

Standing on their own feet: Experiences of young people living with Type 1 diabetes when entering adulthood — A qualitative study

Birgitta Lindberg¹  and Siv Söderberg²

¹Department of Health Science, Luleå University of Technology, Luleå, Sweden; ²Department of Nursing Sciences, Mid Sweden University, Campus, Östersund, Sweden

Type 1 diabetes can complicate the lives of young people. The aim was to describe the experiences of young people living with Type 1 diabetes when entering adulthood. Nine young people were interviewed. The general principles of interpretative descriptions were used in the analysis. Results showed that young people with Type 1 diabetes lived a life like other young people, but they often had to face a lack of knowledge and understanding. Although they knew how to live, it was not easy to be in control. Even if they took responsibility for their illness, support was critically important. They did not think so much about how their illness might impact their future life. Overall, young people described their life situation positively and dealt with their diabetes naturally. To better support and facilitate the transition to adulthood, health care professionals who are engaged with young people living with Type 1 diabetes need to have better insight into how they experience their life.

Key words: Diabetes mellitus Type 1, Young people, Entering adulthood, Everyday life, Nursing, Qualitative method

Received 24 June 2015; accepted 4 September 2015

Background

This study is part of a larger research project focusing on the experiences of living with long-term illness. The emphasis in this study is young people living with Type 1 diabetes, which is one of the most common long-term illnesses in childhood and adolescence, and requires life-long treatment. The incidence of childhood Type 1 diabetes in Sweden is the second highest in the world after Finland.¹

Living with a long-term illness such as Type 1 diabetes can be a difficult and eventful undertaking. Youth is a period of life characterized by major physical and psychological upheavals, and a large part of identity development occurs during this time.² Having a long-term illness during youth can be an additional burden that makes life more difficult.^{3,4} Type 1 diabetes affects the daily life of sufferers both in the present and in the future, and can therefore make life more complicated for young people.⁵ Youth is a time in life that poses special challenges for treating diseases and promoting health.⁶ When providing health care to young people with diabetes, it is important to recognize that young people have many tasks to complete as a part of their development, in addition to managing the demands of their illness. Some young people may have disruptions to their personal development as a result of their diabetes and this may lead to difficulties that need help from experts.⁵ Research^{7,8} shows that adolescents with Type 1 diabetes experience a poorer quality of life than their friends and that they can oscillate between feeling

normal and being different.⁹ However, it is important to highlight that life can be good, even with an illness such as diabetes, provided that the disease is under control.¹⁰ McDonagh and Gleeson argued that it is important to remember that young people with diabetes are primarily young people; treatment should focus on investing in their futures.¹¹

Young people with Type 1 diabetes can sometimes feel misunderstood, which is magnified by the inability of their family and friends to fully understand them and makes them wish that others had more knowledge.¹² To better manage diabetes, adolescents need support from parents and friends, as well as from the team of health-care professionals responsible for their care.⁹ Support by healthcare professionals, parents, and friends is a crucial factor in achieving adherence to treatment in chronic diseases in adolescents.¹³ Despite this, research shows that young people with Type 1 diabetes reported that healthcare professionals are often controlling at meetings and that emotional support is not usually offered.¹⁴

The literature review shows that it is important to increase the knowledge and understanding of what it is like to be in early adulthood and live with Type 1 diabetes. It is critical to review young people's own descriptions about how they experience their life situation when entering adulthood. Only through these accounts can we understand the meaning they give to living with Type 1 diabetes. This insight can help nurses and other

healthcare professionals provide more appropriate care to these young people with diabetes.

The intention of this study was to address a gap in the literature about young people in early adulthood by investigating how young people living with Type 1 diabetes experience their life situation when entering adulthood. Developing a deeper understanding of their lives and experiences can enable the health care community to meet their specific needs. Thus, the aim of this study was to describe the experiences of young people living with Type 1 diabetes when entering adulthood.

