

INKOLA based on Orem's Self-Care Model and its effectiveness on the quality of life and HbA_{1c} in children with type 1 diabetes mellitus

HOTMA RUMAHORBO^{1, A-G}, ATIN KARJATIN^{2, A, B, E, F}, ALI HAMZAH^{1, A, C-F}
 ORCID ID: 0000-0002-2253-4981 ORCID ID: 0000-0002-6828-6100 ORCID ID: 0000-0001-9365-107X

¹ Nursing Program Study, Bandung Health Polytechnic, Indonesia

² Health Promotion Program Study, Bandung Health Polytechnic, Indonesia

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Summary Background. The quality of life for children with diabetes type 1 is determined by the ability of parents to care for their children independently. The INKOLA model was developed from the Dorothea Orem self-care deficit model, which emphasized educational support for patients' self-care and independence.

Objectives. This study aims to determine the effectiveness of the INKOLA model on the QoL and HbA_{1c} of T1DM children.

Material and methods. Our quasi-experimental study with a control group was carried out on 42 T1DM children and their parents. The model of intervention was implemented for four months. QoL was measured twice in the third and fourth months. HbA_{1c} was measured in the fourth month.

Results. There was an improvement in QoL scores in the children after three months of the intervention, but the scores were not significantly different (78.67 ± 11.31 vs 73.01 ± 14.85 , $p = 0.173$). After four months, there was an increase in the QoL score which was significantly different (80.93 ± 10.19 vs 70.80 ± 12.21 , $p < 0.001$). The parents' version of QoL scores after three and four months of intervention showed an improvement, but were not significantly different (three months, 78.42 ± 9.22 vs 78.27 ± 9.64 , $p = 0.961$; four months, 79.62 ± 9.01 vs 78.63 ± 9.52 , $p = 0.734$). The decrease of HbA_{1c} in the intervention group was significant (8.80 ± 1.76 vs 10.59 ± 2.72 , $p = 0.014$).

Conclusions. INKOLA based on the Orem Self-Care Model is effective in improving the QoL and in controlling HbA_{1c} for T1DM.

Key words: diabetes mellitus type 1, self-care, glycosylated hemoglobin A, quality of life.

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Background

Type I diabetes mellitus (T1DM) is a type of diabetes that depends on insulin, generally occurs at a young age, and is caused by damage to pancreatic beta cells due to autoimmune reactions [1, 2]. Diabetes is one of the serious threats faced by the world today. Currently, there are an estimated 1,110,100 cases of diabetes in children and adolescents worldwide, and each year the incidence goes up by 128,900 cases [3]. In Indonesia, there are approximately 273,151 cases of diabetes in children aged infants up to 14 years [4].

T1DM management includes insulin therapy, dietary and activity control, and regular blood glucose and health checks [1, 2]. T1DM is a unique chronic disease in children due to the complexity of treatment and the level of family involvement in successful treatment [5].

In previous studies, T1DM has had a negative impact on the physical, psychological and emotional conditions of children and could reduce their Quality of life (QoL) [6, 7]. QoL reflects disease prognosis and is an important indicator of chronic diseases, including diabetes [7, 8]. Children and adolescents with T1DM on have a lower QoL than healthy children and adolescents [7]. DM has a negative impact on children's lives [8, 9], as it causes depression in children and parents [9, 10] and reduces QoL, exacerbated by poor glycemic control. Similarly, depression is associated with hyperglycemia and micro and macrovascular complications and increases mortality in diabetes [11].

QoL of children correlates with the condition of their parents [12]. Stress in the parents reduces QoL of children and causes poor glycemic control [9]. QoL of children is also negatively correlated with HbA_{1c}; the lower the HbA_{1c} value the better QoL of children with T1DM [11, 12]. Conflicts and the number of children in the family also correlate with QoL of children [13, 14], and optimal glycemic control requires parents' knowledge of childcare and recognition of the burdens and barriers that need to be managed properly [15]. Improved QoL and optimal glycemic control require educational interventions [16, 17]. Patients and families are partners in the treatment and prevention of various diseases, including diabetes and its complications [18, 19]. Therefore, educational interventions for children and parents are important instruments in improving the quality of life for children with diabetes [20, 21]. Family as the main support system for children plays an important role in building children's ability to adapt to lifestyle changes towards optimal QoL [12]. The success of managing the disease depends on the family's ability and skills to provide holistic care for children. Therefore, families need to have sufficient knowledge about diabetes and various physical and psychological changes occurring in children. All parties involved in the life of the children must be aware that children with diabetes need different care than healthy children and adults [22, 23].

