

# SELF-MANAGEMENT STYLES OF THAI ADOLESCENTS WITH PRE-DIABETES AND TYPE 2 DIABETES

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**ABSTRACT:** The rising costs associated with the increased prevalence and earlier ages at which chronic conditions develop have led to growing emphasis on self-management. This includes changes in diet and physical activity to reduce the progress from pre-diabetes to diabetes, and behavioral modification and adherence to medication when diabetes is already established. We explore the patterns of self-management among young people. Sixteen participants (aged 12-19) diagnosed with pre-diabetes or type 2 diabetes, and their primary caregivers, were recruited from the three selected hospitals in Bangkok. We used in-depth interviews for data collection. Based on thematic analysis, we suggest that two illness management styles – “thriving” and “accommodating” – resulted in improved health outcomes. Two other illness management styles – “indulging” and “indifferent” – worsened blood glucose levels and had little impact on body weight. Demographic and psychosocial factors, including health beliefs, self-efficacy of self-care, health-related motivation, and social support, affected adolescents in the four different patterns.

**Keywords:** Self-management styles, Pre-diabetes, Type 2 diabetes, Thai adolescents, young people

## INTRODUCTION

Type 2 diabetes and obesity are now public health problems among children and adolescents worldwide [1]. In Thailand, obesity and type 2 diabetes are increasingly prevalent among young people. This is in association with urbanization and industrialization, shifts to sedentary occupations (and for young people, long hours of schooling and little active recreation) the globalization and commercialization of food products and consumption, and other “lifestyle” changes [2, 3]. Obese youths with pre-diabetes and those with type 2 diabetes have a high risk of cardiovascular disease in adulthood and complications of diabetes among this population results in premature disability or death [4]. This is a serious concern to health care providers and parents in personal, social and financial terms.

Diabetes self-management is critical to delay the development of disease among those identified with pre-diabetes, and to prevent complications among those who already have diabetes. Based on the original family management style framework proposed by Knafl and Deatrick in 1990 and a comprehensive review of research on parents’ responses to children with a chronic illness [5], the

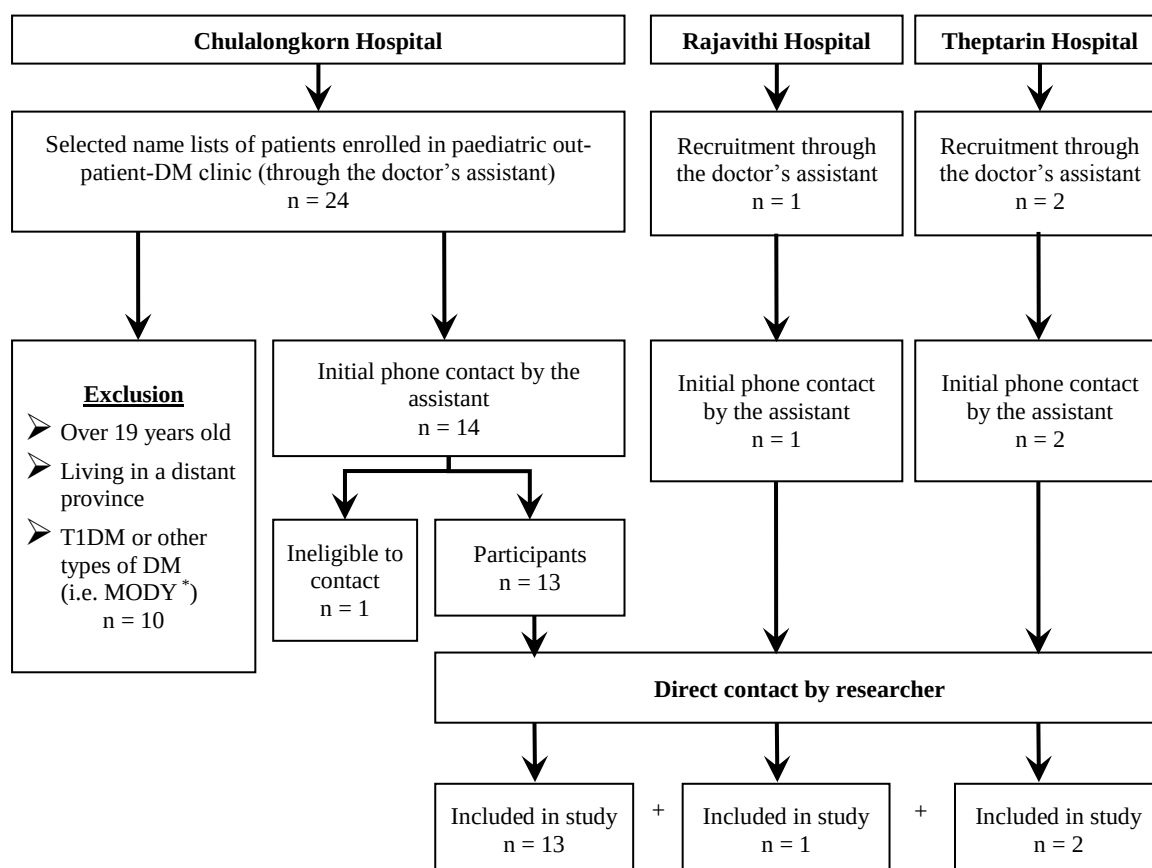
refined framework [6] supports the validity of three conceptual dimensions of family management styles: the definition of the situation, management behaviors, and perceived consequences. The authors describe family members’ perceptions of their situation affecting management behaviors of the illness in everyday life. Perceived consequences of the illness can affect both perceptions and management behaviors.

