Research article

Degrees of freedom – exploring unrecognised patient-empowerment in chronic wounds settings

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ABSTRACT

This study explored an under-researched but critical element of patient empowerment in chronic wound care, namely degrees of freedom. This refers to the personalisation of everyday wound care based on patients' individual needs. To identify degrees of freedom in clinical practice, semi-structured interviews were conducted with 23 patients and 16 healthcare professionals and analysed using qualitative content analysis. The analysis yielded nine degrees of freedom with 42 concrete behaviours of primary control (shaping the actual treatment situation) and six degrees of freedom with 22 concrete behaviours of secondary control (shaping the patient's inner experience). These could be assigned to four main degrees of freedom, namely patients' self-action, cooperation between patients and health professionals, adaptation of treatment to patients' needs, and the use of emotional coping strategies. Furthermore, two types of patients could be distinguished: those who are active and take responsibility for their wounds, and those who remain passive and tend to endure. The implementation of degrees of freedom offers several positive effects, such as patients experiencing outcome efficacy and becoming experts on their wounds. However, there are several implementation issues, such as patient reluctance and time constraints, that need to be overcome first.

Keywords degrees of freedom, patient empowerment, chronic wounds, shared decision making, self-care

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INTRODUCTION

Over the past decades, patient empowerment has become a central approach of health care in both research and clinical practice.[1, 2, 3] In general, patient empowerment aims to place the patient in a more active role in the treatment process via inclusion on an educational, decisional, and practical level.[3-7] However, despite increasing acknowledgement of the relevance of patient empowerment, its defining elements have remained somewhat vague, and a number of different terms (such as patient centredness, patient participation, health literacy, shared decision making) and approaches are associated with the idea of patient empowerment.[5, 8, 9, 10] Notably, a crucial prerequisite for patient empowerment is patient centered care.[8] In a recent systematic review,[11] we aimed to clarify the constituting elements of empowerment in chronic wound care and found that empowerment is mainly attempted via adherence to self-care behaviours, education and shared decision making, and heightened patient control. Moreover, descriptions of patient control and the actual implementation of empowerment are typically given on a fairly abstract level in the literature. Thus, despite a general call for increased patient empowerment, its concrete realisation remains limited. This can be illustrated by the example of shared decision making and education: On the one hand, patients are typically thoroughly informed and reach a decision about their general treatment options (such as maggot therapy vs conventional therapy) together with their health care professionals (HCPs), which is an essential part of patient empowerment. However, on the other hand, patients are involved in their treatment on a global level. The actual execution of the daily treatment tasks is mostly determined by HCPs leaving little opportunity for individual shaping. Hence, in such instances patients remain largely in the role of (passive) receivers of care. And yet, daily wound care tasks provide a unique opportunity for patients to regain (a sense of) agency which we understand as a crucial determinant of empowerment.[11]

To address this, a practical empowerment approach in the context of chronic wounds was developed.[11] Degrees of freedom (DOF) refers to the individual shaping of everyday wound care tasks, which is initiated by patients and based on their distinct needs and wishes, enabling the patients to actively seek control over their wound care. Next to medically required standards, any kind of wound care leaves room for maneuver (i.e., freedom) concerning how exactly it is executed. For example, the dressing change procedure can be briefly paused when the pain gets too intense, the wrapping can be performed clockwise or counterclockwise, patients can involve relatives for emotional support, or windows can be closed for a calm environment.

In sum, the realisation of patient empowerment concerning concrete tasks of clinical practice is rarely found in the literature.[11] More specifically, to the authors' knowledge, no empirical study has been conducted yet that explicitly focused on patients' options of shaping their everyday wound care.

Therefore, an explorative-qualitative method was used in the present study in order to explore the topic in sufficient depth. Such an approach provides a base for subsequent quantitative testing. The aim of the study was to investigate concrete opportunities for implementing DOF in different areas of wound care. It mainly focused on the following questions:

Which DOF can be identified in clinical settings?

Which possibilities and barriers exist for the implementation of DOF in clinical practice?

METHODS

Participants

Of the 39 participants (16 HCPs; 23 patients), patients were consecutively recruited at the outpatient clinic of the University Medical Center Hamburg-Eppendorf (Germany) and additionally via a web page of the founder of the study. All patients enrolled had chronic wounds defined as having failed to heal for 8–12 weeks.[12] Their average age was 73.7 years (range: 51–87) and the underlying diseases causing the chronic wounds were peripheral arterial occlusive disease (PAD; n=11, 47.8%), chronic venous insufficiency (CVI; n=3, 13%), combination of PAD/CVI (n=9, 32.2%) with/without diabetes mellitus (n=3, 13%). Participating HCPs worked at the same clinic and in general practices. This group consisted of wound care nurses (n=3), medical assistants experienced in wound care (n=7), and medical specialists (n=6). The latter included four surgeons and two dermatologists, some of them with further specialisations, and all of them were considerably experienced in treating chronic wounds. Prerequisites for participating in the interview was the diagnosis of a chronic wound for patients, and practicing in wound care for HCPs.

