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Promoting health in children and adolescents with – or at risk of – Type 2 diabetes mellitus in the United States: An interview – study of nurses' experiences of their role

Samuel Jara Josefsson, Minna Allar, Kajsa Landgren and Irén Tiberg
Department of Health Sciences, Lund University, SE-221 00 Lund, Sweden

Introduction: Type 2 diabetes mellitus (T2DM) in children and adolescents is increasing throughout the world and the USA. Previous research has shown that the nurses have an important role in the management of T2DM in children and adolescents, but few studies have covered how the nurses perceive and experience their role.
Aim: This paper aims to describe how nurses experience their role in the care of children and adolescents with T2DM and their families.
Methods: Semi-structured interviews were used to collect the data from eight registered nurses and nurse practitioners who worked in an American university hospital area participated in the study. An inductive qualitative approach was used and the data were analysed through the content analysis. The findings were described in four categories: *overcoming challenges; improving life quality; being cooperative* and *being committed to one's role as a diabetes nurse* forming the theme *Promoting health*.
Conclusions: The diabetes nurse has a key role in the work of promoting health and the results elucidate the complexity of the role. To be able to plan for and to implement an evidence-based approach based on theoretical models of behaviour and consideration of the child's needs, not only requires a commitment from health professionals but also involves education and discussions that require both commitment and managerial and economic support from leaders in children's healthcare and managers of health services.

Keywords: Type 2 diabetes, Professional role, Paediatric obesity, Health promotion, Prevention

Introduction

In addition to the general increase in the global population, studies show that Type 2 diabetes mellitus (T2DM) in childhood has increased globally.[1–3] The prevalence of T2DM in children is significantly higher in the USA (12:100 000) than in Europe (5:100 000).[4] The diagnosis involves physical and psychological suffering for the child and their family and may lead to a variety of complications.[5] Adolescents with T2DM show similar complications as adults, but the complications occur at a much faster rate.[6] Furthermore, children with T2DM experience lower quality of life, more frequent psychosocial issues and depression than children with Type 1 diabetes and the general population.[7] Thus, it is a costly, chronic disease with severe consequences that result in an increased mortality in the affected children.[4]

Being overweight or obese has a strong connection to the onset of T2DM in children and adolescents and is the biggest risk factor.[4,8] When a child is diagnosed with T2DM, a multidisciplinary team – as well as the child's family – becomes involved in the care of the child.[9] The International Diabetes Federation and ISPAD guidelines[10] state that the multidisciplinary team is to include a physician specialized in paediatric endocrinology and/or diabetology, a diabetes specialist nurse and a dietician. Lifestyle modifications, including increased physical activity, improved diet and weight loss are the first line of treatment and prevention of T2DM.[3] Diabetes nurses (defined as a nurse who works primarily with children with diabetes) have a key role in caring and assisting self-management and independence in children and adolescents with or at risk for diabetes by providing adequate education and support[11]; ISPAD Clinical Practice Consensus Guidelines (2014).[12] As a part of the multidisciplinary team, the diabetes nurses are in a favourable position to advocate for positive lifestyle modifications for children, adolescents and their families as well as the general public.[13] Diabetes nurses may help children and their families by assisting them in finding strategies to manage these lifestyle modifications.[14] By educating and supporting the child, parents and extended family, diabetes nurses may increase independence and self-management.[15] The role

Correspondence to: Irén Tiberg, Department of Health Sciences, Lund University, SE-221 00 Lund, Sweden. Email: iren.tiberg@med.lu.se

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is complex and as the guidance for the diabetes nurses of how to support children and adolescents effectively is limited, diabetes specialist nurses are uncertain in their role.[16] This is likely to lead to great variations in the support that child and adolescents receive. It is, therefore, important to highlight how nurses' experience their role to reach a deeper understanding of what area is experienced as problematic. This may guide other researchers in the need of tools and guidelines for the care needed in clinical practice. The aim of this study was to describe how nurses experience their role in the care of children and adolescents with T2DM and their families.

