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Original research

Beyond patient empowerment: clinician-patient advocacy partnerships in wound healing

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Abstract

Background/Aims Enhanced clinician-patient interaction can offer benefits for patient care through harnessing shared knowledge, which can help to address challenges in healthcare. This study aimed to explore the relationship between wound care clinicians and their patients to understand the challenges faced in wound care as well as the innovative strategies that are used to address them.

Methods A qualitative ethnography of three specialist outpatient wound healing clinics in the UK generated 120 hours of observations of consultations as well as 51 interviews with clinicians, patients and their relatives.

Findings The study found that wounds were considered a low-profile condition in healthcare and a taboo by society. In response, clinicians harnessed their interaction with patients to support wound healing research and education – forming clinician-patient partnerships for wound healing advocacy.

Conclusions In addition to encouraging educated participation in self-treatment, advocacy partnerships offered patients a proactive role in increasing the scientific knowledge regarding wound healing.

Key words

advocacy, clinician-patient relationship, ethnography, patient empowerment, wound care, wound healing

Introduction

The clinician-patient relationship has been a long-debated topic in healthcare. In wound care, there has been an emphasis on enhanced interactions between doctors, nurses, patients, as well as patients' family members (Lindsay et al, 2017) to highlight the ways in which harnessing collective knowledge and shared experiences can help to address the challenges facing wound healing (Queen and Harding, 2014). An aging population and a sharp rise in the incidence of diabetes and obesity – linked with wounds and impaired healing – (Harding and Queen, 2010) have marked an increase in the number of patients with chronic wounds (Guest et al, 2017). This is accompanied by a relative reduction in the numbers of clinicians who are specialised in caring for such patients (Bloom et al, 2011). In this resource-constrained context, 'it is almost inevitable that [wound clinicians] will need to develop professional-patient partnerships, [to] increase collaborative care and self-management education, empower[ing] people to think critically and make informed decisions in partnerships with healthcare professionals' (Price, 2011, p.18).

Many people living with wounds do not have access to specialist wound clinics, as much community care is determined by clinicians' personal experiences and remains somewhat inconsistent (Jhass, 2013). With wound care often reduced to dressing changes, the scientific expertise in wound healing may go unacknowledged (Madden, 2012). As a result, wound care may be perceived as a 'Cinderella' service (Young, 2016), as patients with wounds often 'don't know what is going to happen when they have a chronic wound, or who to contact and how' (Lindsay et al, 2017, p.663). In addition, the experience of an unsightly, malodorous hard-to-heal wound can lead to low self-esteem, embarrassment and social isolation, which attaches stigma to living with wounds (Augustin et al, 2012; Aguiar et al, 2016).

Recently, the term 'advocacy' has been used in wound healing in relation to providing patients with assistance to empower them to navigate the complex wound care environment with the support of clinicians and patients' family (Lindsay, 2017; Lindsay et al, 2017). As well as being better equipped to come forward and make decisions about self-care, Lindsay et al. (2017, pp. 674-675) have stressed that patients form an important

part of the wound care team that can influence the allocation of resources to wound healing care and research. However, the debate around the role of patients in clinical development in wound healing needs further exploration.

Background

The research described in this article comes from the author's doctoral study (Galazka, 2018) that explored the development, nature and role of relationships between wound healing clinicians and patients with wounds. This article specifically demonstrates how clinicians and patients can work together in 'advocacy partnerships' that offer socially innovative responses to the challenges in wound care for patients and clinicians alike.

Method

An ethnographic approach was used to study clinician-patient relationships in three specialist outpatient wound healing clinics in the UK, which were staffed by the same core team of clinical academics. Ethical approval of the project was granted by the South East Coast – Brighton and Sussex research ethics committee (16/LO/0559). Management permissions were obtained from the two participating healthcare organisations, which were anonymised along with the obtained data for the purpose of presenting this study. Written consent was sought from patient and clinical participants interviewed in this study. Verbal consent was sought from patients to allow the researcher to observe their consultations, for practical reasons of limited time available for each consultation. The receiving of consent was witnessed by the medical personnel.