In Thailand, there has been little research on the pattern of self-management among young people. In our study, we modified the Knafl and Deatrick’s family management style as follows: two main components of the diabetes management style include perceptions of living with diabetes and management behaviors. Perceived impacts of the illness and some aspects of the sociocultural context, such as parents’ involvement, were also included in the two components. Within the two components, on the basis of this theoretical model, a priori themes [7] were also determined. This ensured that we identified data relevant to these themes.

## MATERIALS AND METHODS

Data was collected using an inductive qualitative approach, derived particularly from interviews, observations and other interactions with 16 adolescents with pre-diabetes and diabetes, and 25 parents. We used grounded theory as a systematic

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\*MODY = Maturity-onset diabetes of the young is caused by genetic defects in  $\beta$ -cell function with predominantly insulin deficiency and the onset before ages between 25 and 30 years [9]

**Figure 1** Recruitment process of adolescents with pre-diabetes and diabetes

method of qualitative research, rather than as a philosophy or theoretical standpoint [8]. The research was conducted in Bangkok, the largest urban area and primary city of Thailand, and in neighbouring provinces (50 – 150 km away from Bangkok): Nonthaburi, Samutprakarn, Nakhon-Nayok, Chacherngsao and Chonburi. All of these provinces are urbanized. Bangkok has increased threefold in the past 40 years to a population of over 9 million. Rapid urbanization has extended to the provinces adjacent to Bangkok and included in this study.

The first author [A1], a native Thai speaker, conducted all data collection and preliminary analysis from May 2007 to January 2008. She recruited 16 families with adolescents who had been diagnosed with pre-diabetes (6/16) or diabetes (10/16) for at least six months (ensuring a correct diagnosis) from three selected hospitals in Bangkok, through paediatric endocrinologists and endocrinologists. All of the 16 participants were aged between 12 and 19 years and lived in Bangkok

and its surrounding areas. Most of them (13/16) were recruited from Chulalongkorn Hospital, with two from Theptarin Hospital and one from Rajavithi Hospital. The recruitment process of the study participants was shown in Figure 1 [9]. All of the 25 primary caregivers, mostly their parents, were included in the study. Only one participant did not live with his parents; therefore his cousin (his aunt's daughter), who looked after him closely, was identified as his primary caregiver in this study.

As this study was based on the small sample size (this was because of the small numbers of young patients with type 2 diabetes registered in the selected hospitals) and the young participants were purposively selected by the doctor and the nurse taking care of them, it was unavoidable to control the doctor's influence on parents' / guardians' decision to join the study. To reduce such bias, I informed the doctors' assistants that I, by myself, needed to explain the details of the whole protocol to all the adolescents and their parents before conducting the interviews, by either telephoning or

meeting them face to face at the outpatient department of the diabetes clinic, or at another place that they felt was convenient.

At the first visit, interviews of the parents were conducted after interviewing the adolescent. Mothers and fathers were interviewed separately to gather information independently, which assisted cross-checking information and explaining different perceptions and understandings obtained from others. Interviews lasted 1-2 hours with each parent and approximately one hour with adolescents. A second interview was requested only if new issues requiring further explanation emerged from data analysis. For the second interview (for some adolescents), I was able to talk to the young participants alone, when parents had trust in, and were more familiar with me. Finally, seven families with adolescents with pre-diabetes or diabetes were visited two or three additional times to interview siblings or other related family members who were not available at the first visit.

