

# Empowerment in chronic wound care—exploring the scope for patient contribution†



Review

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**Abstract: Objective:** In this study, we investigated the concept of empowerment in chronic wound care and propose to facilitate patient control by making use of degrees of freedom (DOF): that is, shaping of everyday wound care tasks initiated by patients and based on their wishes, mostly in terms of patients executing treatment steps, requesting or directing health care professionals to undertake changes, or modifications of internal states.

**Methods:** As a first step, we conducted a systematic literature search, followed by an inductive form of qualitative content analysis, which resulted in the identification of 5 dimensions as main elements of empowerment: education and shared decision making, adherence to self-care behaviors, responsibility and control, general call for empowerment, and DOF. However, the latter are noticeably absent in the literature. To investigate patients' freedom in shaping the wound care process, we conducted a second literature search.

**Results:** A number of possibilities for patients to influence the wound care process could be identified, but experimental or clinical evidence about their effects is missing, their variety is limited, and they are only inadequately described.

**Conclusions:** However, DOF should be an indispensable aspect of *genuine* empowerment, since they allow patients to occupy the role of the agent in the treatment process and give rise to the subjective experience of feeling empowered. Thus, in the third part, we develop a research proposal on how to investigate and include DOF in the clinical practice of wound care. Finally, limitations about implementations are discussed (e.g., patients being reluctant to overcome their passive role, resulting in frustration for health care professionals).

**Keywords:** adherence • chronic wounds • control • degrees of freedom • empowerment • shared decision making

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## 1. Empowerment in chronic wound care—Exploring the scope for patient contribution

Only in the beginning of the 1990s, patient empowerment was recognized as a core dimension in health care<sup>1</sup> and has become an imperative for good clinical practice since then. Also, patient empowerment has

become increasingly popular as a research concept, as indicated by the rise in publication numbers related to this topic. For example, for the search term “patient empowerment” appearing in the title, MEDLINE and

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CINAHL list only 54 entries for the years 1990–1999, 165 entries for the time period 2000–2009, and a total of 349 entries for 2010–2019. The same pattern of results showed up on PubMed. Such publication numbers point to the central importance of empowerment in promoting health and well-being.<sup>2–4</sup> As Adinolfi states in a preface to a recently published book<sup>2</sup> about patient empowerment: “[P]atient empowerment may lead to the awakening of sleeping resources, thus contributing to a more appropriate access to care and better health outcomes” (p. Vii). Similarly, clinical practice guidelines increasingly incorporate recommendations to empower patients.<sup>5</sup> Moreover, various policy regulations support this cause,<sup>6–8</sup> and clinical practice has already partially taken up on this.<sup>9,10</sup> A well-known phrase summarizes it succinctly: “nothing about me without me” (p. S26).<sup>11</sup> But what are these “sleeping resources” that Adinolfi talks about?

Despite the rise in popularity, there is neither a consistent use in terminology nor a consensus about how to define patient empowerment.<sup>2,3,12</sup> It can be considered from different levels (macro, meso, and micro) and perspectives (e.g., patient, provider, and health care system), which result in different types of understanding of how it is conceptualized.<sup>12</sup> Heterogeneous terms such as patient engagement, patient involvement, patient participation, patient centeredness, patient empowerment, and even self-management or self-care are used interchangeably.<sup>5,13,14</sup> Similarly, patients and practitioners each have differing understandings of patient empowerment.<sup>2,5</sup> Because most definitions are rather general and abstract, it remains unclear what the *empowering* aspects really are. That is, what changes in the clinical setting need to be implemented to *empower* patients? In this article, we aim to clarify the role of patient empowerment in the treatment of chronic wounds.

Everyday life with a chronic wound is extremely stressful on a physical as well as on a psychological level. Frequently occurring tasks such as dressing changes cause significant pain and emotional stress for patients. Exploring the potential benefits of empowerment can hence be a fruitful approach to improve living standards with a chronic wound. As will be elaborated later on, there are several different types of patient empowerment depicted. But most accounts of empowerment in wound care neglect a very practical, yet central aspect—namely, patients’ freedom to actively partake in the implementation of concrete wound care tasks and to flexibly maneuver in conducting the relevant tasks according to their own needs and wishes. Moreover, classic approaches such as shared decision making or education about self-care often fail to address an essential characteristic of empowerment sufficiently, which is the subjective experience of feeling empowered.

Although these approaches do have the potential to evoke such feeling in patients, it is rarely addressed in the literature—whether indirectly or directly. We argue that the whole wound care setting allows patients different degrees of freedom (DOF)—a concept we develop—to shape the everyday implementation of wound care and that such involvement gives rise to a subjective experience of feeling empowered (e.g., a patient requests a time-out during a painful dressing change to till the pain recedes). In this way, DOF could realize both practical freedom on a local, everyday level and a feeling of being empowered—something we term genuine empowerment.

As indicated from the previously, a common definition of empowerment is “the process of helping people to make informed decisions to manage factors that affect their lives. Within the context of wound care, empowerment involves providing advice, education, information and practical support that helps the patient and/or carer to establish an acceptable level of control over the management of their wound” (p. 62).<sup>15</sup> This definition does neither preclude DOF and a genuine sense of empowerment nor does it explicitly relate to it. Thus, the question remains whether academic and practical health care workers consider it relevant that patients get empowered at a local level and that patients experience themselves as agents by executing actual control and perceiving it, too. It is therefore of value to know whether studies relating to empowerment incorporate elements akin to DOF.

## 2. Patient empowerment in wound care

To investigate DOF and genuine empowerment in wound care, we conducted 3 steps, which are represented in the structure of this article. In the first step, we identified the relevant elements that constitute empowerment. To achieve this, we systematically searched and analyzed definitions and descriptions of empowerment from 2 sources: (a) best practice guidelines and (b) peer-reviewed journal articles. To capture all depictions of empowerment sufficiently, we covered instances of patients being involved, having control, participating, and making decisions. The second step was to explicitly investigate DOF. To do so, we theoretically and empirically explored patients’ possibilities to shape and engage in the wound care process. As a synthesis of the first 2 steps, we explicate DOF as an unrecognized and under-researched element of patient empowerment in wound healing by identifying them as integral to the concept of empowerment. Additionally, we find that the subjective experience of being empowered and its effects

are mostly neglected in research. Hence, as a third step, we discuss implications of the inclusion of both DOF and the subjective experience of empowerment in empirical research and practical wound care.