Fieldwork, undertaken between June 2016 and April 2017, involved non-participant observations of consultations in the outpatient wound healing clinics and interviews with health professionals, patients and their relatives. In total, 120 hours of observations between clinicians, patients and patients' relatives were recorded as notes and subsequently transformed into just over 80 000 words of typed fieldnotes. Moreover, 50 qualitative semi-structured interviews were conducted with participants purposively sampled from the cohort of health

professionals, patients and relatives who were observed in the clinics. Because the study design allowed for relatives to accompany patients to interviews, 20 interviews involved the researcher speaking to patients alone, or to relatives alone, or to patients and their relatives together. Moreover, 20 interviews were with clinicians working in the clinics who had an interest in wounds and came from multidisciplinary backgrounds (including general practice, podiatry, community nursing, diabetes, vascular surgery, among others) and 10 were conducted with clinical wound photographers. Finally, one interview was with a paediatrician who had consulted specialist wound healing clinicians in the past, but rather than being part of the team of clinicians from this ethnographic study, they had been recruited. The data were analysed using Gioia et al's (2013) approach using codes which was developed from the data and the literature. Subsequently, it was grouped thematically in a three-stage process into concepts, themes and aggregate dimensions. Sections of the data are presented below and pseudonyms given by the researcher are used to refer to the participants.

Results

The study found that wounds were considered a low-profile condition in healthcare and a taboo by society. Patients and clinicians felt that the general level of knowledge about wound healing was unsatisfactory because the complexity of wounds was often hidden away from public view:

'... Wound care is such a taboo subject in society! ... It's not there in the media ... there is not a lot about foot ulcers or gangrene.' (Ella, clinician).

Furthermore, patients reported they that had often been met with indifference towards their wound concerns from other specialists when trying to access wound care. Their stories revealed that sometimes a lack of knowledge about the existence of specialist wound care services complicated their referral. The standards of wound care were not uniformly understood in the community and, at times, specialists wound care services were treated with suspicion about its added value:

'I was just going and going and going and I wish I had been referred earlier so that's a bit of a ... not really a condemnation but it's a bit of statement for the community.'
(Rhydian, patient).

Both clinical and patient participants recognised the significance of talking about wound healing to raise the awareness of the specialty. To promote the perception of wounds as an urgent medical problem that requires advanced care, clinicians harnessed their interaction with consenting and proactive patients who shared the understanding of the complex wound healing environment to support high-quality wound healing research and education.

First, to address the lack of straightforward provision of wound in the community, clinicians sought to get patients, as well as their relatives, more engaged in taking a hands-on and empowered approach to navigating their own wound care:

'You had to do your wound yourself, because no one would see it. They did show us how to do it. 'Oh, you can do this yourself.' (Joanna, patient's wife).

Second, given the academic character of these wound healing clinics, patients were often invited to participate in clinical trials, wound healing seminars, industry events such as presentations of wound dressings, and medical students' examinations. A selection of quotes illustrates the scope of this engagement and patients' altruistic enthusiasm about being part of growing the scientific knowledge about wound healing is presented below:

'Dave has helped us a lot with our wound research', says Ella, a clinician, to the students as she debrides Dave's ulcer. (fieldnotes, July 2016).

'I had to go in for the film crew and talk about [changing dressings] and they photographed the whole time while I was doing it.' (John, patient).

The academic nature of the wound healing clinics played a key role in strengthening enhanced interaction between clinicians, patients and their relatives. Some of the ‘longest serving’ patients with chronic wounds stressed the importance of developing special, professional relationships with clinicians beyond what could be expected within outpatient consultations. Patients recognised the role such relationships played in improving the standards of care in the wider wound care community:

‘If it helps somebody else ... if they can stop somebody from [getting] that, I’m all well and good.’ (Jane, patient)

As a result of their involvement in raising the profile of wound healing, patients evaluated their care as effective even when they knew their wounds could not be healed.

