

Intensive insulin therapy in the primary school setting: A meta-ethnographic synthesis

Anne Marks, Lesley Wilkes, Stacy Blythe and Rhonda Griffiths

School of Nursing and Midwifery, Western Sydney University, Australia

Aim: To explore how intensive insulin therapy is integrated into the primary school setting, to identify support strategies in order to inform policy and practice.

Data sources: Articles between 2005 and 2015, children aged 4–12 years.

Review methods: A meta-ethnographic comparative approach, using reciprocal translation and line of argument synthesis.

Findings: Fourteen studies with qualitative data were included. Seven major metaphors were identified: Oh, it's needles, cover your back, worried about safety, great expectations, I'm not a diabetes expert, like everyone else and working together.

Conclusion: A line of argument and conceptual model was developed from the metaphors and identified; competent diabetes care, risk management and a sense of normality and understanding as key areas that required addressing to improve integration of intensive insulin therapy. Collaboration and planning between the home, health, education and legal systems is also essential.

Key words: Diabetes, Insulin, School, Children, Meta-ethnography

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Introduction and background

Type 1 diabetes is one of the most common, and fastest growing, chronic health conditions in childhood. It is estimated that 80 000 children aged less than 15 years develop Type 1 diabetes worldwide each year.¹ Studies indicate, the annual incidence rate of new cases among children aged 5–9 years is also rising.^{1–5} Consequently, the number of children with diabetes attending primary school has increased and is likely to escalate even further. This will add pressure in terms of resources and planning for the ongoing needs of children, their families, and education and health systems.

In addition, treatment of Type 1 diabetes has changed significantly over the past 20 years. Intensive treatment (four injections or pump therapy) using insulin analogues has improved glycaemic control without the increased risk of hypoglycaemia.⁶ Therefore, the current recommended treatment regime for children with Type 1 diabetes involves either four daily injections of insulin or insulin pump therapy.^{7,8} This intensive insulin therapy also necessitates blood glucose testing four to six times per day to guide insulin adjustment and to detect hypoglycaemia.⁸

The introduction of intensive diabetes treatment for children has placed more demands on the primary school setting (children aged 4–12 years), as insulin and blood glucose tests are required during the school day.

Young children may face obstacles when they enter the school system, as generally parents perform diabetes treatment due to their developmental stage and the complexity of the tasks required.

The rising number of children with Type 1 diabetes in the younger age groups and the use of intensive insulin therapy highlight the need for research in this area in order to ensure that children receive adequate diabetes care at school.

The meta-ethnographic review

Aim

To explore how intensive insulin therapy is integrated into the primary school setting, to identify support strategies in order to inform policy and practice.

Design

The qualitative synthesis was conducted in seven phases following the meta-ethnographic comparative approach by Noblit *et al.*⁹ (Box 1). This method provides a framework to critically and systematically examine qualitative data to enable an interpretive review.⁹ It requires integration and comparison of findings from several studies to provide a new fuller conceptualization from the perspective of the synthesizer,¹⁰ which can then inform nursing practice. To the authors' knowledge this is the first qualitative synthesis focusing on intensive insulin therapy in the primary school setting.

Box 1. Seven phases of meta-ethnography⁹

1. Getting started
2. Deciding what is relevant to the initial interest
3. Reading the studies
4. Determining how the studies are related
5. Translating the studies into one another
6. Synthesizing translations
7. Expressing the synthesis

Phase 1: getting started

The first phase involved identifying a research aim that could be informed by qualitative data and providing a rationale for the contribution the results will make to the area of study.¹¹ The aim of this synthesis was: to explore how intensive insulin therapy is integrated into the primary school setting to identify support strategies in order to inform policy and practice. The aim was decided after conducting a previous literature review and research study examining diabetes care at primary school.^{12–14} It is anticipated that synthesizing the experiences of intensive insulin therapy in the primary school setting and developing a theory model will guide health and education systems in the planning of effective diabetes care at school.

Phase 2: deciding what is relevant to the initial interest

The next phase involved defining the focus of the synthesis, locating relevant studies, inclusion decisions and quality appraisal.¹¹

Search methods

The literature search was undertaken by the lead author (A.M.) and the process is outlined in Figure 1. Search terms were a combination of the following: diabetes mellitus Type 1, diabetes, primary school, diabetes educator, teachers, parents and insulin. Diabetes educators, teachers and parents were initially used as search terms as they were most likely to be experienced in the care of diabetes at primary school. The search was limited to articles published between January 2005 and January 2015 as intensive insulin therapy was more commonly used during this period.

Titles and abstracts from the database search were screened and resulted in 20 relevant articles. The full text of the 20 articles from the database search and 10 articles from hand searching were then reviewed. Articles were included if they were published between January 2005 and January 2015, contained qualitative data about insulin therapy at primary school, involved children in primary school (aged 4–12 years) or those experienced with primary school children (parents, school and diabetes staff). Articles were excluded if they contained quantitative data only, opinions or reviews (16).

Search outcome

A total of 14 articles were included in the final synthesis (Table 1). The articles were from the United Kingdom (6), the United States of America (4), Taiwan (2), Canada (1) and Australia (1), with a combined sample of 407 participants. Six articles^{13,15–19} focussed on primary school and eight articles^{20–27} included primary and high school children. A decision was made to include these mixed articles for the following reasons. Three of the mixed primary and high school studies^{20,23,26} described the experiences of nurses (school or diabetes) and either discussed challenges of diabetes care that relate to both primary and high school children or highlighted differences between the age groups. Similarly Nurmi *et al.*²⁴ reported general diabetes issues relevant for both primary and high school. In addition, the vast majority of participants in Freeborn *et al.*²¹ (12/16) and Wilson *et al.*²⁷ (70/73) were from the target age group. Data were easily identified between primary and high school groups in MacMillan *et al.*²² and although children were aged between 7 and 14 years in the Smaldone *et al.*²⁵ study, the focus of the research was on parents' experiences of adaptation starting from their younger years of diagnosis (5 years of age). Two articles^{16,17} reported findings from the same study and as each had different foci they were both appropriate for the review. All authors agreed on the inclusion of the final synthesis articles.

