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An exploration of the challenges of communication and adherence to treatment for patients undergoing negative wound pressure therapy --Manuscript Draft--

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Authorship

All authors have made substantial contribution to the development and execution of the study, drafting and revising the article and final approval of this submitted version. There are no competing interests to declare.

Ethics

Ethical approval was applied and granted by an NHS ethics committee and the study was conducted in accordance with the Research Governance Framework for Health and Social Care and the principles of the Declaration of Helsinki (last updated 2013).

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Key Messages

- Wound healing is a normal physiological process which can be delayed or expedited by a number of biological and social factors, including adherence to treatment.
- Chronic wounds are common amongst older people and in those with long term conditions and they have important personal and financial consequences for patients and the delivery of health services.
- Delayed healing occurs in a high proportion of patients with chronic wounds, despite delivery of evidence based treatment
- Effective communication and a therapeutic relationship are essential to facilitating adherence to treatment in patients with chronic wounds
- Adherence to treatment is complex and influenced by patient's beliefs about their wound and whether healing is occurring; symptom control; access to lay and professional help and the perceived complexity of medical devices.

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Introduction

The treatment of wounds can be a complex and protracted process, the success of which is partly dependent on adherence to the prescribed regimen ⁽¹⁾. A focus of recent research and development, therefore, has been to develop technologies which can be used in the community and which will enhance wound healing. There is also an impetus for these medical devices to accommodate complex symptoms. Excessive exudate and odour are often associated with delayed wound healing and these sequelae can have profound psychological consequences including feelings of disgust, self-loathing and low self-esteem ^(2,3). Collectively, these factors often disrupt people's lives and lead to social isolation and depression ⁽³⁾. For both health care professionals and patients, complex treatments, particularly those including the use of unfamiliar technology, can pose many practical and psychosocial challenges that may have a significant impact on adherence to treatment^(4,5). This paper explores the adherence of patients undergoing negative pressure wound therapy (NPWT) as part of treatment for a wound and the dilemmas faced in communicating effectively with health professionals .

Many studies have examined the concept of compliance, concordance and adherence with treatment ⁽⁴⁻⁷⁾. However, most papers reviewed either debate distinctions in theory or nomenclature alone or discuss adherence with treatments unrelated to wound healing. Despite the plethora of studies on the subject, adherence cannot be explained by a range of sociodemographic, clinical or personality traits ⁽⁸⁾. Studies in leg ulceration indicate that adherence with treatments such as compression are limited. In a study of 150 patients with leg ulcers, Heinen et al ⁽⁹⁾ found that only 39% displayed adherence to compression while Finlayson et al reported that compression was worn for a median of 4 of 7 days with depression, self-efficacy and knowledge significantly related to adherence to compression therapy ⁽¹⁰⁾. Jull et al found that only 52% of patients wore their stockings daily for the first six months after ulcer healing but 22% had not worn their compression at all ⁽¹¹⁾. Qualitative research showed that trust in the nurse was central to treatment adherence and could influence patient behaviour even if they were not fully convinced of the benefits of treatment ⁽¹²⁾. An educational study aimed at improving patient knowledge was undertaken with 26 patients with leg ulceration. The intervention led to an increase in daily exercise and elevation but no improvement in the time patient's wore compression ⁽¹³⁾.

In addition most studies rely on professional judgments about the level and reason for adherence rather than gaining an exploration from the patient perspective ⁽¹⁴⁾. Poor use of compression is often associated with practical limitations such as the ability to apply and

remove the garment however belief systems, access to practical support and previous experience may also be important determinants ^(15,16).

Professional belief systems about patients with leg ulceration include the concept of the “social ulcer” in which a group of isolated patients seek to maintain a current wound for the perceived gain of receiving professional care ⁽¹⁷⁾. Patients defined in this way are frequently referred to as poorly adherent to treatment or demanding of excessive professional care ⁽¹⁸⁾. Research exploring the relationship between patients with non-healing wounds and their corresponding nursing teams shows a complex interaction in which patients seek to maintain control of their treatment and seek to maintain a “good “ relationship with professionals. Patients often had to work hard to ensure their views were heard by nurses and were consequently labelled as difficult, complaining, or over- anxious. Similar findings with diabetic patients show that those who strive for control or a high level of knowledge are viewed as demanding and having delusions of grandeur above their knowledge level ⁽¹⁹⁾.

Compliance is generally seen as negative and suggests yielding, complaisance or submission and failure to comply tends to be seen as disobedience⁽⁶⁾ .Adherence, on the other hand, emphasises the patient’s freedom to decide and reflects the tenacity patients need to maintain the behavioural changes required to persist with interventions over time⁽⁴⁾ .Concordance, by contrast, emphasises the role of the patient as a co-decision maker who works with healthcare professionals to achieve the best possible therapeutic outcome. The term adherence reflects the degree to which a patient’s behaviour matches the prescriber’s advice and as such this term describes the behaviour of one individual: the patient. Concordance is more complex and relates to the partnership and agreement or shared decision-making necessary for effective prescribing, and describes the behaviour of more than one individual: the patient and the healthcare professional ⁽⁷⁾.

Non adherence with prescribed therapy has been described as a major public health problem and can impose a considerable financial burden on modern health care systems⁽²⁰⁾ .Studies undertaken in the USA, UK, Australia and Canada suggest that general adherence rates for long term medication therapies fall between 40% and 50% and for short term therapies between 70% and 80%.⁽²¹⁾ Of particular relevance to this study is the finding that when treatment regimens are complex or involve lifestyle changes, non-adherence can be as high as 70% ⁽²²⁻²⁴⁾.

Past experience of illness has been shown to have a powerful impact on adherence, particularly the speed of diagnosis, the effectiveness of previous treatments and a patient's confidence in a good outcome.⁽²¹⁾ Equally influential is the patient's perceived severity and complexity of the current illness and the relationship the patient has with the health professionals caring for them ^(6,21). Good understanding of an illness and its treatment, through provision of clear and easily understood information, is associated positively with adherence rates⁽²⁵⁾. Non adherence is seen as a significant barrier to effective medical treatment ⁽²⁵⁾. Therefore, the need for high adherence applies to a wide range of prescribed interventions including medication, dietary modifications, exercise and other life-style changes as well as the use of wound care dressings and specialist technologies.