The INKOLA model [24] (Indonesian abbreviation for Information, Communication and Management) is a model of holistic care that aims to empower children and families to meet T1DM



child care needs for optimal QoL and glycemic control of children. The model is based on the Orem Self-Care Model, which refers to a kind of help that patients need in the form of a supportive education system. This assistance is provided because children and their families can control themselves and their environment, but they need educational support to improve their knowledge, skills and attitudes toward independent child care. This is important given the impact of diabetes causing a deficit in self-care so that the nursing system can provide supportive educational interventions in the community [25, 26].

Objectives

This study aims to examine the effectiveness of the INKOLA model on QoL and the value of HbA_{1c} in children with T1DM.

Material and methods

Design of study

This study used a quasi-experimental pre- and post-test design with a control group.

Population and sample

The study population was T1DM children and their parents who were undergoing outpatient care at two referral hospitals in West Java. The sampling quota was chosen so that the education class would be more effective with 20–25 participants. There were 48 children and their parents in two hospitals, randomly allocated into the intervention and control groups. At the end of the study, there were 42 children and their parents because six subjects dropped out. The inclusion criteria were children aged 4–18 years and suffering from diabetes for > 6 months. The exclusion criteria were children who needed special care related to diabetes or other diseases, such as diabetic wounds, blindness and hypertension and psychological disorders. The condition is a factor which may affect the child's quality of life and HbA_{1c} levels. The author obtained data on medical records and contacted the attending physician to ensure the health status of the children.

Measurement

QoL of children with T1DM was measured using the KINDL® questionnaire for measuring health-related quality of life in children and adolescents, which is a generic instrument to measure the health-related quality of life of children through self-reports [27].

The KINDL® questionnaire consists of 24 items and is divided into six components, namely the physical health component (four items); the emotional health component (four items); the self-esteem component (four items); the family component (four items); the friend component (four items) and the school component (four items). The instrument is also available for both children and parents. The children's version is divided

into three categories, namely 4–6 years, 7–13 years, and 14–18 years. The parents' version is divided into two categories, namely the instrument for parents of children aged 4–6 years and for parents of children aged 7–18 years. For each item, respondents were asked to respond on a five-point Likert scale, namely, never, rarely, sometimes, often and always. The score was calculated by adding up the answer scores (1–5) of each item. The item value of each component was added to obtain the total score.

Cronbach alpha as a measure of KINDL's internal consistency for most of the subscales was 0.70, while the overall scale showed a consistency coefficient of more than 0.80 [27]. Before it was used, the questionnaire was translated to Indonesian using independent forward and backward translation with certificate number: 045/TR/04/2018. The questionnaire has been tested for validity and reliability with an Cronbach alpha value of 0.74. HbA_{1c} using the high-performance liquid chromatography method.

Intervention

The INKOLA intervention model consists of a series of health education activities in various forms such as classroom learning, handbook learning, parent's meeting, and group chats in social media (WhatsApp). Children's health education classes consist of learning and playing, reading the comic book "Diabetes Sahabatku" and chatting in a WhatsApp group. Parents' health education classes consist of seven sessions, getting the *Knowing diabetes in children* handbook and meetings.

Ethical considerations

Ethical approval was obtained from the Research Ethics Committee of the Health Polytechnic Ministry of Health Bandung No: 31/KEPK/TE/01/VII/17.

Research procedure

First, all permits including the ethical approval were obtained. Subsequently, the intervention group was divided into two classes, namely the children's class and the parent's class. The children's class was sub-divided into groups of pre-adolescents and adolescents. The intervention was carried out for four months by a trained community nurse.

Measurement of children's QoL was carried out twice, namely at the end of the third month and the fourth month. HbA_{1c} measurements were taken in the fourth month. Statistical significance was set at 0.05. To test the effectiveness of the intervention on the children's quality of life and HbA_{1c} values, an independent *t*-Test was performed. Data was normally distributed ($p > 0.05$). The software used in data analysis is SPSS version 21.

Results

Demographic data of the children and parents are presented in Table 1.