Methods

Design

The study was qualitative and used semi-structured interviews analysed using an inductive approach through a content analysis. The purpose of this method is to achieve an understanding of the interviewed individual's experience, perceived world and perspective.[17]

Sample

Inclusion criteria were being a registered nurse (RN) or nurse practitioner (NP) who was or recently had been in regular contact with children and adolescents with – or at risk of – T2DM at a paediatric diabetes clinic and a University Hospital in the US state of Virginia. To work as a RN in the state of Virginia, one should have a bachelor degree in nursing from an accredited college or university approved by the Virginia Board of Nursing.[18] A NP must have completed a master's or doctorate program specializing in the field of nursing and have advanced clinical experience beyond the requirements of an RN.[19] The nurses who participated worked at different sites. Some worked with children already diagnosed with T2DM at paediatric diabetes clinics, while other nurses worked in a family health department within the hospital and met children with obesity, and therefore at risk of developing T2DM.

Data collection

Nine nurses fulfilling the inclusion criteria were contacted via a coordinator at a university in the state of Virginia. Eight nurses, both RNs and NPs, responded and were scheduled for face-to-face interviews. Prior to each interview, informed consent was collected. Semi-structured interviews containing questions about the nurses' experiences of caring for children with diabetes, with probing follow-up-questions, were conducted by the authors SJJ and MA. Interviews started with the question 'Could you please tell us about your education and clinical experience'? A pilot interview included into the study showed that the prepared questions with some smaller changes provided answers that corresponded well with the aim of the study. The interviews (mean 25 minutes long) were recorded and transcribed.

Data analysis

The transcripts were analysed using the content analysis.[17] The text was read through several times to obtain a sense of the whole, and then divided into meaning units, condensed into a description close to the text, the manifest content, and coded (Table 1). The codes were compared and – based on similarities and differences – and sorted into categories. Finally, the latent content of the categories was formulated as a theme (Table 2).

Ethical considerations

Qualitative studies with healthcare professionals are not a part of Research ethics approval in Sweden. However, the project plan was reviewed by the Ethics Committee at Lund University, following current guidelines for student projects. Their counselling statement was translated and transferred to the University of Virginia, UVA, which did not acquire any further ethical reviews. The study was conducted according to international Research ethics[20] and informed consent was obtained from each participant.

Results

Eight nurses (six NPs and two RNs) were interviewed. Of these six NPs, five were Paediatric NPs and one was a Family NP. The participants had a total clinical experience of between 5 and 44 years. Analyses resulted in four categories that are presented beneath the headings below. The latent meaning of the categories was concluded in the theme *Promoting Health*.

Promoting health

Throughout the interviews, it became clear that the nurses felt that their primary role in the care and interaction with children and adolescents with T2DM and their families was to promote health. To do so, the nurses had to overcome obstacles, improve life quality,

Table 1 Example of codes.

Meaning unit	Condensed meaning unit	Code
But how you teach them with the dosing and how you help them understand and help their parents understand … how to take the medicine correctly	You have to teach patients and parents to help them understand how to take the medicine correctly	Educating the family as to enable self-management
So the struggle that I've had from the very get-go is trying to get parents to buy in to making changes for the whole family, not just for their child	Struggling to get parents to make changes for the whole family	Struggling to get parents to change

Table 2 Compilation of categories and theme.

Theme	Promoting health			
Categories	Overcoming challenges	Improve life quality	Being cooperative	Being committed to one's role as a nurse

cooperate and build a team as well as being committed to their role as a nurse.

Overcoming challenges The participants described how they struggled to overcome different challenges when helping families to change life style, and how they dealt with their own frustration.

The participants described the experience of having to struggle with how aggravating factors, such as minimal resources, difficulty to find time, lack of adherence, cultural barriers and dysfunctional families, hindered them from providing the care or spending the time that they wanted with the patients and the families. Especially challenging was the interaction with the patients and families while trying to implement lifestyle changes, especially in dysfunctional families or in families where the parents think that the child or adolescent should take sole responsibility for the diabetes management. Likewise, cultural differences could be an aggravating factor, resulting in the family being less compliant towards the interventions suggested by the nurse. Meeting cultural differences with respect proved challenging.