Methods

Design

This design of this qualitative research study relies on interpretive description as developed by Thorne, Kirkham and MacDonald-Emes.¹⁵ Interpretive description was designed by nurses to guide nursing research with the explicit purpose of developing knowledge for nursing practice.¹⁵ This study attempted to answer the research question: How do young people describe experiences of living with Type 1 diabetes when entering adulthood? The strength of interpretive description is to link the interpretation of the description resulting from data to clinical practice,¹⁵ making this method well suited to the research question of this study.

Participants

Nine young people (seven female and two male) diagnosed with Type 1 diabetes participated in the study. The selections of the participants were criterion-based and the participants were selected specific for the purpose of the study. Criteria for inclusion were: young people between 17 and 25 years of age diagnosed with Type 1 diabetes for at least one year prior to the study. Participants were recruited through a letter, outlining the purpose of the study, published on a support group website that targeted adolescents and young adults with Type 1 diabetes. Interested participants were asked to contact researchers for additional information. After voluntary acceptance for participation, appointments for interviews were made. Participants were from different parts of Sweden and ranged in age between 17 and 24 years (median = 22). They reported having Type 1 diabetes for between 1 and 22 years (median = 9). At the time of the interviews, two of the participants lived alone, five were cohabiting with a partner and two of them lived with their parents. Seven of the participants were studying, university ($n = 5$) and secondary school ($n = 2$), and two of them were working full time.

Data collection

Personal interviews with a narrative approach (cf. Mishler¹⁶) were conducted with the participants. The interview started with the question, 'Please tell me about your experience of living with Type-1 diabetes'. Although an interview guide was used, the interviews

remained open ended to allow for a full exploration of experiences and perceptions. The interviews (face-to-face ($n = 3$), telephone ($n = 5$) and real-time videoconferencing ($n = 1$)) were conducted at a time and in a method convenient to the participants. The interviews lasted between 45 and 90 minutes (md = 60), were digitally recorded with the participants' permission, and were later transcribed verbatim.

Data analysis

The data analysis was guided by general principals of interpretive description which allows to openly drawing on theoretical, practical and professional knowledge to guide analytical reasoning, reflection and data interpretation.^{15,17} The first step in the analysis was reading and reviewing the interviews to further understand the implications of the content, first as a whole in order to identify and interpret broad, overarching narratives and early articulations about the phenomenon entering adulthood from the perspective of young people living with Type 1 diabetes. The interpretation process proceeded by coding each interview line by line. A preliminary analytic structure developed from this analytic phase formed the basis for an identification and exploration of commonalities and differences among and between individual experiences. The preliminary interpretation was collected as a number of fifteen broad themes, and repeated analysis resulted in the transformation of the initial themes into six unique themes.

Ethical considerations

The study followed the ethical principles of the Helsinki Declaration.¹⁸ All ethical standards regarding informed consent and the right to withdraw were upheld. The participants were given written information about the study, and if they showed interest in participating, additional oral information was given with an opportunity to ask questions before making a decision to participate. Informed consent was obtained both through written and verbal communication prior to all interviews. The participants were assured about confidentiality regarding the collected information. They were also reassured that the presentation of the results will be performed in such a way that none of the participants would be identified. To preserve anonymity in the results, we decided to exclude leading information of the participants. According to the Swedish law on the ethical review of research involving humans,¹⁹ no ethical review was required, but ethical guidelines and rules were continually and carefully considered to do good and prevent harm or risks.

Results

The analysis of the interviews resulted in six themes: being like everybody else; facing lack of knowledge and understanding; needing to be in control; taking full responsibility; still in need of support; and thoughts on

the future life. The themes are presented in the following sections.

