

Illness, Normality, and Self-management:

Diabetic Foot Ulcers and the Logic of Choice

Abstract

The accounts of three individuals with diabetes, and their experiences with diabetic foot ulcers, are presented in this article. We discuss how the issues of illness, normality, and self-management appeared to each of the affected individuals. Our aim is to show how the perception of diabetes as a disease that can be relatively easily controlled, has consequences for the diagnosis and treatment of foot ulcers. The analysis was partly inspired by anthropological studies of diabetes patients that revealed a discourse of normality in the sense that treatment allows the individual to live a life not necessarily associated with illness. The analysis was also based on the Dutch philosopher and social scientist Annemarie Mol's concepts of the logic of choice and the logic of care that question whether it is appropriate to assign more responsibility to the individual for his or her own illness.

INTRODUCTION

Foot ulcers occur most frequently among patients with type 2 diabetes. The risk of ulcer development increases as the number of years with diabetes increases¹. Diabetic foot ulcers occur primarily among the elderly population. Men have a higher prevalence of foot ulcers compared with women. Overall, it is characteristic for people suffering from diabetic foot ulcers to have reduced physical, emotional, and social functioning¹⁻³. International studies reveal that social isolation, poor education, and low social and economic status increases the vulnerability of these patients and restricts access to care⁴. Diabetic foot ulcers have consequences for the individual patient and his family in the form of long-term morbidity and disability¹. The ulcers cause physical discomfort

and reduce mobility and, ultimately, reduced quality of life and loss of self-esteem^{5,6}. There are strong humanitarian and socio-economic reasons to implement more effective prevention and treatment strategies for diabetic foot ulcers.

In general, qualitative diabetes research has received more attention in recent years, but research on sequelae (e.g. diabetic foot ulcers) is sparse; several researchers have indicated the need for more studies within this field^{7,8}. However, it is well-documented that the lack of knowledge about patients' perceptions of illness in general and more specifically of foot ulcers causes treatment delays and increases the long-term risk of ulceration and amputation⁴. Authors often present these problems as a result of the patients' lack of ability and willingness to comply with health care providers' instructions⁹. Qualitative studies identify a complex interaction of factors; differences in illness perception, communication, and responsibilities between patients and health care providers have key roles¹⁰⁻¹².

The aim of this study was to reveal how the perception of diabetes as a disease that can be relatively easily controlled, and therefore allows the person with diabetes to live a nearly normal life, has consequences for the diagnosis and treatment of foot ulcers. We address this issue in a Danish context using three patient narratives. The three illness narratives illustrate the patients' different strategies for assuming responsibility for their own health. They also reveal how the choices taken by individuals are often systematically inappropriate

Signe Lindgård Andersen¹Maja Pedersen¹Vibeke Steffen²

¹Clinical Research Centre
Amager and Hvidovre
Hospital
Kettegaard Allé 30
2650 Hvidovre
Denmark

²Institute of Anthropology
University of Copenhagen
Øster Farimagsgade 5,
Building 9
1353 Copenhagen
Denmark

Correspondence:
signe.lindgaard.andersen@
regionh.dk

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and misguided, and in conflict with the medical diagnosis and treatment of foot ulcers.

METHODS

Our study was based on data collected during a Health Technology Assessment (HTA) initiated by the Danish National Board of Health in 2011³. The HTA included a part on patients' perspectives that examined how people with diabetes perceived the disease and its symptoms in relation to foot ulcers. The study included a systematic literature review (see note 3) and was supplemented with 16 patient interviews. These interviews deserved a more thorough analysis than that provided by the HTA report; our analysis examined these interviews in more detail.

The HTA board-affiliated physicians and wound care nurses assisted in recruitment of study participants. The qualitative interviews were conducted in hospital wards and in the meeting and teaching rooms at hospitals and clinics in three regions of Denmark. The interviews followed a semi-structured interview guide and were typically 1 to 2 hours in length. Cognitive impairment and mental instability were primary reasons for exclusion. The participants were ten men and six women (age range, 37–79 years). Some of the participants had foot ulcers for a few months; others had contended with foot ulcers for many years. Several patients had undergone amputation surgery. The patients also had other diabetes complications (e.g. eye disease, kidney failure).

The three case studies of the key participants analysed in this paper were selected from the group of 16 interviewees across gender, age, and social status. We chose these participants because they highlighted the challenges people with diabetic foot ulcers encounter when selecting the correct choices and finding the correct balance between normality, freedom of choice, and self-management.

