Developing autonomy in primary school aged children with type 1 diabetes

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Key words: diabetes, children, self-care, autonomy

Abstract

This review considers literature on the self-care of children with type 1 diabetes and applies it to the primary school classroom. It reports that by allowing children to have self-care with their health at an early age, they develop a healthy foundation for lifelong health. This review found that children with type 1 diabetes are able to provide self-care when they develop the cognitive skills to understand how to control their condition, along with social and emotional development to be able to cope within the social environment. It is shown that when care-givers and children monitor the condition closely, better control is achieved resulting in less long-term health problems.

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A healthy start in life is vital for establishing a strong foundation of healthy practices for a person's lifetime. There are many health issues that affect primary school aged children including mental health problems, chronic health conditions and lifestyle health related problems. The 2007/2008 Australian Bureau of Statistics (ABS) National Health Survey (as cited in The Australian Institute of Health and Welfare, 2012, p.17) states that 37% of children suffer from at least one chronic health condition. The figures from this report further indicate that whilst from 2001 to 2008 the prevalence of asthma has decreased and the number of children being diagnosed with cancer has stabilised, the number of children being diagnosed with type 1-diabetes has increased.

The Australian Government Department of Health (2012, para.3), states "There is sound evidence that prevention initiatives early in life are highly effective. Prevention, early detection and early intervention with respect to health, education and social problems can improve outcomes for children." Providing children that have chronic health conditions with the knowledge and skills to take care of their health from an early age can enable deeper understanding of their condition allowing them to achieve better health outcomes.

Purpose and scope

The purpose of this essay is to review literature on children with type 1 diabetes and to discuss the importance of establishing autonomy in disease management for primary school age children. This essay focuses on type 1 diabetes but some of the implications of supporting children with diabetes can be applied to other chronic health conditions as well.

Literature review

Blanson Henkemans, Hoondert, Looije, Alpay, & Neerincx (2012, pp. 51-61) researched details of the support needed for children when self managing type 1 diabetes and the use of a robot to support children within this process. This study was based on interviews with diabetic children, their parents and diabetes caregivers in a semi structured style survey format. The results of the survey revealed that parents play a significant role in the management of their child's diabetes resulting in few complications due to their diabetes management capability. The study suggests that children need to start establishing autonomy prior to puberty so they can become proficient at diabetes management from an early age. Blanson Henkemans et al. (2012), also determined that social robots could be used to "help parents monitor how their children experience their illness and different aspects of its management in regard to mental and physical well-being" (p. 60).

The Blanson Henkemans et al., study had several limitations: a very small sample size was used, the participants volunteered to take part in this study by responding to an invitation, therefore the sample was not randomly selected. This indicates that the sample might not be

representative of all children with diabetes. Another limitation is the absence of quantitative measurements; the results are based on qualitative data only. In addition, there was no robot that this research was actually based on. The robot was an imagined concept that they asked questions about within this stage in the study,.

Kelo, Martikainen, & Eriksson (2011, pp. 2096-2108) considered a number of research articles in an integrative review and synthesised these findings. They determined that the ability of self-care is based on knowledge and skills. Further, the extent to which a child could self-care was related to multiple factors including, their own attitude, motivation, gender, age, and emotional wellbeing; diabetes duration and the level of control, care and support provided by parents, teachers, peers and their healthcare team; along with the school environment (Kelo et.al, 2011, p. 2096). The child needs to be developmentally mature to be able to cope with the demands of the disease and educating the child about diabetes should be appropriate to their development level (Kelo et al., 2011, p. 2106). Parents and other adults that are responsible for the care of the child, must plan and allow an appropriate transition to independence as a significant gift to the child.

Kelo et al. (2011, p. 2098) attempted to eliminate variables that might offer an explanation for the results they reported on. Accordingly, research that was completed prior to January 1998 was excluded as they focused on only more recent papers to eliminate results based on out of date treatments. In their reported method they aimed to only include articles that used children aged 6 to 12 years old, however in the findings two of the articles that included 3 to 18 year olds are noted. Articles about the technical side of diabetes management were excluded, being considered outside the scope of their review.

The research asserts that the diabetic primary school children need to be developmentally mature to be able to cope with the demands of the disease. Kelo et al. states that educating a child about diabetes should be “empowering” to help and promote self-care and to support the parents’ involvement at an appropriate level for their care (2011, p. 2106). Parents and other adults that are responsible for the care of the child must allow an appropriate transition of independence being given to the child.

