our study were more troubled by leakage of copious, malodorous exudate from their open surgical wounds, experienced as overwhelming at times, which caused them to withdraw from usual social activities. Lawton (1998) has referred to the uncontrolled emission of bodily fluids normally contained within the body, as a state of bodily 'unboundedness' that can arouse revulsion in patients and others, resulting in social isolation and loss of sense of self and social identity. Patients living with fungating wounds also frequently report high levels of distress and embarrassment due to wound-related malodour and exudate (Adderley et al., 2014; Alexander, 2009; Gibson and Green, 2013; Lo, 2008; Lo, 2011; Probst 2013; Selby 2009). Probst et al. (2013) have revealed intense feelings of social marginalisation amongst women living with a malignant fungating breast wound and have highlighted the negative impact of the wound on the women's perceptions of their own attractiveness and sexuality. Participants in our own study also alluded to diminished close physical contact with partners, which they attributed to the repugnant nature of their open surgical wound, adding to feelings of isolation and low self-esteem.

The far reaching psychological impacts of living with a chronic wound (low mood, emotional volatility, depression) are well documented in the literature (Edwards et al., 2014; Gorecki et al., 2009; Gibson and Green, 2013; Green et al., 2014) and were clearly identifiable in our participants' accounts. A significant finding was the withdrawal of many patients from the normal work, leisure and social activities that had composed their lives prior to their surgery.

During interviews, patients indicated that their physical and mental resources had become depleted through the dominance of the wound in their lives, and commented that they felt self-conscious about appearing in public, leading them to increasingly disengage from the world beyond the confines of their own home. Severe restriction of physical and social activities frequently resulted in feelings of frustration, isolation, anger and guilt due to enforced dependency; in some cases, these feelings were the prelude to the development of clinical depression.

Previous wounds research has mainly focused on older people with leg ulceration, but what is noteworthy about our study population is their younger age, and the focus of their prime concerns on interference with child care and implications for employment. Patients who had been the main family earner were preoccupied with immediate and longer term financial pressures facing themselves and their family. Predominance of employment related concerns, and financial burden through loss of income, are also reported in findings from a qualitative study with 118 seriously injured patients, of whom 94 (79.6%) were aged 64 years or under (Gabbe et al., 2014).

### 5.3 'Forever healing' process

As their unhealed, open wound endured, patients' hopes and expectations of healing were often not realised. This 'forever healing' process, characterised by a constant need for treatment and care and a diminished quality of life, has been described in patients with venous, diabetic and pressure ulceration (Briggs and Flemming, 2007; Gorecki et al., 2009; Green et al., 2014; Herber et al., 2007; Kinmond et al., 2003; Moffat and Vowden, 2008; Price and Harding, 2004). McCaughan et al. (2013) highlight imparting hope to patients as a fundamental principle of caring, but suggest that raising false hopes in the quest to find an optimal treatment may arouse feelings of disappointment, disillusionment and distrust in staff, and trigger a 'spiral of hopelessness' (Briggs and Flemming, 2007) in patients. This may be challenging for clinicians who need to communicate uncertainty regarding wound progress and likely treatment outcomes.

### 5.4 Impact on sense of self

The sudden intrusion of illness into daily existence has been termed "*biographical disruption*" (Bury, 1982), as it can disrupt the structures of everyday life, overturn personal plans, and require a fundamental rethinking of the person's biography and concept of self. Patients in our study indicated that having an open surgical wound forced them to 'recalibrate' every aspect of their lives, in the process changing their views of themselves, and their role in family and wider social networks. Patients struggled to sustain a positive outlook when healing failed to occur, their state of dependency continued, and hope for a return to the former normality of their lives before surgical intervention receded. Charmaz (1983) has identified four characteristics which may contribute to the psychological suffering of those experiencing chronic illness: living a restricted life; existing in social isolation; experiencing discredited definitions of self; and becoming a burden. These characteristics represent important dimensions of the diminished quality of our study patients' lives as their wounds continued to fail to heal, and their freedom to exercise choice in everyday life remained limited. Charmaz (1983; 1991; 1994) has described the profoundly negative impact that chronic illness (here, chronic wounds) may have on an individual's sense of self. She