Data collection

Data were collected by semi-structured interviews with patients and HCPs between 2020 and 2022, according to the consolidated criteria for reporting qualitative research (COREQ[13]). The audio-recorded interviews lasted 7–75 minutes, on average 29 minutes, and were conducted in person or via (video) call due to the COVID-19 pandemic. The study obtained ethical approval from the ethics committee at the Witten/Herdecke University in Germany, which assured the ethical guidelines of the Declaration of Helsinki were followed. The guidelines for the semi-structured interviews were developed by an interdisciplinary team of psychologists and medical professionals based on theoretical assumptions, observations of outpatient wound clinics, and pilot-tested in two pre-interviews with wound experts. The decision in favor of semi-structured interviews relies on the fact that these serve as an orientation, and, at the same time, allow for a natural course of conversation and adaptions as well as further inquiries during the dialogue.[14] In this regard, a broad variety of DOF could be addressed. This way, we aimed to prevent a reduction of relevant information due to pre-formulated items as would have occurred with existing questionnaires (Table 1). In order to secure that DOF were investigated from both perspectives, the interviews were conducted with both treating HCPs and patients with chronic wounds. Hence, the interview guidelines were tailored specifically for each subsample, namely HCPs and patients.

Within the scope of informed consent, the patients were told about the pseudonymization of their data and the voluntariness of participation and the freedom to answer only the questions they wanted. In (video) calls, such was provided digitally via email.

Data analysis

The 39 recorded interviews were transcribed using Trint (Trint Limited, 2023) and revised manually by the researchers. Transcriptions were analysed according to qualitative content analysis using MAXQDA (VERBI, 2022). Data saturation was reached when no new degrees of freedom were reported. The first author, with an MSc psychology and experience in qualitative content analysis, trained three other coders. Then the four coders analysed the interview transcriptions independently and consecutively following a deductive and inductive approach.[15] As a starting point, two broad categories were used: DOF of primary control, which involves the adaptation of the actual treatment situation; as opposed to those of secondary control, which involves adjusting the inner experience.[11] Then, codes were identified from the transcriptions to generate sub-categories of more fine-grained DOF. As the category system kept enlarging through the ongoing analysis, the deductive application of the codes to text material became more frequent. Finally, the coders discussed inconsistencies until agreement was found, resulting in a final single category system.

RESULTS

PRIMARY CONTROL STRATEGIES

DOF: Patients' self-action

Numerous patients were reported – directly or indirectly reflected by the HCPs – to execute the dressing change either partially or completely by themselves. Such self-guided action can be considered the highest degree of freedom, since in this case patients are completely in control of how and when the treatment steps are performed, based on their personal preferences (such as how firmly the dressing is applied). Hence, with self-action, patients receive the highest

Table 1. Prototypical interview questions

Question type	Example
Warm-up question	"How long have you had your wound for?"
Key issues relating to patient empowerment in health care interventions	"If you take a look at your role in the treatment process: Do you have the feeling that you can actively control and decide anything in the treatment yourself?"
Deepening questions/prompts	"I understand that you get certain instructions and offers. Do you also initiate such actions by yourself [meaning how you manage your wound treatment]?"
Optional questions	"Do you think that for patients a larger scope of action [in managing the wound] is realistic?"

amount of autonomy and freedom of choice possible in chronic wound care. Specifically, some patients illustrated that they are completely in charge of their dressing changes at home: "Disinfect hands, plaster off, disinfect hands, cleanse wound, disinfect again, apply lotion, then apply new plaster, wash hands … . I did that myself from the beginning." The self-execution of the dressing change was often supported by precise but simply-worded, repeated, or even written instructions provided by the HCPs, which can be considered to be enablers for the self-execution: "You have to explain everything a lot more often here, you have to say things in a simple way. … I often write down the single steps [of the dressing change] so they have a written instruction." Another innovative way to support patients is making use of video consultation: HCPs accompany patients live during every step of the dressing change and can help and instruct them remotely.

It became apparent that some HCPs already successfully provided the patients with the freedom to actively choose whether and which parts of the treatment can be executed by themselves and regarded it as helpful: "There was an elderly lady, she knew that we are gentle and relaxed and take our time with her wound. But nevertheless she preferred to do the cleansing of her wound herself. So she should keep doing it, because having control helps her." Furthermore, patients controlled their intake of analgesics prior to, during and after the treatment of the wound. Also, patients cleansed their wound, and applied ointments – which happened during the treatment provided by HCPs, as well as at home. Importantly, patients said they performed risk assessments regarding their wound: They evaluated their wound's condition to identify whether an additional dressing change or consultation with HCPs was necessary. Interestingly, one patient with visual impairment used a webcam for the wound inspection.

DOF: Cooperation of patients and HCPs

The cooperation of patients and HCPs during the dressing change procedure varied with regard to prevalence and type of tasks performed by patients. With cooperative dressing changes, even though HCPs perform essential parts of it, patients actively contribute to the procedure as well. For instance, HCPs and patients often chose the type of dressing together and in close consultation with each other, with the HCPs' professional knowledge and the patients' personal wound experience both playing a decisive role for the final choice. Also, cooperation was manifested in patients' thorough preparation of materials prior to the treatment and handing those to the HCPs during the treatment: "Many of the patients are very prepared. In our case, there are patients that bring their stuff in Tupperware and then hand it to us one-by-one."