Being like everybody else

Young people with Type 1 diabetes reported that they had a lifestyle like other young people. It was important to them to be seen as people like everybody else. One participant said, 'I'm not my diabetes; I'm foremost a person like others'. The participants engaged with school, work and other interests like ordinary people in their age group. Participants emphasized that it was important during childhood to do the same things as their friends and not be hampered by their parents, despite their illness. These young people explained that their parents were supportive and made it possible for them to be involved in a variety of normal activities. It was obvious to them that their parents made an effort to help them live normal lives and not feel different because of their illness.

Those participants diagnosed with diabetes at an early age said they had difficulties imagining a life without the illness, as it was so fully integrated into their daily life. They thought that it might be more difficult to be diagnosed later than earlier in life, as they did not remember and know about a life without diabetes. One participant diagnosed in early childhood said, 'I live my life with diabetes and don't know what it would be like to live without'. Young people diagnosed in adolescence could refer to a life before the diagnosis, and were therefore more aware of the changes they had to make to their lives.

The participants reported that most people close to them, including their family, friends and workmates, were well informed of their illness. However, participants described this as a conscious choice to tell or not tell others about their diabetes because they did not want to make diabetes the focus of their relationship. On the other hand, they said that they wanted other people around them to be aware of what might happen if they had reactions to a low blood sugar level. Several of the participants expressed like this, 'I have told my close friend, if something happens and I need help it's safe for me that they know what to do'.

Facing lack of knowledge and understanding

These young people living with Type 1 diabetes reported that they had to face the fact that most of the people around them did not have much knowledge or understanding about their illness. They noted that, generally, most of the people around them did not understand the different types of diabetes. A common opinion among people they met was that diabetes was caused by unhealthy habits like eating too much sugar. It was a provocative experience to meet this ignorance from other people, which sometimes even included health care professionals. A participant expressed, 'it's provoking to meet ignorant people and misconceptions about diabetes'. The participants said that they often had to defend themselves by explaining that Type 1 diabetes

was not caused by circumstances under their control. Many of the participants stressed the importance of raising awareness about the true nature of Type 1 diabetes. They were willing to teach others about their illness, and a lot of people they met were interested in learning more. Young people stated that raising awareness of the different types of diabetes should also be an important task for healthcare professionals.

Participants said that it was not easy for other people to understand how it felt to live with Type 1 diabetes. They meant that people living close to them as parents, siblings and partners could understand to some extent, but not fully. One participant said, 'I don't think anyone can understand what it feels like to live with it every day'. As they had to constantly account for their illness, it was important for participants to be met with at least some understanding of their situation. Participants reported that sometimes even the people closest to them clearly demonstrated that they did not understand how important it was for the participants to manage their illness. However, many people around them also showed great respect and wanted to learn more about Type 1 diabetes.

Youth people with Type 1 diabetes said that visiting adult services was more difficult because the diabetes nurse often focused on how the blood glucose has been and rarely offered the participants an opportunity to talk about their daily lives. When the participants compared adult health care providers with child healthcare providers, the child health care providers were more capable of considering the total life situation. One participant expressed, 'they forget that I'm a human being and just focus on my blood glucose level'.

Needing to be in control

According to participants, having control of their illness was an important part of feeling good. They were well aware of how their bodies reacted, both when they had control and when they did not have control. They said that they knew how to live to ensure greater control, including eating healthy food, exercising regularly, and having routines for insulin injections and blood glucose tests. Although participants had this knowledge, it was not always easy to implement this information like they should in order to ensure control over their own lives. Some participants wanted to lose control once in a while and not live as they normally did. Young people diagnosed with diabetes as adolescents said that they were strict about eating healthy and that their blood glucose level was in balance after onset. However, both those young people diagnosed as children and those diagnosed at a later age reported that living strictly also meant that they could not be spontaneous; the participants felt limited and thought they could not do all they wanted to do.

Participants said that to be empowered to do everything they wanted to do, it was important that they planned for it. For example, activities like travelling or

hard physical training was described as fully possible with enough planning. A participant said, 'I like to be active doing different kinds of activity, I just have to plan for it'.