Quality appraisal

In order to evaluate and describe the quality of the studies, the lead author (A.M.) conducted a quality appraisal of the articles using criteria described by Atkins *et al.*¹¹ (Table 2). Although a number of authors have assessed the quality of papers included in a synthesis, there are mixed opinions of its usefulness. Quality appraisal can identify gaps in reporting and flaws in interpretation of study findings, which may impact on the results of the synthesis.¹¹ However, articles are often not excluded based on quality assessment, as poorer quality studies tend to contribute less to the synthesis^{11,28} and poor reporting of methods does not necessarily mean poorly conducted research.¹¹ In addition, published research articles are limited in length depending on the journal guidelines, which may prohibit a detailed description of the study method.²⁹

The majority of quality appraisal criteria (11/13) were evident in the 14 articles in this synthesis (Table 2). The two areas that were lacking included justification of the qualitative approach^{13,15,20–22,27} and description of the researchers' role.^{13,19,24,27} All authors agreed to include the 14 articles in the final synthesis as most of quality criteria were addressed and the data were considered important to the study aim.

Phase 3: reading the studies

Data abstraction and synthesis

The third phase involved becoming familiar with the included studies by reading and re-reading articles and

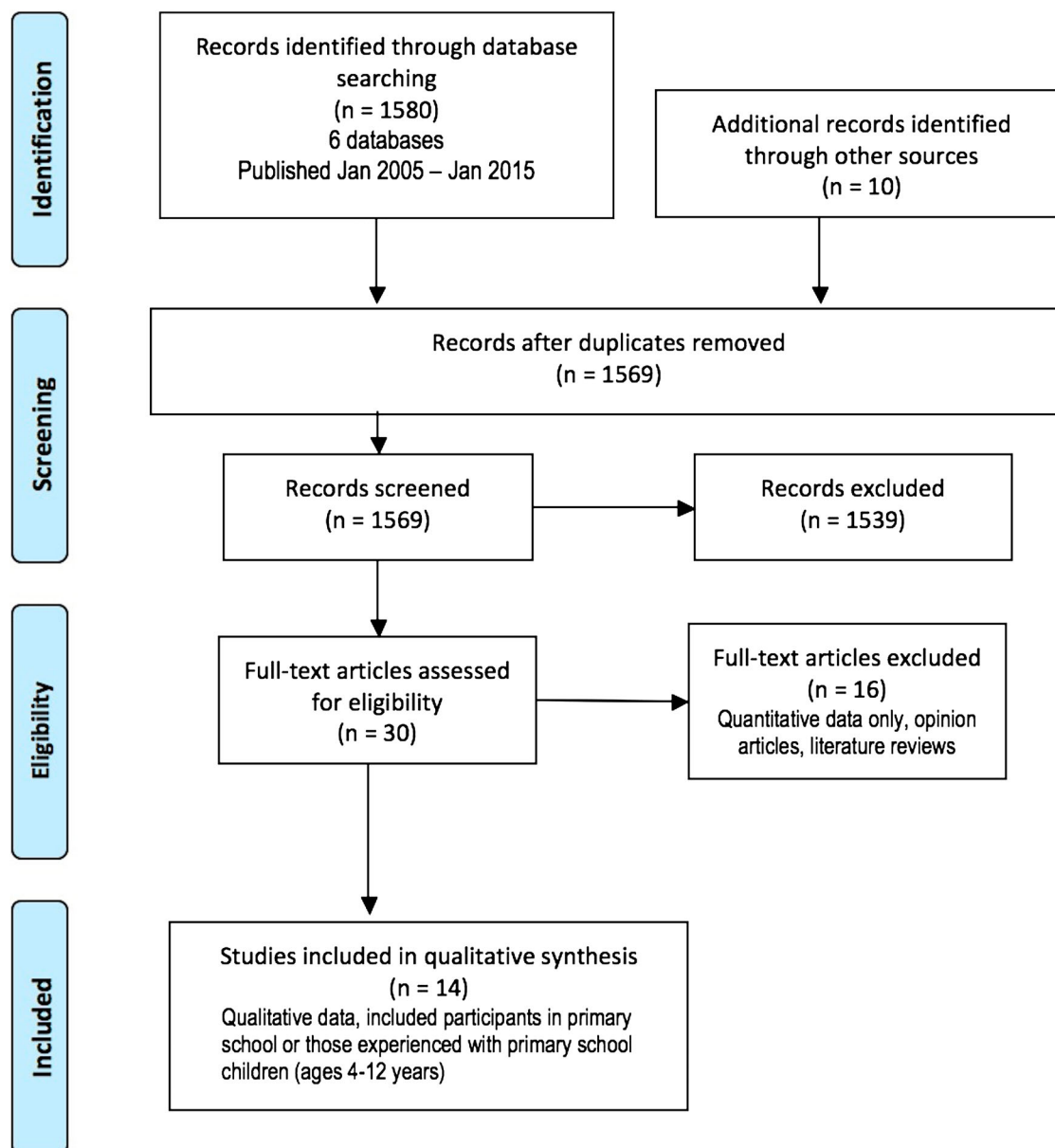


Figure 1 The search process.

identifying key themes.¹¹ All authors read the synthesis articles. Noblit *et al.*⁹ refer to themes, concepts and phrases as metaphors. Metaphors from the 14 studies relevant to the synthesis aim were extracted and recorded on a summary table by the lead author (A.M.). The summary included primary metaphors (data from primary research participants) and secondary metaphors (interpretations from primary study authors).