suggests that since 'selves' are ordinarily situated in networks of social relationship, social isolation typically fosters loss of self. Over time, a diminished concept of self emerges, reinforced by loss of control and powerlessness in relation to some valued attribute or function viewed as fundamental for a positive self-image, such as earning an income, or sexual functioning, both of which were reported by some participants in our study. When ill persons attempt to return to the normal world but fail, as patients in our study reported happened to them, due to feeling unsafe or self-conscious when they ventured outdoors with crutches or with negative pressure wound therapy equipment in situ, they may begin to accept a 'discredited' self and develop the sense of becoming a burden, which can further demean perceptions of self-identity (Charmaz, 1983; Aujoulat et al., 2007). The reports of low mood and depression that featured so prominently in the accounts of the participants in our study may have been a corollary of patients' experiencing an impoverished sense of self due to incapacity caused by their open wound, and increasing feelings of social isolation as healing was delayed. Patients also described attempts to conceal negative feelings from caregivers (partners, family, health care professionals), though repressing these emotions may have further impaired psychological functioning.

### 5.5 Perceptions of health care provision

Experiences of health care service provision varied widely between individual study participants, but common viewpoints were that wound dressings changes should have been more frequent during in-patient hospital stays, and that more information should have been provided on hospital discharge regarding follow up requirements and symptoms of wound infection. Ill-preparedness of surgical patients for discharge from hospital, and lack of co-ordination of post-discharge care, have also been highlighted as occurring amongst post-trauma patients (Christie et al., 2016; Gabbe et al., 2013), prompting recommendations for written discharge management plans that include information on anticipated trajectory and time scales for resuming daily activities. Unfortunately, the uncertainty associated with healing of surgical wounds healing by secondary intention, due to the almost complete absence of epidemiological research (the incidence of surgical wound breakdown, typical healing rates, prognostic factors for wound breakdown and repair are all unknown) prevents properly informed discussion and makes it difficult to predict likely milestones on the path to recovery. However, ensuring that all patients with open surgical wounds receive written information about the signs and symptoms of infection, and details of who to contact should this occur, is likely to be beneficial, as these wounds are prone to infection (Norman et al., 2016). In a qualitative interview study with 17 patients who had experienced a surgical site infection, Tanner et al. (2012) recommended that patients undergoing surgery should routinely be provided with information at discharge about normal and abnormal wound healing and surgical site infection, alongside details of a contact link person, to promote early diagnosis and treatment of infection.

Perceived shortfalls in district nursing services related to unpredictable visiting times, lack of continuity of care, and perceived variable expertise amongst nurses in negative wound pressure therapy. Importantly, patients valued information from the surgeon who had performed their surgery, and were deeply troubled when they received conflicting advice or information from nurses. Receiving conflicting advice from clinicians has also been highlighted as a predominant concern of the 120 patients who had experienced trauma or injury interviewed by Gabbe et al. (2013).

## 5.6 Treatments for surgical wounds healing by secondary intention

Although our study participants generally viewed negative pressure wound therapy as an effective treatment, they reported various drawbacks, including pain during dressing changes when foam rather than gauze dressings were used, a finding reported elsewhere (Upton and Andrews, 2015) that has been attributed to an in-growth of new granulation tissue into the foam that is attached to the dressing (Vuolo, 2009). Some study participants reported feeling too embarrassed to go outside the home with negative pressure wound therapy in situ, due to the bulky appearance of the equipment and their fears that the exudate might be detected by other people. Monsen et al. (2016) conducted an interview study with 15 people who had received negative pressure wound therapy at home for wounds resulting from vascular surgery. In this study, participants similarly reported concerns about the cumbersome nature of the equipment which imposed restraints on every day activities, such as cooking, cleaning, dressing and sleeping, as well as limitations to their social life, due to feeling self-conscious. Abbotts (2010), in a qualitative study with 12 participants with a variety of wound types, identified pain, smell, embarrassment and concerns about nurse training as important patient concerns. In our own study, nurses' varying levels of expertise in use of negative pressure wound therapy appeared to provoke high levels of patient anxiety.