Negative pressure wound therapy is a non-invasive therapy that applies negative pressure in a closed environment to facilitate healing of acute or chronic wounds. The benefits of NPWT include ease of use, efficacy and cost-effectiveness⁽²⁶⁾ .However, as Moffatt and colleagues⁽²⁷⁾ have noted, no studies have been carried out previously to determine how patients and their carers might manage NPWT in the home environment and what impact its relative complexity might have on adherence. This study provides important insight into the challenges faced by patients with complex wounds that require more complex technology for treatment than the simple provision of wound dressings. It also explore participant's ability to adhere to treatment in their search for wound healing.

Aim: The primary aim of this qualitative study was to explore the challenges of communication between patients and professionals and adherence to treatment for chronic wounds using NPWT delivered at home.

The secondary aims were:

- To examine the practical and psychosocial factors that support or hinder the extent to which patients participate actively in the management of their wounds.
- To explore how understanding of a wound can influence acceptance of treatment.
- To explore how attitudes and understanding of NPWT can influence adherence.
- To describe the impact on daily life of using a NPWT system
- To explore how relationships with professionals influence patient adherence
- To explore the challenges faced in effective communication with professionals

Methods

Research design and setting

A qualitative study design using in-depth, semi-structured and digitally recorded interviews was employed to capture the experiences of patients who had recently undergone a period of treatment using a NPWT system. We also explored the challenges faced in patient / professional communication in this interview setting. The sample was designed to capture patients at different times in their treatment with NPWT and to allow a large enough sample to ensure saturation of data was achieved during the analysis.

Sample

A purposive sample of 24 patients were recruited prospectively from community and tissue viability services based in UK National Health Service sites. Prospective participants were approached initially by a member of the usual care team. The treatment adopted in this study combined an advanced wound dressing with a lightweight single use suction pump, which delivers 80mmHg negative pressure and manages wound fluid through absorption and evaporation. In contrast to larger models, there is no requirement for a canister as wound exudate is managed by the dressing that is integral to the device. The system can be worn during everyday activities and is designed to manage exudate for up to one week. The system may need to be changed more frequently if large volumes of exudate are produced. Following recruitment, participants were allocated randomly to one of two subsets who were interviewed at 4 or 10 weeks. Patient recruitment was based on the following criteria;

Inclusion Criteria

- 18 years or above
- currently being treated with a NPWT^{*} system
- capacity to give informed consent
- able to communicate in English

Exclusion Criteria

- terminal illness

Study Context

This study was carried out in wound healing services in the UK who were delivering care to patients with a complex range of wounds that required treatment with advanced therapies such as negative pressure wound therapy (NPWT).

Ethical considerations

Ethical approval was applied and granted by an NHS ethics committee and the study was conducted in accordance with the Research Governance Framework for Health and Social Care ⁽²⁸⁾ the principles of the Declaration of Helsinki (last updated 2013) ⁽²⁹⁾ As such, all participants were made aware that they could withdraw from the study at any time and that in the event of their withdrawal, anonymous data collected so far could not be erased but any identifiable data already collected from participants would be withdrawn at their request. and the Data Protection Act ⁽³⁰⁾ , all data collected was held securely, in a locked cabinet. Access to the information was be limited to the study staff and investigators. Computer held data including the study database was held securely and password protected. In the event that participants became distressed or upset, the interview was terminated if appropriate and the participant was signposted to relevant services.

Recruitment

Participants were recruited from a range of wound healing services in primary and secondary care settings across the UK. All patients were provided with a detailed information sheet about the study and were invited to take part by a local research nurse. Prior to informed written consent being obtained, all patients were given the opportunity to clarify any outstanding questions.

Interview procedure

All interviews were carried out by a single researcher who contacted the participants by telephone to arrange the interviews at a time and venue of their choice. In each instance, participants chose to be interviewed at home or in a place with which they were familiar and where they felt secure, such as the clinic where they were treated routinely.

Each interview was recorded digitally and lasted up to one hour. All participants were given the opportunity to invite a relative or carer to be present during the interview. An interview topic guide (available from corresponding author on request) was used to direct the interview. The content and format of this guide was generated by a multi-disciplinary expert panel consisting of tissue viability nurses and a medical specialist in wound healing. Patients' views were sought about the design of the study and the topic guide for the interviews through a convenience sample of patients with wounds known to one tissue viability service. The topic guide was piloted with 2 patients prior to commencement of the main recruitment and adjustments were made to any questions that patients found difficult to understand and explore. The content was also informed by the key findings derived from

a review of relevant literature pertaining to compliance, concordance and adherence, wound healing, wound management and quality of life. The topic guide covered the following key domains: demographic, health and social background, wound history and treatment, impact of the wound, experience of NPWT; factors affecting adherence and issues of communication with professionals.

Qualitative analysis

Each digitally recorded interview was transcribed verbatim and analysed by a second researcher. The process of data analysis used the analysis method 'Framework' developed by the National Centre for Social Research ⁽³¹⁾. This is a matrix based analytic method that facilitates rigorous and transparent data management such that all stages involved in the analytical hierarchy can be systematically conducted. The framework classifies and organises data according to key themes, concepts and emergent categories. The study had a thematic framework comprising main themes, subdivided by a succession of related sub-topics. These were further refined through familiarisation with the raw data and cross sectional labelling. Once considered complete each main theme was charted on its own matrix. Every case was given a row and each column denoted a subtopic. Data was then synthesised within the thematic framework.

To maximize validity and reliability the analysis of data was moderated by a third researcher and the outcomes were double-checked against the transcripts. Any differences in perception or interpretation were discussed between researchers and resolved through consensus. Data was not validated by participants of the study.

Results

Clinical and Socio-Demographic Characteristics

Participant key clinical and socio-demographic characteristics are presented in Table 1 below. Twelve people were randomised to the early interview group (4 weeks) and twelve to the late interview group (10 weeks). The participants varied in age from 34 to 93 years and half of the cohort was female. The majority of people had complex and long term co-morbidities. Participants were being treated for a number of wounds, including: venous ulcers (n=13), pressure ulcers (n=6), traumatic wounds (n=2), dehisced surgical wounds (n=2) and a rectal abscess (n=1). Eleven participants had a previous history of wounds and in ten of these cases the wounds were venous ulcers. Fifteen people lived with a relative and five lived alone in their own home or rented accommodation. Four people lived in a residential home and two people lived with relatives who required additional support due to

the existence of a learning disability or early dementia. Two participants were employed, one full time and one part time, sixteen participants were retired and one was semi-retired, one had been made redundant and four were unable to work due to poor health.

Insert table 1 here

Categories and themes

The qualitative interviews generated three overarching categories and their related themes which are summarised in Table 2 below.

