Nurses' experiences of conflicting encounters in diabetes care

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Abstract

Aim: To describe nurses' experiences of encounters with patients in diabetes care.
Methods: Focus-group interviews with 17 nurses about their experiences of caring for patients with diabetes. Interviews were analysed by qualitative content analysis.
Results: Four themes described conflicts in their encounters with patients, disclosing a complex professional role as a diabetes nurse. Implementing guidelines at the same time as being patient-centred was found to be problematic. Nurses further viewed medical knowledge as being more important than life experience of diabetes. The nurses' comments were distanced from, and judgemental about, patients as a collective. Finally, the nurses felt comfortable in expert roles, but not in equal and mutual relationships with patients.
Conclusion: The interviews identified a feeling of frustration over conflicting demands between different goals and ideologies for diabetes care. These conflicts may also arise from the difficulty of integrating medical goals and patients' life experiences of illness.

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Key Words

Diabetes nurses; patient education; encounters; conflicts; empowerment; patient-centred approach

Introduction

According to current consensus publications, short-term goals for diabetes care are to avoid hypoglycaemia and to normalise glycosylated haemoglobin (HbA_{1c}), blood lipid levels, blood pressure and body weight, while at the same time promoting patient wellbeing.[1,2] Patient education in self-care is central to diabetes care and a prerequisite for reaching the stated goals. Nurses who care for patients with diabetes are expected to take on an important role in such work, with the aim of supporting patients as they acquire knowledge and confidence. A goal for empowerment in diabetes care has been described as an approach to facilitate self-directed behaviour change among patients, so that they gain mastery over their diabetes.[3] However, educational interventions have only a modest improvement in glycaemic control.[4]

Healthcare professionals, in general, subscribe to the medical view that diabetes is a pathophysiological state, whereas patients experience illness from a life-world perspective.[5] An awareness of the differences between patients' and healthcare professionals' perspectives on health and illness has influenced strategies in patient education and healthcare towards those with a more patient-centred approach. Lewin *et al*,[6] in their review of successful patient-centred approaches, concluded that these improved provider and patient satisfaction. When studying patient-centredness, Little *et al*[7] found that patients graded satisfying communication as most important, followed by partnership and health promotion. The outcome of patient encounters further depends on factors such as time for consultations,[8] counselling skills[9] and attitudes towards patients.[10] Some studies have highlighted healthcare professionals' negative attitudes towards their patients, which have a negative impact on quality of communication and on the outcome of educational efforts.[11,12]

Given the importance of nurses' key tasks in diabetes care compared with poor outcome from traditional patient-education approaches, we sought to highlight the complex professional role followed by Swedish nurses who care for and educate patients with diabetes. The aim of this study was to describe nurses' experiences of encounters with patients in diabetes care.

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Materials and methods

Sampling and participants

Seventeen female nurses (age range 25–54 [mean=41] years) who were starting a university course in diabetes care were asked to participate in focus group interviews about their experiences of caring for patients with diabetes. The participants were mainly working as district nurses in primary health or community care of the elderly, and were caring for patients with diabetes, mostly with type 2 diabetes. One participant was a midwife in primary healthcare and three worked at hospital diabetes units. The nurses had cared for patients with diabetes for between 2 and 20 years (mean=7.1 years). At the time of the study, 10–50% of their work time was devoted to patients with diabetes. Six participants had family members with diabetes.

Data collection

The nurses were divided into two groups and interviewed during the first few days of their university course, before the education programme started. Focus group interviews were conducted according to Kitzinger's principles.[13] In addition to a moderator, an observer participated in the interviews and was responsible for tape-recording, listening, and returning to questions that she considered had not received enough focus. This interviewing style permits group members to open up and reflect on various perspectives and is intended to encourage group thinking, as well as the consideration of individual viewpoints. During the interviews, nurses were invited to share their experiences and to reflect on others' and their own experiences. An interview guide addressed topics related to their daily work and primarily their own encounters with diabetes patients, including obstacles and opportunities. Examples of questions asked were: 'Can you tell us about your experiences of caring for patients with diabetes?'; 'What in your opinion is sufficient self-care?'; 'Can you describe an ordinary encounter with a patient?'; and 'Can you describe when an encounter goes wrong?'

