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Intersecting Health Policy and the Social Determinants of Health in Pediatric Type 1 Diabetes Management and Care

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ABSTRACT

Purpose: Type 1 diabetes (T1D) health technologies are evolving. This is an expensive chronic condition to manage, hence a combination of public and private healthcare funding sources, as well as out-of-pocket payments support disease management. The aim of this paper is to describe two conceptual underpinnings, which can appropriately position the health policy and clinical context of pediatric T1D management and care.
Theoretical Principles: Dahlgren and Whitehead's (1991) "The Main Determinants of Health" framework positions pediatric T1D management and care within the model's four interconnected layers: the structural environment, social and material conditions, support systems and individual health behaviors (p. 11). A health policy in Ontario, Canada, the *Assistive Devices Program (ADP)* for insulin pump therapy [Ontario Ministry of Health and Long-Term Care (MOHLTC), 2016] is also discussed relative to the model's outermost layer: the structural environment. Lipsky's (2010) "street-level bureaucracy", specifically four *dimensions of control* including "distributing benefits and sanctions; structuring the context; teaching the client role; and, psychological benefits and sanctions" (p. 60–65) are then used to position the policy context of the diabetes nurse educator role, relative to the ADP policy.
Research/theory Implications: These conceptual underpinnings could extend beyond the pediatric T1D landscape to position global research in other nursing practice areas, as well as with other patient populations and professional disciplines such as social work and medicine.

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Introduction

Healthcare funding is complex and makes up a significant portion of a government's annual budget. With recent changes in governance in both Canada and the United States, healthcare funding priorities are shifting to align with government platforms. Given the breadth of health

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complexities facing individuals, these funding priorities may not collectively address the health needs of all people. Chronic conditions, in particular diabetes, are on the rise globally, leading to increased healthcare spending by healthcare systems to support disease management and promote favourable health outcomes [International Diabetes Federation (IDF), 2015].

Type 1 diabetes (T1D) is an autoimmune, chronic condition that is generally diagnosed in childhood or adolescence, and “affects up to 10 percent of people with diabetes” (*Diabetes Canada & Diabetes Québec, 2010*, p. 8). Globally, about 542,000 youth aged ≤14 years are living with T1D, with about 86,000 new diagnoses projected annually (IDF, 2015). Europe is the leader among the seven IDF regions in terms of T1D prevalence in this age group (about 140,000 youth) (IDF, 2015). Specific to North America and the Caribbean, 107,300 youth aged ≤14 years are living with T1D, with 16,500 new diagnoses projected annually in this region (IDF, 2015). United States leads all countries globally in T1D prevalence (about 84,100 youth) (IDF, 2015). Between Canada and Mexico, roughly 22,800 youth are living with T1D, with nearly 26 new diagnoses (per 100,000) in Canada annually (IDF, 2015).

The precise cause of T1D is not known, although environmental factors and a genetic predisposition appear to trigger destruction of the pancreas’ insulin-producing beta cells (*Diabetes Canada, 2013*). This results in no or very limited pancreatic insulin production, thus individuals need to regularly monitor their blood glucose levels and administer insulin via syringe or insulin pen, or via continuous subcutaneous insulin infusion (insulin pump) to help regulate blood glucose levels (*Diabetes Canada & Diabetes Québec, 2010*). Diet, exercise and psychosocial factors also have an important role to promote optimal glycated hemoglobin (A1c) levels and avoid potential diabetes-related complications such as nephropathy, neuropathy and retinopathy [Diabetes Canada, 2013; The Diabetes Control and Complications Trial (DCCT) Research Group, 1993], which have implications on healthcare spending.

Upstream approaches such as governments’ investments in health promotion initiatives including cost-effective health technologies such as insulin pumps (St Charles, Lynch, Graham, & Minshall, 2009) may be costly at the outset, although could detract future healthcare expenses (i.e., diabetes-related complications). Disability and mortality from diabetes (T1D and T2D), for example, are the largest contributors (79%) to the total cost of diabetes in Canada (\$11.7 billion), followed by hospitalizations (10%), medications (5%) and healthcare professional/specialist visits (5%) [Canadian Diabetes Cost Model (DCM) as cited in *Diabetes Canada & Diabetes Québec, 2010*]. This corroborates the important role health behaviors (*Diabetes Canada, 2013*) as well as diabetes “self-management education and support” (Haas et al., 2012, p. 2393) have on T1D health outcomes. Government funding is instrumental to support families with the financial costs of managing T1D. Input and advocacy from diabetes specialists including nurses, dieticians and physicians as well as patients and their families are important to guide governments’ upstream thinking related to healthcare funding.