The first category entitled 'living with a wound'; explores the participants' real-life experiences of wounding, the treatment they received and the impact the wound had on their lives. The category embraces three themes: stories of wounding; ineffective early interventions and a disrupted life.

The second category, 'treatment with NPWT', explores participants' experiences of treatment with NPWT and addresses three themes: information, understanding and expectations; disappointment and frustration – a wound unhealed and light, small and effective – a wound healed.

The third and final category, 'adherence ', explores the concept of adherence through the participants' beliefs about their wound, their understanding of treatment and the decisions they made about their treatment both historically and with regard to their current treatment with NPWT. This category also includes three themes: 'they know best' – beliefs and relationships; making decisions; from concordance to adherence and NPWT and adherence.

Insert table 2 here.

Category 1 Living with a Wound

Theme 1.1 Stories of wounding

Accounts of wounding given by participants in this study were diverse and for some the experience was profoundly emotional. Whilst the moment of wounding was easily

identifiable in some instances, in other cases the initial wound seemed minor and was barely noticeable at the time. Participants reported that wounds often resulted from relatively insignificant, everyday injuries and in at least one case it just seemed to appear:

'It was a little scab thing just below my left ankle. That is how they usually start. I don't know how it got there; I don't know what could have caused it. I thought it would get better but of course it didn't.' (CF, 77yrs)

For others, the wound was the result of a life-disrupting event which was obscured by confusion and anxiety. A young mother of a 2 year-old daughter tells of her protracted journey to a diagnosis of inflammation of the coccyx. The failure of conservative management (physiotherapy and steroid injections) led to her having a coccygectomy:

'The pain was horrendous and a week after the surgery the wound broke down. I had been discharged by this time. I felt unwell, really ill and so I went back to A&E a couple of times and was eventually readmitted. The wound was debrided and re-sutured and I was put on antibiotics. The pain was awful again and the wound started to weep a sort of black jam-like stuff. I felt really unwell so I went back to A&E. I was put on different antibiotics and the surgeon decided to use a [large NPWT device]. He said it was the only thing that would work because of where the wound is. It's been terrible really.' (SF, 34yrs)

These findings support the existing literature that highlights the physical and emotional impact of developing a wound ^(32,33,34). Patients and families hold many different beliefs about why and how wounds develop and the treatments that are required. The data demonstrates the different illness trajectories that may lead to wounding and that when it occurs through medical crisis or intervention that it is a frightening event. Previous experience of wounding does not prepare patients for the impact of the symptoms and challenges associated with wound healing and the complex treatments required. In patients with previous experience of wounds there is the fear of uncontrolled symptoms and a long journey to healing.

Theme 1.2 Ineffective early interventions

Participant experiences of treatment interventions varied considerably. A small number reported that their experience was generally positive but for the majority treatments were described as being protracted, uncomfortable and often ineffective. In addition, the data suggest that many of these early interventions could be characterised by delays, misunderstandings, poor communication and tension. One participant, who was obese, described being prescribed compression for his venous ulcer, which was his worst fear:

'I'd had compression before and it was a failure. I couldn't cope with it. It was my weight; it was just impossible to manage with it. I told them I just didn't want to go into compression again. What did they do? They put me in compression and when they took it off my leg was covered with infected spots and my ulcer was infected. It is a failure for me, the nurses, everyone.'
(AM, 46yrs)

This quote highlights a number of issues. Previous experience of compression was significantly influencing the participant's attitude to future treatment. Problems with compression are frequently reported in the literature and require professionals to be prepared to adapt regimes for the individual patient requirements ⁽³⁵⁾. The patient demonstrates an external locus of control, blaming the compression for previous treatment failure and the development of infection rather than considering he had any influence over the situation other than a tacit acknowledgement of his obesity.⁽³⁶⁾ Professionals are faced with the dilemma of a strong evidence base supporting compression therapy and the patient's non-adherence to treatment. There is poor communication and the inability to find a compatible solution. In this situation the patient's strong negative belief systems are influencing his willingness to adhere to treatment.

A participant who was a recovering heroin addict received treatment at his GP surgery that resulted in misunderstanding, friction and anger:

'I knew what it was, it was an ulcer, I'd had one before and I knew it needed special treatment like. I went to my doctor and the nurse kept saying they'd refer me to the ulcer clinic; 'we'll just give it a week'. She did that for a month. They just kept bandaging me up and sending me away. It was just getting worse and began leaking through. I ended up seeing the Practice Manager and making a complaint. She told me there was a three-month waiting list for the ulcer clinic. I went home and got a phone call later that day and the

manager told me I could start at the ulcer clinic the next week. I am very angry about the delay; I think my previous life is still catching up with me.'
(GM, 37yrs)

This quote highlights the difficulties of communication and expectations of the health care system and the patient's fear that previous life habits are influencing professional behaviour towards him. The recommendations for treatment may be in line with recognised practice but the patient's beliefs that he is viewed as a "difficult" or "unpopular" patient convince him that his treatment is being deliberately obstructed. The patient adopts an aggressive and demanding behaviour that while apparently effective in obtaining his immediate treatment may jeopardise his further relationships with professionals who see him as coercive and demanding thus fulfilling his fears. This situation highlights the importance of the therapeutic alliance in planning treatment. ⁽¹⁸⁾

The participant who had an infected wound following a coccygectomy experienced further frustrations as a result of what she calls 'bureaucracy gone mad'. The surgeon wanted to treat her as an outpatient but because she had never been admitted to that hospital this was deemed to be administratively impossible. The delay resulted in considerable anxiety as she was clearly concerned that such a decision would cause further deterioration of the wound:

'The surgeon wanted to admit me to get the [large NPWT device] put on as an outpatient. The hospital said they couldn't do it as an outpatient because I hadn't been an in-patient first. I had to wait for over a week to get that sorted out. I was very worried my wound would get so bad I would need more surgery. Without the device the dressings were lasting only about an hour or two and I often had to change them myself which wasn't easy because I couldn't see the wound.' (SF, 34yrs).

The data supports the anxiety and distress patients feel when dealing with complex chronic wounds. Professionals also face anxiety and dilemmas when they use evidence based treatment that appears ineffective or when "system issues" within the health service influence the smooth transition of care between services. This may be due to many reasons including different access to technical devices such as NPWT in hospital compared to primary care. Patients hold "common sense" approaches to solutions that may be in stark contrast to the reality of a complex and bureaucratic health care system. These situations are further exacerbated when there is poor communication between professionals. In such

situations they may well adopt defensive attitudes that include blaming the patient for adopting unhelpful health behaviours or being “non-compliant “ with treatment in order to cope with their own concerns over treatment failure ⁽³⁷⁾.