Most young people agreed to meet at weekends. A demographic form to be completed with personal details was given to the participants or parents/guardians at the first meeting, once they agreed to participate, and an appointment was made for an in-depth interview at a place of their choice. With the patient's/family's permission, [A1] obtained the young participants' medical and health data (illness history, medical treatment, weight/height measurement, laboratory results and the practice of diabetes control), which provided helpful background to the interviews and our interpretation of the responses.

[A1] developed the questions based on a review of published literature, unpublished theses, and websites related to our research questions. She translated all research tools and conducted all interviews in Thai. Interviewing included unstructured and semi-structured, open-ended questions. Interview questions included these following issues: 1) Social relationship 2) Lifestyle behaviors 3) Understanding of diabetes (causes, signs and symptoms, severity, and treatment and curability) 4) Non-adherence of medical treatment. All participants permitted the author to record the interviews on a digital recorder.

Ethics approval for the research was provided by the two selected hospitals in Bangkok and by the [name of University committee withheld for review]. The third hospital, from which one

participant was recruited, did not require ethics permission other than that provided by the university [details withheld for review]. The consent form for adolescents, aged <18, was signed by parents (or in one case, guardian) after explaining the study protocols. Participants aged 18 and older were asked to sign the consent form themselves. Participants could withdraw from the study at any time without any conditions, and were assured that all personal information would be kept private.

We used thematic analysis [10] to analyse our data manually as the number of cases was small, and in fact, the first author was quite familiar with all the cases because she did all the interviews herself. The analysis involved gaining familiarity with the data, data coding, and searching for and identifying themes. As soon as practicable, after interviewing each participant, [A1] transcribed digital tape-recorded information verbatim and placed it into a database. She then read through the transcripts to get a broad picture and identify any new ideas or questions to be added to the next interviews. She also expanded all field notes in a systematic form (saved as a computer file) on the same day of fieldwork or soon after. Dominant sections of the transcripts were also translated into English. We use pseudonyms instead of participants' names throughout this article.

## RESULTS

### Personal background

The adolescents' demographic and family data are summarized as follow. Young participants with pre-diabetes (6/16) and diabetes (10/16) in this study are relatively homogeneous: the majority (12/16) studied at a secondary school and high school, were 12-17 years old, lived in a nuclear family with one - two siblings, and came from moderately well-off to affluent families. All participants follow Buddhist beliefs. Nine young participants had mothers as a primary caregiver and had at least one family member with diabetes living in the same family. All young participants had a history of childhood obesity. At the time of being interviewed, almost all young participants (14 out of 16) were overweight or obese. One male and one female adolescent had a healthy weight (BMI<sup>1</sup> percentile 5<sup>th</sup> - <85<sup>th</sup>), despite having diabetes; both adolescents had been treated, and learnt more about treatment and self-management of their illness and how to adjust their lifestyle [11].

<sup>1</sup> A body mass index (BMI) percentile for children and adolescents aged 2-20 years is assessed by using the BMI-for-age and sex charts established by the US National Centre for Health Statistics

**Table 1** Diabetes self-management styles across given themes

| Themes                          | Diabetes self-management styles  |                                 |                                          |                                          |
|---------------------------------|----------------------------------|---------------------------------|------------------------------------------|------------------------------------------|
|                                 | Thriving<br>N = 1                | Accommodating<br>N = 5          | Indulging<br>N = 6                       | Indifferent<br>N = 4                     |
| Child's view of self            | Healthier                        | Unwell                          | Well                                     | Unwell                                   |
| Caregivers' views of child      | Well                             | Unwell                          | Well                                     | Well                                     |
| Child's view of the impact      | Unaffected                       | Mostly unaffected               | Mostly unaffected                        | Mostly unaffected                        |
| Caregivers' views of the impact | Unaffected                       | Affected                        | Affected / unaffected                    | Affected / unaffected                    |
| Diabetes priority               | No                               | Yes / No                        | No                                       | No                                       |
| Self-ability                    | High confidence                  | High / low confidence           | Low / no confidence                      | Usually no confidence                    |
| Caregivers' involvement         | Consistent                       | Consistent                      | Inconsistent                             | No involvement                           |
| Child's life goal               | Yes                              | Yes                             | Yes                                      | No idea                                  |
| Self-management practice        | Proactive                        | Passive                         | Reactive                                 | Inactive                                 |
| Lifestyle change (score)        | 9.5                              | 4.5-7                           | 2-4                                      | 0.5-2                                    |
| Health outcomes                 | Weight and blood glucose control | Weight or blood glucose control | Neither weight nor blood glucose control | Neither weight nor blood glucose control |