Discussion

From the perspective of the literature, on advocacy in wound care, the relationships described above could be considered as examples of ‘professional-patient partnerships’ (Price, 2011). These engagements helped raise the profile of wound healing in two ways. Firstly, the partnerships provided advocacy for patients, as well as their relatives, increasing their scientific knowledge about the healing of wounds, while empowering them to work through the barriers to access standardised care. Secondly, they provided advocacy for clinicians, helping increase shared scientific knowledge about wound healing and the visibility of the specialism in the professional healthcare arena.

It has been shown in the literature that supporting people with stigmatised conditions by enabling them to participate in research can be empowering for them (Thornicroft et al. 2008). Therefore, the advocacy partnerships can help patients, and their relatives, move beyond the label of living with wounds. Moreover, Lindsay et al. (2017) suggest that advocacy could be considered in terms of patients’ involvement in establishing research protocols and determining research priorities. Therefore, by inviting patients to contribute to wider wound healing research, educational and commercial events, clinicians in this study empowered patients to not

just actively participate in their own care, but also play a proactive role in efforts to prevent inefficiencies in the development of wound healing in a professionally supportive environment.

Harding (2015) argued that the social environment for the provision of wound care services recognises that health-related quality of life is an important outcome for the development of innovative solutions to care. Therefore, clinician-patient partnerships for wound healing advocacy, that offer patients with chronic wounds a supportive outlet for translating their negative wound experience into positive gains for the community, can be considered as more than patient empowerment. Instead, they can be further linked to clinical emancipation in wound healing through helping raise the low profile and unsatisfactory levels of awareness of the specialty.

Limitations

There are practical limitations to this study that stem from the location of the wound clinics. Their close affiliation with wound healing research facilities may not be available to all specialist wound clinics or non-specialist healthcare clinics that offer wound care services. As a result, some patients in other geographical locations may not be able to become advocates for wound healing through supporting wound research.

Future studies could examine the work of clinicians in community-based non-specialist clinics and ask: in the absence of straightforward access to wound healing research facilities, how else can clinicians involve patients in wound healing advocacy? How can they advocate for highest quality patient-centred care at the same time? What can they learn from patients about what they need and how they can benefit to keep developing innovative solutions in wound care?

Conclusions

This article sought to explore clinician-patient relationships in wound healing through the lens of advocacy to understand how clinicians can manage their interactions with patients in socially innovative ways and respond to the challenges in the wider healthcare environment. While present knowledge on advocacy in

wound care recognises the role of clinicians as patient advocates, it is less explicit on the empowering role of patients as likely advocates for clinicians struggling to get their specialty recognised. Therefore, this article considered advocacy in wound healing in view of the needs of the wound healing community as a whole, while retaining a focus on patient-centred care and patient empowerment. However, creating conditions for developing ‘advocacy relationships’ in healthcare can be seen as more than patient empowerment because it overcomes the traditional role division in which patients are seen as the less powerful party in the relationship. Patients and clinicians can, in fact, actively contribute to a shared wound healing project from their own perspectives to address the low profile of how wound healing affects them both in related ways.

Key points

- The growing population of patients with wounds and the unsatisfactory state of wound care means that clinicians must build partnerships with patients and their families to help them self-care for their wounds as and when necessary.
- The term ‘advocacy’ in wound healing can be considered in two ways, with clinicians acting as patients’ advocates and patients acting as advocates for the wound healing specialty.
- Partnerships for wound healing advocacy between clinicians and patients extend the concept of patient empowerment, enabling patient to actively co-improve standards of care for themselves and for other patients.
- Wound healing research can play an important role in raising the profile of wound care to improve treatment in the community.

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