### 2.1. Patient empowerment: Methods

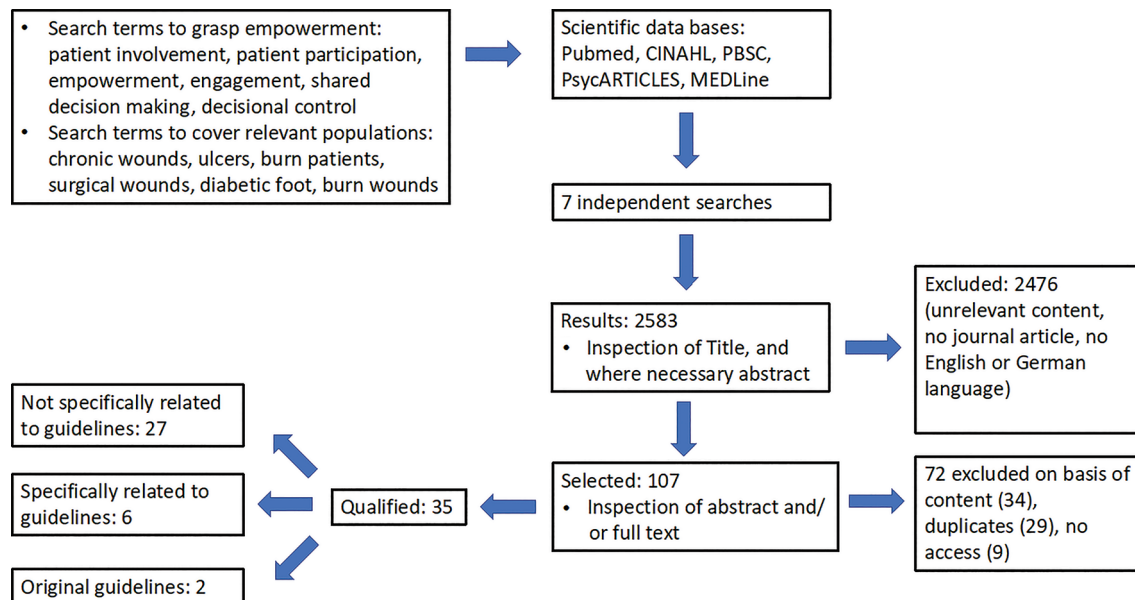
A systematic literature search as well as an additional unsystematic literature search of best practice guidelines and peer-reviewed journal articles was conducted. Search terms (see Figure 1) were combined with the following Boolean operators: “OR”, “AND”, “NOT”, “\*”, for instance, using the search string: “(((chronic wound\*) OR ulcer\*) OR diabetic foot) OR surgical wound\*) AND (((((patient involv\*) OR empower\*) OR patient participati\*) OR patient engag\*) OR shared decision making) OR decisional control).” All types of studies (e.g., empirical research and review) were included without any restriction concerning the date of publication. We included papers published in English or German. Peer-reviewed journals were identified in 5 electronic databases (see Figure 1). Additionally, best practice guidelines were identified via databases (see Figure 1) or Google and websites of organizations publishing best practice guidelines. In total, we found 67 qualified sources.

As a second step, we conducted an additional unsystematic literature search according to the pyramid scheme with the already included papers, on the one hand, and via Google Scholar, on the other hand. For both types of searches, the identification of relevant

sources was carried out as an elimination procedure including the following steps: First, in case of a relevant title, the abstract was read. Second, in case of a relevant abstract, the full text was searched for relevant terms and analyzed with regard to the term’s descriptions; in case of descriptions that included empowerment, the paper was included.

Following this, we conducted a qualitative content analysis<sup>16</sup> with all papers. This type of analysis is frequently used in nursing research and rapidly becoming more prominent in the medical and bioethics literature.<sup>17–19</sup> It is a qualitative analysis method that includes the following steps: After the preparation phase, that is, the literature search, we selected the passages relevant for the analysis, that is, passages including the key terms and descriptions. To be precise, we identified descriptions—direct or indirect—of empowerment in any form. Then, we categorized central aspects of the formerly identified descriptions to provide a deepened understanding: “When formulating categories by inductive content analysis, the researcher comes to a decision, through interpretation, as to which things to put in the same category” (p. 111).<sup>16</sup> Our analysis yielded 5 categories each named after the phenomenon they relate to:<sup>16</sup> DOF, adherence to self-care behaviors, patient education and shared decision making, control/responsibility, and abstract descriptions of patient empowerment.

As a next step, the number of occurrences of each category was counted with the possibility that a single



Note: PBSC, Psychology & Behavioral Sciences Collection

Figure 1. Systematic literature search concerning empowerment.

description could match more than 1 category. Such a qualitative analysis approach is particularly well-suited at the early phase of the research process, when empirical evidence is still sparse and an explorative, rather than an explanative, approach to theory development is in place (see the distinction between the context of discovery and the context of justification).<sup>20,21</sup>

## 2.2. Patient empowerment: Results and discussion

We analyzed all identified descriptions of empowerment and generated 5 categories: DOF, adherence to self-care behaviors, patient education and shared decision making, control/responsibility, and abstract descriptions of patient empowerment. We summarized the results in Table 1, which contains an example and the number of occurrences in the literature. It becomes evident that empowerment most often contains elements of patient education and shared decision making or adherence to self-care behaviors. It is important to note that a single description could refer to more than 1 category.

