Diabetes specialist nurses' perceptions of their multifaceted role

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Summary

The aim of this study was to explore diabetes specialist nurses' (DSNs') perceptions of their professional role in diabetes care.

Exploratory interviews were used to elicit DSNs' perceptions of their professional role. Twenty-nine DSNs working in 23 primary health care centres in northern Sweden were interviewed in focus groups. Data were analysed using qualitative content analysis.

The DSNs described their profession as encompassing five major roles: 'expert', 'fosterer', 'executive', 'leader', and 'role model'. Challenges interpreted as role ambiguities included feeling uninformed, fragmented, resigned, pressed for time, and self-reproachful.

The profession of DSN was interpreted as multifaceted, with various roles and role ambiguities. Patient-centred care and empowerment, which are recommended in diabetes care, can be difficult to achieve when DSNs experience role ambiguity.

Lack of clarity about role demands and difficulty in reconciling different roles may have a negative impact on DSNs' attitudes in clinical encounters and could inhibit patient-centred care. The development of the DSN profession requires improved awareness of the DSN's professional role in the clinical encounter, not only to improve the care of patients with diabetes, but also to retain these professionals.

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Key words

diabetes specialist nurse; patient-centred care; professional role; role ambiguity

Introduction

The diabetes specialist nurse (DSN) in primary care has an important role in supporting patients in their individual disease management and has a key position in diabetes patient education to strengthen patients' self-management and prevent complications.[1–3] According to the International Diabetes Federation, DSNs are expected to: take a comprehensive view of the patient, promoting a healthy lifestyle and supporting patients' self-management;[3,4] be involved in the management of diabetes health care; support the education of patients, families, and health care professionals;[5,6] and make care plans for the patient with other professionals on the diabetes care team.[7] A large cross-national study[8] found that both physicians' and specialist nurses' support of national prevention goals were quite high; however, this study showed that health professionals in the Scandinavian countries had among the lowest rates in endorsing national goals. Hörnsten *et al.*[9] described Swedish DSNs' encounters with patients in diabetes care as conflicted and characterised by difficulties in integrating medical goals with patients' life experiences.

In Europe, almost all DSNs work in primary or secondary care within community health authorities. The DSN's title differs between countries – e.g. diabetes educator, diabetes specialist nurse, or diabetes nurse – as do DSNs' duties, responsibilities, and weekly caseloads.[2,5,6,10–13] Most Swedish DSNs in primary care pass a postgraduate examination as district nurse and have a formal qualification in diabetes care.[14] Swedish DSNs work mainly in primary care settings run by county councils or communities. In Sweden, most work part-time as DSNs, combining their responsibility for diabetes care with other duties such as providing telephone advice, home care, and clinical nursing. Swedish DSNs also have independent prescribing rights, similar to those of community nurses in the UK, for a limited list of medicines.[15,16]

A recent review[17] of the clinical effect and cost-effectiveness of DSNs in the UK emphasised the importance of DSNs to the future of diabetes care. James *et al.*[17] argued that the role of the DSN is becoming fragmented and more research is needed among community DSNs. Hörnsten *et al.*[9] argued that DSNs need to reflect upon their professional role in the clinical encounter with patients, because different understandings and attitudes influence how DSNs deliver care and what they choose to focus on in their work, e.g. providing information, emotional support, or collaboration.[18]

An increasing number of patients with type 2 diabetes will

strain the current health care system, and improvements in the efficiency and quality of care are required. DSNs may be a resource in this development;[19] however, their role is in a state of change, and they have new responsibilities and an increased need of new knowledge.[20] In order that the DSNs can improve the clinical encounters with patients and, additionally, so that the profession can be developed and strengthened, it is necessary to clarify how the DSNs perceive their professional role.

The aim of this study was to explore DSNs' perceptions of their professional role in diabetes care.

Method

Design and setting

The study used a descriptive exploratory approach based on focus group interviews at 23 primary health care centres in northern Sweden. During data collection, the primary health care centres were responsible for general care in specific geographic catchment areas governed by county councils. The health care centres were staffed by GPs and primary health care nurses, some of whom were DSNs responsible for diabetes clinic care. Nurse aids, social workers and psychologists were also available at most of the health care centres.

Participants

The study included 29 participants (27 women, two men), all registered DSNs, with an average age of 51 years. They had 15–41 years of work experience as nurses and 2–19 years of work experience as DSNs. All except two were also educated as district nurses, and all had further education in diabetes care. The participants, who freely volunteered in focus group interviews, worked at any of the primary health care centres in the county council jurisdiction, and all were informed about the study by letter, by telephone, or in person.