No	Variable	Group			
		Intervention (n = 21)		Non-intervention (n = 21)	
1	Age				
	Mean ± SD	12.66 ± 2.68		11.12 ± 3.17	
	Min–max	7.00–17.00		5.00–15.00	
2	Gender				
	male	11	52.4	6	28.6
	female	10	47.6	15	71.4

No	Variable	Group			
		Intervention (n = 21)		Non-intervention (n = 21)	
3	Education				
	kindergarten/pre-school	0	0	3	14.3
	primary school	7	33.3	5	23.8
	junior high school	11	52.4	12	57.1
	senior high school	3	14.3	1	4.8
4	History of DM in the family				
	with history	6	28.6	7	33.3
	no history	15	71.4	14	66.7
5	Parent's education level				
	primary school	6	28.6	10	47.6
	secondary school	9	42.9	4	19.0
	higher education	6	28.6	7	33.3
6	Parent's job (father)				
	laborer/farmer	4	19.0	3	14.3
	self-employed	2	9.5	1	4.8
	private employee	11	52.4	13	61.9
	civil servants/army/police	4	19.0	4	19.0

After the third month			
Variable	Intervention (n = 21)	Non-intervention (n = 21)	p*
	Mean ± SD	Mean ± SD	
Children's QoL pre-intervention	77.03 ± 10.64	73.31 ± 14.64	0.352
Children's QoL post-intervention	78.67 ± 11.31	73.01 ± 14.85	0.173
p**	0.541	0.941	
After the fourth month			
Children's QoL pre-intervention	77.03 ± 10.64	73.31 ± 14.64	0.352
Children's QoL post-intervention	80.93 ± 10.19	70.80 ± 12.21	0.001
p**	0.171	0.511	

* Independent t-Test, ** paired t-Test.

After the third month			
Variable	Intervention (n = 21)	Non-intervention (n = 21)	p*
	Mean ± SD	Mean ± SD	
Children's QoL pre-intervention	75.74 ± 12.65	72.66 ± 14.02	0.462
Children's QoL post-intervention	78.42 ± 9.22	78.27 ± 9.64	0.961
p**	0.302	0.132	
After the fourth month			
Children's QoL pre-intervention	75.74 ± 12.65	72.66 ± 14.02	0.462
Children's QoL post-intervention	79.62 ± 9.01	78.63 ± 9.52	0.734
p**	0.121	0.115	

* Independent t-Test, ** paired t-Test.

Table 2 shows the differences in quality of life (children's version) in the groups after the intervention. After three months of the intervention, there was an increase in the intervention group by 1.64 points and in the non-intervention group QoL decreased by 0.30 points, although it did not show a significant difference ($p = 0.173$). After fourth month, there was an improvement in the QoL in the intervention group compared to the non-intervention with $p = 0.001$.

The measurement results the QoL of children (parent's version) are shown in Table 3.

Although there was an improvement in the quality of life of the parents after the third- and fourth-month interventions, it

was not a significant difference compared to the non-intervention group.

The effect of the intervention on children's HbA_{1c} values are shown in Table 4.

The HbA_{1c} value of the intervention group fell by 0.89, while in the non-intervention group, it increased by 1.24. The difference between the intervention and non-intervention groups was significant ($p = 0.014$).

To clarify the effect of the intervention on children's quality of life, the authors present the results as a graph. Figure 1 shows QoL (children's version) in the intervention and non-intervention groups.

Variable	Intervention (n = 21)	Non-intervention (n = 21)	p*
	Mean ± SD	Mean ± SD	
HbA _{1c} pre-intervention	9.69 ± 2.55	9.35 ± 1.53	0.602
HbA _{1c} post-intervention	8.80 ± 1.76	10.59 ± 2.72	0.014
p**	0.112	0.065	

* Independent t-Test, ** paired t-Test.