Table 2. Degrees of freedom (DOF) of primary control

Patients' self-action • executing dressing change/wound care (completely or partially) • patient-controlled analgesia • wound cleansing • appling ointments • risk assessment (e.g., whether dressing change is necessary)	**Inclusion of family members** • providing instrumental support (e.g., performing dressing change, driving patients to the clinic) • providing mental support
Cooperation of patients & HCPs • choose dressing together • hold bandages • active body positioning • preparation for dressing change	**Expand professional network** • include general practitioner in wound care • include another nursing facility **Planning** • patients' wishes regarding the time schedule are being considered
Adaptation of treatment • asking for pain medication • additional dressing change • recommend how to treat the wound • tell nurse about sensitive areas • patient decides about body positioning • comfortable fit of dressing • abort procedure • patient chooses ointment • pace of treatment steps • patients provide feedback	**Communication** • talk about problems and pain • talk about wound conditions • get familiar with staff • ask questions • speak up for oneself
General patient involvement • ultimate responsibility and own decision • ask patients for wishes concerning treatment execution • reliable appointments	**Everyday adaptations** • non-pharmacological pain management (e.g., try not to put weight on foot with wound) • mobility devices • environment (e.g., relocate bedroom downstairs)

Furthermore, very prevalent was the patients' active body positioning during the treatment performed by HCPs in order to facilitate the procedure: "I keep my foot in the right position. I also hold the paper ruler next to my foot so that they can photograph it more easily." These examples of cooperation illustrate how the treatment procedure is actively influenced by the patients' particular needs, and exemplifies a more autonomous role of patients. Notably, it was emphasised that task sharing between HCPs and patients is actually initiated by patients and can result in helpful support of HCPs: "There are patients who have been coming here for some time now, who say when they come in for the dressing change: 'I'll do the unwrapping myself!' … . If they see that we are under a lot of stress, they say: 'Come on, I'll take the dressing off by myself at first'." Such cooperation can also include decisions about modalities of the dressing change. For example, patients expressed their preference to conduct the dressing change in the doctor`s practice or outpatient clinic instead of having the care service at home, or their wish for a reduction of the care services' visits. Similarly, patients expressed their need for a decreased number of dressing changes, postponing dressing changes, or leaving the hospital. In cooperation, patients and HCPs can evaluate the options and reach a conclusion that considers both patients' needs and medical advice. For instance, the use of vacuum assisted dressings, antibiotics, a larger amount of dressing materials to use at home, or frequent consultation instead of staying in the hospital. Furthermore, patients may propose their own suggestions for their treatment (such as treatment options they have read about) during the consultation – which can be checked for medical appropriateness by the HCPs prior to implementation.

DOF: Adaptation of treatment

Another option for including patients' needs in wound care was reported as patients asking for adaptations of the default treatment procedure, with manifold options of individual adaptations. Namely, while HCPs are performing the dressing change, patients may ask HCPs to adjust the treatment steps, for instance, requesting a countdown from three for the plaster removal (identitified via observation in the outpatient wound clinic), or a less firm dressing. Such requests can also refer to behaviours outside the actual dressing change situation, such as the request to remove the dressing at night to ensure a less painful sleep. Further examples are preferences for compression stockings over dressings so that normal shoes can be worn, the wish for compression stockings with a zipper, or asking for a dressing only. Such adaptations are freely and actively initiated by the patients and often successfully implemented: "The patients say: 'You know, I cannot sit comfortably on a chair today. Maybe I could lie on the couch?' Then I go along with it to a certain extent, that is not a problem." Furthermore, such adaptations are partially realised as a result of HCPs' enquiring questions, which are emphasised as crucial for the treatment process: "Also it is very important that when you have completed the wound treatment, you ask: 'Is this ok for you?' … And if the patient says that the dressing is too tight, then you just have to do it again". However, a number of patients disclosed that they had to firmly and repeatedly demand their needs to be considered by the HCPs: "And if I hadn't intervened three times, I would have walked out today without a prescription for a shoe." Moreover, it was also reported that patients may improve the treatment process by pointing out aspects of the treatment that are currently not a central focus for the HCPs, but nevertheless helpful for wound healing. Thus, patients might sometimes notice what HCPs have overlooked: "If the staff forgets to apply the lotion, I say: 'Just a moment, the lotion has to be applied first'."

The concrete adapations asked for by patients ranged from requesting analgesics, aborting the dressing change procedure due to an intolerable amount of pain, changing the body position, or altering the fit of the dressing. Moreover, patients sometimes requested that a particular HCP they were familiar and friendly with would execute the dressing change. Notably, also the patients' manner of bringing up the wish for adaptation displayed a large variety, ranging from uttering firm demands, suggestions, polite requests to a simple acceptance or rejection of HCPs' offers.

Minor degreees of freedom: Inclusion of family members

In many cases, patients recounted that close family members executed the wound care at home. The inclusion of family members can be considered another source of freedom: Specifically, patients are more free to chose how exactly the dressing change is performed, since family members are likely to be familiar with the patients' special needs and are in a closer personal and trusting relationship, which can facilitate patients' free expression of their preferences. Additionally, familiy members are more flexible in their schedules than HCPs, which leaves room for individual treatment adjustments, for example, in the choice of location (such as in bed or on the couch) or time (after or before lunch), which provides the patient with greater autonomy concerning their daily routines. In line with this, patients repeatedly pointed out to prefered their family members to conduct the dressing change: "I would say my wife is very professional by now, sometimes the plaster is in a better position than after treatment here." Hence, it is also implied that family members might even become experts for the individual patient's wound.