Ethics

The study was approved by the Ethics Committee of the Medical-Odontological Faculty of the University of Umeå, Umeå, Sweden (§375/00, No. 00-323).

Analysis

Each interview lasted about 90 minutes. Interviews were tape-recorded and transcribed verbatim. Pauses, sighs, laughs and emphasis were marked in the text, and used to interpret and further understand the meaning of feelings, nuances and ironies that were conveyed during the interviews. The text was analysed using qualitative content analysis,[14] in which both manifest content (i.e. literal content) and latent content (i.e. underlying message) are highlighted. Firstly, the text was read through to obtain a sense of the text as a whole. Then the interviews were sorted according to different areas of questioning. Next, meaning units were identified and condensed, to shorten the text but retain its core messages. Condensed meaning units were then abstracted and coded, taking into consideration the contextual meaning of the original text. Codes were compared on the basis of similarities and differences, and sorted into schemes labelled as categories and subcategories (not shown), which constituted the manifest content. To ensure agreement between researchers, the categories were further studied and discussed, which led to refinements. Four abstracted themes, interpreted as underlying or latent messages, were then identified as being common to all categories.

Results

When text transcribed from the focus group interviews was interpreted, four themes were identified that describe conflicting situations in nurse-patient encounters in diabetes care. These themes were:

- Implementing guidelines or being patient-centred
- Relying on medical knowledge or knowledge deriving from patients' lived experience of illness
- Being distanced and judging or close and empathic
- Being comfortable in an expert role or uncomfortably equal.

The themes disclosed a complex professional role filled with conflicts. In the following, quotations are given as examples of themes from the original texts.

Implementing guidelines or being patient-centred

When the nurses spoke about using guidelines and medical goals, they did not include stories about patients' experiences and personal goals. Instead, they emphasised the benefits of using the guidelines in diabetes care. When the nurses talked about the guidelines and the medical goals for diabetes care, they talked about diabetes as a disease and a pathological state. In this view, blood sugar limits were seen as definitive, and something patients had to comply with and follow. When, from questions, the nurses were confronted with the various patient and professional perspectives on illness, they put confidence in the medical perspective of diabetes in favour of patient-centredness:

A lot of time is spent talking about blood sugar, especially if it is high or low …which results in a focus on blood sugar, and the importance of it…We have been taught to regard blood sugar as very important and therefore have our focus in nursing there…Viewing the patient as a whole is also important in care, but the blood sugar is most important in diabetes.

However, when they talked about the unique experiences and needs of patients, the nurses had problems justifying a principal focus on blood sugar limits when those competed with patient wellbeing. Instead, the nurses referred to the goals for caring and expressed more empathy. This perspective was particularly prominent when nurses described specific situations in which they made choices that were influenced by ethical considerations; in other words, the goals for treatment conflicted with their patients' emotionally expressed priorities and personal values:

When I meet a patient face to face [struggling], I set my own limits…and in home care, I mainly consider that they should live as well as possible and have [some] quality of life. I know from myself that it is not easy to change one's lifestyle and eating behaviour, and it won't get easier as you get older.

When the nurses, from our questions, imagined how it would be to live with diabetes, the conflicts between medical goals and caring became obvious for them:

You can easily influence the disease progression and your future…but you have to live with it and think about it in daily life. Every day, every time you eat you have to decide whether you can eat this and that…for many people, it is very hard.

This conflict also became obvious when they spoke about deviating from the guidelines and recommended blood sugar limits, since it caused them moral doubts:

Sometimes, but not often, when a patient is struggling a lot, it happens that I give advice to a patient not to be so dutiful and precise, and I thereby imply that self-management is not that important, and…I get quite a bad conscience from this sort of thing and try to avoid it, as it is against the guidelines.