Theme 1.3 A disrupted life

Living with a wound had a considerable impact on the majority of participants especially when taken together with their advancing age and complex co-morbidities. These ramifications were not confined to the physical effects of wounding, and its treatment, but also included significant psychological and social effects. For participants who had experienced wounding on one or more occasions previously, especially those with venous ulcers, the data suggest a cycle of wounding that caused anxiety, fear and uncertainty:

‘I was worried to death because I had such a bad time with the last one. It took such a long time to heal and I had to go to the surgery every three days, I think it was. I was exhausted by the end’. (QF, 84yrs)

The physical effects of wounding varied from one participant to another and demonstrated the cumulative impact a wound and its complications can have on daily activities particularly amongst people who are elderly. An illustration of the burden arising from the complex interaction of physical, social and psychological factors is portrayed by one man who had a rectal abscess:

‘It drains you. I couldn’t understand it at first. I mean I used to chuck 36-gallon drums about but I can’t pick up anything now. The abscess was sapping the strength out of me. I feel the gumption has gone out of me. It’s the treatment. I have to go up to the clinic three days a week and on top of that my wife has just been discharged from hospital.’ (KM, 73yrs)

For others it was the effort it took, disruptive impact and time needed to attend appointments that was a concern:

‘It’s a real nuisance because I have to come to the clinic twice a week and it takes me nearly all the morning. It takes up so much of the day.’ (JF, 80yrs)

The psychosocial impact of having a wound can challenge an individual's body image due to the smell and appearance of dressings or compression bandages. This effect proved to be very dispiriting and the cause of major disruption to the lives of a number of participants:

'It stinks. I can smell it now. It makes me feel sick, it's like dragging a bag of garbage around with you, and it's a horrible smell. It's unnerving; it takes away my self-confidence and I can't stand next to someone. I don't go on buses; I walk because I don't want other people to smell me'. (GM,37yrs)

This response illustrates how people may choose to isolate themselves due to the social stigma they experience, a situation which can have an impact on their psychological well-being. The cumulative burden extends beyond the symptoms of the wound into daily life and the disruption that occurs from treatment. Adherence to treatment requires an assimilation of complex regimes into everyday life and an appraisal that the effort is worthy of the investment of time and effort. While complex regimes may be tolerated for a short time they may become more onerous overtime if there is little perceived health gain by the patient and family ^(38,39).

Category 2 Management with NPWT

Theme 2.1 Information, understanding and expectations

All participants were pleased to be trying NPWT and saw this as an opportunity to try something new which might have a positive effect on wound healing:

....I didn't hesitate; I had no qualms at all. I think I am very lucky to be given the chance because it looks like my wound is going to take a very long time to get better.' (VM, 81yrs)

Participant understanding of wound management including NPWT varied greatly, as did the explanations and information with which they were provided. It is clear that some participants had been given clear explanations about NPWT tailored to their age and capacity to understand while for others it seems to have been explained less sensitively to individual needs:

'It wasn't explained to me because I am deaf. They told my daughter. She was a bit upset because they told her "this wound could be a candidate for a study" as if I had nothing to do with it.' (BF,93yrs)

'It was explained to me very well. I was also shown all the bits and pieces, the dressing, the pump, holster and strap. My understanding is that it exerts a negative pressure, which helps keep infection and detritus getting in the wound.' (AM,46yrs)

Despite mixed levels of understanding about NPWT, the data suggest that participants had quite high expectations and felt it could progress wound healing:

'I had another kind of pump once; it was awful, so big and bulky so I wasn't keen at first. Then they showed me [the system] I couldn't believe how small it was. I was really pleased and I had a little prayer that I would be able to take part. I just knew this one would be better and it would heal my bottom once and for all.' (EF,91yrs)

A few participants took a more cautious view and remained unsure about the outcome of treatment and its ability to stimulate wound healing. These reservations appear to have been based on previous experiences. In one case, as seen in the situation described below, a man with paraplegia had encountered protracted battles with pressure ulcers and in another a woman had recurrent venous ulcers:

'To be honest I don't think it will make much difference to me. For a lot of people it could have advantages but not for me. It's the position of my wound you see; it's just in a bad position. No, I'm not optimistic.' (CM, 53yrs)

'As long as I could still get about I didn't mind and it was very clever with it being so small. I've had these things (venous ulcers) a long time and they all took a lot to get them to mend. I was always a bit unsure, I had my doubts it would be as good as the nurses said it was.' (TF, 83yrs)

Theme 2.2 Disappointment and frustration; a wound unhealed

For eight participants (33%) their experience of NPWT can be characterised as disappointment, frustration and of wounds still unhealed. Much of this appears to be related to difficulties experienced with aspects of the equipment itself, particularly the tubing and buzzing noise which participants tended to refer to as 'the alarm'. In the end, the challenges of living with a dressing with a repeatedly broken seal, and the resulting alarms, proved too difficult in a number of cases:

'The first and second weeks were not too bad, the alarm buzzed just occasionally. By the third week it was buzzing so much I couldn't put up with it. I was in a church members meeting and it kept buzzing and I realised I could not put up with it. I took the dressing off and the batteries out of the pump. I put my own dressing on when I got home until I went to my next clinic appointment. By the third week the wound was infected and had a terrible smell so I decided to withdraw from the trial.' (CF, 77yrs)

In one instance, healing of a wound was associated with recovery and symbolic of an essential step towards a new future for him (GM,37 years) and his family. As a recovering heroin addict, this meant a great deal and in his experience, obtaining a job was partly contingent on the wound being healed. He also believed and hoped that NPWT was the vehicle by which this healing and transition would occur. When it became evident that healing was not going to be achieved, his disappointment was obvious and deeply felt:

'I was pleased to begin with and I thought I was really improving after nine months of struggling. Then it kept beeping so I turned it off. I know I got really anxious about the beeping. The wound just went from bad to worse after I turned it off; it got infected. I got set back because it didn't work properly. I can just tell by the smell that it's worse. I see no worth in it [the system], it hasn't done any good, and it hasn't mended any quicker.' (GM, 37yrs)