Data collection

Focus group interviews are frequently used in qualitative health research. This interview method is used to collect data regarding people's views and attitudes about specific topics, and to allow participants to clarify their experiences and problems through group discussion.[21]

The participants in our study formed five focus groups of three to eight participants each. The interviews were conducted during 2009. Two members of the research team were present during the sessions and acted as either interviewer or moderator.

Each interview lasted 50–90 minutes (median 67) and was voice-recorded. The interviews were semi-structured and included some main topics about the DSNs' role in diabetes care, perceived expectations, and thoughts about patient-centred care. The initial questions were: 'Please, can you describe your main tasks as a DSN?'; 'Can you describe your own part in diabetes care?'; 'Is there anything significant about being a DSN?'; 'How do you look upon yourself as a DSN?'; and 'What expectations do you think others have of you?' Following these questions, we asked the participants whether they wanted to add anything more. The interviews ended when the participants had nothing more to add. The voice-recorded focus group interviews were transcribed verbatim.

Data analysis

The text was analysed using the qualitative content analysis described by Graneheim and Lundman.[22] Qualitative content analysis is a method for analysing communication in a systematic manner.[23] The analysis is a process of interpretation that focuses on similarities and differences between different parts of the text and results in the organisation of the data into categories or themes.[22]

The analysis was performed in several steps. First, the interviews were read through to gain a sense of the whole. Second, the text was divided into meaning units corresponding to the aim of the study, and the units were condensed with their core meanings retained. Third, the condensed meaning units were coded, compared for similarities and differences, and grouped into sub-themes. Finally, from the sub-themes we interpreted threads of underlying meaning and identified five main themes corresponding to DSNs' professional role in diabetic care. Throughout the analysis, the research group discussed the codes, sub-themes, and themes until agreement about suitable labelling was reached.[22]

Ethical considerations

Confidentiality and de-identified presentations of participants' quotations were assured. The study was approved by the Regional Ethical Review Board in Umeå (Dno 00-323M, Dno 06-126M).

Results

The DSNs' perceptions of their professional role are presented in five themes labelled: 'striving to be an expert', 'striving to be a fosterer', 'striving to be a leader', 'striving to be an executive', and 'striving to be a role model'. Themes and sub-themes are described and presented together with associated challenges. Each theme is an interpretation of the meaning of the DSNs' perceptions of the professional role. Sub-themes in bold text headings express characteristics of the various roles. Significant quotations from the original text illustrate the analysis.

Striving to be an expert

This theme included two subthemes: being the teacher and being the specialist. DSNs emphasised the importance of their skills, but perceived these skills as difficult to achieve. They were not in a position to prioritise their own further education, nor did they have time to improve their skills; hence, they also felt uninformed.

Being the teacher. The DSNs described how they educated patients about their new situation, informing them about the disease, possible complications and test results, while recommending changes in diet and increased exercise. '*We can provide the patients with education about complications, and what they can do. If we can get them to understand, they have an opportunity to influence the course of their disease.*'

The DSNs expressed how important it was that they achieved new knowledge themselves. However, they described often feeling uninformed or insufficiently skilled because they lacked time for continuing education. '… *[you] will never get fully trained, since there's always something new to learn.*'

Being the specialist. The DSNs described themselves as specialists, with the broadest and most important knowledge of diabetes and the ability to apply that knowledge critically using advanced skill sets. They described themselves as decisive, flexible, capable and qualified in their work performance, managing most aspects of diabetes care independently. However, it could be difficult being the specialist when some patients had more knowledge and experience of diabetes than the DSNs themselves. '*The difference from before is that patients have so much more knowledge. They have become some sort of experts on their own.*' The DSNs described being a specialist as including a comprehensive view and seeing the patients as individuals. However, they said that lack of time made it difficult to maintain their grasp of each patient's needs. '*It takes time to see the whole person behind the disease; something we lack…*'

Striving to be a fosterer

This theme included three subthemes: being the counsellor, being the monitor, and being the supervisor. The DSNs emphasised prevention, assessment and decisiveness as important in this role, while acknowledging that it also implied them being doubtful and suspicious of their patients.