Evidence of effectiveness for some of the treatments described in this study is limited or absent. Systematic reviews of negative pressure wound therapy for chronic wounds have concluded that there is no valid or reliable evidence that it accelerates chronic wound healing (Ubbink et al., 2008; Dumville et al., 2015). Sharp, sometimes painful, debridement of open surgical wounds was not uncommon in our study, despite the lack of high quality evidence to support its use (Smith et al., 2011). Clinicians appeared inconsistent in their choice of wound products for open surgical wounds highlighting the paucity of good quality evidence to assist decision-making and the need for further research in this area (Vermeulen et al., 2004; Dumville et al., 2015; Norman et al., 2016).

## 5.7 Strengths and weaknesses

Our study was designed to elicit patients' views and experiences of living with an open surgical wound healing by secondary intention and, as far as we are aware, it is the only study of its kind. Purposeful sampling was used to try to ensure inclusion of participants of differing age, gender and ethnicity, with varying levels of personal support, and a variety of wounds with different aetiology and duration. Although only one of our 20 study participants was not white British in origin (5%), this precisely reflects the ethnicity of the people we identified with open surgical wounds in our prevalence survey (Chetter et al., 2016). Significant others (patients' partners, family members and friends) who were present when patients were interviewed often contributed to the interview, and added a further dimension to the findings, though we did not specifically set out to recruit significant others into the study. Patient advisor involvement at all key stages of the research process was an important strength. Our study yielded 'rich' data, providing insights into how patients view and experience surgical wounds healing by secondary intention and enhancing understanding of the impact of these wounds on patients' lives, as well as sensitizing readers to some of the challenges associated with management of these wounds. Our study findings may be considered transferable to other patients with surgical wounds healing by

secondary intention, although decisions concerning extrapolation of the findings should take into account any study-specific contextual factors that may limit transferability. Green and Thorogood (Green and Thorogood, 2014, p 252) have suggested that readers' ability to assess relevance of study findings for other settings or contexts will rely on adequacy of description, and sufficient theoretical analysis, to allow credible inferences about what is general.

## **6. Conclusions and implications**

Findings from our study suggest that the quality of life of patients with open surgical wounds, which are slow to heal or non-healing, is impaired in physical, social and psychological domains, and that these are interconnected. Our findings illuminate the significance of psychosocial effects, due to diminished sense of self, inability to fulfil social roles and obligations and curtailment of normal social activities, as patients' hopes for healing are not met. Our study also highlights the impact of financial pressures on younger patients whose non-surgical wound rendered them unfit for work, and their concerns about consequences for their family and implications for employment in the longer term. The findings also point to a need for improvements in communication with health care professionals, increased continuity of care, and improved consistency of information-giving and approaches to wound management.

Psychological interventions may be useful in helping patients to accept and adapt to their non-healing wound, although we currently know little about which types of intervention may or may not be effective. Results from a recent systematic review (Pinto et al., 2016) of studies concerning surgical complications and their impact on patients' psychosocial well-being highlight the need for further research on how best to support patients who experience a complicated postoperative recovery. Patients' expectations for wound healing may often appear unrealistic, yet clinicians need to manage these expectations within a framework that allows patients some measure of hope for healing, while avoiding the arousal of false hope, which may undermine professional-patient relationships (Briggs and Flemming, 2007). Health care professionals may feel unequipped to deal with the complexity of issues that patients often face and may require support themselves to deal with feelings of frustration and failure when healing is not achieved (Morgan and Moffatt, 2008; Pragnell and Neilson, 2010).

Clinicians face multiple and complex challenges in caring for patients with surgical wounds healing by secondary intention. Assessment and measurement of the physical and psychosocial factors that impact on patients' quality of life require appropriate, psychometrically valid measurement tools, which are not as yet available for use specifically with this patient population. The lack of a robust evidence base for cost-effective wound management makes it difficult for clinicians to adopt an informed approach to the management of non-healing, open surgical wounds. Further research is required in all these areas if we are to better understand and respond to the needs of this patient group.

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### **Conflicts of interest**

None

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Appendix 1: Patient topic guide

Appendix 2: Diagram illustrating Analysis of data using Framework approach

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