Some participants used an insulin pump, which was described as a helpful tool that allowed them to maintain control. None of the participants reported using any smartphone or computer application to manage their diabetes, as they did not find these apps to be necessary. Several of the participants had previously tried to use diabetes apps, but they considered these apps to be more problematic than helpful. They felt like they had better control over their illness by taking their own notes, listening to signals from the body and knowing themselves.

Taking full responsibility

Young people living with Type 1 diabetes said that they had taken full responsibility for their illness, often several years before entering adulthood. When growing up, it was very important for them that their parents gradually relinquished responsibility and trusted them to manage their own illness. They explained that it was often hard for their parents to give up control of the illness, but it was necessary for the participants to manage their own lives. Some of the participants reported having difficult discussions with their parents about letting them taking responsibility for their own illness. They described being grateful for having their parents help during their growth. It's likely that the illness has caused these participants to mature faster than normal young people of the same age because of all the time and focus they had to dedicate to managing their life with diabetes. One participant diagnosed in school age said, 'I have taken full responsibility since I was 15 years old and it has made me more mature compared to my friends'. One of the participants was diagnosed with Type 1 diabetes at the age of 20, which led to this participant taking full responsibility from the beginning. This participant said that the diagnosis at that age was difficult because of the lack of parental or familial support and described a feeling of being very lonely.

Still in need of support

Participants emphasized that even if they stood on their own feet, support from friends and family was critically important. Participants diagnosed at a very young age said that the most important support when growing up was from their parents, especially the mothers. Later in life, as young adults, family support was still necessary but not to the same extent, as support from partners and friends became more essential. Several of the participants expressed concerns about having low blood glucose levels and thereby not being able to take care of themselves. Because of these worries, they often felt safer having people nearby who knew what to do. Participants reported that shifts in their blood sugar levels seemed to affect their whole body, including their temper. It was helpful for them to share this with the people who knew them well so that they could have a

better understanding of their behaviour. Some of the participants found it helpful to share and take part in the experiences from other people with Type 1 diabetes, from support group websites, blogs and patient associations, but other did not want to get involved. One participant said, 'I listen to others experiences, it's supportive'. Another participant said, 'I never read blogs, they affect me in a negative way'.

According to participants, the transition from child healthcare services to adult healthcare services was a great change. Several of them had met the same diabetes nurse and physician since the onset of their illness, and they felt like they knew each other very well. Compared to child healthcare services, adult services focused less on their total life situation and more on their blood sugar levels. They also noted that adult services required fewer scheduled visits. One of the participants had only experienced adult healthcare services, with only a few visits. This participant wanted to have more frequent visits, as she experienced her diagnosis as a difficult situation. She felt very lonely in her illness and was very much in need of psychological and emotional support. Despite the need for support, the relationships and support from healthcare professionals were described by several of the participants as being in the background when compared to the support from more significant people in their lives.

Thoughts on the future life

Young people with Type 1 diabetes said that they felt they were mostly living the life they wanted to live and did not have so many concerns about the future. They were aware of the complications of Type 1 diabetes, but noted that the available medication and treatment has improved and will continue to improve, so they tried to not think about suffering complications in the coming years. One participant said, 'to be honest I rarely think about complications'. Several of the participants mentioned the desire to have children in the future, but knew that it could be different from an average pregnancy and riskier for both the mother and the baby. Participants said that they felt awkward when their diabetes nurse informed them about the difficulties with pregnancy and diabetes. Although it was important to them to receive this information, the unemotional attitude of the nurses made the situation more difficult than it needed to be.