Being the counsellor. The DSNs described prevention work and motivational interviews in their work to support patients' self-management. '*If you find and pick up a small grain of gold in them [the patients], then you can motivate and support them.*' The DSNs put great effort into trying to enhance patients' motivation to make lifestyle changes. However, they expressed doubts about patients who did not manage self-care or did not have the will to make lifestyle changes, and said that motivational work was time consuming. '*It demands so much more time when you work more motivationally with the patients … about them taking responsibility around their own diet and exercise…*'

Being the monitor. The DSNs would have liked more control over the patients and their disease progression and more insight into patients' self-care in daily life. '*But sometimes we want to be able to look through the keyhole to see what they have eaten… Sometimes you think: God, if you only could be at their home and see what actually is happening.*' The DSNs sometimes felt the need to be suspicious about what patients told them, since they did not always consider their patients trustworthy. *'It is not always the truth that patients tell us about their food habits … they tell us what they think we want to hear.'*

Being the supervisor. The DSNs sometimes found it appropriate to push patients to achieve treatment goals. It could also be appropriate to reduce pressure on patients who were too hard on themselves, and it was difficult to know whether or when frightening or confronting a patient was justified. '*It is hard to know how to balance threatening and scaring, or how you say it…*' The DSNs expressed their frustration with how difficult it could be to work with patients who were unwilling to make lifestyle changes, and said they sometimes felt resigned to their limited influence on such patients' health. '*Yes, they expect you will make them healthy so they feel good, but I cannot exercise for them or lock their refrigerator.*'

Striving to be a leader

This theme included two subthemes: being the authority and being the coordinator. The DSNs emphasised their major responsibility and capacity to coordinate diabetes care, but they also felt quite alone, subordinated, and sometimes unappreciated by other professions.

Being the authority. The DSNs described how they took responsibility for coordinating diabetes care among their colleagues, physicians and patients. They described themselves as reliable in complicated situations and important decisions. '*If it weren't for us DSNs, there wouldn't be any diabetes care at all. A famous physician in diabetes once said that, after the discovery of insulin, it is the establishment of the DSN that has been most important in diabetes treatment.*' However, the DSNs also felt subordinated to physicians and frustrated by

their mandatory consultation when unexpected problems emerged. On the other hand, DSNs also described often feeling overwhelmed by responsibility, lonely in their work, and pressured by lack of time. Furthermore, they said they lacked support and appreciation from managers and other professionals and felt that their specialised area of diabetes was seen as low priority. *'It is really hard to provide good diabetes care when you also have to manage all the other work stations. We always have to do this in between everything else, when time permits.'*

Being the coordinator. The DSNs described how they organised and planned diabetes care and coordinated care between themselves, physicians and other professionals. They emphasised that they had a shared mission in diabetes care, collaborating with other professionals towards the same goals, but they also described how troublesome it was to work with physicians who did not take responsibility. *'You can understand each other much better if you have exactly the same treatment goals.'* It was a challenge to remain organised without becoming exhausted. Being the one others came to for solutions was perceived as positive but also as tiring. '*Colleagues and others can come and ask about this and that, and I'm supposed to be like a cog in the wheel and solve their problems.*'

Striving to be an executive

This theme included two subthemes: being the bureaucrat and being the administrator. Striving to be executives, DSNs were hands-on nurses doing practical tasks according to current rules, but they also felt ambivalent and fragmented by performing several different tasks.

Being the bureaucrat. The DSNs worked according to policy documents, guidelines and quality registers, e.g. the National Diabetes Register (NDR). They structured annual meetings with patients following the NDR guidelines, such as discussing test results, and said it was a secure way of knowing they were performing the right tasks. '*I start from the NDR point of view, knowing that I'm doing the right thing. It's a sort of checklist and results in such a structured conversation.*' However, changes in the guidelines in diabetes care could make DSNs feel ambivalent and fragmented. Doubts about which guidelines were the most reliable or how to proceed on occasions when guidelines offered no solution to a problem made DSNs uncomfortable and insecure about clinical encounters. '*It is very difficult to give advice about diet today because there are so many new influences and therefore it is not easy to say, "This is the way it should be".'*

Being the administrator. DSNs said that giving practical service to patients and physicians was important in providing effective diabetes care, and they described how they carried out work tasks based upon patients' wishes and needs and physicians' medical prescriptions. '*We are so used to work such as finding and preparing things. Sometimes it's all I do: getting things ready for others.*' The DSNs also described being pressed for time because they were torn between several different tasks and they expressed that other work tasks, e.g. home visits, telephone advice and clinical nursing, made them fragmented in their work performance. *'It's like a cold shower; you never have time to get acquainted with anything since there is so much other work – you become fragmented.'*

Striving to be a role model

This theme incorporated three subthemes: being healthy, being available, and being engaged. Being a good example, easily contacted when needed, and committed to patients were perceived as desirable qualities in a DSN. However, DSNs' feelings of inability to live up to this somewhat wishful image of themselves could lead to self-reproach and self-doubt.

