

Establishment of Structured Care Program for Children with Type 1 Diabetes in Low Income Countries: Integrated Management of Diabetes in Children (IMDC) Project in Sudan.

Mohamed Elhassan Abdalla^{1*}, Abdelrahim Mutwakel Gaffar², Husam Eldin Elsawi², Huda Haroun³, Bashier Elnaem³

1. Medical Education Unit, Faculty of Medicine- Jazan University, KSA, formerly Department of Paediatrics, Faculty of Medicine- Gezira University, Sudan
2. Faculty of Medicine- Jazan University, KSA, Department of Community and Family Medicine.
3. Department of Paediatrics, Faculty of Medicine- Gezira University, Sudan

*E.mail of the corresponding author: hason75@yahoo.com

Abstract

The Integrated Management of Diabetes in children (IMDC) is a program established to provide a structured care for children with type 1 diabetes in Gezira State, Sudan. It is a result of partnership between Faculty of Medicine –University of Gezira, World Diabetes Foundation and State Ministry of Health.

This project has adopted a collaborative structure of providing care in health facilities, school and with the families. Partnership development with relevant sectors involved in diabetes care is one of the crucial strategies adopted to achieve the objectives.

IMDC project develop the first management guidelines, train health personnel and teachers in schools and empower children and their families, produce local education materials, and the establish reference laboratory and satellite clinics for diabetes care.

In conclusion the care of children with diabetes needs collaboration between the health system, families and the schools. Partnership is crucial to implement programmes aiming at improving the care given to children with diabetes as each partner has a role in diabetes care continuum.

Keywords: Diabete type 1, Sudan, Management, Children

Introduction

Type 1 Diabetes, is the most common form of diabetes in children all over the world (1)(2), In the year 2010 the total number of children in the age group 0-14 years with diabetes is estimated as 479.6 thousands, with 75.8 thousands newly diagnosed annually, this reflects an increase in the incidence by 3% annually (3).

The incidence of type 1 diabetes increases with age with a peak around the age of 10 years and no sex predominance (2). The incidence is showing geographical variations, varying from 0.1 per 100,000 in China to 40 per 100,000 in Finland, however, the studies are not covering all parts of the world.

In the Eastern Mediterranean and Middle East countries the highest incidence is in Egypt with 8 per 100,000 population per year for those aged 0-14 years, and the lowest incidence is in Pakistan with less than 1 per 100,000 population per year (4).

The first study estimating the incidence of diabetes in Sudan was completed in Khartoum State in 1989, it was estimated at 10.1 per 100,000 populations per year for those aged 0-14 year the same study has demonstrated increase in the incidence in children of 7-14 years old in a 4-years period from 5.8 to 10.3 (5) (6).

In Gezira state, the second populated state in Sudan, according to the incidence rate estimated for the Sudan by IDF, the number of cases of type 1 diabetes was estimated to be about 1,500 children in the Gezira state.

Context of care of children with type 1 Diabetes in Sudan

Sudan is an African country with racial, ethnic, religious and cultural diversity with a population of 39.2 million in

2008 and majority of them (72 per cent) live in rural areas (7).

Sudan is classified by the World Bank as one of the lower middle income countries (8). The total expenditure on health is 3.6% of GDP and the general government expenditure on health is only 3.0% of total government expenditure. The average per capita government expenditure on health is only 18 US\$ and the out-of-pocket expenditure accounts for 63.4% of the total health expenditure (9).

Like most of the developing countries, care of children with diabetes is administered mainly in secondary and tertiary levels of health care system generally user fees policy is implemented. Health insurance scheme which was introduced in 1996 mainly covers the employees in the formal business sector. The insurance covers all health cost except for the drugs, where the beneficiaries have to pay 25% of the itscost, which resembles as another factor that increases the burden on families who have members with chronic conditions (10).

A recent study shows that the median annual expenditure of diabetes care was US\$ 283 per diabetic child, this accounts for almost 23.1% of the median annual family income (1222 US\$), and 65% of the family's expenditure on health of which 35% is spent on insulin (5). In spite of this high cost, the glycaemic control is poor in 86% of the patients managed in the public or private clinics (5).

In Gezira state, management of children with diabetes in the public sector usually takes place at rural hospitals and complicated cases are referred to Wad Medani Paediatrics Teaching Hospital (WPTH) which is the main paediatrics hospital in the state.