Discussion

In this article, we explored how young people describe living with Type 1 diabetes when entering adulthood. Results in this study show that young people with Type 1 diabetes describe themselves as similar to other young people in the same age group, which was good for them because they wanted to be seen just like everybody else. This is not uncommon, as young people with long-term illnesses usually view themselves and their lives similarly

to their healthy peers.²⁰ It is therefore significant that nurses are well aware that young people living with a long-term illness seek normalcy, focus on feeling good, and resist being defined only by their disease.²¹ Clinicians need to spend more time on how young people care for their diabetes than on outcomes of that treatment. Despite this, a lot of clinical time is still focused on the devices of diabetes care. Although testing and treatment are important tools in improving outcomes, they will have little impact on adolescent patients until the developmental consequences of diabetes are addressed.²² Understanding the challenges faced by young people living with Type 1 diabetes is an important first step to improving diabetes outcomes for this age group. The challenge must be addressed to assist youth in learning to manage their disease and promote healthy outcomes.²³ It is important for healthcare professionals to understand the emotional, social and cognitive factors for being able to assist young adults with Type 1 diabetes achieve good health outcomes by prioritizing goals and plan flexible, timely, individualized and collaborative treatment.²⁴

Results from interviews with participants in this study show that it is significant for young people growing up with Type 1 diabetes to be enabled to do the same as their friends and not be hindered by their parents. Another study identified a challenging aspect of living with and managing diabetes, which was feeling different or lonely.²³ On the other hand, the young people in this study who were diagnosed at an early age lived a life with the diabetes so integrated in their life that they had difficulties imagining a life without diabetes.

Results show that young people living with Type 1 diabetes often have to face a lack of knowledge and understanding from the people around them. According to Carroll and Marrero,²² it is difficult for friends to understand an adolescent's situation living with Type 1 diabetes. It is important for these young people that their friends and families understand what it means to have Type 1 diabetes. In order to provide support for young people with this illness, it is very important to have knowledge of how they perceive their situation. Young people in this study stated that raising awareness of different types of diabetes is an important task for health care professionals.

Young people in this study emphasized that feeling good meant being in control and living a life in which the illness was integrated into their daily routines. This is in line with other research,⁹ showing that adolescent with Type 1 diabetes feel that living a regular life is the best way to effectively manage their condition. In another study, adolescents expressed a desire to have more control over their lives by being more involved in making decisions about managing the illness.²⁵ However, the general opinion among adolescents was that diabetes exerted control over their lives and thereby required them to take more responsibility than their friends.²²

Young people living with Type 1 diabetes often took full responsibility for their illness several years before entering adulthood. In line with this result, other research highlighted that having diabetes may promote a degree of maturity earlier than others in the same age group.^{26,27} Further, results show that personal growth occurs when these young people are shown respect for their ability, capacity, involvement and trust. It is worth remembering that a long-term illness is an additional burden that can make life more difficult. Another study showed that teenagers with Type 1 diabetes alternate between effectively managing the disease and needing support from others.²⁸ Feeling confident and receiving confirmation from others helps them become independent and learn to better cope with their illness. However, there may be an emotional struggle for young people with diabetes to take care of everyday problems and manage self-care every day for the rest of their lives. Among teenagers with Type 1 diabetes, the transition toward autonomy is complex, characterized as hovering between parental dependency and a willingness to make one's own decision. This situation may lead to confusion about the responsibility of self-management.²⁸ The importance of autonomy support was shown in a study, there the result show an indirect relationship between autonomy support and diabetes distress. Autonomy support was associated with increased perceived competence, which was associated with reduced distress.²⁹ A study shows that the use of a life skills approach, made outpatient visits person-specific and meaningful, improving cooperation patterns by combining reflection sheets and advanced communication skills. This helped adolescents, healthcare professionals and parents to discover the adolescents' resources and reflect on their internal reasons for behavioural changes.³⁰

For children, particularly the older ones, transition was a natural and normal part of growing up, looking forward to the future, moving on, and becoming independent about the choices and decisions they faced. Whilst transition was seen as normal for the children, parents perceived it as more troubling, as they saw it as both as a 'moving on', which was good, and a 'moving away', which brought with it concerns and fears.³¹