> For instance I had a Hispanic mother, who believed that feeding her child showed that she loved her child so she would just feed, and feed and feed and feed her child. And by the time he got into high school he weighed over 400 pounds [180 kg]. [P.2]

The nurses also agreed that diabetes is a family affair, which in turn provides challenges to overcome as many of the interventions need to be accepted and adopted by the entire family.

Having to deal with these aggravating factors the participants described leads to various situations in which they had to deal with their own emotions based on the interaction with their patients and the families. Frustration and feelings of helplessness were among the common emotions the nurses had to face. These feelings were caused by patients and families failing or refusing to commit to the health plan or advices as well as a lack of resources, such as education material, at disposal for the nurses. In addition to these sources of negative emotions, the nurses were also disheartened by the fact that conditions previously found predominantly in adults have now started to manifest in younger children and become a central part of their role.

> You know when I see families like that [unwilling to change] I just want to cry because, it's very frustrating; very frustrating to get people to change their mind-set about stuff. [P.5]

Despite the adversities, the nurses also described the importance of finding positive emotion and how they gathered energy from small achievements.

> … one time in six months or so they might come back and they have done something really good and that keeps you going for the next six months. [P.4]

To face the challenges described, the nurses felt a need to be able to adapt, be flexible and work with many different aspects of the patient care to find and utilize resources most efficiently as to also achieve optimal teaching.

> Yes, it's [the meeting] always based on what level of understanding the child is at based on either their age or their developmental status. And, that can also happen with adolescents too, that you would have to go by … what their level of understanding is. [P.4]

Having to adjust one's approach mainly became relevant in the education of the patients and families and the nurses stated that it was crucial to identify how prepared the families were to change to optimally adjust the care and interventions.

Improve life quality The participants described a mission to improve patients' and families' self-management by encouraging and educating them, so they could improve their life quality.

The nurses described that improving the patients' self-management was a key to manage their illness and current life style successfully. Nurses also agreed that a continuous development of the patient's self-management was an important part of their role. It was exemplified as being a mentor trying to engage patients and families, being supportive, providing tools and making the families comfortable and cooperative.

> [*Interviewer*]: 'In what way do you work to improve the self-management capability of these children?'
> [*Participant*]: 'So educationally, we teach them about testing their blood sugar, we teach them about dietary things, being on low carbohydrate, you know counting their carbs. We talk about all sorts of health education things, like you know managing your body, going to the dentist. / … / [we are] calling school nurses and making sure that they're also co-partners in care and they're aware of what medications this person is on, and then just generally, you know, checking on the kids via email or telephone conversation. And also, you know, teaching parents to manage the, manage all these things.' [P.7]

The participants agreed that education was the key to improve self-management and improve life quality.

They took every opportunity to talk about the importance of health and factors that affect health and T2DM as to reinforce the patient's knowledge and understanding and by extension, their adherence to treatment. They felt that the education had to be tailored depending on the patient's pre-understanding of the illness and it was crucial to incorporate the entire family in the education as the parents play a vital part in the management for their child's diabetes. This was also true for older patients as adolescents also need support and supervision even though they are more able to make choices for themselves.

> … if you can get the family to buy in, absolutely [it helps]. / … / especially if [the patients] they're younger, they don't have a choice in what's changing because the parents have made that decision for you, to try to change things to improve their health and their child's health … [P.5]

All participants agreed that the family's part in the patient's situation was of utmost importance. To encourage the family, the nurses stated the importance of keeping positive attitude towards the patients and families as a way to promote self-management and compliance and to ensure that the education does not cause feelings of guilt. In relation to the patients, the participants described their role was (among others) to develop therapeutic relationships and to encourage children to involve their friends and teach them about T2DM and how they can support them. To do so, it was important to focus on keeping the education positive as to not make the patients ashamed.