Marvicson, (2008, p. 477) investigated the relationship between maternal environment, self-efficacy for diabetes management and child glycaemic control. The overall focus of this study was based on mothers as they “typically assume the primary responsibility of the diabetes supervision”, (Marvicson, 2008, p. 478). This study states that school age children require more independence than is advisable. The study found that a mother’s coping resources significantly predicted maternal self-efficacy. The more support the mother received the better they were at taking care of their diabetic child.

The results of the study indicated that the mothers had less confidence in their ability to adjust the child’s management plan if the child was not going to be with them for an extended time with instances like sleepovers for example. Results taken from the child’s blood glucose meter indicated that when mothers closely supervised their children, the children had better metabolic control resulting in better lifetime health and wellbeing (Marvicsin, 2008, p. 481).

This study used “test retest” to try to eliminate problems with self-reporting but it was determined that with the items that were addressed some of the results might not be entirely accurate. To verify results Marvicsin used blood glucose monitor readings to give an accurate measure of diabetes control. It was determined that self-efficacy may not be correlated to the tests conducted (2008, p. 482).

A similar but much earlier study, conducted by Leonard, Skay & Rheinberger (1998), surveyed 100 different items of information used to determine self-efficacy. The results indicated that whilst mothers were confident in their own ability of managing their child’s diabetes, they were less confident in their ability to transfer their skills of diabetes management to their child (p. 230). This research suggested that when parents transfer the responsibility of management to their child that their own skills in the management of diabetes will diminish. It is also suggested that children may not manage their disease to the extent that the parents do.

Leonard et al. (1998) also determined that conflict between the mother and child can hinder the transfer of diabetes management skills to the child and that further research needs to be conducted to address dealing with this conflict (p. 231). Several different ways were used to measure data in this survey to cater for logistic data and concept data using multivariate models. It was noted that the strongest multivariate of independence was conflict (p. 229). It is interesting to note in this context Jordan and Kelfer (as cited in Leonard et al., 1998) state that children feel upset when they are treated differently and many feel very restricted in regards to their level of independence, and also “children have a need to maintain control over decisions involving their health by participating

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in decisions but not necessarily taking responsibility for them" (p. 225).

Klingensmith, Kauffman, Schatz, & Clarke (2001, p. S111) give advice for the care of children with diabetes in the school setting. It is recommended that children and youth should, with parental consent, be able to implement their own diabetes care at school to an appropriate extent based on their knowledge and experience with diabetes. The age at which children are able to do this is very individual and specific to the child and depends on their willingness and capabilities. Suggested guidelines for the care of diabetic children in the school setting are offered, and usefully inform practices in the school for school personnel, parents and diabetic children. Appropriate care in the school environment is necessary to ensure the child is safe in the immediate setting, but long term it is vital for both their wellbeing and academic performance (Klingensmith et al., 2001, p. S108). Therefore understanding the effects of the condition both immediate and long term is vital for all teachers.

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Application to the child within the primary school setting

The Australian Institute of Health and Welfare (2012, p.17) states that chronic health conditions can impair and delay growth and development of a child physically, socially and emotionally. The research review indicates that in order for a child with diabetes to develop self-care they must be developmentally able to cope with their condition. Teachers and school support staff can adopt many practises to assist diabetic children in dealing with this disease and should be encouraged to take further steps to learn the best way to help support a child develop the necessary skills to do this.

Primary school age children are able to provide self-care when they are socially, cognitively and emotionally ready. Exactly when these developments occur is different for every child however, Erik Erikson's theory of psychosocial development provides some insights into stages of development and these stages can be related to progress towards self-care. Faw (1995) states that Erikson's theory suggests that people develop through a series of eight stages where they encounter a crisis or conflict at each stage. Erikson's suggests that people progress through these stages around similar ages and the stages are sequential. When a crisis is resolved, social and emotional growth and development occurs and a person proceeds to a new stage of development. According to Aden, Benner & Ellens (1992) growth can only occur in the midst of a crisis (p.37).

According to Erikson, autonomy is the second stage of development and this usually occurs when a person is a toddler, this is the stage where a child develops more independence and self-control (Chapman, 2006). The second developmental crisis that is relevant to a diabetic child developing self-care is Erikson's fourth stage, the stage of industry vs. inferiority. Chapman (2006), states that this stage usually occurs during the primary school years and this is a time when a child develops skills and competence. Although the fifth phase according to Erikson, usually develops during adolescence it may happen earlier for diabetic children. According to Benner (1987), Erikson relates phase five to identity formation; usually adolescence is a time for a person to learn their identity in relation to the world around them (p. 24).