Minor degreees of freedom: communication

Communicative acts offer several degrees of freedom. Precisely, communication can serve the purpose of making patients' needs visible, for instance, the need for information. In line with this, the most prominent form of this DOF was the communicative act of asking questions. Specifically, this DOF is characterised as patients having the freedom to ask questions concerning each aspect of the ongoing treatment that they are interested in: "Now and then I ask the staff: 'What is this or that? What is that for?' and then I get an answer". This DOF should contribute to patients' becoming experts in their wound and its treatment and facilitate patients' self-execution of wound care at home. Another communicative act that may serve as a DOF is the personal introduction of the staff. Patients appear to have an interest in knowing the HCPs and their exact role in the treatment (such as nurse, doctor) and may demand such introduction: "They have not introduced themselves so far. So I would like to know who is who, who am I dealing with?" Moreover, patients may use strong communicative acts to assert themselves when their individual needs are not met by the HCPs and their requests are de-emphasised: "I just assert myself, because it is my body and it is my pain. If nursing staff says that I should be able to stretch my legs for five minutes, I say: 'No I am not. When you have the amount of pain I am having, then we can talk'."

Minor degreees of freedom – everyday adaptations

Degrees of freedom are not only significant for the actual wound treatment and the clinical setting, but also for everyday life with chronic wounds. Patients can aim to adjust, for instance, their furniture, vehicles, clothing, or their daily routines to facilitate the continuation of a satisfying and independent daily life. Such concrete adaptations can be developed entirely by the patients themselves. Still, advice and education in this regard may also be provided by HCPs and then modified by the patients according to individual needs. Patients cited a broad range of concrete adaptations, including major changes, as well as minor adjustments or new routines, for instance: "I got a new car with an automatic transmission because of this diabetic foot. Before, when I had a manual transmission I could not step on the clutch with that foot. And then I modified my bike, so that I can also use the pedal and that my foot fits on it."

SECONDARY CONTROL STRATEGIES (COPING)

Building relationships

Building relationships improves the patient-HCP interactions and the experience of wound care. In this regard, emotional and social support can be actively requested. One patient asked a HCP to hold her hand to receive comfort and get distracted and in contact with the staff who otherwise seemed indifferent and dull: "You know, if you just stand there … you're not helping anybody. … You can come up to me, talk to me, hold my hand and stuff. And that's what she did then. But you had to suggest it first. Nothing came of itself." Furthermore, patients seem to have a need for private talk about "everything under the sun", including activities, everyday life with family members, but also grievance and loss of significant others, and in general all "human" aspects. Patients do initiate such talk, or it develops while HCPs and patients get to know each other over time. Private talk is important and can occur naturally: "Where blood flows, words flow. Because at that moment a valve is opened where man can let go, and at that moment I give him the space."

Distraction

Private talk can also function as a distraction to the dressing change and to pass time, and "usually [it is] already done and … they're still talking". Of course, it can further serve as a distraction from pain. Thinking about other, random stuff is another strategy. Furthermore, behavioural pain management can be achieved by, for example, taking a deep breath and screaming loudly when the patch comes off, or taking a deep breath and holding it to endure intense pain. Playing games on a smartphone, reading, or listening to the radio can distract from the constant, daily wound pain as well.

Relaxation, stress reduction, and cognitive techniques

To bolster a sense of well-being and to alleviate pain during wound care, relaxation and stress-reduction techniques (such as breathing exercises, progressive muscle relaxation), aromatherapy, heat or cold, or acupuncture can be incorporated. In addition, noise stemming from mobile phones or open windows can be taken care off. Although these procedures call for assistance from HCPs in some cases, they can readily be asked for, shaped, and implemented by patients. On a philosophical (existential) level, cognitive reframing and reinterpretation of what living with a chronic wound means, can possibly encourage a more realistic and positive outlook. A focus on positive mood and autogenic training could be helpful for this.

Predictability

Predictability of a painful stimulus can attenuate fear, anxiety, and pain itself.[16, 17] During the dressing change this is of avail when HCPs state in detail what they are doing: "And of course I communicate everything I do at that moment, especially when the wound is in the back, when he doesn't see it or when he doesn't know what I'm doing." Such predictability also renders wound treatment open for adaptations, since patients can react to the next treatment step beforehand. One patient reported: "They tell me what they do. So that I probably don't get scared. So that I know if something is going to hurt me." Moreover, transparency about the treatment course and the healing process can increase predictability even for the patient: "I think that's very important … that you know what's happening there and also a perspective on the wound healing is presented … how long it takes, that it won't be quite so fast, but that there is a good chance of healing." Thus, it is important to assess healing chances and times accurately and convey this information to patients, which was emphasised by a patient stating: "I would simply like to have a reliable statement on how it will actually continue and whether the treatment really helps. The staff always tend to say that it helps, but it doesn't." This also demands the truth about whether changes occurred and whether they were positive or negative. To this regard, taking photos of the wound and showing them to patients

Table 3. DOF of secondary control (coping)

Building relationships • social/emotional support: holding hands • private talk	**Passive pain management** • think of other things
Distraction • watching TV, listening to music • conversations	**Relaxation/stress reduction** • aroma therapy • silent environment, elimination of sounds • presence of family members
Cognitive techniques • autogenous training • optimism • cognitive reframing	**Predictability** • patient observes treatment • obtain realistic assessment of wound healing • transparency about treatment course • taking photos of wound • HCPs state/explain what they are doing

can be helpful, especially for visually impaired persons and for wounds on the back of the body, to document the progress which "then you can follow like in a flipbook".