> … it helps [in the long run] if it's a positive visit, you know you keep it positive, you don't rag on them. / … / you can't preach up them and lecture and make them feel bad … / … / When we talk about weight I usually do this thing, I don't wanna focus on weight. Talking about your weight makes you feel bad it's kind of negative thing. Talking about health … is a positive thing you wanna be healthy, so like try to present positive things [when educating]. [P.8]

Being cooperative The nurses described their role as being a coordinator. The role meant being part of a multi-professional team. Sometimes, the team worked closer together and sometimes nurses were more autonomous. It was described as important that everyone in the team worked towards the same goals and followed the same guidelines. It was important for nurses to talk to other health care providers when they felt insecure. Some interventions were deemed to be more successful if implemented by others than the nurse.

> I mean we couldn't do any of this without our dieticians. Cause I can give my little words of encouragement or few sound bites but the dieticians sit down and talk to them for half an hour, they go through their diet history and their activity and give them very specific things and some hand-outs … [P.8]

Most – but not all – of the nurses felt that they received adequate support from the organization they were working for. All the nurses felt that they were in a natural position to plan and coordinate the care. This included making health plans, ensuring that the patients were treated at the correct clinic and with the proper care. In the preventive work of T2DM, the nurses involved other professionals to monitor and support the at-risk-children. While discussing the nurses co-working with the physicians, it was described that they felt like they were striving towards the same goal.

> … we [nurses] would do whatever we needed to do, as the physician would. So, I feel like a peer to them in terms of the kind of care that I'm able to give. Cause it's the same as what the docs do. [P.5]

Being committed to one's role as a nurse This category contains statements about being a passionate advocate for the patient and about a continuous strive to learn more about diabetes.

The nurses stated that one of the most important aspects of their role was to meet the patients with a holistic approach and to be an advocate for the patients in all aspects of the care and to fight for their rights to receive proper care.

> I think that in nursing our biggest role is that we're advocates. We're the number one advocate for our clients or our patients. And I don't know that you see that in other professions. [P.2]

In addition to feeling, the urge to advocate the nurses also described a devotion to their work. They wanted to make a difference, be persistent and felt empowered when the patients made improvements. They felt that a nurse had a specific role and held a lot of influence over patients, families and other professionals. Strong relationships between the nurses and their patients were described as important, emphasized by a feeling of being the last resort for the patients.

> … I adore these kids, I mean I just, I feel really close to them, we build really strong relationships … [P.6]

The participants described that their own education had provided them with knowledge that facilitated the general role as a nurse. Regarding the field of diabetes, however, the education had prepared them poorly. The knowledge and understanding of T2DM was gathered throughout practical experience and the hands-on experience provided an expertise that later on facilitated the meetings with the patients and families. To provide the best possible care, the nurses mentioned the importance of further education in their field and being able to assimilate the experiences on the job.

> So I've learned most of my diabetes … is on-the-job-training as well as attending conferences and educational and reading so, I've been able [to increase the knowledge of T2DM], but my education was certainly a very good basis … for doing what I do [family care]. [P1]

Discussion

Understanding the experience of the role of diabetes nurses in the care of children and adolescents with T2DM and their families is central to keeping in mind the complex situation the role implies. The diabetes nurses believed that their main role when interacting with children and families with T2DM was to promote health. To optimize the care and promote health, the nurses had to overcome various challenges such as lack of adherence, lack of resources or cultural barriers. A way to overcome these challenges was to be flexible and able to adapt to various situations. Still, the nurses often felt as though they did not get enough resources to provide the care that they wanted.[21] Nurses are used to negotiate the ever-changing environments and conditions, which are their daily practice and nurses are good in keeping the service going no matter what.[22] However, lack of time and resources might not allow for reflection and analysis in a more holistic way.

One of the major obstacles the nurses had to face, and one of the things that caused the most frustration, was the lack of compliance of some children and families. This led to negative emotions and difficulties reaching optimal care. Patient-centred care is crucial to achieve better adherence and to support self-management[23] and self-management education programmes are distinct from simple patient education or skills training, in that they are designed to allow people with chronic conditions to take an active part in the management of their own condition.[24] While the clinical works often lack an explicit theoretical basis, research evaluations of self-management education programmes are usually based on theoretical models of behaviour. Self-efficacy theory[25] is a social cognitive theory that states that the key predictors of successful behaviour change are confidence in the ability to carry out an action and expectation that a particular goal will be achieved.