Before each interview, each participant was given information about its purpose and was reminded that his or her responses were voluntary and anonymous. A physician provided information about the study to each participant and verbal consent was given to the researcher before the interview began. The participants could withdraw from the study at any time.

ANALYSIS

“Normal” with diabetes

The conversations with the diabetic foot ulcer patients revealed a conspicuous lack of disease perception among the group. A number of significant contributions to medical anthropology have demonstrated the perception of illness as a gateway to understanding disease management^{13,14}. However, this approach seemed inadequate for patients

with diabetic foot ulcers. They often insisted on living, and strived to live, as normally as possible despite serious foot ulcers. The published literature's emphasis on “compliance” as a key factor in the treatment of foot ulcers also seemed inadequate.

There is a long tradition of studying the variation in the interpretation of disease over time and across societies and cultures within the anthropology of health¹⁵. Perceptions of illness in different clinical contexts, and in relationship to different diagnoses, have been analysed^{13,16}. The perceptions and expectations of health and disease have key roles in prevention and treatment. However, when examining perceptions of illness among people with diabetes, the most significant finding is the very strong emphasis on normality.

The Danish anthropologist Regnar Kristensen has shown how the Danish Diabetes Association's language changed around 1980. Instead of having diabetes, affected individuals were referred to as being a person with diabetes¹⁷. This change also affected perception (i.e. from being diabetic patients to being diabetics). The change in language reflected a change in health educational efforts. The emphasis shifted from considering diabetes as only a metabolic dysfunction, to including the physical and mental being of the whole person. The diagnosis was thus expanded to an identity in which the disease aspects and patient roles were reduced in scale in favour of a health discourse that identified the diabetic as a responsible manager of his own health. As a result, the patient (and significant others) can be inclined to conclude that if a diabetic complies with the requirements of the triune treatment (i.e. insulin, diet, and exercise), it is paradoxically now considered “not normal” to be ill as a diabetic¹⁷.

The Norwegian anthropologist, Per Kristian Hilden¹⁸, has emphasised that technological and organisational developments in diabetes treatment are key factors contributing to normalisation of the disease. He shows how patient education and biomedical regulations for people with diabetes have an almost exaggerated focus on normality that tends to reduce the effects of the disease on the cultural and social understanding of the self¹⁸. Diabetes treatment mostly emphasises self-management and the diabetic's ability to self-care. A crucial component of self-management is the claim that the knowledge, technology, and practical aspects of treatment available to people with diabetes make it possible to control, and reduce the severity of, the disease. In particular, technological development of treatments incorporating blood glucose testing (e.g. HbA1c tests) simplifies the meaning of to “be in control of the life with diabetes”.

The consequence of the increased focus on normality

via instrumental regulation and self-management is that successful treatment increasingly becomes the patient's responsibility. The social scientist and philosopher, Annemarie Mol, describes two fundamentally different ways of viewing and managing the relationship between the patient and the health care system¹⁹; the two views are "the logic of choice" and "the logic of care", respectively. "The logic of choice" includes the idea and the ideal of free personal choice. Since the 1970s, personal choice has assumed an increasingly important role in the health care system. For example, emphasis on patients' rights and informed consent is a counterweight to the paternalism that characterised the relationship between the patient and the health care system¹⁹. Introduction of the "logic of choice" results in radical changes; the physician increasingly assumes the role of manager and provider of solutions and the patient is redefined as the consumer of these services, writes Mol. Considering this general trend in the health care system allows understanding of the increased focus on self-management, freedom of choice, and personal responsibility in diabetes care and the efforts to live a normal life. Mol proposes "the logic of care" as an alternative to "the logic of choice". "The logic of care" is a pragmatic approach to therapy that focuses on how to live with the disease. The question becomes not who is responsible, but what must be done. The development of the disease over time does not occur in a linear sequence. It involves a tortuous path with unexpected twists and turns, so there is no direct correlation between personal choice and health condition¹⁹. Patients act as individuals who make choices and as individuals who are part of a network of countless other activities and assessments beyond the clinical context of the disease. The patient and the health care providers contribute with solutions to, and act in relationship to, the problems, changes, and unforeseen events that occur in a life with diabetes¹⁹.