Being healthy. The DSNs described themselves as being interested in healthy living (healthy food and proper exercise) and as living healthy lives themselves. '*We are healthy people. We walk in the forest in well-fitting shoes … carrying a back-pack and eating healthy food.*'

However, these high standards were difficult to maintain. One DSN said that the picture of the healthy DSN was somewhat true, but mainly wishful thinking. '*We are healthy as a group … but not all of us as individuals … at least not at my health care centre.*'

Being available. The DSNs expressed that being available for both patients and colleagues was important to inspiring feelings of safety. '*I think it is most important that the patient can contact us, that we are here for them when they have questions, that they can call us any time.*'

However, the DSNs also described how several time-consuming tasks hindered their availability to patients with diabetes, and they expressed feelings of self-reproach for not always being reachable. *'We are supposed to be everywhere and quite often it is not possible to reach us until the following day.'*

Being engaged. The DSNs described their desire for close, regular and equal contact with their patients. Being engaged meant being personally committed to individual patients in their particular life situations. '*Yes, I was determined that we had to help this man, otherwise he would die of some sort of circulation disease … I could cry for this person.*' However, the DSNs

were troubled by their inability to get on well with all of their patients. They expressed self-doubt when they scrutinised their feelings towards having failed to motivate patients. *'It is a personal failure if it does not go well.'*

Discussion

We found the profession of DSN described as a multifaceted, potentially powerful position, incorporating the roles of expert, fosterer, executive, leader and role model; however, challenges interpreted as role ambiguities revealed the DSN in a less powerful professional position. In studies from the UK, DSNs are described as educators, interpreters, monitors, modulators and referrers.[6,24] This set of role descriptions, somewhat different from our findings, may be due in part to the UK studies' inclusion of specialist nurses working in the management of various chronic diseases other than diabetes. The UK studies also included audit and service evaluations which may mirror a particular perspective. Our study investigated only how Swedish DSNs perceived and described their professional roles working in diabetes care in primary care settings.

The role of expert

The role of expert included being both a teacher and a specialist. The Swedish Council of Technology Assessments in Health Care[3] has stated that increased pedagogical skills are necessary for professionals in diabetes care who conduct group patient education. However, the DSNs in this study saw their continuing education as a low management priority. Expert nurses face a new paradigm in which patients need to be supported in their own problem-solving skills, and patients themselves are considered experts in their own lives, if not in the disease.[25] Graue *et al.*[26] have argued that, to improve patient outcomes, DSNs need better skills in finding and interpreting research to ensure their practice is evidence based. Patient-centredness and empowerment are recommended in diabetes care,[3,27] but compliance approaches are still commonly used.[28–30] DSNs find it problematic to fulfil high medical standards and simultaneously emphasise patient-centred care.[9] Implementing patient-centred care and empowerment approaches have been shown to be difficult when professionals experience role ambiguity.[31,32] Lack of control over the professional role may influence DSNs negatively and hinder their ability to work in partnership with patients.[31] Therefore, knowledge about DSNs' perceptions of their professional roles will be valuable in enhanced patient-centred care and patient education.[32,33]

The role of fosterer

The role of fosterer involved being a counsellor, monitor, and supervisor. Our results showed that DSNs expressed role ambiguity in their fostering role, i.e. being suspicious and losing hope in patients who were unwilling to amend harmful health-related behaviours. According to Whitehead,[34] such resignation might lead to patients' resentment and rejection of DSNs, reinforcing the professionals' suspicion of patients' poor self-management in an unhealthy cycle. The DSN is central to improved care for chronic diseases and patients' adoption of healthy behaviours.[35,36] However, feeling resigned and not in control of their professional roles may cause DSNs discomfort and result in their excessive worry over patients,[31] which they may then express in their work by alternating between frightening patients and comforting and encouraging them. The conflicting needs to both frighten and comfort the patient have been found among GPs in their preventive work with diabetes patients.[37]