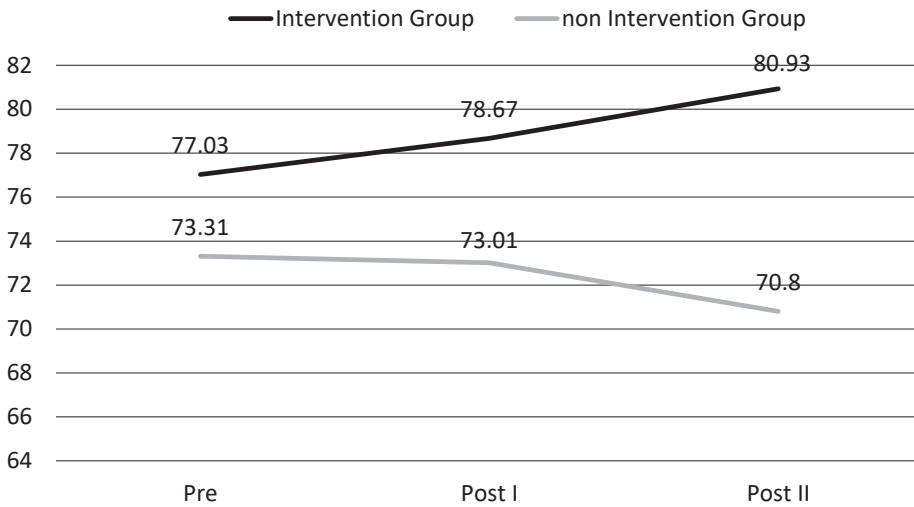


Figure 1. The difference in QoL (children’s version) between the intervention group and the non-intervention group

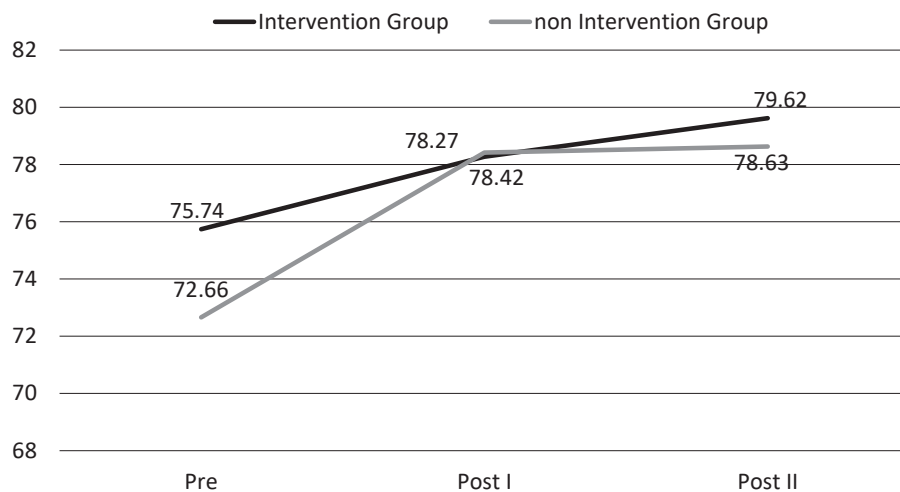


Figure 2. The difference in QoL (parent’s version) between the intervention group and the non-intervention group

In the intervention group, there was a tendency for the quality of life to increase, in contrast to the non-intervention group which showed a downward trend.

Figure 2 shows, QoL (parent’s version) in the third month showed an increase, but then there was relatively no improvement after the fourth month.

Discussion

The results show that the INKOLA intervention model could increase the children’s QoL score both in the children’s and the parent’s groups. Improving the QoL of children with diabetes through an educational approach is consistent with the results of previous studies [20, 21]. Nursing interventions based on Orem’s theory have been shown to improve QoL for diabetic patients [22].

The different quality of life scores between the children’s and the parents’ groups was in accordance with previous studies [12, 14]. The non-significant increase in QoL according to the parents’ questionnaire version is probably caused by various factors such as physical, psychological, and social ones. Anxiety, stress, and depression are not only experienced by T1DM children but also by their parents [9, 12]. Comprehensive information provided in the intervention regarding diabetes in children can be either valuable or stress-triggering for parents, especially if the parents are at the pre-contemplation or contemplation stage. Therefore, a special approach is needed and more time for parents to recognize and understand diabetes in children. Increased quality of life score for children’s versions and decreased HbA_{1c} after the intervention are in line with the results of previous research [16, 17]. There are several reasons for the strength of the INKOLA model, such as the availability of books, and learning methods that emphasize the empowerment of

parents and children. Learning materials are presented as text (book and comics) which can be read anytime as necessary. Play activities can reduce stress in children and promote socialization and close connection with one another [20].

Limitations of the study

The main limitation that needs attention for further research is the psychological variables of the children and parents.

Conclusions

INKOLA based on the Orem Self-Care model is effective in improving the quality of life and controlling HbA_{1c} in children

with T1DM. Therefore, it is recommended that nurses and other health workers in the community use the INKOLA model.

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Address for correspondence:
Hotma Rumahorbo, PhD, Assoc. Prof.
Nursing Program Study
Bandung Health Polytechnic
Jalan Dr Otten No. 32
Bandung Post Code: 40171
Indonesia
Tel.: +62 22-4231057
E-mail: hotma_rumahorbo@yahoo.com