Till 2007, there were no guidelines neither for management of diabetic children nor for management of diabetic emergencies. Follow-up for children with diabetes was made in medical referred clinics in the hospital among other patients. The services offered for children with diabetes were mainly hospital-based and the role of families and schools were underestimated by most of physicians. In WPTH which is a referral hospital none of the children with diabetes have their HbA1C tested at all because the hospital laboratory did not have the capacity to perform this test.

In Sudan, children with type 1 diabetes and their caregivers have a significantly lower QOL scores compared to type-2 diabetics and their caregivers and the general population (11), (16) To address all of the above challenges, the Integrated Management of Diabetes in Children (IMDC) project; was initiated as a collaborative work implemented by WPTH in Collaboration with the Faculty of Medicine-University of Gezira, Gezira State, Ministry of Health and supported by the World Diabetes Federation (WDF).

Paper Objectives

The aim of this communication is to share the experience of developing an integrated care program for children with type 1 diabetes mellitus in low resourced countries with health professionals to enhance the quality of care provided to children with type 1 diabetes.

The specific objectives are to:

Describe the planning and implementation of structured and integrated care program for children with type 1 diabetes mellitus in low resourced countries such as Sudan;

Discuss the challenges that face the program and how they were managed

Project planning phase

The Integrated Management of Diabetes in Children (IMDC) project in Gezira State, Sudan is collaboration between Faculty of Medicine-University of Gezira, Wad Medani Paediatrics Teaching Hospital (WPTH), Ministry of Health, Ministry of Education in Gezira State and supported by the World Diabetes Federation (WDF).

A literature review along with several consultations between different partners took place. The aim was to adopt an evidence-based planning process in the design of the project.

The design of the programme activities aimed to support the care of children with diabetes in the three settings; the

health facility, the home and the school. Arising from the evidenced role of each as published in the literature, the following continuum of care has been developed.

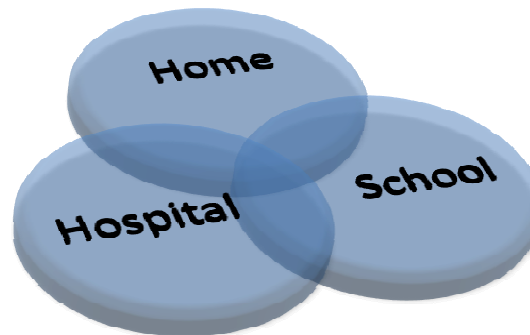


Figure 1: Type 1 Diabetes mellitus continuum of care in IMDC

In the planning phase of the IMDC, a workshop that involved all stakeholders was conducted. The outcome of that workshop was a clear definition of the role of each partner in the project. High level commitment from all partners was obtained.

IMDC goal, objectives and strategies:

The IMDC goal is to improve the quality of care provided to children with diabetes through hospital, schools and families. The objectives of IMDC are to:

1. Improve the clinical care for children with diabetes in Gezira State.
2. Establish dietary and psychological support units for children with diabetes and their caregivers in Wad Medani Paediatrics Teaching Hospital.
3. Develop registry, information and referral systems to facilitate follow-up, monitoring, planning and research in diabetes.

In order to achieve the project objectives the following strategies were adopted:

1. Partnership development with relevant sectors involved in diabetes care;
2. Infrastructure development for WPTH and other hospitals in the state to improve the quality of diabetes care for children;
3. Development of guidelines and information-education-communication (IEC) materials;
4. Training of health personnel, teachers and care givers involved in diabetes care;
5. Establishment of registry and information system.

Clinical care

The primary goals of diabetes management are maintaining normal blood glucose level and achieving relatively normal quality of life (QOL) (11)(12). An approach based on the others experiences, like that proposed by the European region have been considered in IMDC (13).

The clinical care guideline is prepared as initial step in the project, based on the international guidelines and adapted to local context to be the first type 1 diabetes clinical care guidelines in Sudan (<http://www.worlddiabetesfoundation.org/documents/proposal-diabetic-ketoacidosis-management-guidelines>).

Training workshops were organized on the new guidelines and on how to run diabetes mini-clinics for 110 health

personnel working in WPTH reference clinic, PHC settings and diabetes mini-clinics in a period of 2 years.

Reference Paediatric Diabetes clinic in WPTH was established. The clinic provides regular clinical care for children with diabetes two times per week according to the new guidelines. The children can be registered directly in this clinic or referred from the mini-clinics; which are four clinics established in the state.