Phase 4: determining how the studies are related

This phase required a comparison of the study metaphors to determine how they were related and to identify the appropriate form of synthesis.³⁰ On review of the summary table, three common metaphors became apparent: diabetes care, risk and knowledge.

These metaphors were used to guide the next stage. Studies were directly comparable as they discussed similar issues with integration of intensive insulin therapy in the school setting. Although studies provided different perspectives from various participant types, countries and ages, the findings were generally not in opposition to each other. Therefore, the appropriate form of synthesis was considered to be reciprocal translation (directly comparable) and, in addition, a line of argument synthesis to create a new conceptual model.

Phase 5: translating the studies into one another

Studies were then translated into one another by comparing metaphors from one article with another to find similarities and differences.¹¹ Articles were organized according to the participant type: children, parents,

Table 1 Literature summary.

Author/location	Aim	Method	Sample	Findings
[1] Alderson <i>et al.</i> ¹⁵ <i>United Kingdom</i>	To investigate the seldom published views of children with Type 1 diabetes about their condition and ways in which they share in managing their medical and health care with adults	Semi-structured interviews	24 children aged 3–12 years	Children had high level of knowledge, understanding and skill. Key goals to be normal, just get on with life
[2] Boden <i>et al.</i> ¹⁶ <i>United Kingdom</i>	To examine the concerns of primary school staff working with children with Type 1 diabetes and their parents, and relate these concerns to the views of health care professionals working with school personnel	Semi-structured interviews	22 teaching staff from 13 primary schools 5 diabetes nurses	Concern about injecting and BGL testing, reactions of parents to school decisions, fear
[3] Boden <i>et al.</i> ¹⁷ <i>United Kingdom</i>	To explore the attitudes of primary school staff in relation to managing children with diabetes			Concerns about managing a pupil with diabetes: apprehension and expectations, vulnerability and accountability, problematic or risky children, the school environment
[4] Darby ²⁰ <i>United States of America</i>	To examine the experiences of school nurses caring for students receiving insulin pump therapy	Semi-structured interviews	11 school nurses: all experienced with elementary and/or middle school students (age 5–14)	Feeling scared, developing trust, knowing your students, working with Children's Hospital, teaching and learning, talking the talk, dealing with pump problems, calculating challenges
[5] Freeborn <i>et al.</i> ¹⁸ <i>United States of America</i>	To identify challenges children and youth with Type 1 diabetes encounter from their own perspectives	Focus groups	16 children aged 5–12 years	Low blood glucose, self-care activities, feeling different or alone
[6] Freeborn <i>et al.</i> ²¹ <i>United States of America</i>	To identify school challenges faced by children and adolescents with Type 1 diabetes mellitus and identify opportunities for nurse practitioners to provide leadership and direction to children, adolescents, parents, schools and communities related to Type 1 diabetes mellitus care and management	Focus groups	14 mothers and seven fathers of 16 children – Mean age 9.08 years (SD 3.78) 12/16 aged 4–12 years	School personnel, the medical directive plan, the child's classmates, school lunches, physical education class
[7] Lin <i>et al.</i> ¹⁹ <i>Taiwan</i>	To explore the essential structure of mothers' life experience when helping 1st–3rd grade children with diabetes make life adjustments at school	Interviews	12 mothers of 1st–3rd grade children (7–9 years)	Worrying about the child's safety, creating a safe environment, building the child's self-care abilities, improving academic achievement, assisting with peer relationships, normalizing the child's life
[8] MacMillan <i>et al.</i> ²² <i>United Kingdom</i>	To explore perceptions of facilitators and barriers to physical education in youth with Type 1 diabetes and to determine how schools can help these individuals to be physically active	Interviews and focus groups	8 children 7–9 years, 8–12–14 years, 16 parents, 2 drs, 3 dietitians, 4 nurses, 37 teachers	Differences between primary and secondary school, areas requiring address at all schools, what teachers and schools can do to help accommodate youth with Type 1 diabetes
[9] Marks <i>et al.</i> ¹³ <i>Australia</i>	To explore the management of Type 1 diabetes in Australian primary schools (K-yr 2) from the parent's perspective. Explore concerns of parents and strategies for improvement	Questionnaire including open-ended questions	66 parents of children in kindergarten – year 2 ages 4–8 years	Taking an interest, a normal school experience, away from me in other people's care, training, training and more training
[10] Marshall <i>et al.</i> ²³ <i>United Kingdom</i>	To examine the role of nurses in supporting care of children with diabetes in schools and early years settings	Focus groups and individual telephone interviews	47 nurses involved in delivering support in schools	Ambiguity and inadequacy of legal and other national guidance, unpredictability of schools' responses, practical problems in establishing support for children's diabetes care, limited evidence about effective practice, variations arising from uncertainties about best practice
[11] Nurmi <i>et al.</i> ²⁴ <i>Canada</i>	To explore a parent's sense of meaning in relation to the parenting of a child with Type 1 diabetes	Interviews	13 parents of 10 children – age 7–17 years	Being like everyone else, protecting the children
[12] Smaldone <i>et al.</i> ²⁵ <i>United States of America</i>	To explore perceptions of psychosocial adaptations in parenting young children with Type 1 diabetes (T1DM) from diagnosis through childhood	Interviews	14 parents of 11 children aged 7–14 years	Diagnostic experiences: frustrations, fears and doubts. Adapting to diabetes. Negotiating developmental transitions

Continued

Table 1 Continued.