Case 1: "Normally, I don't have foot ulcers"

The study participant, Jytte, was 62 years of age. She was diagnosed with type 2 diabetes 17 years previously. The interview revealed a very committed, independent, and active woman with an academic background. In many ways, she had lived her life unaffected by her diabetes until 1 year ago, when she developed a foot ulcer. After a run, Jytte found a blister under her big toe that quickly developed into a wound. She thought it was harmless and over the next three months she tried to encourage healing by changing her footwear and cleaning the lesion. She decided she would not trouble her physician with such a small wound. Eventually, the wound developed a severe infection. Jytte visited the hospital and surgery was performed.

The interview with Jytte revealed her efforts towards normality and her pragmatic approach to disease. She basi-

cally regarded herself as healthy. When asked how the foot ulcers affected her life, she exclaimed, "Normally, I don't have foot ulcers", which indicated that she viewed the foot ulcer as a temporary problem. She distanced herself from this chronic disease. She explained her attitude:

"I want to live as close to normal as possible. I'd rather not be made sick. Sometimes there is also someone out here at the centre (The Diabetes Health Care Centre), who asks why I don't make some more blood glucose tests. And I say it is because it makes me feel medicalised. There are those that measure their blood sugar every day and measure blood pressure constantly. I don't think that is necessary for me. If I did, I would feel sick constantly. I don't think I am."

Generally, technological management of diabetes plays a major role in a patient's health beliefs and lack of experience with illness. A person with a well-regulated and uncomplicated diabetes does not feel the presence of the disease; it remains an abstraction (i.e. Witttrup's "shadow disease")²⁰. The sense of disease was absent for Jytte. She preferred to talk about her educational background, career choices, and grandchildren, and not her life with diabetes. As Hilden points out, the technological management of diabetes allows the patient to live a normal life – which is what Jytte made a virtue of – and to maintain the freedom to prioritise and choose one's own lifestyle (18). Hilden writes:

"The promotion of self-management serves to link choice to the general understanding of living a normal life. The implication is that diabetes should no longer be considered an impediment to the free choosing of what life to live, which in the cultural context is taken to characterise normal life"¹⁸.

Thus, it is the responsibility of the individual with diabetes to self-manage the illness and to control the extent to which the illness should affect daily life. ►

The positive message about the well-controlled diabetic partly explains why people with diabetes are generally not as concerned about understanding or explaining their illness as people with other chronic diseases such as cancer²¹. There was no clear illness perception in Jytte's responses or in the responses of other study participants. Instead, they often referred to doctors when asked about their condition. Diabetes is a complex disease because several conditions occur simultaneously in the same patient. Many patients act in ways that differ significantly from what is expected by healthcare providers. Jytte felt she could self-manage the wound, so she implemented footwear changes and used foot baths:

“I thought I had to be careful and change to some other shoes, and then I could probably make the wound go away. But you cannot. (...) I simply could not make it heal. Now I have learned that you should not just postpone it and think that you can handle it yourself. Usually you cannot. (...) But you don't like to be any trouble”.

Because she had many years of experience with diabetes and self-management, Jytte concluded that she could handle her own wound. But, by trivialising it as a small impairment, she unintentionally prevented the healing of her foot ulcer. In Jytte's case, the abstract perception of illness and the effort to live life as normally as possible had the serious consequence of development of a severe foot ulcer.

“Homework” and strategic risk assessment

Grøn et al. uses the concept of ‘homework’, which refers to the activities that the health care system instructs chronic disease patients to perform at home for care of their condition²². These multi-faceted tasks require adaptation to, and modification of, family routines and everyday situations²². Homework implies a context of social complexity in which the patient is confronted by a number of ambivalent situations characterised by tension between sociality and treatment considerations²². This tension often results in Campbell et al.'s ‘strategic non-compliance’; the patient deliberately defies the health care provider's instructions in an attempt to achieve a balance between being a patient and live an acceptable life⁷. The concepts of ‘homework’ and ‘strategic non-compliance’ are useful for understanding the circumstances of patients with diabetic foot ulcers. As they attempt to lead normal lives, they are confronted

with dilemmas that they try to solve pragmatically and based on their personal experiences.