A well-equipped laboratory was established to provide services for children from WPTH reference clinic and the diabetes mini-clinics. The reference laboratory provides free services to all diabetic children.

The Reference Paediatric Diabetes clinic includes nutritional and psychological support units. The nutritional unit provides training in nutritional aspects of diabetes care to caregivers, health personnel from PHC setting and diabetes mini-clinics. The psychological support unit provides its services to children and their families. Home visits were conducted to some families for a better understanding of the living conditions of children.

Information and registry system was established for the project. This system is both paper and computer based; it is composed of records of all children attending the clinic and the mini-clinics. All information about patients' clinical developments is registered, retrieved and updated in each visit. Referral records were also developed to ensure flow of information between the central and mini-clinics. A clear referral system between the mini-clinics and the reference diabetes unit in WPTH was created.

Family care

It is known that, up to the age of 8 years management responsibility of children with diabetes, lies on the shoulders of parents, after that age some of the responsibilities start to get transferred to the sick adolescent (14). Arising from this fact, the IMDC has integrated a component of family care, which composed of the following; Blood glucose measuring devices were provided with training for children and their caregivers on how to use the device to enhance home monitoring.

Empowerment of children with diabetes and their caregivers is one of the strengths of the IMCD project. The capacity of the project nurses and nutritionists on techniques and methods to educate and empower children and caregivers to deal with diabetes was developed through specialized training workshops. Small group training about e; insulin storage, insulin injections and nutritional aspects is conducted as part of the routine clinic service.

Health education activities to increase the awareness of the community were conducted by medical students from Gezira University as part of the community based programmes academic modules. Almost 500 families in 53 villages have received health education about diabetes.

School care

Children spend almost half of their day at schools, so, the role of the school is necessary in the diabetes care. It is recommended that all schools should have policy for care of children with diabetes (15).

Schools based survey was conducted by the project to identify children with diabetes in the schools, a total of 115 children with diabetes in basic schools in Gezira state were recorded.

Thus, a tailored training programme for school teachers to care for children with diabetes was developed. Almost 205 teachers were trained; with the priority given to teachers from schools where diabetes cases exist.

Along with school teachers training, the project has distributed blood glucose measuring devices to schools where children suffering from diabetes exist. The teachers were requested to submit reports to the project about their observation on children with diabetes.

Schools visits were conducted by the care team when needed. Remarkably, one of the children was diagnosed as having diabetes in response to one of the trained teacher's observation. The teacher noticed that the child is passing urine more frequently; he then made the child's family bring him to the clinic after arranging an appointment with the doctor in the clinic.

Insulin supply:

IMDC project provided insulin free of charge for all registered children. Currently the total number of registered children is 732 in the reference clinic and the four mini-clinics. The average amount of insulin needed by each child

is 900 U/month.

Sustainability

To ensure the sustainability of the project, different strategies have been adopted starting in the planning phase. These strategies proved to be effective because the external fund of the project (WDF contribution) was only for the period 2007-2009 and till now (2012) all activities are going on.

In the planning phase, the project was carefully designed to fit into the existing system.

- ✓ The project operates using available manpower of the existing service delivery system.
- ✓ No external hiring was sought.
- ✓ All facilities and premises used by the project belong to the existing system (WPTA and mini-clinics, university premises).

Leadership and partnership were the project's strongest assets.

- ✓ Project's mission, vision, objectives and resources were made clear to all stakeholders. This ensured a sustainable internal and external environment.
- ✓ The state ministry of health allocated a separate item in its budget for covering insulin cost.

The Health Insurance Corporation is now using the project's reference laboratory for its clients. Revenues from these services added a new source of income to the project.

All services are free of charge but a smart subsidization scheme was developed and adopted by the project to cover the cost of some services (disposable syringes and strips), while ensuring affordability. Social workers classify patients into three categories according to socioeconomic status, which eventually made patients eligible for full free services, partial or no subsidization prices.

Evaluation and Initial experience

The following indicators were used to monitor and evaluate the progress of the project:

Number of registered children who were served by the project.

Number of trainees and training sessions for each category.

Number of health education sessions conducted.

clinical care indicators supported by measurement of HbA1c and number of admission due to keto-acidosis.

This is the first trial to establish structured care for children with diabetes in Sudan, the experience and outcome is promising.

