The Family's Involvement in Diabetes Care and the Problem of 'Miscarried Helping'

a report by
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Behavioural and psychosocial aspects of health problems have proven to be critically important. Seven of the 10 leading causes of death in the US are related to unhealthy behaviour, such as smoking, overeating and excessive alcohol consumption.[1] In addition, psychological problems, such as depression, and social problems, such as family conflicts, have adverse effects on the course of diseases, including diabetes.[2] While medical treatment innovations for diabetes continue to advance, healthcare providers now recognise that they too must advance in their ability to respond to behavioural and psychosocial factors that impact optimal diabetes management.

Non-adherence to the diabetes treatment regimen is possibly the most common reason for poor health outcomes among people with diabetes. The rates of non-adherence to diabetes regimen tasks are highly variable, but obviously have significant consequences on diabetes outcomes and the effectiveness of treatments. Research indicates that non-adherence ranges from 35% to 70% for not following the prescribed meal plan, 20% to 80% for improper insulin administration, 30% to 70% for inaccurate blood glucose testing, 23% to 52% for inadequate foot care and 70% to 80% for inadequate amounts of regular exercise.[3–6] While non-adherence to diabetes treatment *per se* is not a diagnosable psychosocial or behavioural problem, it is related to many psychosocial factors. Interventions targeting these factors have proven effective in improving adherence and metabolic control in people with diabetes.

A variety of empirically supported psychosocial interventions are used for treating non-adherence and poor metabolic control in people with diabetes.[7] Several psychosocial treatments implemented with children with diabetes have shown promise in promoting positive health behaviour, psychosocial functioning and health status.[8–10] Of the psychosocial interventions that have been empirically examined, those involving multiple family members have demonstrated some of the most positive outcomes.[11–15]

For example, previous research has examined the efficacy of involving parents in a crisis intervention programme upon diagnosis of their child with diabetes. Findings from this study support the involvement of multiple family members in promoting positive health behaviour in youths with diabetes.[8]

Other studies have examined concurrent psychosocial intervention sessions for youths with diabetes and their parents. Findings from these studies suggest that separate psychosocial treatments for youths with diabetes and their parents promote better metabolic control and increase treatment adherence in these youths than in those who received standard treatment.[10] In addition, multi-family group meetings with youths with diabetes and their parents were effective at improving glycaemic control at the end of the intervention and at a six-month follow-up.[16] Thus, family-based psychosocial interventions for youths with diabetes have proven to be effective in improving treatment outcomes. However, a closer look at the complex interaction between family dynamics and health outcomes reveals that it may not be so simple.

Family Involvement in Diabetes Care – Pros and Cons

The social support literature lends credence to the idea of involving family in an individual's health and disease management in the hope of optimising adherence to treatment regimens.[17] This is particularly evident in the chronic illness literature.[18] However, this same literature suggests that the family can have deleterious effects on the health of individuals and their management of chronic health problems.[19] Research on youths with diabetes and their families has clearly demonstrated the negative impact that family involvement can have on both disease status and management. Specific family factors that have been linked to health behaviour and health outcomes in youths with diabetes include general family relations, family conflict, family composition, family communication and illness-specific family interactions.[13,20–27] Of the family factors that impact health behaviour and health status, family conflict emerges as a primary issue that needs attention.[17]

Many of the conflictual interactions between youths with diabetes and their parents revolve around how the youth is managing their diabetes. Anderson and Coyne outlined a process known as 'miscarried helping' for understanding how interpersonal conflict emerges in families of children with a chronic illness.[28] Anderson and Coyne highlight how good intentions on the part of care-givers result in interpersonal conflicts between youths with chronic health problems and their parents, further polarising the two parties and putting the youth's health at greater risk.[28] The concept of miscarried helping is derived from the literature on social support, family systems and health.[29–30]

There are several reasons why the family is the primary focus when examining miscarried helping. First, those closest to an individual with diabetes are family members who are most likely to assist with day-to-day demands. Second, family members are the most likely to advise or influence a child with diabetes around issues of disease management and general healthcare.[17] Third, the family represents a model for health behaviour, including diet, exercise and interactions with the healthcare team. Finally, the psychological benefits/burdens of family interactions have been found to directly impact health status, including metabolic control.

Miscarried Help Paradigm

Miscarried helping involves an investment on the part of the care-giver to be a good helper coupled with the belief that their helping will result in better health outcomes. The help from the care-giver is less about what the youth wants and needs and more about what the care-giver thinks is best. In cases where the youth's health does not improve, as is often the case in diabetes, the care-giver feels like a failure. A sense of disappointment and failure gets communicated from the care-giver to the youth both explicitly and implicitly. The youth becomes angry at the care-giver and feels blamed for his/her health problems and feels pressured to accept help that is not wanted. What started out as an attempt to improve health and health behaviour becomes an interpersonal conflict. This further polarises the care-givers and the youth. Ultimately, the interpersonal conflict that emerges from the process of miscarried help results in the care-giver blaming the youth for his/her health problems. In addition, the presence of miscarried helping can result in a show of defiance by the youth. For example, the youth might react by not telling others about a change in health behaviour, resulting in poorer health.

The interventions for addressing the dynamic of miscarried helping in families of youths with diabetes can be implemented as primary treatment or preventive care.[31] Miscarried helping can be addressed directly by holding a discussion with the youth and their family about the helping process and how and when it goes awry. This approach to addressing miscarried helping might also involve a skills-based component that targets improved communication skills and problem-solving around diabetes care.

Conclusions

Effective diabetes management requires adherence to a chronic and complex regimen and, accordingly, non-adherence is the norm rather than the exception. Psychosocial treatments may be used to improve adherence to the diabetes regimen and, more generally, to develop sustained pro-diabetic lifestyles.

Involvement from family in diabetes care can be very helpful in sustaining a healthy lifestyle; however, it is clear that not all kinds of involvement from family in diabetes care are helpful. Nowhere is this more evident than with youths with diabetes and their families. For adolescents with diabetes, the involvement of family in diabetes management is even more precarious. By nature of adolescent development, youths desire greater independence from parents. A care-giver who is over-involved in the daily management of the diabetes or quick to personalise medical setbacks may inadvertently place that adolescent at risk of poor outcomes. Being aware of the risk of miscarried helping between individuals with diabetes and their family members is critical to avoid unnecessary conflict. ■

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