### 2.2.1. Adherence to self-care behaviors

In more than half of the sources (44 of 67), self-care behaviors were mentioned. These behaviors are focused on daily activities<sup>27</sup> to improve physiological functioning and prevention or better healing of chronic wounds. They include physical activity and a healthy diet but also medical behaviors such as inspecting the wound or even performing wound care activities by themselves. Two aspects that increase self-care performance can be identified: education about the benefits of self-care behaviors and practical strategies (e.g., instructions and “Look After Your Legs” program).<sup>28</sup> Similarly, self-care

behaviors are often found in the literature, since they are considered as a way to let patients participate in the wound care process. In this way, empowerment means knowledge and skill to apply self-care behaviors.<sup>29,30</sup> In line with this, empowerment programs specifically focused on self-care have come to existence.<sup>31</sup> Since these behaviors are empirically tested and medically advisable, they can be considered a necessary and inevitable part of the wound treatment and not so much an autonomous decision and behavior of patients. Patients can, of course, choose not to perform self-care behaviors, but that will have negative consequences inevitably. From this perspective, empowerment based on self-care can be understood as adherence. That is, the patient is informed about the benefits of performing and the harmful consequences of neglecting such behaviors, is taught how to use them, and adheres to the medical advisor by performing them. Of course, patients gain more freedom to organize their days when they can carry out some wound care activities by themselves that otherwise must be done by professional health care providers. However, patients remain in the position of passively receiving and following instructions from the medical staff and cannot reclaim the role of the agent that actively exerts influence in the treatment course. Although engagement with self-care can affect patients to feel empowered and perceive control to a certain extent,<sup>32</sup> it is assumed that such feeling stems from the experience of self-efficacy (i.e., patients’ belief that they are able to perform self-care behaviors). But—even less than in shared decision making (see later)—the patient does not have control to alter the wound care process according to his/her own wishes or ideas. In this regard, empowerment has been criticized as being only “a lip-service with a traditional paternalistic attitude and practice behind it” (p. 300).<sup>4</sup>

Category	Number of occurrences	Example
DOF	17	“Encourage individuals to request a ‘time out’ during any procedure that causes pain...” <sup>22</sup>
Shared decision making/educated patient	38	“Every patient has the right to receive relevant information, support and encouragement from the nurse which will permit him/her to make informed choices” <sup>23</sup>
Adherence to self-care behaviors	44	“This study developed and piloted a patient-centered pressure ulcer prevention care bundle for adult hospitalized patients to promote patient participation in prevention. The care bundle had 3 core messages: (1) keep moving, (2) care for your skin, and (3) ensure a good diet” <sup>24</sup>
Control/responsibility	8	“Empowerment is a collaborative approach□the patient’s potential to adapt to the disease, to change its course, and to extend individual responsibility for dealing with the disease is considered and emphasized” <sup>25</sup>
Abstract descriptions of patient empowerment	7	“The clinician should endeavor to involve and empower patients to optimize pain management.” <sup>26</sup>

Note: DOF, degrees of freedom.

**Table 1.** Categories of patient empowerment and its frequency of occurrence in the literature.

### 2.2.2. Patient education and shared decision making

In 38 sources, a reference to educating the patient or shared decision making was made. Education means giving information about the wound and its treatment to the patient. Treatment advice is not simply followed, but a deeper understanding of its necessity and its working mechanisms is provided. As a result, the patients become experts for their own conditions and presumably can develop a feeling of competence, in addition to actively contributing to his recovery. Patient education aims at a role transition from the patient being a purely passive receiver to more active adherence. In medical practice, patient education can occur, for instance, via written education materials.<sup>33</sup> Education can be considered as a necessary aspect and a prerequisite for patient empowerment, since only with the help of education, patients can make informed decisions about their treatment.<sup>11,34</sup> Closely connected to—and building on—education is shared decision making: To decide which treatment plan should be followed, patients need to be knowledgeable about different treatment options and accompanying benefits and risks. With shared decision making, physicians and patients decide which treatment goals should be aimed for and choose which actions should be taken to reach them together to encourage patient participation.<sup>35</sup> Thus, empowerment in shared decision making aims at making the patient a partner in wound treatment, not just a mere object of treatment. Importantly, it has to be acknowledged that patients and medical professionals have differing types of expertise, but both are valuable and integral to wound healing.<sup>36</sup>

Nevertheless, the active role implied here is clearly restricted since its primary working mechanism is negotiating different treatment options that are ultimately predefined by the condition of the wound and by the alternatives offered by the medical staff. In this way, it seems likely that in many cases, the goal is treatment matching, that is, “patients successfully aligning their own characteristics to the characteristics of available treatments alternatives”<sup>37</sup> than choice making per se.<sup>37</sup> In accordance with this, “in medical research, the benefits of patient participation are commonly interpreted as matching effects.”<sup>37</sup> In addition, shared decision making in wound care is rather concerned with global decisions about the treatment (e.g., what type of therapy should be followed), and not with local decisions on a day-to-day basis (e.g., which bandage should be used). Such global decisions are probably made only at isolated points in time, and afterward, the patient has no predefined control to alter it. In support of this view, Michie et al.<sup>25</sup> state, “In working with patients with a chronic illness, it may not be helpful for health care professionals (HCPs) to consider that they have achieved a

‘patient-centred’ consultation if they have succeeded in eliciting and matching their patients’ beliefs about illness and treatment. HCPs should develop their awareness of, and skills in achieving, our suggested second step of patient-centredness, patient activation. This means finding ways of increasing the active role and control that patients take within, and consequently beyond, the consultation” (p. 204).

Nonetheless, the questions of what scope shared decision making has in clinical practice, how often decisions are made together, and which specific decisions are shared at all are a matter of debate of its own. Taken together, education and shared decision making empower the patient in a way that he/she can feel important and included, and support him/her in co-directing the treatment course at a global level. But active partaking in the treatment process itself at a local level is not integral to shared decision making.

### 2.2.3. Control and responsibility

Eight cases rather generally called for more control and responsibility on the part of the patients. Patients should be more in control about the wound management or about their own involvement in the treatment course. Examples include statements such as “patient centred care involves sharing control of interventions or management of health problems with patient” (p. 65).<sup>38</sup> Unfortunately, no further explanations of what is actually meant by control were given and neither were specific proposals on how to achieve it. Only few examples create a more specific impression. One relates to self-care when stating that “physical activity was seen as a life-long treatment strategy to increase circulation. Hence, physical activity called for self-management, a personal initiative and individual responsibility. ... Physical activity gave a feeling of taking responsibility and being involved in the treatment” (p. 279).<sup>39</sup> Another refers to the result “that 3 simple messages that patients could understand, use, and control the extent to which they participate were effective in engaging patients in [pressure ulcer prevention] care” (p. 392).<sup>30</sup> Still, even this leaves room for interpretation. To conclude, due to the unspecific character of most descriptions, it remains unclear whether and how patients can be empowered by calling for increased control and responsibility. How exactly can control of wound management look like, and for which specific behaviors should patients be responsible? Depending on the specific nature of the behaviors (self-care adherence, executing treatment themselves, directing treatment), descriptions of this category could rather refer to adherence, on the one hand, or rather to DOF, on the other hand, and would accordingly constitute different modes of empowerment.