The main achievements could be summarized in the following points:

A reduction in DKA admissions by 77.78% was achieved in 2 years. The number of children admitted with diabetic ketoacidosis has been reduced from 180 in 2006 to only 40 in 2008, of which none were admitted due to lack of insulin.

The impact on HbA1c levels showed that the percentage of children with poor control (>9%) has fallen from 66% to 38% and the group in good control (<7.5%) has increased from 16% to 60%.

The full report about the project can be found at the world diabetes foundation website (<http://www.worlddiabetesfoundation.org/projects/sudan-wdf06-167>)(16).

Development of dedicated staff through numerous training activities that accompanied the project contributes to the effectiveness of the project.

Challenges

1- Scarcity of local studies to give evidence for the development of the Guidelines of management this has been overcome by adaptation of the international guidelines to the local context of Sudan through the participation of experts.

2- Most pediatricians in the hospital feel uncomfortable for having one guideline to follow in management. The project has overcome this issue through discussions, inviting expertise in the process of endorsement and enhances a sense of ownership.

3- Rapid turnover of the trained health worker impacted negatively the implementation of the project clinical activities. Regular follow up of mini-clinic especially in remote hospitals and health centers to identify health workers who need training was part of routine supervisory visits.

4- Insurance of regular insulin supply for all children with diabetes is one of the major challenges. Also some children with diabetes live in villages where there is no electricity supply; insulin storage is the main concern of this group. At the beginning the cost was covered by WPTH and Al Rahma Society (charity organization operating inside the hospital), then the State Ministry of Health took the responsibility. The International Diabetes Federation –Life for Child Programme also supported the insulin supply for 25 children for 2 years. The authors still believe that insulin supply is the most challenging issue in the IMDC project and may hinder the success of such a project in developing countries.

5- The transport means for implementation and supervision was a serious problem when at the start of the project, then it is resolved through collaborative effort of the university and other partners.

Conclusion

The experience of IMCD project in Gezira state Sudan shows that the implementation of a well-structured care program of diabetic children organized within the PHC system in low income countries is feasible and can improve their glycaemic control. The care of children with diabetes needs collaboration between the health system, families and the schools. The key to achieve good glycaemic control in type 1 diabetes is the provision of insulin as it is a major financial constraint for families with children suffering from diabetes in developing countries like Sudan.

All those who showed desire to implement similar approaches in organization and management of care of diabetic children were assisted by the projects' team. As a result two neighboring states Sinnar and Kasala started similar projects and were well supported by project administration.

Partnership is crucial to implement programmes aiming at improving the care given to children with diabetes as each has a role in the diabetes care continuum.

Bibliography

1. *ISPAD Clinical Practice Consensus Guidelines 2006–2007 Definition, epidemiology and classification*. Maria E. Craig, Andrew Hattersley. 2006, *Pediatrics Diabetes*, Vol. 7, pp. 343-351.
2. *Worldwide childhood type 1 diabetes incidence – what can we learn from epidemiology?* Soltesz G, Patterson CC, Dahlquist G. *Suppl. 6, 2007, Paediatric Diabetes*, Vol. 8, pp. 6–14.
3. *Diabetes in the Young: a Global Perspective*. *International Diabetes Federation*. [Online] [Cited: October 27, 2010.] <http://www.diabetesatlas.org/content/diabetes-young-global-perspective>.
4. *Diabetes in the young*. *Diabetes Atlas, third edition*. Belgium : International Diabetes Federation, 2006.
5. *Economic burden on families of childhood type 1 diabetes in urban Sudan*. Hind Elrayah, Mohamed Eltom, Ashraf Bedri, Abdelrahim Belal, Hans Rosling, Claes-Göran Östenson. 70, 2005, *Diabetes Research and Clinical Practice*, pp. 159-165.
6. *Prevalence of insulin-dependent diabetes mellitus (IDDM) in school children in Khartoum, Sudan*. A. Elamin, M.I.A. Omer, Y. Hofvander, T. Tuvemo. 1989, *Diabetes Care*, Vol. 12, pp. 430-432.
7. Central Bureau of Statistics. *Fifth Sudan Population and Housing Census – 2008*. Khartoum : Central Bureau of Statistics, 2009.
8. World Bank Group. Sudan reports. *World Bank*. [Online] World Bank, 2010. [Cited: Dec 15, 2010.] <http://www.worldbank.org/>.