### Patterns of diabetes self-management

Diabetes self-management styles refer to patterns of illness management based on adolescents' and caregivers' perceptions and behaviors. Four management styles - thriving, accommodating, indulging and indifferent - are identified. According to the findings, the indulging was the most common style and followed by accommodating and indifferent management styles, represented by six, five and four respondents, respectively. Thriving management style is a rare pattern; only one young woman presented this style. Regarding the components of perceptions and management behaviors, all themes, sub-themes including lifestyle change scores and patterns of management presented above are summarized in Table 1.

#### Thriving Style – “I can do it”

A thriving management style involves a sense of success, intention, positive thinking, and perceived self-ability. The factors influencing this include perceptions of “no illness” and “being healthy,” with the person holding onto the idea of well-being, the perceived self-ability to manage the illness, having personal goals both related and unrelated to diabetes (i.e. body image and health), having supportive caregivers in diabetes tasks, having plans to control diet and exercise, and taking practical and determined action in self-management.

As indicated in Table 1, only Sib-jed had the highest total score (9.5) and a high score for all indicators, implying good health outcomes - healthy weight and normal blood glucose value. Two main factors –the influence of other people and body image – affect her decision to alter her behavior to be healthy. Social pressure on her from family

members included blame and complaints about the expenses associated with her diabetes and her education. Her relatives would say to her: “[You] are often sick...how much money [you] waste,” or “[If you] don't study, you'll be a fool.” These negative pressures motivated Sib-jed to manage her illness and to study hard. While Sib-jed's self-consciousness of her weight, and the pressures placed on her by other family members, may be regarded as negative, her self-confidence played a key role in her self-management behaviors.

#### Accommodating Style: “I need help”

The second most common management style, the accommodating style, allowed for compromise and negotiation between the young person and their caregiver, with the caregiver the most important factor ensuring success in disease management. Compared with other management styles, here caregivers working closely and continuously in diabetes management were most supportive and active, and they were most likely to be concerned about their child even when diabetes was not a family focus. They viewed their children as “ill,” and considered the illness to have serious impact mainly in relation to study and planning for a future career. The “accommodating” adolescents, in contrast, viewed themselves as “ill” or “not well” because they felt that they had something wrong inside their body, even though they also explained that the illness did not affect their lives due to the absence of symptoms and their ability to maintain routine activities. These adolescents tended to be relatively passive, and adhered to self-management practices under their caregivers' supervision. Lifestyle scores over 5 implied improvement of lifestyle. Their health outcomes were usually poorer

than among the thriving adolescents, with higher weight gain and high blood glycaemic levels. Nueng's total lifestyle score was the highest (7 scores) of the five "accommodating" adolescents, whose scores varied from 4.5 to 7. Nueng and Sib-sii, the first and the second healthiest respectively, each had one good health outcome: Nueng had achieved normal weight although he had failed to lower his blood glucose in the normal range, while Sib-sii had failed to reduce his weight but succeeded in controlling blood glucose in the normal range. Compared with the others, Nueng's family and Sib-sii's family represented the most combined intention and effort to manage the illness. A close relationship between the adolescent and the caregiver in disease management, active responses of the caregiver in taking care of the adolescent and supportive family members and family environments, determined this style.

#### **Indulging Style – "I will change it later"**

The most common management style, the indulging style, is presented by six adolescents – two young women and four young men. Their lifestyle scores are low, ranging from two to four points, and their health outcomes were unsatisfactory - overweight or obese with high blood glycemic levels. These results suggest poor diet and little exercise, and poor adherence to self-management. Being "normal" or "well" was the most commonly perceived identity among adolescents and caregivers adhering to an indulging diabetes management style. For these participants, diabetes was not a significant concern, and their life goals were unrelated to their health.