Author/location	Aim	Method	Sample	Findings
[13] Wang <i>et al.</i> ²⁶ Taiwan	To obtain an understanding of the essences of five experienced Taiwanese school nurses' lived experience of caring for students with Type 1 diabetes mellitus (T1DM)	Semi-structured interviews	Five school nurses 3 from elementary schools (aged 6–12 years)	I try to put myself in the parents' and students' shoes, I am not a diabetes expert, managing T1DM requires teamwork, caring for students is a struggle with practical limitations
[14] Wilson <i>et al.</i> ²⁷ United Kingdom	To examine how children with diabetes are managing their condition in the school setting using pump therapy and multiple daily injections	Questionnaire	Seventy-three parents of children aged 4–11 years (70), 12–16 years (3)	Clinical needs, pump therapy, social activities

Table 2 Quality appraisal of articles¹¹.

Question	Yes	No
1. Is this study qualitative research? Contains qualitative data	14	0
2. Are the research questions clearly stated?	14	0
3. Is the qualitative approach clearly justified?	8	6
4. Is the approach appropriate for the research question?	14	0
5. Is the study context clearly described?	14	0
6. Is the role of the researcher clearly described?	10	4
7. Is the sampling method clearly described?	14	0
8. Is the sampling strategy appropriate for the research question?	14	0
9. Is the method of data collection clearly described?	14	0
10. Is the data collection method appropriate to the research question?	14	0
11. Is the method of analysis clearly described?	14	0
12. Is the analysis appropriate for the research question?	14	0
13. Are the claims made supported by sufficient evidence?	14	0

school staff and diabetes staff. Metaphors from the first article were compared to the second article using the three categories previously identified as a guide. The synthesis of the two articles was then compared to the next article and so on. During this process, further metaphors were identified and refined, with a final total of seven metaphors: Oh, it's needles, cover your back, worried about safety, great expectations, I'm not a diabetes expert, like everyone else and working together (Table 3). Interpretation was conducted predominately by the lead author (A.M.); however, all authors agreed on the final metaphors. Primary metaphors from the views of the participants in the original research and secondary metaphors from the primary study author's interpretations are also presented in Table 3. Direct quotes from participants in the original research are provided in Boxes 2–8. The superscript numbers in both Table 3 and Boxes 2–8 refer to the corresponding article in Table 1. A conceptual model was developed from these metaphors and will be discussed in phase 6.

Findings

Oh, it's needles!

The literature revealed that primary school teachers' initial reaction to having a child with diabetes in their class was emotional.¹⁶ These emotions were often related to the use of needles and included fear, nervousness, panic, terror and anxiety.¹⁶ Diabetes health professionals in two studies reported teachers' fear of administering insulin and felt that some schools adopted an 'anti-insulin approach'.^{16,23} Fear frequently resulted in nonparticipation, lack of interest and unwillingness of the school to assist with diabetes care.^{13,16,21} The insulin regime prescribed by the diabetes team was influenced by the school's level of involvement.¹⁶ Therefore insulin administration may be avoided at school.

When principals were difficult to contact²¹ the child's return to school was delayed. Unwillingness to assist

Table 3 Summary of concepts and metaphors.

Concepts: synthesis from review authors (conceptual model Figure 2)	Primary metaphors: views of research participants in primary studies (quotes: Boxes 2–8)	Secondary metaphors: interpretation from primary study authors
Managing risk	<p><i>Oh, it's needles:</i> Emotional responses to invasive diabetes care from school teachers and school nurses. Reluctant to assist. Impression that the school didn't care. Insulin pump therapy preferred by schools and children. Diabetes nurse's role is to negotiate care with schools.^{1,2,4–6,9,10,13,14}</p> <p><i>Cover your back:</i> Inconsistent legal framework. Risky pupils: risk minimization from staff. Vulnerability and accountability.^{2–4,6,10}</p> <p><i>Worried about safety:</i> Hypoglycaemia: school nurses and parents aimed to minimize risk. Parents questioned competence of teachers. Lack of supervision: poor teacher/pupil ratios. Under and over reaction.^{2–9,11–13}</p>	<p>Stigma related to needles – perceive child as ill, not normal. Teacher's fear is related to adult–child relations being dangerous or subject to misinterpretation. Nurse's role – encourage gradual self-care, assist, educate.^{2–4,13}</p> <p>Lacking consistent approach. School policy reflects an emphasis on illness and control of insulin. Policy and legislation is inadequate – schools determine what adjustments are made with no accountability. Nurses need to inform policy change to protect the health of the child.^{3,6,10,14}</p> <p>The mother's role of protector and educator aims to provide safety at school. Safety requires education, adequate staff and ongoing support. Nurses advocate for a safe school experience.^{4,5,7,9}</p>
Competent diabetes care	<p><i>Great expectations:</i> Expectations of school staff (management plan, administer insulin, to do everything). Confrontational approach from parents (put staff off, pressure). Teachers are not nurses (not teachers role, burden, limited support). School nurses workload too large to focus on diabetes. Expectations of parents (over-relied on). Diabetes nurse's role to mediate.^{2,3,6,8–10,12,13}</p> <p><i>I'm not a diabetes expert:</i> School staff lack diabetes knowledge, understanding of seriousness and unpredictability of diabetes. Gap between medical knowledge and practical application. School nurses willing to help but lack training, not diabetes experts. Education and training is important, often provided by parents and diabetes nurses.^{1–3,5–9,11–14}</p>	<p>Health related risks – managed by professionals outside health care area. Role of primary school is to safeguard and protect children. Diabetes care is assumed activity for primary school teachers – pseudo mother figure.^{3,6,10,12,14}</p> <p>Young children are able to self-care beyond usual child development theories. Role of teachers widely debated – increased training decreases anxiety. Knowledge needs to be translated into action.^{1–5,8,9,11,14}</p>
Normality and understanding	<p><i>Like everyone else:</i> Diabetes care inconvenient: leaving class, insulin at office excludes student. Interrupted activities: missing/disrupting meal time or class activity, feeling different, unable to participate. Normalizing: No special treatment, being like everyone else, regular kids. Impact on friendships.^{1–3,5–9,11–14}</p>	<p>Mothers build school support to normalize diabetes – accept that injecting insulin is normal. School view diabetes as a medical condition that is not a regular part of life. Parents felt this was detrimental to social health of the child. Integration of diabetes care into education and social aspects is vital, but relies on school awareness and assistance.^{3,5–7,9,11,13}</p>
Collaboration	<p><i>Working together:</i> The importance of school networks, support systems and communication (parents and diabetes nurses attended school, requires a whole school approach, school taking an interest, working in partnership, health care plan). School nurses felt isolated.^{2,4,7–10,12,13}</p>	<p>Collaboration, communication and continuity are required between parents, children, school and health professionals. Collaboration requires increased funding and resources. Diabetes services are ideally positioned to support children at school – important role of diabetes nurses.^{1,2,4,7–10,12,13}</p>

