

Adolescents with Diabetes and Their Illness Management: A Critical Review

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Abstract:

The purpose of this study is: 1) to overview the knowledge from the literature about adolescents and their diabetes management; 2) to review the knowledge from the literature in adolescents' developmental perspective and their diabetes management; 3) to discuss nursing care and interventions for adolescents with diabetes and their family.

The 63 articles provide the following conclusions: 1) Adolescents are at risk for poor illness management; however, there is a limitation to the conclusion that the stage of adolescence is a risk factor. There is a need for longitudinal research to investigate illness management and its relations to adolescence' developmental perspectives. 2) Nurses need to assess adolescents and their families to balance between "dependence" and "independence" based on adolescents' readiness for illness management. 3) It is important for nurses to assess adolescents' diabetes management systematically, not only with metabolic control. Nurses need to help adolescents and family work together as well as include them in the decision-making process. Peer support groups and psycho-educational interventions are helpful to improve psychological adjustment to diabetes and metabolic control.

Keywords:

Adolescents, Diabetes, Illness management

INTRODUCTION

Insulin Dependent Diabetes Mellitus (IDDM) is one of the common endocrine childhood chronic illnesses. Though it affects one of every 1000 children under 18 years old in the U.S., IDDM has no cure. Compared to children in the U.S., Japanese children have a lower risk of developing IDDM: one to two children out of 100,000. However, we should not underestimate the impact of diabetes. According to a report from the Japan Diabetes Society (2001), the prevalence has been increasing from 1.53/10⁵ to 2.0-2.8/10⁵ in the last two decades. In addition, children with Non-Insulin Dependent Diabetes Mellitus (NIDDM), which is typically prevalent in the obese and in those over age 40, have increased from 2/10⁵ to 4-6/10⁵ due to dietary modification to a Western style diet.

Children with diabetes and their family must adjust their life to the illness. Diabetes management requires

complicated day-to-day regimen, such as insulin injections, monitoring of blood glucose levels, management of hyperglycemia and hypoglycemia, and careful regulation of diet and exercise. It is imperative for children to actively cooperate and carry out day-to-day management to avoid long-term complications.

Previous literature identifies adolescents as "at risk" for psychosocial adjustment problems and poor diabetes management (Amer, 1999a; Grey, Cameron, & Thurber, 1991, 1997; Williams, 1999). The series of psychological, social, and physical changes during adolescence contribute to poor diabetes management. For example, adolescents seek more autonomy or may experience rebellious feeling, spend more time with peers than family, and undergo hormonal changes of secondary sex development. Adolescents struggle to balance between their developmental demands and diabetic management demands.

It is important for nurses to recognize factors that pre-

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dict adolescents' poor diabetic management, which have a reciprocal relationship with their psychological adjustment. In addition, Wysocki and colleagues found that problems adjusting to diabetes in early adolescence tend to persist into young adulthood (1992). Thus, there is a need to identify adolescent individuals who are at risk. It is critical to intervene to prevent further maladjustment problems and complications as soon as possible. Moreover, research on the impact of diabetes on children and adolescents is prolific in the U.S. and Western countries, while little research is reported in Japanese articles. It would be beneficial to review the recent literature in Western countries and use the knowledge as a guide for providing better nursing care for Japanese adolescents.

The purpose of this study is: 1) to overview the knowledge from the literature about adolescents and their diabetes management; 2) to review the knowledge from the literature in adolescents' developmental perspective and their diabetes management; 3) to discuss nursing care and interventions for adolescents with diabetes and their family.

METHOD

To review the articles, I have used computerized databases, CINAHAL, MEDLINE, and PsychInfo with the following key words: child, adolescent, diabetes, illness management, adherence, compliance, and self-care. The search is limited to English-language, from 1990 until present. A total of 92 articles were found, and after careful review, 63 articles were included. In this present study, the term "illness management" includes both compliance and adherence.

OVERVIEW OF THE LITERATURE

Over the last two decades, research has paid considerable attention to the risk factors predicting poor illness management, since poor diabetic management, often measured by blood glycemic levels (HbA1c), leads to serious complications. Previous investigators have used different terms, such as "compliance" and "adherence," similar in meaning (Amer, 1999b). There are many studies to investigate diabetes adherence to/ compliance with diabetic management. Diabetes management/ adherence is examined with various psychosocial parameters; for example, adjustment and ego-defense level (Jacobson et

al., 1990), self-efficacy (Littlefield et al., 1992; Ott, et al., 2000), self-esteem, anxiety, depression and psychopathology (Kovacs, et al., 1990; Kuttner et al., 1990), family response (Faulkner, 1996), social support (Burrighs, Harris, Pontious, & Santiago, 1997), and coping strategies (Boland, & Grey 1996; Grey, Cameron, & Thurber, 1991; Nakamura & Kanematsu, 1994).