Relying on medical knowledge or lived experience

Medical knowledge about diabetes treatment was viewed as being more important than patients' knowledge derived from individual experiences of having a disease. The nurses viewed their priorities and preferences – not only medical knowledge – as being more important than the patients' preferences. When they talked about adequate knowledge, they referred to medical knowledge, thereby minimising the value of the patients' experiences. In the interviews, it emerged how the nurses used their 'more adequate' knowledge about treatment goals and appropriate blood sugar levels in patient education, since they considered that patients often had limited knowledge about appropriate self-care. The nurses regarded appropriate self-care as very important and said they would become frustrated if, due to inadequate knowledge, the patients did not value self-care recommendations:

It disturbs me when some patients say they would prefer to live a few years less if they could be spared the trouble with blood tests and insulin injections, since they don't know what is best for them.

The conflict between medical knowledge and lived experience sometimes spoiled the consultations. The nurses' ideas and experiences of patient education were that it should follow a stepwise predetermined plan, while many patients either did not want any medical information or wanted to know everything immediately:

At the first meeting, I want to inform the patient somewhat, but a lot of patients are one step ahead…and are really treading on my toes. They want to learn about self-tests and want to prick their fingers and, at that moment, I feel that the discussion has taken a wrong turn. It is wrong to me…but, on the other hand, they maybe want to do something practical, and don't have enough energy to listen to all the information…it is normal for nurses to feel like this…I mean, [to feel] that the consultation has gone wrong.

However, they acknowledged that they understood why patients sometimes ignored the nurses' health advice and made their own choices instead:

A lot of people can't easily make their own choices, as they lack knowledge and the right experiences…but, on the other hand, they don't ask for everything we want to impart to them and therefore ignore our advice.

Being distanced and judging or close and empathic

The nurses often talked about patients as a group and less often as individuals. They became more distanced and prejudiced when they talked about groups of patients and described them more negatively, with more negative characteristics or in subordination, when they regarded them as a collective group:

Many patients need a lot of advice and pointers if they behave totally wrong, which is common. The only thing we see during their hospital treatment periods is how they stand and eat cookies from the tin or chew on chocolate all day long. Then I, as a medical professional, become very…strict.

Furthermore, when distanced, the nurses often judged patients as problematic and non-compliant, referring to them as 'smokers', 'overweight people', 'liars' and 'patients who do not take responsibility for their self-care':

A lot of patients tell us that they exercise and eat well and are living a perfect life, and wonder why their [blood sugar] values are so high. It's at that moment that our problems become obvious. We can't counter their claim with anything because we know they're not telling us the truth.

Other groups of patients, for example the elderly, children and patients with dementia, were also judged on the basis of a collective view, and thereby were distanced – although more sympathetically – as they may have been considered to be more vulnerable:

There's no use in informing elderly people about complications, since they'll die before they get any.

Conversely, when nurses described close, individual meetings with patients, they often talked about each patient's uniqueness and specific problems, which showed that they also valued patients positively and with empathy, which were interpreted as being close:

I must learn to understand and respect that she hasn't got the same goals as I have…The most important thing for her may be to eat a bun, since she doesn't have much else that'll please her in her situation.

Being comfortable in an expert role or uncomfortably equal

The fourth theme dealt with an ongoing change in the authority and professional role that nurses experienced in relation to autonomous, informed and sometimes healthy patients. This was interpreted as leading to a feeling of insecurity and role ambiguity among the nurses. The analysis revealed how patients who behaved in a subordinate way made nurses comfortable and confirmed them in their professional roles by expressing their need for support and asking for the nurses' expertise. On the other hand, the theme expresses how uncomfortable nurses may feel about not being an expert and not being needed, and how difficult it is to handle patients who feel well:

If they are ill, it's easy to reach them with advice, but if they're well, it's quite a bit more difficult to give concrete proposals that they will comply with or even listen to.

