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Original article

Balancing Parental Involvement With Adolescent Friendly Health Care in Teenagers With Diabetes: Are We Getting It Right?

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ABSTRACT

Purpose: Current guidance about adolescent-friendly health care emphasizes the benefits of seeing young people alone for confidential consultations. Yet in young people with Type 1 diabetes mellitus (T1DM), parental involvement has been shown to contribute to better diabetes control. This study aimed to better understand how these apparent tensions are reconciled in clinical practice by identifying how frequently adolescents with T1DM are seen alone and exploring parents' opinions about this.

Methods: A convenience sample of consecutive parents of adolescents (aged 12–21 years) with T1DM was recruited from the outpatient clinic of a specialist diabetes service and asked to complete a 30-item written survey.

Results: A total of 137 surveys were returned from 146 eligible parents (94%) of whom 106 had complete data. Thirteen percent of adolescents with T1DM had ever been seen alone for a confidential consultation with their doctor. The most common concern for parents about confidential care was not being informed about important information, not just about T1DM, but also about common adolescent risk behaviors and mental health states.

Discussion: These findings suggest that young people with T1DM are not being routinely seen alone for confidential care. This could be attributed to: parents or adolescents declining confidential care; clinicians being time-poor and/or lacking the necessary skills; or a culture of uncertainty about the value of confidential care. A discussion is now required about how best to enact adolescent-friendly care in the chronic-illness outpatient setting, where parental involvement is understood to be important for effective chronic illness management.

IMPLICATIONS AND CONTRIBUTION

This study suggests that rates of confidential care for adolescents in chronic illness outpatient settings are low. Parents also feel conflicted about confidential care for adolescents in this setting. Understanding how to attend to both parent and adolescent perspectives is an important clinical and research opportunity.

The presence of a chronic illness can challenge healthy adolescent development [1–3]. Adolescence entails exploring and forging one's own identity through connection with peers and experimentation with different ways of being and behaving. Establishing an independent and autonomous life, distinct from parents, is also an important component [4]. In contrast, chronic illness often entails routines, health vigilance and a high degree of assistance from parents [1,2]. This tension can create complexity for health professionals involved in the care of young people. In this paper we use the example of Type 1 diabetes

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mellitus (T1DM) and the practice of confidential care to explore this tension further.

Parents play an important role in achieving effective diabetes management for their adolescent children [3,5,6]. Parental involvement in adolescent diabetes management is strongly associated with better adherence to blood glucose monitoring and better glycemic control [5,6]. In order to achieve this, parents of adolescents with diabetes are often involved in parts of their children's lives that parents of nondiabetic adolescents would regularly disregard [7,8]. Although parental involvement is important, a delicate balance is required to achieve optimal management. Too much parental involvement can lead to family conflict, which is then associated with poorer diabetes management, control, and adherence [7–9]. Yet too little parental involvement can result in poor diabetes control, with associated health risks for adolescents [5,6]. Interventions aimed at improving parent-child teamwork around diabetes management tasks have been shown to positively impact diabetes control [10].

Appreciation of the importance of parental involvement for adolescents with diabetes can be placed within the context of what is considered to be quality health care for adolescents more generally; increasingly referred to as "adolescent-friendly" health care [11,12]. The Society for Adolescent Health and Medicine (SAHM) has outlined multiple recommendations for developmentally appropriate care [13]. These are clear about the need to provide confidential consultations to adolescents, without parents present, in which psychosocial assessments can be undertaken. The HEADSS approach to assessment is advised by SAHM. HEADSS is an acronym that stands for **H**ome, **E**ducation, **A**ctivities, **D**rugs, **S**ex, and **S**uicide that is used by health professionals to assist them in remembering to assess aspects of young people's psychosocial environment [13,14]. Similar recommendations are also made by organizations such as the American Academy of Pediatrics and the Royal College of Paediatrics and Child Health in the United Kingdom [15,16]. The provision of confidential care to young people does not preclude parental involvement; the goal is to continue engaging parents in addition to providing a private space for young people with the ultimate aim of strengthening the family system as a whole. In its guidelines on management of diabetes in adolescence, the International Society for Pediatric and Adolescent Diabetes (ISPAD) acknowledges the difficulties clinicians can face in achieving a balance between facilitating increasing autonomy for adolescents and incorporating parental involvement. The importance of maintaining an index of suspicion for mental health problems and risk behaviors in adolescents is also noted. ISPAD recommends recognizing adolescents' need for privacy and confidentiality and encouraging self-reliance and self-efficacy while retaining the trust and support of parents and family [17].

Routinely consulting with young people confidentially and undertaking psychosocial assessments can be justified on the basis of four arguments. First, young people have a right to have their developing autonomy recognized. Second, in order to prepare young people for adult health care they require practice and experience at engaging with health professionals alone [18]. Third, adolescents with diabetes have poorer psychosocial outcomes, experiencing higher rates of depression, anxiety, and disordered eating and poorer school completion rates than their nondiabetic peers [19–21]. Fourth, adolescents view confidentiality as vital for their ability to engage effectively with health professionals. When explicit assurances of confidentiality are provided to adolescents, they are more likely to seek health care, disclose sensitive matters, and return for future visits [22–25]. When confidentiality is not assured, adolescents engaging in risky behaviors will cease seeking health care related to those behaviors [24]. Although confidential care with associated psychosocial assessment is important for all adolescents, it is therefore particularly important for adolescents with diabetes.

In Australia, healthcare professionals work within laws that derive from the U.K. legal system, in which adolescents are able to make autonomous decisions without their parents' knowledge as long as they are deemed to be a mature minor; defined as possessing "sufficient understanding and intelligence to understand fully what is proposed" [26]. From the age of 15 years, adolescents in Australia are also able to obtain their own Medicare card (separate from their parents' card), which allows them to access the health system at reduced rates and without their parents' knowledge. The provision of confidential care for adolescents, therefore, largely relies on the discretion of individual health professionals in Australia, and there remains little information about how consistently adolescents in Australia receive confidential care. With the added complexity that chronic illness brings, there is a particular need to explore how the practice of confidential care is enacted in chronic illness outpatient settings.

The current study aimed to explore adolescent-friendly practices in the setting of a pediatric diabetes outpatient clinic, with a focus on parental views about confidential care for adolescents. Specifically, parents of adolescents attending the diabetes outpatient clinic were surveyed to document: (1) how often their child had been seen alone by doctors at the clinic for a confidential consultation; (2) the topics they believed should be shared with them following a confidential consultation between the doctor and their child; and (3) the key benefits and harms they believed to be associated with confidential care for their child.

Methods

Setting

The study was conducted at a large socioeconomically diverse tertiary pediatric diabetes clinic in Melbourne, Australia. At the time of the study, the clinic had 1,589 patients with T1DM, of whom over half were aged >12 years. All young people attending this clinic are seen at 3–4 month intervals for medical review with a pediatric endocrinologist. Appointments at this clinic are overwhelmingly made by parents and adolescents are generally accompanied by their parent(s). The service offers all families access to diabetes nurse educators and dedicated dietetic and medical social work support. Appointments with these clinicians are organized through a separate diabetes allied health clinic as required; not all adolescents are seen in this clinic.

Recruitment

A convenience sample of parents of 12–21-year-old adolescents who attended the diabetes clinic was approached to take part in the study in the 3-month period between March and June, 2011. Parents were recruited by a research assistant in the waiting room during one clinic per week. All parents were approached; those unable to speak or read English were excluded. Following a verbal description of the study, consenting parents completed a brief (10-minute), anonymous written survey of 30 questions. Parents were instructed to place completed