Type 1, diabetes is a complex condition that requires numerous skills to be able to manage the disease and in treating the whole child, it goes beyond the administration of correct medication and diet. According to Atkinson, Eisenbarth & Michels (2014, p. 69) most commonly type 1 diabetes is diagnosed between the ages of 5-7 years of age or pre-puberty and can be caused by an immune or auto immune response in the body that may be triggered by environmental factors. The current treatment for type 1 diabetes is exogenous insulin therapy delivered by subcutaneous injections and as stated by Atkinson, Eisenhart & Michel (2014, pp. 72-73), most modern countries utilise the technology of insulin pumps and continuous glucose monitoring.

Cognitive development in helping to understand physical symptoms

For children to be able to understand diabetes, to result in self-care, a child must have developed the cognitive skills to understand how to best manage the physical symptoms of the condition. In a primary school a teacher could help a child to develop understanding by ensuring that they too research and learn about the disease, allowing them to be able to provide assistance to the child also, if needed.

The most immediate risk for a diabetic child that a teacher, staff and the child needs to be aware of is hypoglycaemia. Hypoglycaemia, or a low blood sugar level, occurs when the blood sugar level drops below an appropriate safe level. Students need to be aware of these symptoms so they can treat themselves for this but there may be times when they can not recognise the symptoms. A teacher that can recognise the symptoms of hypoglycaemia may see the child displaying these symptoms and can ask the child to test their sugar level. Some of the symptoms of hypoglycaemia as detailed by Briscoe & Davis (2006, p. 116), are: paleness, sweating,

palpitations, shaking, fatigue, excess hunger, disorientation, headache and nausea. Failure to treat hypoglycaemia can result in loss of consciousness for the child. Litvin, Clark & Fisher (2013) report that hypoglycaemia can have detrimental effects on the brain and brain development and if severe can cause "brain damage, long-term cognitive dysfunction and even sudden death" (p.1922).

For children with diabetes the ability to develop the skills necessary to be able to understand the physical aspects of their condition and their health, whilst developing the skills to measure, understand and respond to their medical needs with the use of medication, would be developed during the skills and competence phase of Erikson's theory. A child needs to be cognitively developed at this stage to be able to understand how to control their illness, and attaining the cognitive development required to take care of the physical aspects of the condition, will enable the child to be have more autonomy.

Social development and emotional development

A diabetic child also has challenging social issues that they need to address as they seek to feel included and valued in their class. Children who have diabetes may feel isolated, misunderstood and different from other children. It is important for teachers to ensure that diabetic children are included in all classroom and play ground activities. It was indicated in at least one study that children can sometimes feel parents or teachers do not understand what they are experiencing, so it is important for both to show empathy towards the child and seek understanding of how they feel. In order to allow the child to feel comfortable discussing how they feel with the teacher or other students in the class, it might be worthwhile asking the child if they would like to talk to the whole class about diabetes. Allowing the child to tell others about it and allowing them to feel that these people can understand them would help them to feel more comfortable in the classroom, to be able to test their sugar levels within the class, and if they preferred, not the leave the room to also inject or use a pump without the fear of being judged by other students or teachers.

Having a chronic medical condition can require a child to address some developmental aspects earlier than may be encountered by their peers. This may mean that a diabetic child could develop into a phase of identity crises that Erikson relates to as the adolescent development phase quicker as they struggle with a crisis of trying to find their identity of being a 'normal person'. It is important for teachers to also realise that students may have emotional swings as they come to terms with accepting their condition. Supporting the child emotionally and helping to set up a system within the classroom to support the child's emotional needs with peers would be beneficial and assist the child in feeling comfortable within the classroom.

Conclusion

Berger, (2014, p. 328) suggests that for children with chronic health conditions middle childhood is a time for them to establish good health habits in order to be able to maintain good health and form lifelong healthy habits. Research shows that primary school aged children have the ability to use self-care when they are cognitively, socially and emotionally developed to understand how to control their disease. Diabetes is a complicated condition to manage and parents can find it difficult to allow children to take some independence in their condition. It is important for parents and teachers to support the development of the child to the self-care stage.

Establishing the ability for primary school-age children to be able to take care of their own health is very important and this becomes even more important for a child that has a chronic health condition. There are many implications for teachers in assisting diabetic children feel ready to take steps towards self-care. Within the primary school setting it is extremely important for caregivers who are responsible for diabetic students to have a thorough understanding of the disease and how a student may be affected by some of the difficulties that can arise from diabetes. Helping a child to establish fundamental understanding and providing support of healthy practices, along with social and emotional support can be life saving and life changing for a diabetic child. TEACH

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