with diabetes care created stress for families and gave the impression that the school did not care or was not interested.¹³ Parents expressed that transferring from injections to an insulin pump relieved some of the stress from school staff.²⁷

However, school nurses responsible for children using insulin pump therapy described similar emotions to teachers. Initially, they were scared, intimidated, apprehensive and overwhelmed.^{20,26} They had no previous experience with insulin pumps and although they were nurses, they described the pump as being a ‘scary bird’ with ‘hidden dangers’.²⁰

One study found that the role of diabetes specialist nurses in integrating insulin therapy into schools was challenging. Nurses identified the need to negotiate with head teachers as they determined the level of cooperation from other staff.²³ Nurses appealed to the school’s moral responsibility and implications for the child.²³ The level and accuracy of diabetes knowledge held by school staff were often linked to how positively and promptly they responded.²³

Children with diabetes expressed the daily challenge of testing glucose levels and administering insulin, which caused pain and inconvenience.¹⁸ They also felt that insulin pumps were easier than injections. Interestingly, children’s ability and willingness to use needles were not age related.¹⁵ Some very young children aged 4 years were injecting themselves whilst a number of older children (aged 11 years) wanted their mothers to inject.

Box 2. Oh, it’s needles!

‘I think initially it was like, oh, it’s needles, ooh’ (School teacher, UK).²

‘You’ve got an element of nervousness going into the school, thinking, is this school going to be happy to do these injections?’ (Diabetes nurse, UK).¹⁰

Cover your back

This metaphor outlines concern about the risk for children and staff when intensive insulin therapy is used at school. Teachers spoke of their anxiety when dealing with the health care needs of someone else’s child, the reactions of parents and how their actions were open to external critique and legal investigation.^{16,17} School staff were also apprehensive about exposure to and interaction with children’s bodies during diabetes care.^{17,23} Teachers felt it was important to have formalized policies and procedures for their own self-protection.^{16,17}

However, teachers also understood that effective management would reduce disruptions in class. They reported constant surveillance, checking up and chasing of students with diabetes in all areas of the school and off-site trips.¹⁶ Teachers thought of children with diabetes as ‘risky pupils’ and became competent risk managers over time.¹⁷

Diabetes professionals reported teachers’ fear of being sued and concerns about how their actions stand

legally.^{17,23} Teachers’ concern about litigation often occurred due to advice provided by external parties such as first aid trainers.¹⁷ Similar feelings of apprehension were expressed by school nurses who understood the seriousness of becoming the sole provider of care for students on insulin pumps.²⁰ The need to ‘check and double check’ insulin therapy was emphasized.

Diabetes nurses in the UK stated that the legal and policy framework was inadequate.²³ There was no legal duty that required school staff to administer or supervise medication.²³ Authority and enforcement to ensure children received adequate support was also lacking. Diabetes care had to be negotiated on a case-by-case basis with individual schools and support was dependent on ‘good will’.²³ In the USA, federal law mandates schools to complete a medical directive plan; however, a number of parents reported that their child did not have a plan because they did not think it was important or the school thought it was unnecessary.²¹

Box 3. Cover your back

‘...you just get accused of all sorts of things that you do for the good of the child...like some people would say “oh, you took her out of her lesson, she should have been in there working, she was perfectly alright,” but you always err on the side of caution’ (School teacher, UK).²

Worried about safety

Nine studies reported concerns about safety at school. Starting school was a difficult time for mothers who worried about the shortage of teachers, lack of care and physical safety.¹⁹ Diabetes professionals were concerned about teachers’ ability to identify and treat hypoglycaemia quickly, particularly in large class sizes.¹⁶ Parents were also concerned about how to negotiate with school personnel.²⁵ They were worried about the competence of staff to provide care and found it difficult to entrust someone else with their child.^{13,19,24,25} Changes in school timetables without communication with students and parents were also a concern.¹⁶ Parents wanted to protect their children from emergencies and often advocated for their needs.^{13,19,21,24}