Theme 2.3 Light, small and effective; a wound healed

The majority of participants (n=16, 67%) had a positive experience of NPWT. This group commented favourably about the size of the device, its lightness and its effectiveness in healing or reducing the size of their wound. There were some problems with maintaining a seal, which led to 'the alarm' sounding, but, in most instances, people managed this well. The overall sense from the data is that these interviewees were positive about their treatment, despite having some concerns about aspects of the technology (such as the tubing 'getting in the way' etc.). The critical difference between those who gave positive or negative feedback appears to be the higher level of motivation expressed which was linked to their positive experiences of NPWT. There was clear evidence of individual commitment to persevering with treatment. Participants also believed that the treatment had progressed well for them personally, and above all, they were delighted with the positive outcome:

'It's so small it's marvellous isn't it? Not like the other one I had, that was like carrying a dog around with you all the time. I couldn't wait to show it to my neighbour. It worked much better straight away, and the dressings seem to be easier to put on. I have to keep my wits about me though when I am getting dressed, I have to remember I am attached to something, but I'm really thrilled with it.' (EF, 91yrs)

'I am really delighted with [the system]. I have it with compression and it works very well. The amount of stuff coming out went down to almost nothing after seven weeks and by nine weeks it was healed. It really didn't affect me very much. The pump and leads got tangled up sometimes but I managed to sort it out quickly. I still went to the supermarket, to church and I even went to a 90th birthday party.' (JF, 80yrs)

Further positive experiences of NPWT were reported by a young mother with a dehisced wound. Although she had only been using NPWT for three weeks, the merits outweighed the obvious challenges she still faced. During this period the device was changed daily as a large volume of exudate was produced. Furthermore, due to the position of the wound it was very difficult to obtain an adequate seal and this was compromised subsequently by movement and sweat which tended to loosen the dressing. Irrespective of these difficulties, after 3 weeks the wound had reduced from a depth of 6cm to 1cm and at the time of the interview there was no exudate or unpleasant smell:

....[the system] is brilliant and it changed everything for me. I can go out without worrying about leakage from the wound through the dressing and

my clothes. The pain is gradually improving and, for the first time in ages, I feel clean. [The system] changed the way I could be (SF, 34yrs)

Category 3 Adherence and communication

There was a complex interaction of factors influencing patient's attitudes and behaviour towards adherence to treatment with NPWT and other medical interventions. These included the attitudes towards and relationships with professionals and how their concerns could be expressed and responded to. Closely related to this was the ability to make collaborative decisions about treatment and to negotiate change when they perceived that treatments were ineffective or unhelpful. There was evidence of a range of different relationships as well as frustration with professionals who did not develop therapeutic relationships leaving them to feel impotent and unsupported.

Critical to this study was the belief that NPWT was a radical solution that would lead to wound healing. Patient perceptions of "success" or "deterioration" in the wound were tangibly linked to their willingness and ability to continue with treatment. The ability to tolerate the disruptive effects of the equipment were linked to whether patients perceived an improvement or deterioration in healing or the development of complications such as infection which they often attributed to the device. However the pattern of response was more complex and influenced by factors such as the age of the patient, their attitudes and problem solving capacity self-efficacy when adjustments to the device were required or their lifestyle and access to practical help with the equipment when difficulties occurred. For some, adherence to treatment was a requirement of their commitment to the professionals caring for them and in some cases to their families who supported them. The issues of undergoing NPWT are in part a reflection of the participant's wider beliefs systems about their health.

Theme 3.1 'They know best': beliefs and relationships

The participants varied considerably in the degree to which they understood their health problems and their beliefs about the nature of the relationship that should exist between patients and health care professionals. The data suggest that levels of understanding about health issues tended to reflect how patient/professional relationships were enacted. Many older participants believed in the paternalistic 'they know best' approach and tended to take a passive role in their care:

'I do believe that we should leave doctors and nurses to get on with what they are trained to do, they know best don't they?. No, I'm not one for asking questions or to complain. My generation were brought up not to do that. It would have to be pretty bad before I'd question or complain.' (KM, 73yrs)

"They said this machine will help my wound and I believe them, they've done the training not me. Not for me to question what they say is it?" (JF, 80 yrs)

For some elderly participants with paternalistic views of professionals they felt the benefit of the close family support offered by younger relatives. These relatives acted as advocates and saw it as their responsibility to try and understand what was happening and ask questions if necessary on behalf of their relatives:

'I do find it difficult now to remember tablets and things like that. I don't know what half the tablets I am supposed to take are for. My daughter sorts all that out for me. She uses a special container and I just have to take them tablets from the right little pot thing, so that's what I do and I hope for the best.' (QF, 84yrs)

"My daughter looked at the information about the machine. She said it would help and so I am trying it now. I rely on her to help me decide a lot. I used to be able to do more but now I am not so sure what is right, she knows the right way for me so I trust her."(EF,91)

For the younger participants, establishing relationships with health professionals was not something they found easy but they recognised its importance. Similarly, asking questions or challenging decisions about their care was often difficult. By negotiating with health care professionals and seeking out information about their health problems they developed a level of self-confidence, a key factor towards being heard and ensuring that their wishes were considered when agreeing treatment plans:

'I was completely inexperienced and unprepared for what happens in a hospital and dealing with doctors and nurses. Before this spinal problem I had never been ill in my life. I hear so many different opinions I don't know what is going on. I must admit I don't manage things very well with the

doctors but I do try to make them hear me, which isn't always easy, I'm learning the hard way I suppose but I do get angry and depressed.' (OM, 53yrs)

'Before I could be discharged [from the specialist hospital] I had to attend fifteen classes on how to take responsibility for my own welfare. It was drummed into us that we had to take an active part in our treatment. That gave me a lot of confidence and I feel more in control now. I know it's not easy but in my case this is for life so I have to be involved. I have a great relationship with my GP; we go on the Internet and find things out together.' (DM, 57yrs).

Theme 3.2 Making decisions: from concordance to adherence

The data suggest there was little evidence of concordance, between patients and health care professionals. Collaborative decision-making and genuine attempts by professionals to empower patients were absent, to a large extent, from the stories the participants shared. Attitudes to concordance (true collaborative decision making) ranged from passive acceptance by a few at one end of the continuum to a proactive minority. The majority fell in the middle ground, which could be characterised by a desire for information and control over their treatment and wellbeing which was largely unfulfilled, and often resulted in frustration or anger. Passive acceptance of professional knowledge and power was alluded to by a number of participants:

'Nothing was really explained to me, I wasn't bothered, I just let them get on with it. They know what they are doing so I don't get involved, it's straight forward enough.' (FM, 68yrs).