In general, individuals with diabetes have practised active homework for years because the disease is managed through daily blood glucose measurements, insulin injections, and regulation of diet. The life of patients with diabetic foot ulcers however is characterised by great physical discomfort, which includes long periods of time not walking or putting weight on the foot so that the ulcer can heal. The patient's homework is then paradoxically reformulated into a passive waiting. This quest to behave perfectly at rest is an almost impossible task, which prevents the patient from accomplishing normal social roles. This results in a reduced quality of life (e.g. physically, socially, emotionally, and economically) in all aspects of being for the patients and their relatives²³. Their homework must be adapted to a reality in which they are aware that agency is likely to worsen the wound, while passive waiting reduces their social contacts and participation in society. Preben's responses illustrate this dilemma.

Compared with the other participants, Preben was a relatively more experienced diabetic foot ulcer patient. He had recently completed his first period of hospitalisation for foot ulcer treatment. After treatment at the hospital, patients like Preben often find themselves in a contradictory situation at home. Previous experience with life as an active diabetic corresponds poorly with the treatment requirements of passive waiting; the requirements of wound healing often lose ground for normality. Case 2: “I have a son and he gets no food then”

Preben was 53 years of age. He was a trained chef who lived alone with his son. He chose to stay for the weekend at the hotel that was affiliated with the hospital. Preben was characteristically easy-going; he loved to use his high spirits and good cooking to please others. Preben had many years of experience managing type 2 diabetes, while the foot ulcer first appeared less than 6 months ago. His district nurse discovered the ulcer and immediately referred him to the hospital. Shortly after hospitalisation, he underwent surgery and had a challenging recovery period because he was instructed not to walk or lean on his foot. He stayed at home for a short period, but it was difficult for him to comply with the instructions. He expressed frustration that he would not be able to purchase groceries and cook for his son. He was unable to cope with the circumstances at home, so he returned to the hospital because he felt safer and more cared for in that environment. The wound was in remission at the time of the interview, but Preben was concerned about how he would cope after he was discharged from the hospital.

Like Jytte, Preben lacked a concrete sense of the serious nature of foot ulcers. He referred to the condition as a “luxury problem” that he should not complain about. This perception affected his approach to the management of the ulcer at home. In that environment, he had to confront his inability to prepare food for his son if he complied with the health care providers’ recommendations to avoid walking. The patient’s strategic risk assessment emerges especially in relationship to reliance on other people for assistance with everyday practical tasks and personal care. The patient experiences humiliation when compelled to request help. To maintain autonomy and dignity in social relationships many patients chose mobility instead of ulcer healing²⁴. Preben commented:

“I had no wheelchair. I had a pair of crutches, and then I had to make some food and ... (shrugs) ... I have a son, and he will not get any food then. (...) Then you want to use the toilet. Ah, it doesn’t matter if I just stomp on my toes, I thought. And then it goes wrong, of course. You want to be independent, you know, and I prefer to do things by myself. I will not ask for help, though I have to. I get home care now. But to stop me from cooking, that, I will not do. I will cook no matter how old I get”.

Preben experienced the consequences of long-term treatments and learned from his negative experiences. Eventually, he understood the importance and the need to accept assistance from others. Later in the interview, he said, “Now I don’t bother anymore.” However, he was still affected by the dilemma of managing self-care and continuing to cook even though the activity would have negative effects on ulcer healing.

Preben might have understood the seriousness of his condition and the consequences of walking on the ulcerated foot. In practice, however, the patient confronts other stand-alone and competing issues, so other solutions are selected to achieve a balance between a desirable life and ulcer healing. The article on homework²² indicated that consideration of social relationships is often included in the circumstances during which the patient acts inappropriately. In particular, fear of social isolation and of being a burden to others combined with the effort to maintain a normal everyday life causes the patient with diabetic foot ulcers to act inappropriately in relation to ulcer healing. For Preben, it was the utmost pleasure of cooking for his son. For other patients, assuming responsibility for their personal hygiene may provide a minimal sense of personal empowerment and autonomy. Passive waiting as homework complicates the patient’s role and the efforts to be a “good patient”. Diabetes treatment generally encourages self-management based on the principles of

freedom and normality. It thus defines the independent and active patient as the good patient. However, foot ulcer treatment requires the opposite response of passivity and relinquishment of normality.