A number of strategies to improve safety at school were highlighted. Teachers had emergency documents and photos at key points within the school.¹⁶ Students were positioned in class to enable easy observation and access.¹⁷ Parents attended special school occasions that had a lack of predictable structure.^{13,24} Parents felt that increased communication enhanced safety at school.^{13,19} This was particularly important during the first few days of school. Mothers insisted on being involved until their child was capable of handling themselves. They set up a support network to safeguard their child, including staff and peers.¹⁹ Some strategies negatively impacted on children’s participation. For example, physical education teachers who feared

hypoglycaemia during activity used excessive caution and discouraged participation.²²

Box 4. Worried about safety

'I'm concerned that he may fall under the radar especially when the regular class teacher is absent' (Parent, Australia).⁹

Great expectations

In terms of diabetes care at school, the varied expectations of school staff and parents were discussed in a number of studies. Parents expected school administration staff and teachers to assist with developing a diabetes management plan.²¹ A number of parents expected the school to administer insulin and were upset when they refused.¹³ Some parents were frustrated that the school could not do more to help children in emergencies such as inject glucagon for hypoglycaemia, possibly due to fear.²⁴

In contrast, some parents were concerned about the burden on class teachers who were often given the full responsibility of care due to lack of support from other school staff.¹³ Parents were concerned that teachers were expected to manage their usual teaching duties and diabetes care.

Diabetes health professionals expected schools to accept help and advice and be willing to learn and participate in diabetes care.¹⁶ However, they were aware that some parents expected the school to do 'absolutely everything' and felt that this confrontational approach could scare staff.¹⁶ Diabetes professionals were concerned that this approach may prevent schools from assisting with care or developing policies for inclusion of diabetes at school.¹⁶

Teachers expressed that they were 'expected to wear so many hats' and that they were unsure how to prioritize.¹⁷ In addition, they felt overloaded and questioned the logistics of caring for children with specialized health-care needs in the classroom.¹⁷ The level of pressure varied depending on the behaviour, age and personality of the child.¹⁷

Teachers expected parents to be involved in supporting their child's diabetes.¹⁶ If this support was not provided there were implications for teachers. Teachers described these parents as 'Less engaged' and 'Irresponsible'.¹⁶ The approach by school staff varied depending on their role. For example, part-time physical education specialist teachers felt that only full-time school staff should be responsible for diabetes care.²²

Schools that had nurses on staff also had problems with providing diabetes care. School nurses discussed how busy they were with large workloads, which often made it difficult to provide adequate care.²⁶ One parent described their frustration when the school nurse wanted everything written down.²⁵

Box 5. Great expectations

'Teachers, they train to teach and the sad fact is that it's just not diabetes that impinges on their time...So, I do have sympathy for teachers who are suddenly asked to give an injection and monitor blood sugars' (Diabetes specialist doctor, UK).⁸

I'm not a diabetes expert

Parents, teachers and diabetes professionals highlighted the issue of limited training and knowledge of school staff.²² Diabetes nurses felt that staff lacked basic knowledge about Type 1 diabetes which was influenced by personal experiences and attitudes.²³ Some parents also stated that the school did not understand the seriousness of Type 1 diabetes, which impacted on the care provided.^{13,21,27} Knowledge of diabetes varied depending on the type of school staff. For instance, physical education specialist teachers were often unaware of students with medical conditions and had limited communication with others.²²

Teachers reported gaining information from experience or 'on the job' and second-hand knowledge.¹⁶ This often led to confusion about diabetes management and had serious consequences.²²

In addition, parents were concerned when the school was under- or over-responsive. One parent recalled a time when staff over-reacted to hypoglycaemia, despite a clear plan of action being in place.²⁴ Another parent was concerned about the school's casual response.²²

Teachers reported the disconnect between knowledge and practice.¹⁷ Similar issues were raised for school nurses, as they expressed their lack of adequate diabetes training and a sense of incompetence at times.²⁶ Knowledge they acquired during nursing training was often out of date and did not cover new technology. In addition, there was a gap between dealing with real-life situations and education. Often, students were the experts.^{15,26}

School nurses also expressed their lack of education and experience with insulin pump therapy.²⁰ However, they became experts over time, described as a 'growing up process'.²⁰ Some teachers thought that diabetes education from professionals would be useful.²² Teachers reported that formal training and increased knowledge improved confidence and reduced the feeling of panic.¹⁶

Diabetes nurses provided training for schools; however, the support they provided varied. Some nurses provided numerous visits for a newly diagnosed child until staff were competent and others provided two visits.²³ Parents would then continue to supervise until the staff could manage on their own. Some nurses provided annual visits for ongoing education although the increasing number of children has made this difficult.

Box 6. I'm not a diabetes expert

'There is still quite a big jump between knowing the information to then actually having a child in your care' (School teacher, UK).³

Like everyone else

Young children wanted to be accepted as normal and 'just get on with life'.¹⁵ They resented 'boring diabetes care' that interrupted activities¹⁵ and were tempted to avoid the process.¹⁸ Children often discussed the inconvenience rather than the pain of treatment.¹⁵ Missing meal breaks or other class activities at school were common complaints.¹⁸ One girl was concerned about being singled out, as she thought that she would lose her friends because of diabetes.¹⁸ Another boy was annoyed when his friends treated him differently and thought he needed protection.¹⁸ Some children expressed their frustration with other people's negative attitudes towards diabetes that created problems for them, such as a teacher refusing to take them on an outing.¹⁵

Parents and diabetes staff felt strongly that children should not be treated differently because of diabetes.²² This occurred a number of times due to inappropriate action of school staff, possibly due to lack of knowledge. Parents in one study stated that their child missed school activities including sport, class work and time with peers.¹³