### 2.2.4. Abstract descriptions of patient empowerment

Seven sources relate to patient empowerment in a general sense without exactly specifying its implementation. In several cases, the imperative to empower, involve, or participate is simply stated.<sup>40–42</sup> Some descriptions indirectly create a general connection to more specific concepts such as shared decision making,<sup>43</sup> education,<sup>44</sup> or self-care<sup>45</sup> but do not elaborate on it. Some announce abstract ideals of autonomy, patient rights, or health literacy.<sup>5,42</sup> For example, patient-centered care is defined as “a multidimensional concept encompassing the attributes of patient participation, power, shared decision making, knowledge sharing, communication with patients, and respectful, collaborative partnerships.”<sup>43</sup> Even more than descriptions of the category “Control and Responsibility,” this category contains information that is too vague to determine exactly what kind of empowerment should be achieved for patients, in which way it can be reached, and whether it is more about a general inner state of the patients or concrete behaviors (e.g., dressing change). Thus, it is impossible to determine to what extent patient empowerment exists.

### 2.2.5. Intermediate synthesis: Developing the concept of DOF

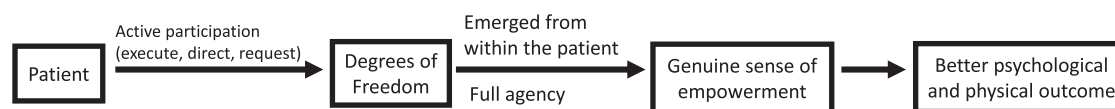
Prior to describing the literature search concerning DOF, the categories identified so far will be synthesized, and on that basis, the concept of DOF will be developed. To begin with, it is noticeable that empowerment seems to constitute primarily a general state that functions at a global level. For instance, with shared decision making, patients are empowered to choose from a range of treatment options, but the actual execution of the chosen treatment in everyday life is determined by HCPs. In other words, although patients' preferences might be included at a global level (e.g., which sort of treatment), on a day-to-day basis, the patient remains in a passive role, simply being exposed a certain treatment. The same holds true for self-care behaviors. On the one hand, adherence to self-care behaviors is—of course, rightly and importantly—emphasized as a critical healing determinant in which patients get assigned a role as contributors to their own healing. But, on the other hand, all input (e.g., what kind of self-care behaviors should be done) stems from HCPs, and patients remain rather passive receivers of recommendations for actions. In such situations, patients likely do not experience genuine empowerment in terms of exerting or perceiving control on a local level (i.e., everyday implementation of wound care tasks). What remains missing (in the literature), although it is at the core of the concept of empowerment, is patients being their own

subject of empowerment, that is, patients using their own immanent power as human beings to *empower themselves* and thereby reclaim the role of the agent in their wound treatment. In our view, this could be realized by actively seeking control over everyday wound care tasks. Reasonably, such control must not oppose medical advice. In addition, patients have differing preferences, skills, and capabilities (e.g., physical handicaps) to exert control. Thus, depending on the medical context and patient characteristics, there exist different DOF to shape the implementation of wound care. We assume three general kinds of DOF: (a) patients (instead of HCPs) execute wound care tasks (e.g., execute some or all steps of the dressing change), (b) HCPs perform the dressing change but patients ask or tell HCPs to adapt the way of care execution to their needs (e.g., little breaks to minimize pain), or (c) patients change their subjective experience through communication and control of attention and thoughts (e.g., talking to the HCP to receive emotional support). In this way, DOF can be conceptualized as concrete modes of control emerging from the patients themselves and thus reclaiming the role of the agent as patients. We illustrate this in Figure 2.

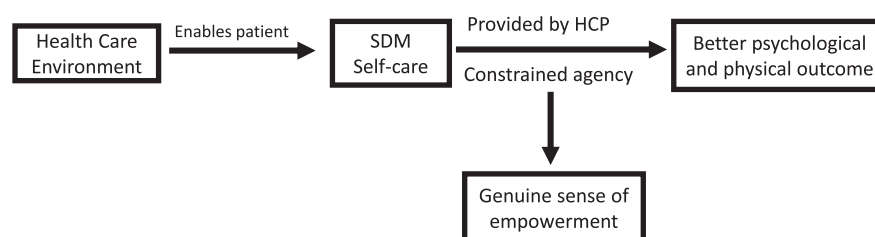
To conclude, in our view, freedom at a local level has the potential to constitute a genuine sense of empowerment in contrast to only being passively empowered through complying to self-care instructions or being involved in global treatment decisions as stipulated in the concept of shared decision making. As a consequence, such freedom should be at the core of any empowerment approach, since it does not only involve patients as subjects who have to be asked for treatment preferences (e.g., shared decision making) or assistance (e.g., education to self-care) but also because it has the potential to create a personal feeling to be in control on the patients' side. In other words, patients will no longer be placed only in the (theoretical) center of wound care as the permanent focus of HCPs and ultimately receiving care passively. Rather, they will perceive themselves as actually being in the center, having actual control to impact wound care, and being the agent in the treatment course.