9. World Health Organization. Sudan Country Profiles. *World Health Organization Regional Office for the Eastern Mediterranean*. [Online] WHO Regional Office for the Eastern Mediterranean, 2010. [Cited: Dec 15, 2010.] <http://www.emro.who.int/sudan/> .
10. Mohamed, Gamal Khalafalla. Financing health care in Sudan: Is it a time for a bolishing of user charge. *Sudanese Journal of Public Health*. January 2007, Vol. 2, 1, pp. 38-47.
11. Awadalla, Abdel W., et al., et al. Subjective Quality of Life of Outpatients with Diabetes: Comparison with Family Caregivers' Impressions and Control Group. *Journal of Ntional Medical Association*. May 2006, Vol. 98, 5, pp. 737-745.
12. Collins, Margret M., et al., et al. Quality of Life and Quality of Care in Patients With Diabetes Experiencing Different Models of Care. *Diabetes care* . April 2009, Vol. 32, 4, pp. 603-605.
13. International Diabetes Federation. European Diabetes Policy Group, A Guide to Type 1 (Insulin-dependent) Diabetes Mellitus. *International Diabetes Federation, European Region*. [Online] 1998. [Cited: October 15, 2010.] European Diabetes Policy Group 1998. International Diabetes Federation, European Region. A Guide to Type 1 (Insulin-dependent) http://www.diabetesguidelines.com/health/dwk/pro/guidelines/type1/2_1.htm.
14. Streisand R, Swift E, Wickmark T, Chen R, Holmes CS. Pediatric parenting stress among parents of children with type 1 diabetes: the role of self-efficacy, responsibility, and fear. *Journal of Pediatric Psychology*. 2005, Vol. 30, pp. 513-521.
15. International Diabetes Federation (IDF) Middle East and North Africa (MENA) Regional Meeting .Supporting the Implementation of the United Nations Resolution (UNR) on Diabetes (61/225) in Middle East and North Africa. *International Diabetes Federation*. [Online] April 18, 2009. [Cited: October 20, 2010.] <http://www.idf.org/webdata/docs/IDF-Action%20Plan-EN.pdf>.
16. Integrated Management of Diabetes in Children. *World Diabetes Foundation*. [Online] [Cited: October 20, 2010.] <http://worlddiabetesfoundation.org/composite-1118.htm>.
17. Naughton, Michelle J., et al., et al. Health-Related Quality of Life of Children and Adolescents With Type 1 or Type 2 Diabetes Mellitus: SEARCH for Diabetes in Youth Study. *Arch Pediatr Adolesc Med*. 2008, Vol. 162, 7, pp. 649-657.
18. Awadalla, Abdel W., et al., et al. Diabetes Mellitus Patients' Family Caregivers' Subjective Quality of Life. *Journal of the National Medical Association*. May 2006, Vol. 98, 5, pp. 727-736.
19. Emmanouilidou, E, et al., et al. Quality of life of children and adolescents with diabetes of Northern Greek origin. *Hippokratia*. 2008, Vol. 12, 3, pp. 168-175.
20. Barnard, Katharine, et al., et al. Fear of hypoglycaemia in parents of young children with type 1 diabetes: a systematic review. *BMC Pediatrics*. 2010, Vol. 10, 50. <http://www.biomedcentral.com/1471-2431/10/50>.
21. BJ, Anderson. Family conflict and diabetes management in youth: clinical lessons from child development and diabetes research. *Diabetes Spectrum*. 2004, Vol. 17, pp. 22-26.
22. Katharine Barnard, Sian Thomas, Pamela Royle, Kathryn Noyes and Norman Waugh. Fear of hypoglycaemia in parents of young children with type 1 diabetes: a systematic review. *BMC Pediatrics*. 2010, Vol. 10, 50.
23. International Diabetes Federation. IDF diabetes atlas 4th edition. *IDF diabetes atlas* . [Online] 2009. [Cited: 12 3, 2010.] <http://www.diabetesatlas.org/map?id=9>.
24. Zhang, Ping, et al., et al. Economic impact of Diabetes. [book auth.] IDF. *IDF Diabetes Atlas fourth edition*. s.l. : IDF, 2009.
25. World Bank. Sudan Data. *World Bank*. [Online] World Bank, 2010. [Cited: Dec 16, 2010.] <http://data.worldbank.org/country/sudan>.