Research shows that no clear single factor consistently predicts poor illness management. The various parameters interplay with attributes of the child, family, illness, and environmental factors. Those factors influence adolescents as risk factors and also resistance factors which mediate or buffer risk factors. The interaction is complex and has a non-linear and multi-dimensional relationship (Amer, 1999a ; Wallander & Varni, 1992).

Studies confirm that children with diabetes are vulnerable to develop psychological adjustment problems and psychopathology, such as depression and eating disorders for adolescent girls (Blanz, et al., 1993; Grey et al., 1995; Golden 1999). In addition, a recent review found that some combination of the following factors make adolescents vulnerable and place them at greater risk for poor diabetes management: female gender, high stress level, poor self-perception, poor coping, and stressed mother (Amer, 1999a).

On the other hand, scant research examined illness management from developmental perspectives, especially for children and adolescents. (Dunbar-Jacob, et al., 2000). Methodological difficulties may explain the lack of research from developmental perspectives. Most research uses cross-sectional design. Amer (1999a) pointed out, for example, a longitudinal study would be necessary to competently establish the notion that the increasing age from childhood to adolescence deteriorates metabolic control.

DEVELOPMENTAL PERSPECTIVES

As children reach adolescence, they develop formal operational thought; they become capable of comprehending abstractions and hypothesizing unobservable constructs. This cognitive development allows adolescents to plan ahead and to grasp the complex tasks in diabetes management (Hanson, 1990). Also, adolescents are establishing autonomy. Parents and health care providers expect adolescents to be more independent in self-care and manage the illness competently. In addition,

parents begin to yield diabetes management responsibility to adolescents.

According to the research that investigated developmental changes in diabetic self-care, children and adolescents by age 12 are capable of playing a significant role in their diabetes management using the 38 skills recommended by the American Diabetes Association (ADA). (Wysocki, Meihold, Cox, & Clarke, 1990). In the same research, investigators show physicians, nurses, and other health care providers estimating that, by age 14, 50% of adolescents master all of the 38 skills.

Adolescents' performance of self-care diabetes management is not always sufficient. Several investigators have speculated that inappropriate expectation for self-care responsibility may cause poor metabolic control. Saucier and Clark (1993) found that children aged 10-14 who participated actively in self-care management have poorer metabolic control than same-age children who are less active in diabetes self-care. Consistently, Wysocki and colleagues (1996) found that adolescents who engaged in excessive self-care autonomy demonstrated poor adherence, diabetes knowledge, and glycemic control.

In fact, a study reported that adolescents' often mismanage diabetes (Weissberg-Benchell et al. 1995). Food-related mismanagement, such as eating an inappropriate diet, is common within the 10 days before a clinic visit. The main concern is the relatively high prevalence of adolescents' missing a blood test and falsifying results (29%) because the actual results were too high, and missing an insulin injection (25%). This study also revealed that there were significant differences between adolescents' admitted mismanagement practice report and parents' expectation of adolescents' mismanagement. The result indicated parents underestimate the frequency of mismanagement behavior.

As reasons for mismanagement, first, the most frequent is "forgetting," since immediate reward from playing with peers and their acceptance may outweigh reward for diabetes management (Cerreto & Travis, 1984). Second, Giordano et al. (1992) and Dickinson (1999) explain early adolescents' preoccupation with the present. Young adolescents may understand that how they manage diabetes at present will influence their future health condition; however, their focus is fully in the present. The lack of future concern makes engaging in diabetes management less of a priority. Third, fantasies, from a

false sense of security, may also influence adolescents' management (Harter 1990). Giordano et al. (1992) stated that adolescents try to believe miracles; for example, by following religion and ignoring their medical regimen in order to test their fantasies and beliefs. Having fantasies and believing miracles may be their coping strategies to handle their emotional disturbance.

During the process of diabetes-management responsibility transferring from parents to adolescents, previous literature widely suggested gradual transfer with parents' supervision is necessary; thus, family involvement becomes less directive, more indirect, cooperative, and emotionally supportive (La Greca, 1998). Considering that during adolescence metabolic control deteriorates, nurses need to take a closer look and re-examine the transferring process to guide adolescents and family. Follansbee (1989) recommends assessing adolescents' self-care readiness based on each adolescents' need in a multi-dimension, such as knowledge, cognitive complexity, performance, locus of control, and family environment. Parents' active involvement as a supervisor is required; however, research shows parents' overly rigid or perfectionist pattern for diabetes management is harmful for the management. The author suggested that the adolescent and family work as a team during this transferring process. Nurses need to be concerned with how to best keep the family supporting adolescents' diabetes management.

Lastly, contrast and ambivalence characterize the adolescent period (Cerreto & Travis, 1984). Adolescents describe the benefit of diabetes management as freedom; at the same time, it becomes a barrier, a burden of responsibility (Hanna & Guthrie, 2000). Even adolescents who seem to experience no problem with diabetes management may not always be competent. Adolescents wax and wane in being independent. They learn from the process of their trials and errors to be competent for diabetes management. Thus, it is important for nurses to help adolescents and also families to guide by achieving a balance between the adolescents' perception of freedom and the burden of responsibility, and to reinforce the positive aspects of their benefit and by helping them to ameliorate the negative aspects of illness management (Hanna & Guthrie, 2000a, 2000b).