It is difficult to navigate in the gap between the hospital and the home environments. The interviews with Preben suggested that he was concerned about returning home and reassuming responsibility for self-care. He chose to remain at the patient hotel for a week although from a therapeutic perspective he was ready to go home. Preben is a good example of how the transition from the hospital’s safe environment to the challenging situation at home mirrors a shift from the logic of care to the logic of freedom. In the hospital context, he understood that he could receive support for his personal care and that he would be cared for without having to manage the foot ulcers. As he said: “Out here (at the hospital) I am carried on my hands and feet. It’s great”. Preben and the other patients experienced the health care system as primarily a caring environment. Problems arise when the logic of care is limited to the hospital context, and personal responsibility for the illness is returned to the patient at the time of discharge from the hospital.

Personal responsibility, guilt, and the logic of choice

In the previous sections, we illustrated how patients experience physical and practical burdens in relation to the development of foot ulcers. The psychological consequences (e.g. guilt and self-blame) that often accompany strategic non-compliance can be a heavy burden for patients with diabetic foot ulcers. As previously discussed, the linguistic shift from having diabetes to being a diabetic has expanded the concept of diabetes from referring to a metabolic dysfunction to including the patient’s personal identity. Kristensen problematises this change and suggests that people with diabetes are more vulnerable because their entire identity becomes threatened by the disease¹⁷. When the diabetes patient did not comply with the treatment requirements, he ‘sinned’ against the doctor and against the object of the doctor’s interest (i.e. the body). But, as the emphasis shifted to self-management the responsibility for, and control of, treatment was partly transferred to the patient¹⁷. The diabetic now sins against himself. Emotions such as guilt, anger, and frustration are now directed towards the self. The less successful diabetic may now confront the burden of both illness and failure as a person, and this change in sense of responsibility has caused more people with diabetes to experience psychological problems¹⁷. In Hilden’s view, the emphasis on self-management and personal responsibility becomes problematic with the appearance of complications:



“I would like to argue that, to the extent that one attempts to attribute the long-term complications from which one suffers to type 1 diabetes, the logic of self-management ‘backfires’. This logic effectively attributes long-term complications, not to diabetes mellitus as such, but to its management and, hence, to the person in charge of that management”¹⁸.

The responsibility for the development of sequelae is placed on the person with diabetes; several of the patients with foot ulcers blamed themselves for their current circumstances. This is illustrated by the responses of the participant, Mathias, who had struggled with diabetic foot ulcers for years.

Case 3: “If only I had listened properly”

Mathias was 37 years of age at the time of the interview. He used to work as a slaughterhouse worker, when he was diagnosed with diabetes in 1992. His first foot ulcer developed 5 years before the interview. When the foot ulcer first appeared, Mathias was preoccupied with earning an income. Despite warnings from others, he ignored what appeared to be a minor scratch. The diabetes education provided by the hospital had informed him about possible sequelae. However, because the ulcer was not painful he did not visit a physician until he detected an odour. His response was too late, and the fourth and fifth toes and part of the foot were amputated. During the year following surgery, he was readmitted to the hospital many times for problems related to the healing process, for new emerging ulcers, and for surgery. The disease gradually affected all aspects of his life. He took early retirement, gave up playing football, lost his friends, and felt physically, socially, and psychologically crippled. Frustration, depression, and self-blame emerged concurrently with the lack of progress during healing. Severely depressed, Mathias attempted suicide a year before our interview. The poor healing response and need for amputation forced Mathias to understand the severity of his foot ulcers and triggered guilt, anger, and depression. These emotional responses were supported by the rhetoric that emphasised personal responsibility; Mathias developed low self-esteem. During the interview he repeatedly commented that his present condition might have been avoided if he had listened to the doctors’ advice, “If only I had listened properly, it might never have happened. Then you blame yourself”.

Annemarie Mol explains that “the logic of choice” goes along with guilt and self-blame. When one makes a personal choice, one is also responsible for the consequences of that choice; there is only one to blame for negative outcomes¹⁹. A patient’s sense of logic informs him that the circumstances that emerge after a choice has been taken must be the consequences of that choice. Although individuals recognise that they constitute a large part of everyday experiences, coincidence and unforeseen incidents are not part of this framework. The logic of choice has a chronological time line that moves from information (neutral) to selection (value-laden), then to action (technical) and evaluation¹⁹. The following statement indicated that Mathias assessed his current condition as a direct consequence of the choices he selected: “It all goes back to the fact that I was too stubborn and stupid when I got the foot ulcer. So it all goes back to the foot ulcer”. This view retrospectively reduces the complex interactions between daily incidents and events to a single determinant and to individual choice between well-defined options. The consequence of placing the emphasis on personal responsibility and apparently free choice rather than on caring and professional advice is that the disease becomes a psychological burden for patients.