One study reported that the location of medication administration is typically near the school office, often due to risk minimization by the school.¹⁷ However, this practice prompted peers to question where they were going and parents are often unhappy with the lack of classroom integration.^{17,24} It was noted that some school staff felt that separating education and medical needs was beneficial.¹⁷

Strategies to increase integration of students with diabetes were discussed in the literature. Parents and health professionals suggested that practical management strategies should not single children out, but 'subtly keep an eye on them'.^{16,24} Reviewing school policy to provide easy access to equipment and medication was also important.¹⁶ When children were a little older (8 years) parents would allow increased independence to try to normalize their life.^{19,25} Some parents reported increased independence and time with peers when their child moved to insulin pump therapy.²⁷ Likewise, children on insulin pumps stated it was easier than injections.¹⁸

Box 7. Like everyone else

'I hate diabetes! Because at school I am doing my work and then mom takes me away ... And it just sucks when I have to get away from all my friends...' (8-year-old boy, USA).⁵

'If her teacher is not there, she has to stay home as no else has been shown how to do sugar tests or knows how to look for signs (hypoglycaemia)' (Parent, Australia).⁹

Working together

Eight studies highlighted the importance of working together through communication, trust and partnership to support diabetes care at school. Parents felt at ease when the school had a positive approach, were cooperative and understanding.¹³ They felt that staff had a genuine interest in their child and were appreciative when the school was willing to learn about diabetes and support their child.^{13,25}

Teachers expressed the need for parents to be known and trustworthy before they would assist with insulin injections.¹⁷ Communication between teachers, parents and students was considered essential for a trusting relationship and confidence.²² Diabetes nurses commented that some parents create a feeling of unease amongst school staff, which may increase the reluctance of staff to get involved in care.²³ When establishing diabetes care procedures for schools, diabetes nurses often acted as mediators between the school staff and parents.²³ Health-care plans were used as a tool to share information.²³

In addition, many school nurses cooperated with parents and teachers in order to create a supportive environment and effective diabetes management at school.^{20,26} They understood the vital role that parents played due to the young age of the child and their lack of total independence. However, parental involvement with the school often impacted on employment with some leaving their jobs completely.¹³ School nurses often felt isolated. Although they wanted to work in partnership with diabetes professionals, it was difficult to organize.²⁶ This limited the opportunity for interdisciplinary communication and education.

Box 8. Working together

'They (school staff) have made transition to school so much easier' (Parent, Australia).⁹

'I can't say that would be a policy I would adopt with every parent because even though they say "oh that's fine"...with some parents you just never know' (School teacher, UK).³

Phase 6: synthesizing translations/discussion

This phase involved synthesizing translations by refining metaphors and creating new concepts and models. This phase builds on the first level of inference (translation of cases into one another). A line of argument synthesis is the second level of inference, which requires construction of an analogy about relationships between studies, interpretation and clinical inference about the whole line of argument.⁹ The studies described different perspectives on intensive insulin therapy integration at school; therefore arranging metaphors to construct a line of argument provided a more comprehensive, new interpretation of issues.³⁰

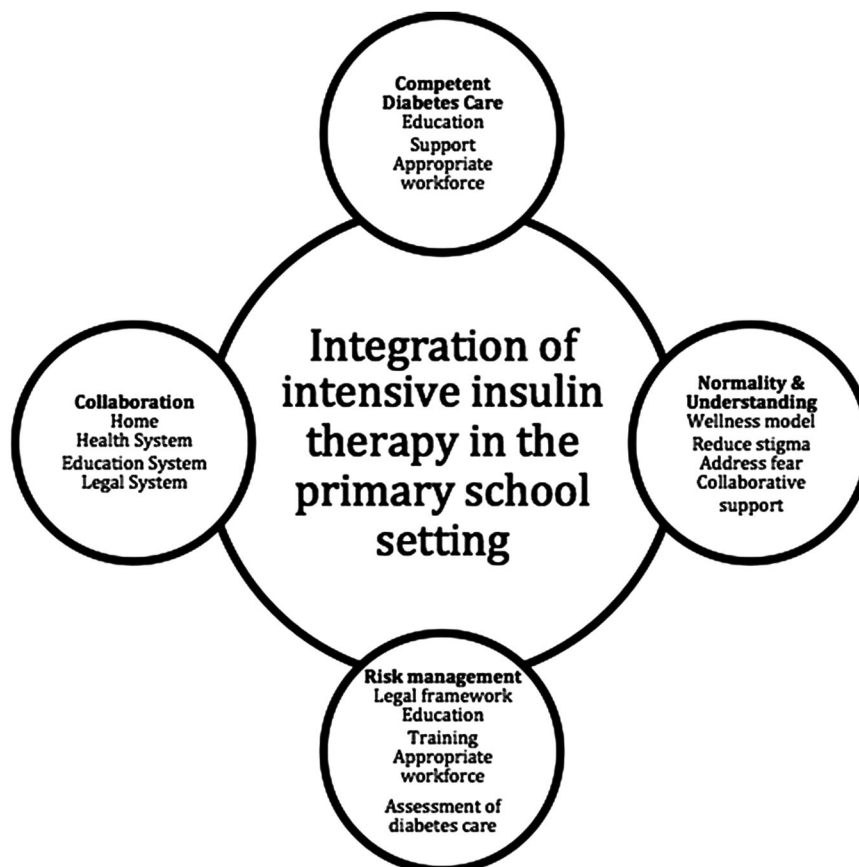


Figure 2 Integration of intensive insulin therapy conceptual model.