The nurses said that they were more comfortable when they had more knowledge about the disease than the patients. They regarded knowledge as increasing their professional power:

Some patients have even more knowledge than I do and ask questions that I can't answer…I then realise how limited my knowledge is, much less than that of some patients, and this is not the modern situation I want to adapt to …Should I?

The nurses were also somewhat doubtful about an equal and mutual relationship between caregiver and patient (i.e. being in a partnership), which they perceived as being a goal of current educational strategies:

In the '60s and '70s, when I started nursing, it was more precise. Fifteen grams of butter and two potatoes…and now? Suddenly it has become too liberal. My standpoint is that if I meet patients who need exact advice, I have to give them exact advice, as otherwise they most often don't manage the situation.

The nurses experienced a conflict between, on the one hand, viewing patients as equal, autonomous, independent and powerful – trusting their ability – and, on the other, doubts about 'letting them free'. All nurses considered health advice and patient education (i.e. transferring medical knowledge) to be the main focus in diabetes care, to provide patients with the tools to become independent. At the same time they doubted the patients' ability to practise self-management on their own. When we asked them to reflect on the rationale for their decisions to reprove patients, they answered that both their education and the expectations of others (e.g. society and their work organisation) about their professional roles had influenced their standpoints:

Maybe we are good at giving patients and ourselves a guilty conscience through our advice. It's easy to give pointers, but not so easy to refrain from doing it. It's in our genes, I think… District nursing is highly associated with giving concrete advice, very fast and clear advice, and that's the end of it.

Discussion

The four themes identified and described above provide insight into the complex role of the diabetes nurse. The conflicts seem frustrating since the nurses expressed a lot of struggling. We interpret that frustrations could be caused by conflicting ethical demands which are derived from the different goals that characterise diabetes care. This frustration and the conflicts related to diabetes nurses' professional roles need to be highlighted and discussed. If these role conflicts remain unsolved, they may counteract effective patient-centred counselling and empowerment in patient education.

The first and second themes illustrate nurses' priorities about written guidelines and medical advice. The nurses felt forced not to deviate from guidelines, becoming frustrated when medical goals and knowledge conflicted with patients' personal goals. When the divergences were obvious, it seems that the nurses preferred to lean on medical knowledge and guidelines without attaching great importance to patients' personal goals, in order to avoid conflict. They could, for example, give strict advice on goals for blood sugar levels, even if it was obvious that their advice did not suit a patient's lifestyle and therefore was impossible to achieve. A Danish study of interactions between healthcare providers and diabetes patients with poor glycaemic control[15] found patterns in approaches which disempowered the patients in problem solving. The professionals studied viewed life and diabetes as two distinct entities.[15]

Several studies have compared the perspectives of healthcare providers with those of patients with respect to diabetes and their views on aetiology, symptoms, blood sugar, prognosis and therapeutic goals.[16,17] These studies indicate that healthcare professionals in general form part of a 'disease' paradigm, mainly viewing diseases as biochemical and physiological malfunctions, and as deviations from the normal. The varying patient and healthcare personnel perspectives about diabetes have been described by authors such as Loewe and Freeman,[18] who reported that patients are more concerned with visible manifestations of this disease (such as blindness and amputation) than with the invisible manifestations that may concern healthcare professionals to a higher degree. In another study, patients with diabetes emphasised difficulties in the social domain and the impact of the disease on their lives, rather than viewing it as a pathophysiological problem.[19] Hunt *et al*[17] reported that patients evaluate diabetes control in terms of how they feel, whereas practitioners are concerned with measuring blood glucose concentrations: a conclusion that may summarise the problem with divergent perspectives on illness.

Nurses have to make ethical choices and may have difficulties integrating a biomedical view of diabetes with a view of the patient as a person with individual needs. If they give priority to reaching medical goals, they give priority to a biomedical paradigm which has the potential to objectify patients in the process of reaching satisfying measurements.[19] Conversely, if they take a more personal view and fail to convince patients of the benefits of sufficient self-care, patients are at greater risk of developing diabetes-related complications. This dilemma may be the underlying reason for the conflict we found in themes one and two.