Support was significant even for young people standing on their own feet. These results are in accordance with previous research showing that parental support was the most important form of support for children growing up with this illness.^{22,32} However, as young adult support from partners and friends became more important, and parental support became somewhat less important over time. Friends provide support to young people with diabetes by accepting them into their group, treating them as normal people, and at the same time, worrying about their feeling sick.¹⁰

Young people in this study found it hard to decide whether to inform others about their diabetes, as they did not want to be treated as outcasts because of their diabetes. On the other hand, having people nearby who

knew what to do if they needed help gave them a valuable sense of security. This agrees with other research showing the importance of having friends who understand diabetes so they could help in case of sudden fluctuations in blood sugar levels.²⁵ Friends became a source of support for young people with diabetes as they became less dependent upon their families. As noted by Adams, it is worth bearing in mind that chronic illness has a considerable impact not only on the patient, but also on the patient's family, friends, employment and social support network.³³ Part of a nurse's role is to recognize this impact and provide support, education and encouragement to the patient and the family.

Young people in this study reported that visiting adult healthcare services was more difficult because the diabetes nurse often focused only on the blood glucose level and it was rare for the young people to have an opportunity to talk about their daily life. When comparing adult healthcare services with child health care services, the child health care service were generally more successful in considering the total life situation of these young people with diabetes. Result indicates that the transition from child healthcare services to adult health care services was a great change for young people with Type 1 diabetes. According to another study, adolescents with chronic illness undergoing healthcare transitions often have substantial unmet needs.³⁴ Well-organized healthcare transitions are needed to ensure high-quality care, so improvements are clearly needed in this area of health care for young people with diabetes. A literature review stated that the transition from children and youth to adult care does not always work well for young people with diabetes.¹¹ Ultimately, the timing of transfer to adult care should be determined by patient readiness rather than age.³⁴ In most research studies, it is accepted that the transition process should respond to the needs of the individual young person and, therefore, has to be participative, flexible and supportive.³⁵

As result shows, young people with Type 1 diabetes did not worry much about the future. This is in line with another study showing that young people are more cognizant of the events and their meaning when they occur and less about the consequences they may bring in the future.¹⁰ This behaviour may be seen as uncommitted and irresponsible, since no priority is given to preventing diabetes complications. On the other hand, another study showed that thoughts about diabetes-related complications frighten young people, who are more concerned about becoming independent and being able to plan for the future and who may not necessarily think about what life without diabetes would have been like.¹²

Limitations of the study

One limitation of this study is that this inquiry involved a limited number of participants; the results might have been different with more participants. On the other hand, qualitative inquiry focuses in depth on a relatively

small sample selected purposefully, so there are no criteria or rules for sample size. The sample size should be large enough to achieve variation of experiences, but small enough to permit a deep analysis of the data.³⁶ However, one strength of this study was that the participants were spread out across the country. They were all interested and willing to share their experiences, which might have influenced the results to be positive; those who were not interested in participating might have different experiences. The researchers were open to identifying when sufficient density of the data was achieved, which occurs when the researcher judges that further data gathering would not contribute to deepening the understanding of the phenomenon studied. Thorne recommends follow-up interviews in order to clarify data meaning.³⁷ In this study, we did not conduct any follow-up interviews, because our initial interviews yielded a large amount of richly described data. One challenge of the analysis was to find the appropriate degree of interpretation and abstraction without changing the participants' own descriptions. During the analysis, the researchers tried to be as open-minded as possible to avoid influencing the interpretations. The analysis was guided by discussions between the researchers in the search for interpretive descriptions of the phenomenon. The researchers agreed that the presented description was the most reliable, although alternative descriptions were considered. Results from this study are contextual and cannot be generalized, and this is not the goal of qualitative research, but the results from this context can be cautiously transferred to others in similar situations.