A line of argument and conceptual model was developed from the metaphors, to address the synthesis aim, primarily by the lead author (A.M.). However, all authors agreed on the following line of argument; integration of intensive insulin therapy into the primary school setting requires competent diabetes care, risk management and a sense of normality and understanding. In addition, collaboration and planning between the home, health, education and legal systems is essential in order to achieve effective integration.

The four overarching concepts from this line of argument are illustrated in the conceptual model (Figure 2) above: (1) competent diabetes care, (2) risk management, (3) normality and understanding and (4) collaboration. A discussion of these concepts follows.

Competent diabetes care

Children need competent diabetes care that is integrated into school routines. Competent care requires education, support and an appropriate workforce. Planning should commence early at the time of diagnosis or prior to transition to school. Parents are often in shock at this time; therefore education and support from diabetes specialist staff are essential. School staff also require education and support. However, as they are not medically trained or diabetes experts, the focus should be on key information only, so they are not overwhelmed.^{16,23}

Although diabetes nurses and teachers appear to be the most significant staff supporting children with diabetes at school, further exploration of what constitutes an appropriate workforce in both health and education systems is warranted.

Risk management

Risk management of diabetes care at school includes supporting legal frameworks, education, training, an appropriate workforce and assessment of diabetes care (type of insulin delivery). The legal implications of assisting with diabetes care including child protection and medication errors are concerns. Legal frameworks appear to be inconsistent, too rigid or non-existent.^{16,21,23} Therefore, diabetes care at school is negotiated on an individual basis, which is challenging for diabetes nurses, parents and schools.

Although there has been some development in the past few years, consistent legal frameworks to support young children who require administration or supervision of insulin at school are lacking. Disability legislations in most countries protect the rights of children with diabetes to access education without discrimination and support requests for the school to make reasonable adjustments for diabetes.^{31–33} However, although diabetes school policies and care plans are often mandated by legislation, there are instances when these are not in place.²¹ In

addition, there is no legal duty that requires non-medical personnel to administer or supervise medication. When diabetes teams are considering the appropriate type of insulin delivery, an assessment of the capability of the child and the available resources within the home and school setting is required in order to minimize risk.

Normality and understanding

To create a sense of normality and understanding of diabetes at school, it is important to advocate for a wellness approach,³⁴ reduce stigma, address fear and provide collaborative support. Segregation of diabetes care away from usual school activities and negative attitudes from school staff and peers suggest that diabetes is seen as an illness. In comparison, children, parents and diabetes nurses refer to diabetes as being a normal part of life.^{15,22,24} Collaboration between home, health, education and legal systems is required to explore integration of care into usual school routines and enhance normality, understanding and a wellness approach.

Collaboration

Collaboration between home, health, education and legal systems is essential for integration of intensive insulin therapy. Diabetes care that the child receives at home needs to be transferred to the school setting; therefore participation from parents is important for successful transition.^{13,19,24} As full-time carers, they are the most familiar with their child's diabetes. Parents who are consistently engaged with the school enhance the likelihood of safe, integrated care for their child. However, some parents sacrifice full-time employment and careers to provide this level of engagement.¹³ Often, the increased time required to coordinate care at the school is due to lack of alternative resources, for example diabetes nurses, school nurses or teacher support.

In the health system, diabetes nurses have adopted a key role in advocating and negotiating diabetes care at school.²³ This role requires a high level of skill, is time consuming and challenging due to the increase in diabetes incidence rates. Young children usually require assistance from adults due to limited ability to self-care. In the education system, school teachers are often asked to take on this role. Due to the invasive nature of diabetes care (needles for glucose monitoring and insulin delivery), an emotional reaction of fear and avoidance is common.^{16,20,21} Integration of care into the classroom for an inclusive school experience is recommended for children with diabetes. However, a teacher's main role is to educate, not provide medical care and many lack diabetes knowledge and experience.^{22,23} In addition, they are expected to cope with a number of other health and behavioural conditions in the classroom. Their workloads do not allow for the medical needs of children that require supervision or assistance.

School nurses are also under the same workload pressures and are not available at all schools, nor are they employed specifically for diabetes.^{20,26} They, too, often

lack specialized diabetes knowledge. Although they are nurses, they are often apprehensive about care and responsibility.

Collaborative networks with the legal system are required to develop consistent frameworks and policy in order to successfully integrate intensive insulin therapy in the primary school setting.

Conclusion

Intensive insulin therapy has not been well integrated into the primary school setting and has created issues for children, parents, education and diabetes staff. Risk management, competent diabetes care, a sense of normality and understanding and collaboration were identified as key areas that required addressing to improve integration of intensive insulin therapy in the primary school setting. Health and education systems need to advocate for the development of legal policy to provide consistency and the provision of an adequate workforce to cope with the increasing numbers of children with Type 1 diabetes.

Limitations

There are limitations that should be considered when interpreting the findings of this synthesis. Although an attempt was made to search a wide number of appropriate databases, relevant articles may be available from other sources. The data base search was also limited to articles that were published in English, which may have excluded valid studies in other languages.

Phase 7: expressing the synthesis

The final phase of the synthesis process involves the dissemination of information to appropriate audiences. The line of argument developed from this synthesis was expressed using a simple visual conceptual model. These findings are published in a professional nursing journal in order to highlight the key issues and contribute to development of future frameworks necessary for diabetes care at school. Synthesis findings have also been presented at a nursing diabetes conference.

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- Substantial contributions to conception and design, acquisition of data or analysis and interpretation of data.
- Drafting the article or revising it critically for important intellectual content.

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