Framework to differentiate degrees of freedom

The degree to which patients are able to freely choose how to care for their wounds depends heavily on the distinct allocation of these tasks (who is in charge of each wound care task). Based on our review[11] and the subsequent research process four main categories of DOF were proposed which can also be considered four types of task allocation: First, patients may execute parts of their own wound care (DOF: patients' self-action). Second, patients and HCPs may execute treatment steps cooperatively (DOF: cooperation of patients and HCPs). Third, the dressing change is performed by the HCPs, but their performance is altered according to the individual needs and wishes of the patients (DOF: adaptation of treatment). Importantly, though such reshaping may alter the usual treatment procedure, these changes can and should only be applied inside the scope of what is medically recommended and possible. Notably, freedom does not result from patients performing or reshaping wound care tasks per se, but from patients being free to decide about how, where, or even when those are performed. Fourth, the use of strategies for handling situations that are physically or mentally stressful can be considered a DOF (DOF: coping strategies[18]).Especially emotional coping strategies are important, that is, coping strategies that help patients to modify their inner emotional states. Notably, what is perceived as a helpful coping strategy may vary heavily between individual patients and situations.[14] These four categories of task allocation provide possibilities to adapt procedures to varying degrees (Figure 1).

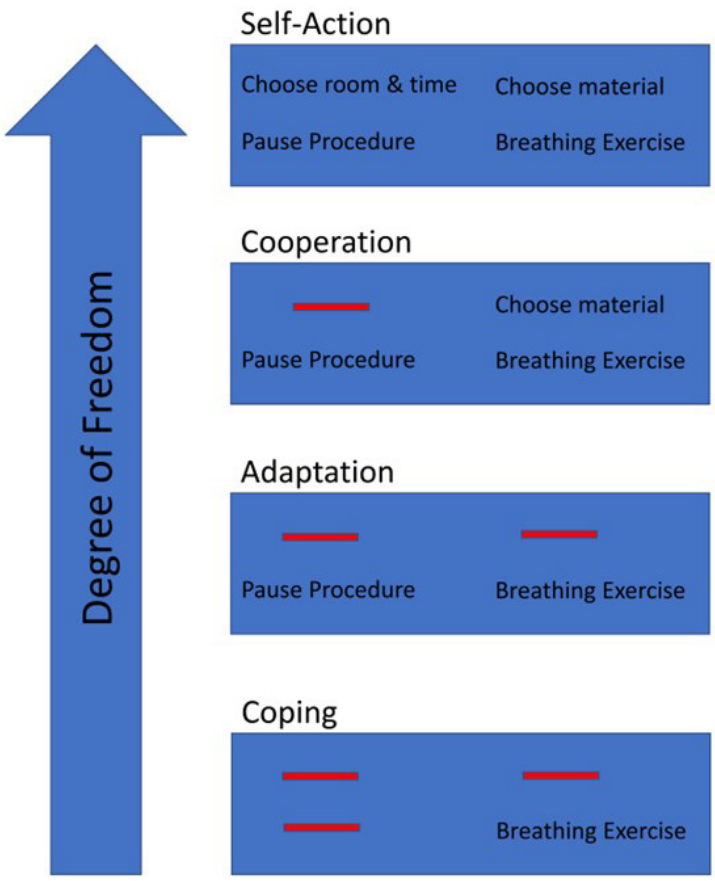

Figure 1. Varying degrees of freedom (DOF) resulting from different ways of sharing wound care tasks between patients and HCPs. This sums up the DOF determined and the strategies identified in Hackert et al.[11]: Higher DOF allow more direct behaviours and decisions to control and shape the wound care.

Implementation problems

Although DOF can be useful psychologically and in practical terms, when facing the concrete implementation, there are a number of potential barriers to overcome. For instance, a hostile atmosphere in the outpatient clinic and among the HCPs can be detrimental for the successful implementation of DOF. HCPs speaking ill of other fellow HCPs in the presence of patients could reduce patients' trust in HCPs. Also, such behaviour might promote an aggressive attitude towards other HCPs, or the clinic in general. Hence, one prerequisite for DOF is a proper and respectful communication style among the team members.

Another potential barrier for a successful implementation of DOF is the lack of patients' comprehension concerning the correct procedure of the dressing change. Patients stated in some cases that they were not able to do anything but to communicate "how I feel about certain medical procedures" and cannot get involved any further because they are not medical professionals. At the same time, patients may have ideas and preferences that are unrealistic or impossible from the clinical point of view. Other patients are simply not willing to engage in wound care. Also, they believe that a certain degree of pain during the medical procedures is inevitable: "With certain medical procedures – I just put it simple as it is – there is nothing I can do and there is nothing to change or adjust either. So, when I say it hurts, it just hurts and there is nothing that the staff can do about it. That's just the way it is." In this vein, there appears to exist a passive type of patient. For such passive patients, there is no (need for a) possibility to adapt the treatment procedures: "No, no, the wound is being taken care of professionally and I just let it wash over me. That's just the way it is and there is nothing wrong with it." Similarly, patients may lack the necessary medical knowledge for their wound care or even for cooperative wound care. This can prevent, for instance, cooperative choice of dressing material, since patients are not aware of what exact products exist: "In the actual treatment, I cannot say: 'I'd like this and that', because I don't know all there is in the first place."