Mol argues for the logic of care as an alternative to the logic of choice. The logic of choice attributes the responsibility for illness to lack of control and to poor choices. Within the logic of care framework, illness is viewed as basically uncontrollable and unpredictable. Mol writes that in spite of what we would like to believe, the disease cannot be controlled¹⁹. From the logic of care perspective, Mathias’ choice to continue working despite the presence of serious foot ulcers was only one choice among other choices and actions that could not be ascribed unambiguous consequences, including that he was now confined to a wheelchair and received state-funded social security payments. This process is interactive; the need to choose, claim responsibility, and assume guilt constantly shifts positions. This process is referred to as “shared doctoring” by Mol. Unlike the discourse of normality in diabetes treatment, life with diabetes cannot be subjected to a higher level of control¹⁹. By contrast, she describes life with diabetes as a life of continuous adaptation.

The logic of care represents a more pragmatic approach to disease and treatment. Compared with the discourse of choice, the logic of care is more harmonious with most of the experiences of patients with diabetic foot ulcers. Analysis of the experiences of Jytte, Preben, and Mathias revealed that life with diabetic foot ulcers includes tension between illness, normality, and self-management. Managing life with diabetes is much more complex than making correct

and informed choices. The conflicting demands between social responsibility and an active life versus ideal wound care and passive waiting result in a difficult balancing act between different considerations rather than a straight forward road with rational choices and correct solutions.

CONCLUSION

Analysis of these three empirical cases revealed a group of patients negatively affected by a discourse of normality, self-management, and the logic of choice. Patients with diabetic foot ulcers experience sudden changes. They move from normality to illness, from care during hospitalisation to self-management at home, and from the role of the active diabetic to the passive patient with diabetic foot ulcers. These changes make them particularly vulnerable and expose them to negative consequences that are greater than those attributable to the disease itself.

Synthesis of the normality discourse within diabetes treatment with Annemarie Mol's concepts of the logic of choice and the logic of care in the treatment of diabetic foot ulcers clarifies understanding of the contradictory situations that patients experience. Both the resourceful and active patients and the disadvantaged and passive patients behave inappropriately when they attempt to select the correct choices during management of their health problems. Paradoxically, total passivity is often the main requirement for the patient with diabetic foot ulcers. Close collaboration between the clinical reality and the patient's everyday life, and the correct balance between logic of care and logic of choice are crucial for a successful treatment outcome.

Clinical recommendations

Based on the findings of this study, we propose some recommendations for clinical practice. First, it is important that the clinician understands important aspects of the patient's everyday life (e.g. social and work commitments). Lack of this information may challenge the patient's ability to follow treatment instructions for care of the foot ulcer. Second, the clinician should emphasise to the patient that compared with a normal ulcer, a diabetic foot ulcer has different characteristics and is a much more severe lesion. Finally, the patient must be reminded that his new circumstances require total passivity and that this requirement conflicts with the general recommendations about exercise and activity that are given during the treatment of diabetes.

NOTES

1. This manuscript is a revised and translated version of an original article published in the Danish peer-reviewed journal: *Tidsskrift for Sygdom og Samfund* in 2013, volume 19, pp. 121-140. In 2013, the paper was reprinted in the Danish magazine, *Sår*. The journal and the magazine have been informed about, and have agreed to, publication of the edited reprint of the article.
2. The patient survey included in the Health Technology Assessment on diabetic foot ulcers was conducted by the author. Parts of it have been published in the National Board of Health Report (2011). We thank the Danish Board of Health and the entire project team for their cooperation. We especially thank Niels Ejlskjær for encouragement and for assisting us with contact with the patients. We also thank the patients who kindly participated in the interviews.
3. A literature search of seven databases (Medline, Embase, CINAHL, Psych Info, and International Biography of Social Science (IBSS)) was performed. The search terms were: diabetic foot ulcer, diabetes and patient experience, diabetes and adherence, diabetes and patient care, diabetes and anthropology. We also performed a general literature search on people with diabetes and their experiences with diabetes and foot ulcers in REX (The Royal Library) and in the Literature Database (DSI library). Thirty out of the 130 studies that the search revealed were included in the patient perspectives section of this report.

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