Conclusion

The knowledge gained from this study can give healthcare professionals insight into how young people experience living with Type 1 diabetes when entering adulthood. It is worth bearing in mind that people with Type 1 diabetes are in need of lifelong healthcare services and therefore the relationship with their healthcare service is of paramount importance to them. In general, the results show that young people describe their life situation as positive and they deal with their diabetes naturally. They are skilled in managing Type 1 diabetes and can thereby get the best out of their lives. They can experience well being when they live a normal life like others in their age group. However, the lack of knowledge and understanding from other people in their life affects them. From that point of view, it is significant to change traditional nursing care and to be more open-minded about meeting them from their perspective and with a focus on their individual needs, instead of focusing primarily on treatment and blood sugar levels. It is important to plan for a smooth transfer to adult health care services, which indicate the need for a planned transition programme. For ensuring a smooth transition to adult health care service it is vital with support and information. Development of autonomy helps young people

to make decisions and take care of themselves. An important task is learning the skill that will help them managing their own lives and make choices. This awareness is of utmost importance for healthcare professionals who are engaged in treating young people with Type 1 diabetes, to enable to support and facilitate entering adulthood with a more complex level of understanding of their unique experiences. To succeed, it is vital to meet them and listen to their experiences, identify their unique needs, give them attention as individuals and support them by strengthen their autonomy.

Acknowledgements

The authors would like to thank all participants for their willingness to share their experiences.