Importantly, DOF should demonstrate a psychological, social, and medical benefit: First of all, it is assumed to be personally valuable to patients and their well-being, especially facilitating a more pleasant experience during dressing changes. Second, it can benefit HCP–patient relationships and the whole wound care setting. Third, it can presumably increase and improve wound healing. To provide a sound understanding of possible working mechanisms behind such benefits, one must keep in mind that choice must be an integral part of all instances of DOF (e.g., patients can choose whether and how they

## Patient-Realized Empowerment



## Other-Realized Empowerment



Note: SDM, shared decision making

**Figure 2.** Patient-realized empowerment and other-realized empowerment.

direct the HCP or patients choose which treatment steps they want to do themselves), as well as that choice is integral to power in general. Hence, choice is essential to empowerment. Relating to the benefits of choice, empirical research has found patient choice to improve clinical outcomes. For instance, letting participants choose which hand they will use in a cold pressure task is effective in alleviating pain.<sup>46</sup> Similarly, choice can intensify placebo responses to pain and anxiety/stress.<sup>26</sup> Another effect of freedom can be found in studies about self-administration of medical procedures. It has been shown that self-administration of analgesia reduces the total amount of analgesia needed.<sup>47,48</sup> The rationale behind this is that choice is linked “to personal control and personal control to positive health outcomes” (p. 550).<sup>26</sup>

The act of choosing is beneficial in itself, but a heightened perception of control is additionally helpful. For example, participants in two groups experiencing test anxiety could choose between 2 treatment options, but one group believed assignment happened by chance and the other group performed worse on a test than the group that had a greater sense of control. Next to performance, a greater sense of situational control decreases the negative mood, for example, in caregivers.<sup>49</sup> The proposed mechanism is that “exercising personal control over medical decisions via choice alters an individual’s subjective appraisal of a treatment and treatment-related events which, in turn, alters responses. Consistent with this interpretation, the impact of choice on pain relief was statistically mediated by positive evaluations of the treatment.”<sup>46</sup> Pertaining to

this, thoughts of personal control mediate the efficacy of choice,<sup>37</sup> which likely is relevant to feeling empowered. In line with this, having greater agency (i.e., making a choice completely on one’s own) leads perhaps to even stronger placebo–expectation effects than shared decision making.<sup>50</sup> Applied to our ideas, DOF should be of avail presumably because of the strengthening of autonomy. However, findings concerning the effects of control and choice are mixed depending on the kind of control (e.g., behavioral vs. cognitive control) and dependent variable (anxiety, painfulness, endurance).<sup>51</sup> Importantly, benefits depend on patient characteristics such as desire for control<sup>37</sup> or independent vs. interdependent self-construal.<sup>46</sup>

Taken together, with more DOF, patients can experience that they can effectively change their wound care and healing. In other words, when patients make use of the available DOF, it leads to the resulting experience that they can affect their own healing through control and be agents in their wound care treatment. This should generate a genuine sense of empowerment because patients can (partly) control their environment and their wound healing according to their own individual wishes.

### 2.2.6. DOF

In 17 of 67 cases, we found descriptions akin to DOF: Six can be further categorized as *autonomous wound care*, five of which were related to patients performing wound treatment (especially dressing changes) themselves.<sup>22</sup> One was concerned with the patients’ freedom

of action related to applying compressions: “They can choose to loosen bandages, remove stockings, leave them on, or not put them on to begin with” (p. 31).<sup>36</sup> Thirteen of the total 17 cases contained *freedom of choice*. In most cases, this refers to patients choosing the dressing type<sup>34</sup> and compression intensity.<sup>36</sup> Other choices included the support surface<sup>52</sup> and debridement technique.<sup>53</sup> Five cases incorporated descriptions of *directing the HCP*. Examples include requests from the patients directed at the nurse (e.g., requesting a time-out during painful wound care procedures),<sup>52</sup> adjusting the dressing according to patients’ wishes,<sup>54</sup> or patients’ preference for turning/adopting a comfortable position.<sup>55</sup> Six cases addressed DOF in an *abstract way*.<sup>56</sup>

It is important to note that none of the descriptions explicitly incorporate the psychological subjective experience, that is, they do not elaborate on the effects of having or making use of DOF (e.g., do patients feel empowered and what effect results from the feeling of being empowered?). Rather, the descriptions point to the possibility of freedoms in the first place. The psychological side has to be researched on its own in the future (see section *Establishing DOF in Academic Research and Clinical Practice*).

To conclude, patient empowerment is mostly depicted as the concept that patients are educated and involved in global decisions about what kind of treatment they receive and encouraged to perform self-care behaviors. Elements of DOF are found in the literature to a much smaller degree (17 cases in comparison to 38 cases of shared decision making and 44 cases of adherence to self-care). In addition, such descriptions were rather vague and refer, in most cases, to patients performing dressing changes themselves, or choosing the dressing type or compression intensity. Hence, DOF are only explored to a limited extent in the wound care literature in relation to empowerment and are therefore a neglected element of patient empowerment. Furthermore, there is an overall lack of research concerning the subjective experience of empowerment and its effects. (Thus, all statements in this article about the subjective experience of empowerment and its effects remain to be tested empirically.) Closing that research gap is inevitable to clarify the full potential of patients’ empowerment.

### 3. DOF in wound care

Our first literature search revealed that DOF are only rarely addressed in relation to empowerment. However, it remains possible that important aspects of freedom like choice, thoughts of control, patients executing tasks, agency, and situational control—as illustrated earlier relating to other medical and psychological domains—have been reported more generally and not explicitly linked

to empowerment. Thus, it would be important to know whether research akin to DOF, but independent from empowerment, has been published in the wound care literature. Have insights from clinical practice emerged? Have specific actions that contain elements of such freedom been investigated in experimental or field studies? Has it been explored whether such actions do relate to personal thoughts of control and the feeling to be in control? Therefore, a second literature search concerning DOF was necessary. Based on the results of the first literature search, we assumed that there would be no research explicitly investigating aspects of genuine empowerment or DOF. Hence, we searched much more broadly for any incident of patient participation that could potentially evoke a sense of control. That is, we searched for all situations in which patients executed treatment steps, requested something from HCPs or asked them to adapt care tasks, made changes to their personal (wound) situation, or shaped otherwise their own wound care.

#### 3.1. DOF: Methods

Concerning DOF, the systematic literature search, the additional unsystematic literature search, and the identification of relevant sources were carried out the same way as for the literature search for empowerment described earlier; see Figure 3 for an overview. In total, we found 50 qualified sources.