NURSING IMPLICATIONS

Previous studies have showed there are many factors inter-related to adolescents' diabetes management. However, in the clinical setting, nurses may tend to overlook those factors and focus only on the data of metabolic control. Dickinson (2000) points out clinicians under the medical model tend to emphasize index of "numbers." Nurses often look at the data of blood glucose levels only and judge adolescents as compliant or non-compliant, or label them as "Good control" or "Bad control." The author reminds us to see each adolescent as a unique individual, and as a whole person.

In addition, nurses and other health care providers believe that good adherence to the medical regimen leads to good metabolic control; however, it is not true. Recent studies showed that metabolic control is not a valid measure of adherence since adherence and metabolic control are not directly correlated (Bond et al., 1992; Du Pasquier-Fediaevsky, 1999). Nurses should assess adolescents' diabetes management systematically, not only with metabolic control. Thus, it is important to comprehensively assess adolescents' illness management using psychological aspects as well as physiological data sets. Nurses need to listen to adolescents' story and to understand their experience of living with diabetes.

Nurses also should provide management options and include adolescents and families in the decision-making process for their diabetes management. In the former research, compliance and adherence were used interchangeably. Recent researchers from the clinical view have defined carefully the difference between the terms "compliance" and "adherence" from the point of who makes decisions about treatment. Adolescents and their family have the right to make decisions about their own care; this view is called "adherence." They do not just follow or obey the medical advice from health care providers who are authority figures; to do so is "compliance" (Dickinson, 1999; Tim & Lowes, 1999). Those studies state that nurse should use "adherence" rather than "compliance". This is an acknowledgement that adolescents and their family are active, knowledgeable, and independent participants in their own care.

Furthermore, nurses need to provide circumstances where adolescents can freely discuss their concerns and worries as well as give encouragement and reward for their good performance. Daneman (1991) wrote that adolescents' mismanagement, such as falsifying blood test results and cheating, may be coping strategies to please

or to avoid being badgered by parents or health care providers who are authority figures. Negative comments and criticism hinders adolescents' psychosocial factors, such as self-efficacy, self-esteem, and motivation (Littlefield, et al., 1992). Christian et al., (1999) suggested that adolescents need several learning experiences to build confidence in becoming more independent from parents; they are "to gain on going factual knowledge, to be allowed to make choices, to have opportunities to validate choices, to practice complex decision making, and to spend periods of time away from their family to practice new skills."(p.259).

Grey et al. (2000) reviewed interventions for adolescents and reported what kinds of interventions are effective. This study found that traditional educational interventions help adolescents to increase knowledge about diabetes, but are not effective in improving their metabolic control. On the other hand, psychosocial interventions, time-limited, structured psychoeducational interventions and peer support groups are efficient to improve adolescents' psychosocial adjustment as well as their metabolic control. These psychoeducational interventions include social skill training and problem solving using actual diabetes scenarios. Family interventions, such as parental skills and conflict resolution are also effective to reduce the parent-child conflict about their illness management.

CONCLUSION

This study suggests that there are considerable factors contributing to poor adolescents' illness management. Research identified adolescence is the stage of risk for poor metabolic control and adherence/ compliance. However, the cross-sectional design of those studies has limitation in confirming the results. Thus, there is a need to investigate longitudinally adolescents' metabolic controls and predictors of adherence/ compliance from developmental perspectives. Secondly, it is important for nurses to assess adolescents comprehensively and individually with developmental perspectives. It is critical to help adolescents and families work together, especially illness management responsibility shifts from parents to adolescents. Nurses need to carefully assess adolescents' cognitive and emotional readiness for taking illness management responsibility. Also, nurses should assess family involvement and guide how family can best support

the adolescents. Third, nurses and other health care providers should include adolescents and their family in their treatment decision-making process. Recent study showed that including adolescents in peer support group or psychoeducational interventions is efficient to improve their adherence / compliance as well as metabolic control.

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【資 料】

糖尿病を持つ思春期の子供と病気管理： クリティカルレビュー

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【要 旨】

この研究は、1) 糖尿病を持つ思春期にある子供の病気管理に関する研究の概要、2) 思春期の子供の糖尿病管理について、発達論的観点から報告された研究の概要、3) 思春期の子供への看護実践について、1990年から現在までの文献をまとめて報告する。研究結果は、1) 心理社会的観点から思春期の糖尿病管理についてまとめられた研究は多数報告されているが、発達論的観点から報告された研究は少ない。2) 思春期の子供は心理社会的適応や糖尿病管理に対し、リスクにある。家族での病気管理・サポートが不可欠であり、医療者は患者、家族を含めて援助を行う必要がある。3) 看護者は思春期の患者、家族を積極的に治療に関する決定プロセスに参加するよう促し、心理教育・サポートグループも有効である、と報告されている。

【キーワード】 思春期、糖尿病、病気管理

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