ORCID

Birgitta Lindberg  <http://orcid.org/0000-0001-7140-625X>

References

- Berhan Y, Waernbaum I, Lind T, Möllsten A, Dahlquist G. Thirty years of prospective nationwide incidence of childhood type 1 diabetes: the accelerating increase by time tends to level off in Sweden. *Diabetes*. 2011;60(2):577–81.
- Cullberg J. Kris och utveckling: En psykodynamisk och socialpsykiatrisk studie. Stockholm: Natur och kultur; 2003.
- Woodgate RL. Adolescents' perspectives of chronic illness: "It's hard". *J Pediatr Nurs*. 1998;13(4):210–3.
- Boice MM. Chronic illness in adolescence. *Adolescence*. 1998;33(132):927–39.
- Doherty Y, Dovey-Pearce G. Understanding the developmental and psychological needs of young people with diabetes: implications for providing engaging and effective services. *Pract Diabetes Int*. 2005;22(2):59–64.
- Christie D, Viner R. ABC of adolescence. Adolescent development. *BMJ*. 2005;330:301–4.
- Faulkner MS. Quality of life for adolescents with type 1 diabetes: parental and youth perspectives. *Pediatr Nurs*. 2003;29(5):362–8.
- Wilson V. Students' experiences of managing type 1 diabetes. *Paediatr Nurs*. 2010;22(10):25–8.
- Huus K, Enskär K. Adolescents' experience of living with diabetes. *Paediatr Nurs*. 2007;19(3):29–31.
- Damião EBC. "Being transformed by illness": adolescents' diabetes experience. *Rev Lat Am*. 2007;15(4):568–74.
- McDonagh J, Gleeson H. Getting transition right for young people with diabetes. *Eur Diab Nurs*. 2011;8(1):24–9.
- Roper SO, Call A, Leishman J, Ratcliffe GC, Mandelco BL, Dyches TT, *et al*. Type 1 diabetes: children and adolescents' knowledge and questions. *J Adv Nurs*. 2009;65(8):1705–14.
- Kyngäs H, Rissanen M. Support as a crucial predictor of good compliance of adolescents with a chronic disease. *J Clin Nurs*. 2001;10(6):767–73.
- Scholes C, Mandelco B, Roper S, Dearing K, Dyches T, Freeborn D. A qualitative study of young people's perspectives of living with type 1 diabetes: do perceptions vary by levels of metabolic control? *J Adv Nurs*. 2013;69(6):1235–47.
- Thorne S, Kirkham SR, MacDonald-Emes J. Interpretive description: a non-categorical qualitative alternative for developing nursing knowledge. *Res Nurs Health*. 1997;20(2):169–77.
- Mishler E. Research interviewing: context and narrative. Cambridge, MA: Harvard University Press; 1986.
- Thorne S, Kirkham SR, O'Flynn-Magee K. The analytic challenge in interpretive description. *Int J Qual Methods*. 2008;3(1):1–11.
- World Medical Association [cited 2015 June 21]. Available from: www.wma.net/en/10home/index.html
- Svensk författningssamling 2003:460 lag (2003:460) om etikprövning av forskning som avser människor [Ethical review of research involving humans] [cited 2015 June 21]. Available from: www.riksdagen.se/sv/Dokument
- Taylor RM, Gibson F, Franck LS. The experience of living with a chronic illness during adolescence: a critical review of the literature. *J Clin Nurs*. 2008;17(23):3083–91.
- Taylor RM, Gibson F, Franck LS. A concept analysis of health-related quality of life in young people with chronic illness. *J Clin Nurs*. 2008;17(14):1823–33.
- Carroll AE, Marrero DG. The role of significant others in adolescent diabetes: a qualitative study. *Diabetes Educ*. 2006;32(2):243–52.
- Freeborn D, Dyches T, Roper SO, Mandelco B. Identifying challenges of living with type 1 diabetes: child and youth perspectives. *J Clin Nurs*. 2013;22(13):1890–8.
- Rasmussen B, Ward G, Jenkins A, King SJ, Dunning T. Young adults' management of type 1 diabetes during life transitions. *J Clin Nurs*. 2011;20(13):1981–92.
- Christian BJ, D'Auria J, Fox LC. Gaining freedom: self-responsibility in adolescents with diabetes. *Pediatr Nurs*. 1999;25(3):255.
- Berntsson L, Berg M, Brydolf M, Hellström A. Adolescents' experiences of well-being when living with a long-term illness or disability. *Scand J Caring Sci*. 2007;21(4):419–25.
- Carroll AE, Marrero DG. How do parents perceive their adolescent's diabetes: a qualitative study. *Diabet Med*. 2006;23:1222.
- Karlsson A, Arman M, Wikblad K. Teenagers with type 1 diabetes – a phenomenological study of the transition towards autonomy in self-management. *Int J Nurs Stud*. 2008;45(4):562–70.
- Mohn J, Graue M, Assmus J, Zoffmann VB, Thordarson H, Peyrot M, *et al*. Self-reported diabetes self-management competence and support from healthcare providers in achieving autonomy are negatively associated with diabetes distress in adults with Type 1 diabetes. *Diabet Med*. 2015;32(11):1513–9. doi:10.1111/dme.12818
- Husted GR, Esbensen BA, Hommel E, Thorsteinsson B, Zoffmann V. Adolescents developing life skills for managing type 1 diabetes: a qualitative, realistic evaluation of a guided self-determination-youth intervention. *J Adv Nurs*. 2014;70(11):2634–50.
- Marshall M, Carter B, Rose K, Brotherton A. Living with type 1 diabetes: perceptions of children and their parents. *J Clin Nurs*. 2009;18(12):1703–10.
- Leonard BJ, Garwick A, Adwan JZ. Adolescents' perceptions of parental roles and involvement in diabetes management. *J Pediatr Nurs*. 2005;20(6):405–14.
- Adams J. Life experience for an adolescent with type 1 diabetes: nursing strategies to support a healthy lifestyle. *Whitireia Nurs J*. 2012;19:18–26.
- Bowen ME, Henske JA, Potter A. Health care transition in adolescents and young adults with diabetes. *Clin Diab*. 2010;28(3):99–106.
- Kime N. Young people with type 1 diabetes and their transition to adult services. *Br J Commun Nurs*. 2013;18(1):14–8.
- Sandelowski M. Sample size in qualitative research. *Res Nurs Health*. 1995;18:179–83.
- Thorne SE. Interpretive description. Walnut Creek, CA: Left Coast Press; 2008.