The third and fourth themes can be discussed together. Further analysis may have found a connection between expert-judging-distant and close-empathic-equal. Many quotations supported this hypothesis. The nurses defended their standpoint about using 'relevant' medical knowledge in their strict recommendations or pointers as benefiting patients in the longer term, since they expressed that people with high blood sugars do not know what is best for them if they do not change their lifestyles.

The nurses also referred to guidelines and were obviously influenced by 'risk thinking' derived from epidemiology. Epidemiologists are basing their assumptions not on individual patients but on groups, or on distance. The larger the group, the better the assumption. Nurses are working in various paradigms, either having the care of the individual patient or having guidelines – the care of a large population – in the foreground. This difficulty may be one reason for their judgemental views of patients when they somewhat belittled them at a distance. They have learned that smokers, overweight people, and patients who mismanage their self-care are at higher risk of developing complications. Unfortunately, the nurses' efforts to support these patients with strict advice has had limited effects on their diabetes balance, which is discouraging, but instead of questioning their own strategies, the nurses in our study blamed the patients for their lack of success. Lerner[20] suggested that healthcare professionals, when failing to reach goals for effective treatment, often blame the patient for being a 'bad patient' rather than questioning the quality of their care.

Is it problematic for a professional to be expert and equal at the same time? The paper entitled *Myth of empowerment in chronic illness*[21] argued that it is usual for caregivers to call attention to the importance of patient participation and decision making but, at the same time, to act as though they were the ultimate decision makers, themselves. From our interviews, it seems to be difficult to be equal and at the same time experience being significant to the patient. This conflict is interpreted as connected to the nurses' view of their role as being experts and superior. Their uniqueness and significance seem to be related to their medical competence, and their task is to transfer their competence to patients. This is quite a traditional view, and not particularly patient-centred.

The final theme revealed that patients who assume a traditional patient role validate the nurses, which can be considered to reflect hierarchical power relations in diabetes care. When using the term 'traditional patient role', we refer to the role patients assume to adapt to caregivers and their expectations of 'good' or 'well-behaved' patients who accept their illness.[19] 'Ill' patients who accept their disease (and submit to the advice of care providers) are considered to be more motivated and compliant; consequently, nurses are more successful with them. In our interviews, the nurses said they found it problematic to adapt to a more liberal view of patients, and explained how their education had influenced them by shaping their identity as district nurses. Doctors and nurses are both expected to practise a more patient-centred and empowering approach in diabetes care.

Our results show that professionals experience a lot of frustration in encounters with patients who are non-compliant or who question their expert knowledge. They seem not to agree sufficiently about the patient-empowerment approach to make it practicable. The patient-centred approach reduces professional power in favour of patient power, enabling patients to make informed choices that suit their lifestyle and psychosocial situation on the basis of their own motives. It is a new role to grow into, and requires reflection as well as time for carers to be trained in this new way of working.

Conclusion

The interviews identified a feeling of frustration among diabetes nurses over conflicting demands between different goals and ideologies for diabetes care. The conflicts may stem from a role change from being a traditional and authoritarian nurse, who transfers appropriate medical knowledge to patients, to a patient-centred nurse focusing on the patient's personal needs and growth. These conflicts may also arise from the difficulty of integrating medical goals and patients' lived experiences of illness. It is important to remember that the Swedish organisation of diabetes care is not universal. Many Swedish district nurses with responsibility for diabetes care have other patients and tasks, and are not full-time diabetes nurses.

In the information era, the knowledge gap between patients and healthcare professionals has narrowed and society has lowered its level of obedience to authorities; therefore, healthcare professionals' attitudes and roles need to change. Instead of questioning non-compliant patients, it is time to approach the problem from a different angle and ask whether they are non-compliant as a consequence of insufficient care. A recommendation is to include self-reflection and increase education about empowerment philosophy in nurse training programmes. However, changed attitudes and roles must be supported by the organisation and it is possible that compliance with guidelines has been supported far more than patient-centredness, perhaps for economic reasons.

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Conflict of interest statement

None

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