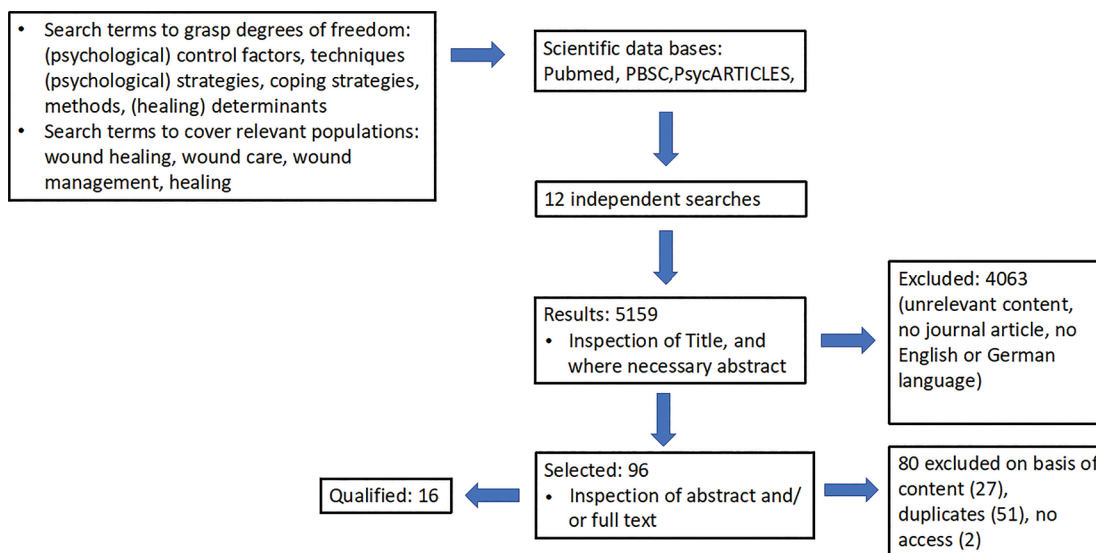
#### 3.2. DOF: Results and discussion

Again, we conducted a qualitative content analysis (described previously) including the former identified qualified sources. To identify relevant descriptions of DOF, we considered the search terms but also the study design in general. In addition, descriptions of patients/HCPs behavior and statements were included in the analysis, since most descriptions were not explicitly related to concepts such as empowerment and control (the complete list of DOF on request). The results of our analysis yielded 5 categories (Table 2), 3 of which were further subcategorized:

- see Table 3 for primary control strategies during dressing change
- see Table 4 for secondary control strategies during dressing change
- see Table 5 for primary control strategies not restricted to the dressing change context.

The distinction between primary and secondary control is in line with the two-process model of control: “In this model, primary control is achieved by directly changing the environment or situation, while secondary





**Figure 3.** Systematic literature search concerning DOF.

Degree of freedom	Number of occurrences	Example
Primary control during wound care	21	Time-out: Patient can pace procedure <sup>22</sup>
Secondary control during wound care	14	Relaxation <sup>57</sup>
General techniques (not restricted to wound care)	25	Talk and share thoughts <sup>57</sup>
Abstract descriptions of freedoms	10	Autonomy support to increase power and responsibility <sup>59</sup>
Beliefs (about empowering behaviors)	5	Self-efficacy beliefs about to apply bandages <sup>60</sup>

**Table 2.** Categories of DOF and their frequency of occurrence in the literature.

control is attained by changing one’s self to adapt to the conditions” (p. 526).<sup>23-60</sup>

### 3.2.1. DOF: Primary control strategies

We could identify a number of possibilities for patients to directly shape treatment procedures during the dressing change, which encompassed choosing, directing, or self-doing. Thus, they have the potential for genuine empowerment as outlined earlier (Table 3). Such behaviors can be understood as primary control strategies, as the outer situation, not the inner experience of patients, is proactively changed.<sup>61</sup> Since such behaviors are the focus of this article, they are to be described in further detail.

There are several possibilities to directly alter the situation of dressing changes. Most identified behaviors relate to treatment procedures executed by the patient, which were formerly carried out by HCPs. Examples include the cleaning of wounds or removal of dressings. It implies a direct act of empowerment, since such self-doing gives the patient great control over the implementation of wound care tasks. The patient becomes the controlling instead of the controlled subject and the

actor of the treatment and is therefore in command. Shaping the treatment situation is another possibility to attain primary control. This should be evident in directing the HCP how to perform certain procedures such as telling him/her how fast to go, which limb to start with, or taking time-outs. As the patient is (partially) in charge of the treatment execution, it should be genuinely empowering. Furthermore, patients can make decisions directly impacting the treatment. For instance, they could decide whether and who should support them during dressing change, or they could choose a body positioning most comfortable to them.

Other proactive alterations of the treatment situation, which are not part of the dressing change itself, include singing. Such behaviors are freedoms to act in an individual way, in which the patient is not restricted by medical specifications. In addition, with patient-controlled analgesia, the patient is in control over the amount of analgesia they gets.

Communicative acts can give a sense of empowerment, since they signal that the patient is the subject around whom treatment takes place and, above that, reduce passivity. This happens, for instance, when the

Item	Strategies
Wound cleansing	Washing of wounds
	Choose type of washcloth and water temperature
	Decision over who does the washing
	Choose start time for bathing and bath toys (when patients are children)
	Remove splints
Pace	Debridement (not recommended anymore according to medical standards)
	Time-out/patients pace procedures
Dressing change	Tell nurses how fast to go
	Dressing change
Pain medications	Remove dressing
	Reapply dressing
	Choose dressing together with health professional
	Hold bandages
	Collecting dressing materials (when patients are children)
Other	Patient decides body positioning
	Patient-controlled analgesia
Other	Choose type of pain medications
	Conversation: ask questions, tell nurse which are most sensitive areas
	Decision which family members are present at dressing change
	Self-massage
	Singing
	Decide which limb or area to start with (in case of several wounds)
	Risk assessment (e.g., signs of infection and when to seek professional help)

**Table 3.** Primary control strategies during wound care.

patient asks questions or informs the HCP about the most sensitive wound areas. Although this does not necessarily result in changes to the treatment steps per se, patients are in control of the interpersonal situation.