The purpose of this paper is to describe the conceptual underpinnings of a sequential mixed methods study (Creswell, 2014) of parents of youth living with T1D and diabetes nurse educators in Ontario, Canada. The aims of this research are to: 1) assess the impact of a provincial health policy, Ontario’s *Assistive Devices Program (ADP)* for insulin pump therapy, relative to the T1D health needs of youth; and, 2) delineate the diabetes nurse educator’s role and impact on accessing diabetes health technologies. A cross-sectional survey is being piloted and administered to parents of youth living with T1D (younger than 18 years of age) using injections or an insulin pump (for at least one year). Youth can be using continuous glucose monitoring regularly (e.g., six or more days a week) (Ruedy, Tamborlane, & Juvenile Diabetes Research Foundation *Continuous Glucose Monitoring Study, 2012*) or sometimes. Following this, semi-structured interviews will be conducted with diabetes nurse educators including Registered Nurses (RN), clinical nurse specialists and nurse practitioners to build on the survey results, and to better understand the policy context of this specialized nursing role. Statistical

analyses of the quantitative data will involve inferential statistics including the independent *t* Test, One-way ANOVA and logistic regression, as well as a sensitivity analysis of the costing data (Drummond, Sculpher, Torrance, O’Brien, & Stoddart, 2005). An inductive content analysis approach (Elo & Kyngäs, 2007) will be used to analyze the qualitative survey and interview data, before triangulating the data sources.

Two conceptual underpinnings position this study. First, Dahlgren and Whitehead’s “The Main Determinants of Health” (p. 11) framework (Fig. 1) positions the socioeconomic (SES) factors inherent to pediatric T1D management and care. Lipsky’s (2010) four *dimensions of control* (Table 1), which characterize “street-level bureaucrats” (p. 3) situate the policy context of the diabetes nurse educator role. An Ontario health policy, the ADP for insulin pump therapy (Ontario MOHLTC, 2016) will be used as an example of how Lipsky’s (2010) ideologies can position nursing research.

These frameworks can offer nurses, researchers and educators conceptual clarity about the different socioeconomic factors youth living with T1D and their families are faced with, as well as means of exploring these empirically. In this context, Lipsky’s (2010) ideologies also demonstrate how clinical and policy competencies can intersect in T1D care. Moreover, they enable us to more distinctly recognize the policy context inherent to nursing practice, which may appear clouded at times by the profession’s strong clinical underpinning.

Insulin Pump Therapy and Continuous Glucose Monitoring

Insulin pump therapy is an intensive form of insulin therapy used to manage diabetes (*Diabetes Canada, 2013*). A small cannula lies in the subcutaneous tissue, and is connected to a small pager-like device (insulin pump) via a piece of tubing (Animas Canada, 2017). There is also an insulin pump available with no tubing (Insulet Canada Corporation, 2016). This health technology continuously delivers rapid-acting insulin (basal component), and individuals also administer additional insulin via the pump for carbohydrate intake (bolus component) (Animas Canada, 2017). The diabetes healthcare team and families decide upon individualized settings to program into the pump including hourly basal rates, insulin sensitivity factors and carbohydrate ratios.

Continuous glucose monitoring is an evolving diabetes health technology. A CGM sensor measures the amount of glucose in the interstitial fluid (Dexcom Inc., 2017). A transmitter is attached to the sensor and wirelessly sends this glycemic data to another device (i.e., insulin pump, smartphone) (Dexcom Inc., 2017). This data can inform the family and healthcare team how glucose levels are trending (i.e., direction and speed) over time and between mealtimes (Dexcom Inc., 2017). Individuals using an insulin pump or injections can use CGM.

Researchers have found these health technologies can positively impact youth living with T1D and their families. Clinical benefits include improved blood glucose levels (Chase et al., 2010; Churchill, Ruppe, & Smaldone, 2009), fewer low blood glucose level episodes with insulin pump use (Mack-Fogg, Orłowski, & Jospe, 2005) and perceived preclusion of low blood glucose levels with CGM use (Cemeroglu et al., 2010). There are also psychosocial benefits of insulin pumps including promoting lifestyle flexibility (Owen, 2006), feelings of normalcy and independence among youth (Shulman, Miller, Daneman, & Guttman, 2016), as well as better health-related quality of life compared to youth using injections (Lukács et al., 2013).

Families can also benefit from these health technologies. Parents have reported feeling less stressed or worried about their child/teenager’s diabetes (Opipari-Arrigan et al., 2007; Pickup, Ford Holloway, & Samsi, 2015), less worry about low blood sugar levels, better quality of life (Cemeroglu et al., 2010), and easier diabetes management with insulin pump use (Alsaleh, Smith, Thompson, Al-saleh, & Taylor, 2014). These health technologies, however, are expensive, corroborating the importance of government and private healthcare funding sources to support families with the cost burden.

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