'I can talk to the nurses but not the doctors. Some make you feel as if you're just like I was in the factory where I worked, a number, a clocking in number. They don't even look at you when they are talking. I do what they say and then ask the nurse afterwards.' (LF, 76yrs)

For others, difficulties with communication proved to be an obstacle to effective collaborative therapeutic relationships even at the most basic level. In one case, the daughter of a 93-year-old and profoundly deaf participant believed her mother was ignored by professionals. This reported behaviour is illustrated by the following comment:

'They don't tell thee, they just do it to thee.' (BF, 93yrs).

One participant recalls never experiencing collaborative decision making about his treatment even though he wanted a good relationship with his GP and active involvement in his care:

'I wanted to feel I was helping. I wanted to be involved. It was important because I wanted to get this thing healed. I was just another face to him in his busy day. They never heard what I was saying they just did what was necessary and sent me on my way. It's my drug addiction, it gets in the way; they see a drug addict, they don't see me.' (GM, 37yrs)

Professionals react to different patient groups in diverse ways and may be unaware they hold prejudicial attitudes and unconscious biases. This male patient felt his previous use of drugs was a major factor in achieving concordance and that his treatment was affected as a consequence.

Knowledge of clinical services did not necessarily enable people to participate in decision making about management of their wounds. One registered nurse described how she felt excluded from decisions about her care and believed staff were defensive about the circumstances:

'Everyone seemed so defensive about what was happening. I certainly wasn't included in decisions about the device [large NPWT device]. I was left in the dark about the delay. In the end I found out it was an administrative problem and really about who was going to pay for it. I was in a lot of pain and felt so frustrated. The surgeon never explained the reason for the delay and he still hasn't.' (SF.34yrs)

In contrast, one man with a spinal injury reported that he was involved in decisions about his treatment. He attributed this to the experience and confidence he had gained whilst being treated at a specialist hospital, an environment in which he was encouraged to take responsibility for his own care from an early stage of recovery:

'If they don't include me I ask to be. Just recently they did a review of all my drugs. The doctor and me we went through them all and he explained why I needed some and not others. He asked me if I agreed with him, I thought

blimey you are the top man; I'm not going to disagree. But I know what he was doing. I am stuck with this for the rest of my life and we have to work together. This is how it has to be.' (DM, 57yrs).

Adherence to treatment was considered an important aspect of care by all participants. Similarly, most people reported that they adhered to the regime prescribed. Irrespective of this, there was evidence that adherence was influenced and often compromised by a variety of personal and situational factors.

There was a strong belief that taking medication as prescribed was their primary responsibility as a patient and that it would have a beneficial effect. For instance, one participant reported: *'If you want to get better, you take the tablets, that's what treatment is for isn't it?'* (LF, 76yrs) whereas another commented: *'I owe it to the doctors and nurses to do my bit.'* (UM, 82yrs).

However, a number of examples of poor adherence to treatment emerged from the interviews. The reasons cited for non-adherence included reduced capacities, such as impaired memory, eyesight or dexterity. The importance that participants placed upon taking medication was evident from their descriptions of the compensatory strategies they adopted to help overcome their incapacities:

'Short-term memory was gone, I had to think; did I take that or not? I forgot to take erythromycin and other things as well, a couple of times. Because of that I put all my medicines on a chart and I tick when I take them otherwise I'd forget.' (HF, 79yrs)

'I have a lot of trouble with blister packs of tablets. When you are blind like I am, blister packs are really difficult. Tablets pop out and I lose them. I have lost them a few times and I have missed a dose or two. My daughter and son sort them out for me now.' (HF, 79yrs).

'I have a very strict routine. I get my tablets and inhaler ready in plenty of time and put them out in the same place each time. I have to be really careful and strict with myself otherwise I would forget.' (QF, 84yrs)

The data in this study bring to the fore a range of underlying, often idiosyncratic, decision-making processes that participants make when choosing whether or not to adhere to

treatment. In the case of one participant with diabetes there appears to be a contradiction between his stated understanding of his condition, its seriousness and his approach to treatment:

'I know how important it is, if I don't keep to the treatment it could be serious like going blind, mind you I have heard they have found a treatment for that now. I'm not that good at keeping to my diabetic diet. I do have a few sweets, chocolate and cakes sometimes. I don't tell anyone. I know I shouldn't but I can't resist them. I also like a few pints at the pub. I'm not that worried because I keep a check on my blood sugar.' (FM, 68yrs)

In another case, a participant's arthritic symptoms were so severe and the treatment ineffective, that he felt justified in seeking out alternative medications through the Internet and felt unable to discuss this with his doctor before undertaking this action:

'I was going through a really bad patch with my arthritis in my knees. I wasn't sleeping and the pain was really bad and stopped me doing the things I wanted to do. What the doctor was giving me was doing no good at all and I thought there might be something better. I got something from the Internet and took that for a while but in the end what the doctor was giving me was better. I didn't feel I could tell the doctor, frightened to I suppose, but it was my decision and I don't regret trying.' (VM, 81yrs).

Theme 3.3 NPWT and adherence

The majority of participants found NPWT relatively straightforward to manage on a day-to-day basis, however there were considerable variations in their experience. For some people the perceived complexity of the technology clearly influenced their adherence and willingness to continue treatment, particularly if they did not perceive the wound to be healing or if troublesome symptoms such as pain or infection continued. Participants frequently judged their progress by comparing the current treatment with NPWT and previous treatments. Psychological reactions to the difficulties of treatment ranged from extreme anxiety to a belief that this was a necessary part of treatment and therefore of little concern. While the data indicates that elderly patients frequently reported these difficulties

and were more reliant on family or professional help to solve these problems they were also reported in some younger patients.

For others long term adherence with NPWT was influenced by other factors such as how much the device was an intrusion on daily routines such as bathing, sleeping and social activities and the time required for treatment and the management of the device itself.

“I found washing difficult. I like a bath twice a day but I couldn’t manage with the device so I ended up showering and I had to make sure I did not trip over the tubing, I miss the bath.”(RF 57)

“I had to be very careful at night not to lie on the tubing. I like to lie on my side but I couldn’t and that was hard. ” (NF,80)

“I was very anxious at night that I would lie the wrong way and set the alarm off and I would not know what to do” (PF, 86)

“I found that the treatment was taking up so much time. Not just waiting for nursing visits but solving problems. I have to live with a wound and this is just too much else that makes it too difficult. It’s difficult to say, but this is my life and it’s hard already. “ (MM,44)

For other participants they were pragmatic about these issues and found rapid solutions including asking for help from family.