### 3.2.2. DOF: Secondary control strategies

Patients can also achieve a sense of empowerment when they control their inner states and bodily reactions to the dressing change context. Although there are still a few inconsistent findings, in many cases, such strategies have been shown to reduce pain and anxiety or have some other benefits. We classified them in 7 categories (Table 4): distraction (e.g., watching TV), comfort (e.g., warm blanket), communicative acts (e.g., alleviate pain and stress through effective communication), relaxation (e.g., breathing exercises), cognitive techniques (e.g., reappraisal), environment (e.g., calm environment), and

Item	Strategies
Distraction	Reading; TV; conversation; virtual reality; interactive stories on a video game device; headphones
Comfort	Holding something (side rail); extra blankets; repositioning; warm blanket; presence of a benign and caring adult; ask (verbally or non-verbally) for comfort
Communicative acts	Social support (e.g., sharing and discussing emotions and experiences with other patients); hold hands; influence a patient's perceived pain and stress through effective communication; parental visiting
Relaxation/stress reducing strategies	Breathing exercises (e.g., deep breathing); music; (visual) imagery (e.g., imagine to be on a beach); pictures; massage; progressive muscle relaxation; touch; aromatherapy; multi-modal stress management; biofeedback
Cognitive techniques/coping mechanisms	Appraisal/cognitive reframing/reinterpretation of the context; positive evocation to focus on recreating a pleasant memory and to create a positive emotional state, imaginative transformation of sensation or imaginative lack of attention (delivered by psychologist); focus on positive aspects of wound management (e.g., improved health, removed pain); cognitive attribution: benign meaning to pain (gaining information about reasons for pain, avoid catastrophizing); minimization; coping skills intervention; use euphemisms for painful stimuli; mental focus on physical sensations
Environment	Calm environment (e.g., no mobile phones); minimize sensory input (e.g., from open windows)
Predictability	Education about dressing change procedure and pain relief strategies; health professionals state what they are doing while treating the patient

**Table 4.** Secondary control strategies (during dressing change).

predictability (e.g., health professionals state what they are doing while treating the patient).

### 3.2.3. DOF: General techniques

Not only in the dressing change context but also in any other situation, patients can apply general techniques to deal with their wound experience. Those strategies can be further subcategorized into primary and secondary control strategies. In this passage, the focus will be on the primary control strategies (Table 5).

During and outside the wound dressing change, patients can actively take part and be in control in several ways. They can be autonomous, for example, when they take off bandages for a short time to reduce the itching or when they can decide when they want to see the HCP. They can also change their personal environment in a way that it benefits everyday life with a wound (e.g.,

Item	Strategies
Autonomy/predictability	<p>Take off bandages for a short time to reduce itching</p> <p>Reduce dependence on caregivers</p> <p>Input into daily schedules and routines</p> <p>Schedule dressing change according to patients wishes/when patient feels best</p> <p>Planning: seeing a nurse to check the wound should fit working hours of patient</p> <p>Possibility to refuse treatment</p>
Environment	<p>Change personal environment (e.g., mobile bathtub for better hygiene)</p> <p>Create familiar environment (e.g., in hospital)</p>
Pain medication	<p>Initiative in using or not-using pain medication</p> <p>Ask for pain medications</p> <p>Patient-controlled analgesia</p>
Communicative acts	<p>Speak up for oneself</p> <p>Remind nurse when she/he forgot something</p> <p>Interaction with other patients or health professionals: Music and dancing with health professionals</p> <p>Talk and share their thoughts; communicate concerns, feelings, etc.</p> <p>Ask questions</p> <p>Direct requests (e.g., ask for pain medications)</p> <p>Empathetic conversations between patients and health professionals</p> <p>Inform patients about wound dressings and treatments to empower them to participate in their care</p> <p>Negotiating care between patient and nurse</p> <ul style="list-style-type: none"> <li>- Synchronize role expectations</li> <li>- Requests for patient's permission (e.g., to remove items from medicine box)</li> <li>- Dispute over responsibility for carrying out or deciding on care decisions; patients stating their actions, then seeking permission</li> <li>- Give patients feedback about their care performance in a sensitive, empowering way</li> </ul> <p>Express feelings and thoughts</p> <p>Dictate how to treat the wound (patients can become assertive when they have the impression the care is not executed to professional standards)</p> <p>Social support</p> <p>Social closeness (with a person having a similar wounding-experience)</p> <p>"Laugh and a joke" (p. 558)<sup>62</sup> between patient and nurse</p>
Emotional disclosure	<p>Expressive writing about a traumatic event</p>

**Table 5.** Primary control strategies.

a mobile bathtub for better hygiene); they can decide on the intake of pain medication and utter direct requests; they can express their feelings and thoughts concerning the wound to the HCP or discuss the responsibility for carrying out or deciding on care decisions.

Next to the afore-reported strategies, we were able to identify abstract descriptions of empowerment in wound care and connections to beliefs concerning empowerment (e.g., self-efficacy beliefs to dress the wound). Since these do not hint to direct possibilities of control strategies, we do not elaborate on them further.

Taken together, only few specific primary control strategies are previously described, and in most cases, strong empirical support is missing. In addition, explicit

approaches (e.g., leg clubs<sup>24</sup>) to genuine empowerment seem rare. Experimentally investigated were methods of participation in children and adolescents with burn wounds who took part in their dressing change to increase predictability and controllability; for example, self-mediated debridement vs. therapist-mediated debridement. The results showed better psychological adjustment and less pain when children participated.<sup>58-60,63</sup> Such approach has been developed more than 30 years ago and has been used seldom since then.<sup>64</sup> Furthermore, it was tested mainly in case studies or with small sample sizes.<sup>60,63-65</sup> Accordingly, Bush and Maron<sup>66</sup> call for further investigation regarding techniques related to perceived control.

## 4. Establishing DOF in academic research and clinical practice

DOF are expected to be beneficial, since they supposedly increase patient satisfaction and reduce aversive experiences on the side of patients and HCPs, and care is partially facilitated. The actual advantage of DOF is that the patient can be the actor in the wound care process and not *just* be involved (e.g., as with shared decision making, which leaves the doctor as the expert and the wound as more central than the patient). It is likely that employing DOF is favorable in clinical settings (e.g., dressing change during a special wound consultation hour) and ambulatory settings (e.g., professional home care/nurses visiting the patient) but also when wound care is done by family members.