In the present study, the nurses strived to work in a family-centred manner. Family-centred care (FCC) has been widely embraced by children's nurses and is the model of choice in directing care delivery in many children's units globally, and the research indicates that implementation is problematic and minimal evidence exists about the impact and effectiveness of FCC for children and families.[26] The principles of FCC include information sharing, respect and honouring differences, partnership and collaboration, negotiation and care in the context of family and community. This perspective has been criticized recently, saying that the focus on strengthening families' knowledge, skills and ways of coping potentially detracts from consideration of the children's needs. Turning to view the care of children from the perspectives of children themselves, as belonging to a family, will change the child's position.[27] The nurses described that the goal of promoting health could, sometimes, be hindered due to the lack of motivation of families. This posed a challenge as being family-centred includes accepting and respecting a family's decision. Boström *et al.*[16] reached a similar conclusion where they stated that nurses found it more time-consuming when working with patients who were not motivated to modify their lifestyle and that the diabetes nurses were unsure in their role. Changing the focus to a Child-centred care (CCC) approach might better grasp the child's way of demonstrating how to be engaged in a vulnerable situation from its own perspective. Although there often is a commitment to hearing children's voices, progress on facilitating choices and involvement in healthcare are rare and more research is needed.[27]

Strengths and limitations

The first two authors (SJJ and MA), students at bachelor level at Lund University, Sweden, collected data in face-to-face interviews with diabetes nurses at a university hospital in the US state of Virginia. Credibility deals with the focus of the research and refers to confidence in how well data and processes of analysis address the intended focus. As T2DM is still relatively unusual among children and adolescents in Europe, a paediatric diabetes clinic in the USA was chosen, where there are diabetes nurses who were more likely to have the experience essential to answer the aim of the study. Choosing participants with various experiences increases the possibility of shedding light on the research question from a variety of aspects. In this study, participants' various ages and experiences contributed to a richer variation of the phenomena. Furthermore, data were collected at four different sites but in one federal state that probably imply limitation of transferability of the results. Trustworthiness of interpretation was increased by including rich quotations which allows the reader to look for alternative interpretations.[17]

Conclusion and clinical implications

The diabetes nurse has a key role in the work of promoting health and the results elucidate the complexity of the role and have shown that the nurses experience a myriad of challenges that aggravates their endeavour to promote health. Reframing the approach of facilitating children's healthy behaviour could be the first step in a long process. To be able to plan for and to implement an evidence-based approach based on theoretical models of behaviour and consideration of the child's needs not only requires a commitment from health professionals but also involves education and discussions that require both commitment and managerial and economic support from leaders in children's healthcare and managers of health services. To promote a healthy lifestyle

in children with, or at risk of Type 2 diabetes, this result also further emphasizes the need for specialized education in diabetes care but also in paediatrics.

Conflict of interest

The authors declare that there are no conflicts of interest.

ORCID

Samuel Jara Josefsson http://orcid.org/0000-0002-5249-9400
Kajsa Landgren http://orcid.org/0000-0002-5595-5774
Irén Tiberg http://orcid.org/0000-0001-6057-491X