“Well it’s no big deal; if the alarm goes off I know what to do. It does not worry me at all.” (IM, 67)

There was evidence that the complexity of the device affected adherence and would have implications for long term use in a proportion of patients. The patient perceived complexity of the device was manifested through the invasive nature of the buzzing and flashing lights and the challenge of managing the tubing, and occasional disconnections of tubing from the dressing. It is clear from the data that the principal cause of non-adherence and, ultimately, withdrawal from using the NPWT, was the level of perceived technical complexity:

‘The first two weeks were quite good but the third week it started to buzz and then stop. I put up with it for as long as I could. I took it off one night

because it was so bad. I told the nurse at the next visit. I said I would give it another week. Then it buzzed in church and that was it. I took it all off, the batteries out everything and I told the nurse I wanted to end using it.' (CF, 77yrs)

'The thing was keeping me awake at night and it kept on buzzing. Sometimes the tube would come out when I was asleep and off would go the buzzing. I had to try and get the tube back in. The worst thing was being refused service at the pub in the hospital grounds because the barmaid could hear the thing buzzing. Said I had to get a doctor's letter if I wanted to be served. It wasn't worth it in the end so I withdrew.' (FM, 68yrs)

'The alarm just kept beeping. Its where the wound is (sacral area), they can't get a seal so it keeps beeping. They spent an hour and a half trying one time. I couldn't stand it so I took the dressing off. I had taken the batteries out a few times just to get some peace. It wasn't just where the wound is it was with me being turned every few hours; it couldn't cope with that. I think it's a brilliant idea but for me it was the right dressing on the wrong wound.' (OM, 53yrs)

Levels of adherence with NPWT are determined by a number of important factors. These include not only the perceived level of complexity of the equipment and the extent to which it fitted with daily life, but also the 'motivation' of participants to complete treatment, the efficacy of the treatment as perceived by participants and the availability of social support.

'I have been quite anxious about things especially the alarms. I just couldn't have managed any of this without my daughter. The tubes, the noise, It would have been impossible.' (BF, 93yrs)

'it made a positive difference to me, it has changed my life in such a short time. It's so important to keep to the treatment plan and do what you are told to do even if that is difficult.' (SF, 34yrs).

'I think it is so important to finish the treatment, I said I would do that and I will, I'm still hoping my wound will suddenly turn the corner.' (JF, 80yrs)

The study included a randomisation of patients to an early or late interview in order to explore any differences regarding more prolonged use of NPWT. However the analysis failed to identify major differences between the experiences of these groups.

Discussion

The focus of this qualitative study was to explore the experiences of patients undergoing NPWT and to examine the factors that influence adherence. To aid clarity in this discussion, the term concordance is used to denote collaboration between the patient and health professional to achieve the best therapeutic outcome ⁽⁷⁾. While adherence is used to emphasise the patient's persistence and tenacity to complete a treatment regimen ⁽⁴⁾. In order to achieve the primary and secondary objectives of this study, it was important to ground participant accounts within the context of their experience of living with a wound. Context is important because it is known that both concordance and adherence to treatment regimens are decision-making processes by which patients balance their concerns about treatment options, against their perceived need for the treatment and its perceived benefits. Such decisions are based on a range of influencing factors that include physical ability, attitudes and past experience ^(21,38). In addition, concerns about the cause and progress of a condition can influence a patient's experience of illness and ultimately adherence with treatment ^(39,40).

The effects of a chronic wound and its treatment are well documented and echo the experiences that the participants in this study describe ^(32,33,34). These experiences concern: ineffective interventions, delayed healing times, pain, leakage of wound exudate, smell, the psychosocial impact of the wounding itself and the consequences of an unhealed wound for body image, independence and self-confidence. The patient accounts provided in this study confirm that these experiences can be life disrupting and long lasting. In addition, early interventions are described as being protracted, uncomfortable, often ineffective and characterised by delay, misunderstanding, poor communication and tension. The common thread running through the majority of patient experiences, which often led to friction and anger, was loss of control over their wound and its treatment. Patient control has also previously been shown to be important for effective engagement in treatment and motivation to achieve healing ^(32.)

The context of the participants' past experience of living with a wound and their accounts of adherence with treatment prior to entering the study demonstrate that collaborative decision making, and the empowerment of patients by health care professionals, was rare. Reasons given by participants ranged from a passive acceptance of the dominance of professional knowledge and power and a belief that the professional knows best; to a desire for information and control over their treatment that was largely unfulfilled. The latter occurred due to a range of factors including: poor communication between health professionals and participants, sensory impairments such as deafness or blindness that impeded communication and lack of the necessary skills, confidence or experience to question or challenge health professionals. The literature indicates that problems of communication are often at the centre of poor adherence to treatment and that the quality of the relationship between the patient and professional, the clarity of the information given, and the manner in which it is given, can greatly influence levels of adherence ⁽⁴⁾. Labelling of patients according to their lifestyle choices, behaviour or social settings could also have a negative impact on communication and opportunities for collaborative care ⁽¹⁸⁾.

All participants in this study saw adherence to treatment as important. Indeed there is evidence to indicate that a number of participants viewed adherence as a primary responsibility and a way of contributing to the therapeutic contract. Those participants who gave accounts of non-adherence fell into two groups. The first of these groups was small and included people whose non-adherence was the result of poor memory or a combination of poor eyesight and reduced dexterity. Work by Horne and colleagues (2005) has categorised this behaviour as unintentional non-adherence, as it results from limitations in capacity or the patient's resources ^(7,41). Examples of such impairments and unintentional behaviours include: forgetting to take medications, failing to follow instructions correctly when using medical devices (such as metered dose inhalers or walking aids) and difficulties opening medicine containers (such as blister packs or child-safety caps).