Unlike the two previous management styles, a key element in "indulging" adolescents included *taam jai paak* (a lack of self-control in eating food). Caregivers were permissive, and subsequently, *taam jai paak* became a habit, which was difficult to change. The self-management practice of "indulging" adolescents differed from other groups: they were usually reactive to self-management tasks, not adhering to diet control, exercise or medication on a regular basis, but complying when their doctor's appointment was approaching. Caregivers were inconsistent in their involvement in diabetes management, and so these adolescents failed to change their unhealthy habits, resulting in poor health outcomes. Additionally, in terms of a healthy lifestyle model of family members, this did not appear to influence "indulging" adolescents. This was possibly because parents, regardless of their own experience of diabetes, had eaten relatively freely and exercised little in the past. As

their own health deteriorated and they developed complications, they acknowledged the importance of adherence to self-management themselves, but their children were mindful of their prior behavior, were familiar with the behaviors of other family members, or thought that complications would develop only when they were much older. Therefore, a good role model in relation to diet and exercises, over a short-time frame, did not appear to affect the behavior of "indulging" adolescents.

#### **Indifferent Style: "I don't want to change it"**

Both negative perceptions and poor management themes predominated in the last management style: having no confidence in and failing to adhere to self-management, no caregivers' involvement and no explicit life goals. The major characteristics of "indifferent" adolescents were ignorance of health, illness, life goals and self-care. "Indifferent" adolescents had difficulties not only with their diabetes self-management, but also with their daily lives: they paid less attention to study, they had friends their parents regarded as disruptive, and they were regarded as isolated and aggressive. Familial factors such as child-rearing styles, family financial problems, family conflicts (i.e. parent-child and father-mother), and low parental involvement all appear to have influenced these perceptions and behaviors.

The four adolescents presenting this management style include one female (Sri, 14) and three males (Kaow, 18, Sib-ed, 16, and Sib-sam, 14). Like "indulging" adolescents, those in this management style had family members with diabetes who did not adhere to self-management and did not change their unhealthy lifestyle. Caregivers (in almost all cases) were rather distant and problematic, and the young people rarely consulted them when they had problems. Most also had conflicts with their caregivers and/or other family members. The lifestyle scores of adolescents with indifferent management style, ranging from 0.5 to 2, lead to poor health outcomes, similar to those in the indulging management group. Sib-sam had the highest lifestyle score (2 points), while Sri had the lowest score (0.5 points).

#### **DISCUSSION**

Based on thematic analysis, we were able to identify only one case of good self-management (thriving) of diabetes, while all other young participants either presented a fair (accommodating) or poor self-management of diabetes (indulging and indifferent). The two successful diabetes management styles (thriving and accommodating)

are concordant with Dalton and Vargas 's studies [12], suggesting that the success of long-term weight control among obese children and adolescents requires changes in family food patterns, along with exercise and positive reinforcement approaches such as parental praise. The two successful diabetes management styles suggest factors and strategies in managing the illness effectively, which may potentially be employed by other adolescents with poor self-management.

The “indulging” adolescents were a potential target for an intervention (e.g. health education on disease and healthy behaviors), who could switch to “thriving” with greater cooperation from family and friends, and higher self-efficacy. However, attention is needed from family and health care providers to indifferent adolescents, to encourage them to think about their life goals as a first step, and encourage their shift to an accommodating style. Setting a goal is important in promoting self-efficacy with respect to diabetes management [13]. Therefore, collaboration among patients, parents and health care providers in setting optimal goals suitable for an individual’s lifestyle may potentially result in effective diabetes treatment and management. In addition, working on family relationships may be a strategy for “indulging” adolescents and “indifferent” adolescents.

Due to the relatively homogeneous sample (i.e. age, ethnicity, and urban settings) and the small sample size of adolescents with pre-diabetes and diabetes, the study cannot be generalized to adolescents with other chronic illness or to healthy adolescents. Based on my results from the two successful self-management styles, further studies should focus on the family (not only the individual) as the unit of analysis, as health and wellbeing always occur in a family context [14]. A heterogeneous study sample (i.e. different socioeconomic classes, cultural backgrounds and different geographical regions) is also needed in future studies. A selection bias for such studies may be addressed by recruiting young patients from the community rather than hospitals only. Furthermore, a larger study should be considered as there might have the association between important social and behavioral factors and adolescents with the different types of self-management.

#### ACKNOWLEDGEMENTS

We thank all participants and health care providers who participated in our research. Our special thanks also come to Professor Suttipong Wacharasindhu for his advice in medical treatment and diabetes

self-management and to Ms. Suphab Aroonparkmongkol for recruiting participants at King Chulalongkorn Memorial Hospital.

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