References

1. International Diabetes Federation. *Key findings, 2014*. Retrieved 2015 Mar 5, from International Diabetes Federation. Available from http://www.idf.org/diabetesatlas/update-2014.
2. Dabelea D, Mayor-Davids E, Saydah S, Imperatore G, Linder B, Divers J, *et al.* Prevalence of type 1 and type 2 diabetes among children and adolescents from 2001 to 2009. JAMA 2014;311(17):1778–86.
3. Nader N, Kumar S. Type 2 diabetes mellitus in children and adolescents: where do we stand with drug treatment and behavioral management? Curr Diabetes Rep. 2008;8(5):383–88.
4. Reinehr T Type 2 diabetes mellitus in children and adolescents. World J Diabetes. 2013;4(6):270–81.
5. American Diabetes Association. *Complications.* Retrieved 2015 Mar 5, from American Diabetes Association. Available from http://www.diabetes.org/living-with-diabetes/complications/.
6. Tryggestad J, Willi S. Complications and comorbidities of T2DM in adolescents: findings from the TODAY clinical trial. J Diabetes Complicat. 2015;29(2):307–12.
7. Jaser S. Psychological problems in adolescents with diabetes. Adolesc Med State Art Rev. 2010;21(1):138–51, x-xi.
8. Hannon T, Rao G, Arslanian S. Childhood obesity and type 2 diabetes mellitus. Pediatrics 2005;116(2):473–80.
9. Zeitler P, Fu J, Tandon N, Nadeau K, Urakami T, Bartlett T, *et al.* Type 2 diabetes in the child and adolescent. Pediatr Diabetes 2014;15(20):26–46.
10. International Diabetes Federation & International Society for Pediatric and Adolescent Diabetes. *Global IDF/ISPAD Guideline for Diabetes in Childhood and Adolescence*. Retrieved 2015 Nov, from International Diabetes Federation. Available from http://www.idf.org/sites/default/files/Diabetes-in-Childhood-and-Adolescence-Guidelines.pdf.
11. Kenny J, Corkin D. A children's nurse's role in the global development of a child with diabetes mellitus. Nurs Child Young People. 2013;25(9):22–25.
12. Swift P. Diabetes education in children and adolescents. Pediatr Diabetes ISPAD Clinical Practice Consensus Guidelines 2009 Compendium. 2009;10 (Suppl. 12):54–57.
13. McKnight-Menci H, Sababu S, Kelly S. The care of children and adolescents with type 2 diabetes. J Pediatr Nurs. 2005;20(2):96–106.
14. Rabbitt A, Coyne I. Childhood obesity: nurses role in addressing the epidemic. Br J Nurs. 2012;21(12):731–35.
15. Lange K, Swift P, Pankowska E, Danne T. Diabetes education in children and adolescents. Pediatr Diabetes 2014;15(20):77–85.
16. Boström E, Isaksson U, Lundman B, Egan Sjölander A, Hörnsten A. Diabetes specialist nurses' perceptions of their multifaceted role. Eur Diabetes Nurs. 2012;9(2):39–44.
17. Granheim U, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Education Today 2004;24(2):105–12.
18. Virginia Board of Nursing. Laws Governing Nursing, 2014. Retrieved 2015 Mar, from Virginia Board of Nursing – Laws and Regulations. Available from http://www.dhp.virginia.gov/nursing/nursing_laws_regs.htm.
19. American Association of Nurse Practitioners. What's an NP? Retrieved 2015 Nov 16, from American Association of Nurse Practitioners. Available from https://www.aanp.org/all-about-nps/what-is-an-np.
20. World Medical Association. *WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects*. Retrieved 2015, from World Medical Association. Available from http://www.wma.net/en/30publications/10policies/b3/index.html.pdf?print-media-type&footer-right=[page]/[toPage].
21. West E, Barron D, Reeves R. Overcoming the barriers to patient-centred care: time, tools and training. J Clin Nurs. 2005;14(4):435–43.
22. Greenwood S, Wright T, Nielsen H. Conversations in context: cultural safety and reflexivity in child and family health nursing. J Fam Nurs. 2006;12(2):201–24.
23. Robinson J, Callister C, Berry A, Dearing A. Patient-centered care and adherence: definitions and applications to improve outcomes. J Am Assoc Nurse Prac. 2008;20(12):600–7.
24. Foster G, Taylor SJ, Eldridge SE, Ramsay J, Griffiths CJ. Self-management education programmes by lay leaders for people with chronic conditions. Cochrane DB Syst Rev. 2007;2007(4):CD005108. doi:10.1002/14651858.CD005108.pub2.
25. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. Psychol Rev. 1977;84(2):191–215.
26. Shields L, Zhou H, Pratt J, Taylor M, Hunter J, Pascoe E. Family-centred care for hospitalised children aged 0–12 years. Cochrane DB Syst Rev. 2012;10:CD004811. doi:10.1002/14651858.CD004811.pub3.
27. Coyne I, Hallström I, Söderbäck M. Reframing the focus from a family-centred to a childcentred care approach for children in healthcare. Child Health Care. 2016. doi:10.1177/1367493516642744.