The second group included two people whose non-adherence was the result of deliberate decisions to make changes to the treatment they had been prescribed. Horne et al ⁽⁴¹⁾ categorise this as intentional non-adherence, which they define as an intentional action that is rational in terms of patient beliefs, circumstances, priorities, preferences and experiences but which differs from medical expectations and rationality. One of the participants in this group was diabetic and reported that he ate sweets and cakes regularly and enjoyed a pint of beer without telling the health professionals who cared for him. The data suggest that the beliefs this patient held about his illness enabled him to minimise its severity and its potential consequences, which ultimately had a negative impact on his adherence to

treatment. This falls in line with The Health Belief Model ⁽³⁶⁾ which would suggest that in order for adherence to be achieved, patients must believe that they are vulnerable or susceptible to an illness or its consequences. And moreover, that these consequences could be a serious threat to their health and wellbeing if treatment is not followed ^(36,37). In a second example, a man in his eighties with severe arthritis and whose symptoms were so severe, despite prescribed medication, sought an alternative from the Internet. Patient expectations and experiences of symptoms are known to influence medication concerns, especially if there is evidence that the medicine is not working.⁽⁴²⁾ Studies have shown that elderly patients can engage in intentional non-adherence by making decisions to change or stop their medicine without professional advice. Factors that influence such behaviour include the experience of side effects, symptom changes and the perceived inefficacy of the prescribed treatment.⁽⁴³⁾

The data suggest that the most significant determinant of adherence came from the technological aspects of the device to deliver NPWT and patient judgments as to whether the treatment was helping or hindering their wound or symptoms such as pain ⁽⁴⁴⁾. The majority saw it as an opportunity to try a new treatment, which might have a positive effect on wound healing. Indeed, the expectations of the majority were generally high at first and they believed that wound healing would be achieved. These beliefs could be attributed to procedural reactivity and a response to the attention participation in a study provides ⁽⁴⁵⁾. It could also indicate that the participants were eager to take some control over management of their wounds and this was demonstrated through their willingness to participate.⁽⁴⁶⁾ Studies suggest that patients, particularly those with long term conditions, make decisions about treatments that fit with their own beliefs and personal circumstances.⁽⁴⁷⁾ Research also supports the notion of “necessity beliefs” in which beliefs about a treatment’s efficacy are likely to contribute to perceived need, although this may differ from patient to patient.⁽⁴⁸⁾ Some decision making might also have been influenced by the fact that participants were involved in a study which is an artificial situation. It is known that patients seek out and are more accepting of treatment approaches that are believed to be manageable, tolerable and, in their view likely to be effective ^(3,49).

Participant understanding about the technology in particular and the study in general, varied greatly as did the explanations participants received. It is clear from the data that understanding did vary between participants and was probably lower amongst older people, although the implications of this for levels of adherence are not clear. A number of studies have confirmed that the relationship between a participant’s knowledge of a treatment regimen and their level of adherence is tenuous^(50,51). The existing literature is study

involved a participant group with a range of ages, backgrounds and illness experience. The existing literature demonstrates that even when information is communicated effectively, understanding and retention can be surprisingly low ⁽⁵²⁾ and this could have impacted on our study findings. For example, a number of the participants were over the age of 75 years and it is this group that studies suggest are at greater risk of non-adherence to treatment regimens due to lack of understanding, memory, other cognitive impairments and polypharmacy⁽⁵³⁾

The general experience of NPWT varied between participants and this was contingent on a number of factors. These included individual clinical and personal situations, the degree of success with which the device appeared to contribute to wound healing, the level of perceived complexity of the technology, the availability of social support and degree to which the device intruded into their daily life. For the majority (n=16, 67%) the experience of the device was positive. The size, weight and effectiveness of the device in healing or reducing the size of a wound were the most significant factors. The feeling conveyed overall by this group was one of commitment to persevering with treatment irrespective of the difficulties encountered because of the possibilities of a positive outcome.

For a minority of participants (n=8, 33%) their experience was one of disappointment, frustration and of a wound still unhealed. Several people in this sub-set encountered problems with aspects of the technology, particularly with the tubing and alarms. These features caused such disruption to their lives that participants felt that eventually it would be preferable to withdraw from the study rather than continue. Such experience is well documented in the literature. With the stress of dealing with specialist technology, alarms and managing the technicalities of NPWT, identified as barriers to adherence ^(5, 54). There is an important need to minimise the stress and anxiety associated with NPWT if patient wellbeing and adherence is to be maximised ⁽⁴⁴⁾. When interpreting these findings, it is important to note that studies show adherence rates are generally higher in trials than in real-world studies ⁽⁵⁵⁾. Participation in a trial or study can disrupt everyday life and can create considerable anxiety, be highly demanding and for some, become overwhelming ^(56,57).

Conclusion

The aim of this qualitative study was to explore the challenges of communication between patients and professionals and adherence to treatment for chronic wounds using NPWT delivered at home using a small, lightweight and portable system and to explore the factors that can have an impact on personal engagement with a treatment regime. This study captured the experiences of a heterogeneous sample who varied in age, had different wound

types, histories and experiences. Irrespective of this, the data need to be viewed with some caution because the accounts are limited to those of patients. The equally important professional perspective is absent.

The findings of this study highlight several of the problems associated with wounds and the impact these can have on a person's wellbeing, perception and adherence with treatment. They also illustrate the subtlety of the information needs of different age groups and the need for improved collaborative decision-making between patients and health professionals. Central to the findings of this study is the importance of helping patients and their social supporters understand treatment so they can take an active interest in the treatment provided and retain a sense of control. The motivation this fosters and the positive impact this can have on adherence with treatment is clear. This is particularly relevant when treatment involves the use of specialist technology. The demystification and simplification of technology is essential as this enables patients and their social supporters to rectify problems as they arise. Whilst this study reveals the distinction between intentional and unintentional non-adherence, further qualitative research is needed to help achieve a better understanding of this distinction in the field of wound care. Such research is important as it will inform treatment strategies designed to minimise the impact that non-adherence with treatment can have on wound healing and ultimately on the lives of patients.

In summary, the findings arising from this study indicate that NPWT was tolerated by the majority of patients and was perceived to be beneficial. In some instances NPWT was reported to transform wound healing, the management of symptoms and consequently the lives of those involved. In contrast, for those who had poor wound healing, experiences of NPWT tended to be less favourable.

Adherence to treatment is known to have an impact on the effectiveness of many treatments and outcomes of long term conditions. As noted above, patients who participated in this study prioritised each element of their care differently and this was noted to vary over time. A number of recommendations can be drawn from this study which all warrant further investigation.

- It is important, that health care professionals encourage patients to be open about their concerns and the limits of their adherence when being asked to follow complex and protracted treatment regimen.
- The predicted outcomes of the treatments offered need to be explained where these are known and the limitations of current practice and understanding of pathophysiology need to be acknowledged. In this way, mutual understanding of the

challenges faced by both patients and professionals can evolve, with the aim of developing a collaborative relationship that will foster sustained adherence to therapy.

- When treatment outcomes are disappointing or healing is protracted, it is important that both patients and clinicians consider a shift in the focus of attention from a purely curative approach to symptom control.
- As both intentional and non-intentional adherence can occur, different surveillance and intervention strategies should be incorporated into treatment plans.

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