Patients' lack of medical knowledge can be reduced by HCPs, since they can and should provide patients with necessary medical information and education. Thus, HCPs' willingness to do so is also a relevant factor for DOF implementation. Notably, the amount of time dedicated to one patient is of great significance as well: Patients also noticed that in some cases dressing changes were conducted in such short time-periods that there was hardly time for questions. In the same vein, the frequent change of personnel within the nursing services can prevent the development of a trusting familiarity between patients and HCPs – which, in turn, can keep patients from expressing their needs and asking questions. Another barrier regarding the nursing service was a potential lack of qualified personnel resulting in an even tighter time schedule. Also, HCPs can be overburdened by the challenge of treating chronic wounds. This challenge is further impeded by problems such as unhygienic conditions at patients' homes. Moreover, it is possible that some special requests from patients (such as special dressing material, cold plasma therapy) cannot be met, as not all options are covered by health insurances. Such restrictions can result in frustration and uncomfortable situations for HCPs, as well as for patients.

Another aspect that is likely to influence the applicability of DOF (especially self-action) is the location of the wound. In cases in which the wound is located at body parts that are not in the patients' field of view, autonomous, independent wound care is severely restricted. In addition, there were further physical (mobility), practical (hygienic environment), or psychological (dementia) reasons why patients may not be able to perform the wound care on their own. Some patients also felt disgusted by their wound or scared of the bacterial exposure and that they will not fulfill the necessary hygienic standards for proper wound care.

Moreover, some patients were hesitant about speaking up for themselves, uttering their needs, demanding a change of the standard procedure because they are unwilling to criticise the HCP. For instance, one patient disclosed that she did not want to address the HCPs wearing non-sterile gloves during the treatment although she was worried about the bacterial exposure because she did not want to insult them or make them feel patronised. Thus, she put her own needs aside out of fear that the relationship towards the HCPs would suffer and become less personal and colder. This example emphasises the importance of HCPs creating a trusting atmosphere in which individual needs can be uttered, are heard, and positive feedback is provided. In the same vein, a number of patients expressed that their wishes, preferences, or complaints were not reacted to, which is detrimental to DOF implementation.

Another important aspect of the interviews was the identification of a number of patients who did not take their wound seriously. They spoke about it as if it did not belong and was alien, to them. They seemed to push it out of their minds. This was particularly evident in patients with diabetic neuropathy. Because of this denial, missing motivation to engage in wound care, and neglect of self-care behaviours, HCPs experience frustration and reluctance to focus on increasing patients' autonomy.

DISCUSSION

The present interview-study investigated patients' freedom to shape chronic wound care according to their needs (their DOF). It emphasises that DOF in the form of primary control strategies are mainly distinct task allocations, which was self-management of dressing changes, cooperation with HCPs, and adaptation of the standard treatment executed by HCPs, whereas secondary control strategies were coping strategies. Moreover, several minor DOF were identified that are not addressed by these four categories of DOF, such as the inclusion of family members or communicative acts within the patient-HCP relationship.

A core characteristic of DOF is patients' self-determination in how wound treatment is being conducted. When patients are free to choose or conduct, for instance, the fit of their dressing or the ointment application according to their individual needs, they gain a certain amount of self-determination and power over the treatment situation. Thus, DOF enable patients to empower themselves. In other words, DOF have the potential to increase patient empowerment significantly – since they explicitly address self-determination. Such self-determination (manifested as empowerment) is not only recommended by researchers and medical organisations, but also highly appreciated and strived for by a large number of interviewed patients: "A) it's my body, B) it's my life, and I can decide about it myself. … as long as I am mobile so that I can do it myself, I want to do it myself and I do it myself. Because I also think for myself and I have learned that I have to take care of my body myself." From that quote, it becomes evident that patients have an actual need for self-determination, which can be met via heightened patient empowerment. Hence, implementing an increasing number of DOF in clinical practice will result in the fulfillment of patients' crucial psychological needs. This is of special importance, since the physiological wound experience is closely intertwined with psychological aspects: Psychological aspects have an effect on the state of the wound, as well as living with a chronic wound affects patients' mental state and their general well-being.[19] In this sense, the term "chronic" does not only refer to the wounds' healing duration itself, but to the associated psychological states such as stress, anxiety, depression, shame, or pain as well. Patients living with chronic wounds and the related pain suffer from severe psychological consequences, such as anxiety, social isolation as a result of being ashamed of the wound odor, depression, negative body image, general loss of quality of life, and so forth.[19]

At the same time, psychological aspects such as depression,[20] rage,[21] anxiety,[19] anger expression,[22] stress,[23] social support, or coping techniques are associated with healing of the wound. As a result, patients might experience a fatal downward spiral. To exemplify, a person suffering from the diagnosis of a chronic wound is likely to become increasingly ashamed of going into public places because of the wound odor.[19] Furthermore, they are also likely to be afraid of certain public places, such as a bus or the subway because they might bump themselves and their wound and worsen the condition of the wound. This is especially likely with patients of advanced age, which represent the largest group of patients with chronic wounds.[24]