### 4.1. Implementation of DOF in practice

Next to an academic question about the benefits of DOF, it is important to examine whether patients are already involved in everyday clinical practice at all. First of all, a survey with 1000 nurses showed that only a few involved patients in the dressing change procedure, for example, to remove the dressing.<sup>65</sup> Patients have a similar impression as only one-third states that health care workers try to involve them, albeit patients seem not to be eager to overcome their passivity, which results in frustration for health professionals who work on partnership building.<sup>32</sup> A recent interview study has shown that from the perspective of HCPs, patients are already in control when they are educated and instructed for self-care, believing that this would lead to good relationships without being too paternalistic, but patients are “not directing treatment” (p. 89),<sup>32</sup> which would signify a degree of freedom. In addition, although taking responsibility (e.g., self-care) is assumed to be a problem for some patients, there is also the possibility that HCPs disempower patients.<sup>32</sup> Pertaining to patients, it can rather be assumed that they want to gain more agency, since they feel insecure or vulnerable because they lack control over the dressing change procedure.<sup>66</sup> To name a specific degree of freedom, choosing the right dressing together seems possible, since “practitioners also had the freedom to use the product of choice all (61%) or most (36%) of the time”,<sup>65</sup> but often HCPs do not have enough knowledge about properties and availability of products.<sup>65</sup> If this is not the case, it is difficult to involve the patient in a decision as the HCPs cannot advise or guide him or her.

Still, implementing DOF in nursing—and daily clinical practice—will not occur without facing a number

of obstacles that need to be overcome. First, nursing care only has a limited amount of time that can be dedicated to each patient (especially with outpatient care). Hence, it can be difficult to include time-consuming new aspects such as a patient’s special wishes (e.g., “wait a moment”) or giving comprehensive instructions (e.g., concerning debridement).<sup>64</sup> In addition, it might be challenging to implement a role switch from a passive to active patient as each patient’s individual wishes (e.g., take more responsibility vs. pass over responsibility) has to be taken into account. To achieve this, informative and supportive communication between patients and the medical staff is a prerequisite to enable patients to actively partake in the treatment course.<sup>4</sup> On the other hand, when patients see other nurses who might not support active participation, relinquishing formerly acquired control might result in heightened distress in patients.<sup>61,64</sup> To this regard, HCPs might be reluctant to allow DOF at all.<sup>23</sup>

Furthermore, only patients desiring greater control might benefit from greater choice,<sup>37</sup> and patients with action-oriented coping might benefit more from self-mediated debridement than patients with a passive coping style.<sup>61</sup> Therefore, coping styles have to be taken into account, too. For example, patients coping especially via information seeking should benefit from primary control such as the freedom to execute treatment steps or patient-controlled analgesia,<sup>64</sup> whereas for patients with an avoidant coping style, secondary control (e.g., relaxation and distraction) should be more suited. In addition, confrontational coping styles include, in fact, more controlling and extroverted behaviors, but they are also more competitive (e.g., they likely challenge professional advice more often) and related to non-healing,<sup>67</sup> which is why increasing control should also be implemented reasonably and in accordance with HCPs.

The following challenges are to be translated into action: First, nursing care has to learn about the beneficial effects of DOF, such as handing over responsibility to the patients, or handing over concrete tasks to patients, which should result in a relief in daily (clinical) practice for the HCPs. Second, HCPs should guide patients to gain increasing autonomy in the treatment of their own wound; to be precise, patients should be motivated to abandon their passive role and adopt their new active role in the wound treatment process. Potential problems that have to be overcome might also emerge from the fact that HCPs and patients will increasingly be cooperating at an eye-to-eye level. The HCPs might feel threatened by the increasing competency of the patients or be unable to promote such autonomy on the patient’s side.

## 4.2. Research outlook

As becomes evident from our analysis of the current literature, not all relevant aspects of empowerment are recognized and researched equally. Both systematic literature searches concerning components of patient empowerment and DOF in wound care are indicative of a gap in research and clinical practice relating to crucial elements of empowerment: patients' genuine sense of empowerment emerging from the possibility to shape and control wound care at a local level and the patient reclaiming the role of the agent in the treatment course. Thus, research about prerequisites and effects of DOF seems timely and promising. Moreover, it would be fruitful to elucidate the subjective side of empowerment and identify which practices lead to a perception of control and agency.

In principle, any kind of wound care procedure that is open to modification could be a suitable object of investigation: patients executing wound care tasks on their own, directing HCPs, changing the social and physical environment, becoming an expert in wound care by being informed about wound care practices, or receiving emotional support by asking for comfort, and so forth. Research could examine the effects of such behaviors on (a) perceptions of control and agency, (b) the HCP–patient relationship, and (c) wound healing. Different settings could be considered, and different methods could be applied: experiments to identify the isolated effect of patients performing the dressing change on wound healing, qualitative interviews to illuminate satisfaction and subjective experiences of control, or long-term studies using Likert-type scales looking at the effects of having choices (e.g., choosing between different bandages or change the sequence of treatment steps, where possible) on HCP–patient relationships.

## 5. Conclusion

This article suggests that empowerment can be a crucial aspect of improving everyday life of patients with chronic wounds. Research in other medical domains has demonstrated that increasing power, control, and freedom of choice on the patients' side can result in

better clinical outcomes.<sup>26</sup> However, this article has shown that a core aspect of empowerment, that is agentive control over the wound treatment at a local level, is largely missing in wound care research and presumably in clinical practice. These DOF in the treatment of chronic wounds, which we consider a central prerequisite to genuine empowerment, need to be researched in more detail in the future (see research proposal) to clarify the promising effects on wound healing and patients' well-being. It also remains open to discuss the role of individual patient needs. In addition, such research could elucidate another neglected aspect of empowerment, which is the subjective experience of feeling empowered and its effects. Taken together, we think that investigating DOF is a reasonable approach, as with DOF, patients reclaim agency of the wound treatment in everyday life and shape the treatment according to their subjective wishes at a local level. This way, a genuine sense of empowerment can emerge, which, in turn, can be investigated and further researched in terms of consequences.

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## Conflicts of interest

All contributing authors declare no conflicts of interest.

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