The role of leader

The role of leader included being the authority and coordinator in diabetes care. DSNs saw collaboration with other professionals as vital. According to Hansson *et al.*,[38] district nurses in primary care are more willing to collaborate than are physicians. Nurses' collaboration with physicians may be a way to lighten the burden on DSNs, but such collaboration with other professions may also be seen as a threat by DSNs because it may lead to the replacement of specialist nurses by other less educated health assistants.[39] Patient outcomes have been shown to improve when DSNs organise diabetes care, and DSNs seem to have stronger organisational ability when they have control and management of functional diabetes teams.[40] Some authors argue that it could be clinically effective,[41] as well as cost effective, to designate the DSN as the leader in diabetes care.[19]

The role of executive

The role of executive concerned being both a bureaucrat and an administrator. The NDR guidelines[42] greatly influenced the DSNs' work and were often a tool to help the bureaucrat structure the clinical encounter. However, it could be a challenge for the executives to look beyond clinical measures and focus on supporting self-management instead.[40] The DSNs in our study described an ambiguity between their specialised mission and the included role of administrator. Occupying specialist nurses with hands-on work and lower skill work may be a deliberate short-term decision taken to prevent the nurses from becoming too powerful while

saving labour costs in a decreasing health care budget.[39]

The role of role model

The role of role model entailed being healthy, available, and engaged. Role models in health care may inspire patients by being good examples, but the DSNs' expectations of being good examples were sometimes difficult to fulfil. Being role models might affirm their professional credibility, and nurses who have integrated healthy behaviours into their own lives might feel higher professional adequacy,[43] but patient-centred encounters are more dependent on equality and partnership than on role modelling.[44] Being a role model, e.g. being slim and healthy, may actually increase the distance between the professional and the patient not fulfilling such goals. There is a need for nurses in the care of chronic illness to reflect upon their own role with the patient and to become more aware of their own attitudes.[45,46] In interactions with patients with diabetes there may be a need of support for psychosocial issues[47] and the aspect of role modelling versus equality becomes of particular interest.

Overview of roles and expectations

The DSN's profession is multifaceted, encompassing several roles and expectations. Multiple roles could lead to role ambiguities through the imprecision generated by overlapping expectations.[48] It is argued that nursing roles in general are in transition from the ideal of a selfless, tender, domestic approach to a more technical, autonomous and collaborative approach.[49] Patients' expectations and views on nurses' attitudes are also essential to highlight in order to decrease role problems. Traditional aspects of diabetes nursing, such as a one-sided disease perspective, professionals' high adherence expectations, and paternalistic attitudes, have been described as problematic issues in efforts towards patient-centred care.[50]

Strengths and limitations of the study

A strength of this study was the focus group interview design, which is effective for clarifying experiences and problems related to specific topics and considers all participants as active members of the group. The small size of some focus groups might be a limitation, but smaller focus groups can also have benefits due to the more intimate climate.[21] This study is limited to the context of DSNs working in Sweden, but we believe that the findings may be transferable to other contexts and other countries, since the work tasks and responsibilities in Sweden are similar to those in the UK, for example, and follow international guidelines.[4] Unlike DSNs in the UK, however, Swedish DSNs in primary health care most often do not work full-time in diabetes care, which may relate to the too sparsely populated geographic catchment areas to support full-time DSN positions, especially in northern Sweden. The increasing demands and challenges that come with increasing numbers of patients, more complex work tasks and more nurse-led clinics, will influence the future role of DSNs, not only in Sweden, but internationally.[20]

The trustworthiness of these results was established through several discussions among the research team during the analysis. In addition, we presented the findings to one-third of the participants in a later session in which the participants expressed their recognition of the interpreted roles.

Conclusion and relevance to clinical practice

The results demonstrate that the DSN has a multifaceted profession with various roles that can be quite complicated to combine. The DSNs described themselves as experts, fosterers, leaders, executives and role models, and they emphasised their strength and capability.

However, role ambiguities indicated their position was less powerful than they wished or believed and had a smaller positive impact in clinical encounters with patients. Patient-centred care and empowerment, recommended as successful approaches in diabetes care, can be difficult to accomplish when DSNs experience role ambiguity.

The main indication for clinical practice is the DSNs' need to strengthen their professional role to emphasise patient-centred care and empowerment; hence, awareness about their roles and attitudes in encounters with patients and other professionals need further study.

Observation of the clinical encounter and the interaction between DSNs and patients may be a topic for further research.

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Declaration of interests

There are no conflicts of interest declared.

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