As a result, increasing avoidance of leaving home and going to public places can emerge, which, in turn, fosters growing social isolation. In the same vein, a person suffering from chronic wounds is likely to be hesitant or even reluctant to build new relationships. Especially for women, living with a chronic wound and the necessity to wear unaesthetic orthopedic shoes can even lead to a negative body image and, eventually, the subjective loss of femininity,[19] which fosters further avoidance of social interactions. Such social isolation often entails a weakened social support system for the affected person and fosters depression and stress – the risk for which is already heightened due to the chronic wound itself. Unfortunately, such heightened stress can have detrimental effects on the wound healing,[23] which, again, intensifies and extends the experienced stress amount. Similarly, depressive symptoms entail a stronger focus on bodily experiences. Such focus, again, results in magnified attention to the pain and, thus, the intensified experience of pain, which is a predictor of depression itself.[25]

These illustrations emphasise the unmistakable intertwinement of psyche and the diagnosis of a chronic wound and hereby underline the tremendous potential of DOF to improve patients' wellbeing and wound healing. Patients' magnified freedom should fulfill their psychological needs including a sense of individuality and control and furthermore evoke the subjective experience of being empowered. Such experience implies that the addressed

needs originated in – and the power to fulfill those emanated from – the patient. Therefore, the subjective side of empowerment is a necessary constituent of what can be termed genuine patient empowerment. Nevertheless, the subjective experience of empowerment has not been addressed hitherto and can, thus, be considered an especially promising branch of future research on the topic.[11] Moreover, it has to be noted that DOF's potential to let patients' individual needs be heard and considered during the wound treatment may also contribute to laying grounds for person centered care (PCC).

In order to enable patients to make use of DOF, HCPs could "offer" the freedom to patients. This has to be combined with patient education concerning wound care and hygiene standards to ensure that patients have sufficient health literacy (for example to reach a free, shared and informed decision about dressing materials). Unfortunately, it is unlikely that all patients will strive equally for participation and the associated fulfillment of their psychological needs. A dispositional barrier for the engagement with DOF is the fact that a number of patients appear passive or even reluctant to get involved in their own wound care. This refers especially to people with diabetes and such, who are of advanced age. These are unfortunately the people who develop chronic wounds most frequently.[24] Additionally, in people with diabetes, a so-called "body island loss" occurs, in which the feet and lower legs with wounds are only perceived as environmental factors and no longer as belonging to one's own body.[26] Patients therefore often go to the doctor far too late and sometimes with serious lesions on their feet. This ignoring of one's own disease also massively influences wound care; as it is neglected.

A large number of older patients who have internalised a paternalistic approach to health care, suffer from medical (such as dementia) or psychiatric (such as depression) problems, or display other personality traits that impede the strengthening of autonomy. Such passivity of patients could also be observed in the interviews, with a few patients even stating explicitly that they do not wish to be involved. More often, however, they appeared unengaged in reflecting about the treatment process: They neither discussed personal needs or wishes regarding the treatment process or were unable to identify those. Nor did they provide ideas for adaptations of the treatment process. Such passivity can be a result of years of illness and treatments without substantial improvements. Other potential reasons might be a lack of skills regarding cognitive reflection (about details of the wound care process) and a lack of personal engagement with the research subject. To overcome such limitations, future interviews might include short memory exercises to strengthen self-reflective capacities (for example, try to remember your feelings, thoughts, and behaviours about your last dressing change). In addition, HCPs could also be reluctant to transfer power and freedom to patients, especially when dressing changes are strictly time-bound (for example due to economic specifications by insurance companies). In such cases, HCPs are likely to prefer performing dressing changes without involving patients because they believe it to be time-saving. At this point, systemic factors, such as time constraints and availability of monetary resources, become apparent and emphasise the importance of structural, political conditions necessary for implementing DOF in wound care practice.

IMPLICATIONS FOR CLINICAL PRACTICE

Implementing DOF in clinical practice should enable patients to gain significantly higher autonomy, a larger amount of control and it takes their individuality and distinct needs into account. More specifically, three positive effects are expected to be induced (empirically, still to be tested): First, the sense of action control should increase the patients' wellbeing in general and reduce their pain experience in particular. Second, interactions between HCPs and patients should be constructive and harmonious, not least because patients performing certain treatment steps themselves would ease the work for HCPs and result in a better coordinated process. Additionally, patients are expected to experience less resentment, since their individual needs are taken into account to a higher degree. Third, wound healing can actually be improved due to expectancy effects based on a more positive attitude. Although the implementation of the DOF may appear to involve additional work and time, the added value to the treatment strategy will certainly outweigh this when it becomes part of clinical routine.

CONCLUSION

DOF describe patients' potential to shape everyday wound care tasks through coping (least freedom), adaptation, cooperation, and self-action (highest freedom). Adding to existing approaches like shared decision making and patient education, DOF bear the potential to genuinely empower patients on a daily basis by increasing their control and self-determination. In 39 interviews with HCPs and patients we identified a range of specific behaviours which can be implemented in practice in order to gain three potential benefits: wellbeing and less pain; harmonious interactions between HCPs and patients; and better wound healing.

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CONFLICT OF INTEREST

The authors declare no conflict of interest related to the study.

Implications for clinical practice and further research

- DOF have the potential to empower patients by transferring control to them over everyday wound care tasks, thereby, taking patients individuality and distinct needs into account.
- Promising effects on wellbeing, pain experience, HCP-patient interaction, and wound healing can be expected.
- Possibilities and barriers to implementing DOF in different settings (e.g. clinic, outpatient care, nursing home, mobile nursing care) and for different patient identities (proactive vs. passive) should be elucidated.
- Subjective effects, especially experiences of feeling empowered, need empirical testing.

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REFERENCES

1. Garattini L, Padula A. Patient empowerment in Europe: is no further research needed? *Eur J Health Econ*. 2018;19(5):637–640.
2. Palumbo R. *The Bright Side and the Dark Side of Patient Empowerment: Co-creation and Co-destruction of Value in the Healthcare Environment.* Springer Cham; 2017.
3. Wounds International. *Optimising patient involvement in wound management.* Best Practice Statement; 2016.
4. Bravo P, Edwards A, Barr PJ, Scholl I, Elwyn G, McAllister M, et al. Conceptualising patient empowerment: a mixed methods study. *BMC Health Serv Res.* 2015;15(1):252.
5. Fumagalli LP, Radaelli G, Lettieri E, Bertele' P, Masella C. Patient empowerment and its neighbours: Clarifying the boundaries and their mutual relationships. *Health Policy.* 2015;119(3):384–394.
6. Tambuyzer E, Van Audenhove C. Is perceived patient involvement in mental health care associated with satisfaction and empowerment? *Health Expect.* 2015;18(4):516–526.
7. Reichardt C, Königer D, Bunte-Schönberger K, Van der Linden P, Mönch N, Schwab F, et al. Three years of national hand hygiene campaign in Germany: what are the key conclusions for clinical practice? *J Hosp Infect.* 2013;83:S11–S6.
8. Gethin G, Probst S, Stryja J, Christiansen N, Price P. Evidence for person-centred care in chronic wound care: A systematic review and recommendations for practice. *J Wound Care*. 2020;29(S9b):1-22.
9. Hickmann E, Richter P, Schlieter H. All together now – patient engagement, patient empowerment, and associated terms in personal healthcare. *BMC Health Serv Res*. 2022;22(1):1116.
10. Acuña Mora M, Sparud-Lundin C, Moons P, Bratt E-L. Definitions, instruments and correlates of patient empowerment: A descriptive review. *Patient Educ Couns.* 2022;105(2):346–355.
11. Hackert B, Weger U, Stuermer EK. Empowerment in chronic wound care – Exploring the scope for patients` contribution. *Frontiers of Nursing.* 2024;11(1):1–16. doi: 10.2478/fon-2024-0001
12. Dissemond J, Bültemann A, Gerber V, Jäger B, Münter C, Kröger K. Further definitions and spelling of the wound treatment. *Hautarzt.* 2017;68:415–417.
13. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349–357.
14. Gläser J, Laudel G. *Experteninterviews und qualitative Inhaltsanalyse als Instrumente rekonstruierender Untersuchungen. 4.* Auflage ed. Wiesbaden: VS Verlag; 2010.
15. Rädiker S, Kuckartz U. *Analyse qualitativer Daten mit MAXQDA: Text, Audio und Vide.*Springer VS; 2019.
16. Czarnecki ML, Turner HN, Collins PM, Doellman D, Wrona S, Reynolds J. Procedural Pain Management: A Position Statement with Clinical Practice Recommendations. *Pain Manag Nurs.* 2011;12(2):95–111.
17. Oka S, Chapman CR, Kim B, Shimizu O, Noma N, Takeichi O, et al. Predictability of Painful Stimulation Modulates Subjective and Physiological Responses. *J Pain.* 2010;11(3):239–246.
18. Dorsch Lexikon der Psychologie. 2021. *Coping.*
19. Upton D, Upton P. *Psychology of Wounds and Wound Care in Clinical Practice.* 2015.
20. Renner R, Erfurt-Berge C. Depression and quality of life in patients with chronic wounds: ways to measure their influence and their effect on daily life. *Chronic Wound Care Manag Res.* 2017;4:143–151.
21. Augustin M, Maier K. Psychosomatic aspects of chronic wounds. *Dermatology and Psychosomatics/Dermatologie und Psychosomatik.* 2003;4(1):5–13.
22. Gouin J-P, Kiecolt-Glaser JK, Malarkey WB, Glaser R. The influence of anger expression on wound healing. *Brain Behav Immun.* 2008;22(5):699–708.
23. Walburn J, Vedhara K, Hankins M, Rixon L, Weinman J. Psychological stress and wound healing in humans: A systematic review and meta-analysis. *J Psychosom Res.* 2009;67(3):253–271.
24. Martinengo L, Olsson M, Bajpai R, Soljak M, Upton Z, Schmidtchen A, et al. Prevalence of chronic wounds in the general population: systematic review and meta-analysis of observational studies. *Ann Epidemiol.* 2019;29:8–15.
25. Brown GK. A causal analysis of chronic pain and depression. *J Abnorm Psychol.* 1990;99(2):127.
26. Sonntag K, von Reibnitz C. "Leibesinselschwund": Fallstricke in der Behandlung vermeiden. *Pflege Z.* 2017;70(8):30-34.