

Review Article

Children with diabetes friendly services: A blueprint

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ABSTRACT

Children with diabetes, despite their small numbers, form a population with needs different from adult subjects with diabetes. This emphasizes the need to establish child- friendly standards in services rendered to these children. The care providers for children with diabetes are quite heterogeneous and include generalists, paediatric subspecialist and endocrinologists and care is delivered in various circumstances. Various aspects of caring for children need to be taken into account when a system is created for children with diabetes. This includes but is not limited to physical infrastructure of the system, qualified medical personal with experience in handling children and quality systems to maintain cold chains for insulin and laboratory reporting. The system should be able to reach out to other stake holders that include the community and family of children with diabetes. The system should be subjected to self audit, and performance on various key indicators should be assessed.

Key words: Family centered care, pediatric diabetes, patient centered care, type I diabetes

CHILDREN WITH DIABETES ARE SPECIAL

The global pandemic of diabetes respects no boundaries, not even age. Though the vast majority of people with diabetes are adults, CwD form a significant group. The fact that CwD need attention separate from that given to adults with diabetes is accepted now. A unique anatomy and physiology altered pathology and differences in response to pharmacology all support the statement that CwD are special.

HETEROGENEITY OF DIABETES CARE

As awareness grows and research progresses, diabetes care facilities are increasing, both in quantity and quality. While some are stand-alone centers, others are part of

general health-care set ups. Some limit care to adults and others to CwD, while others handle all people with diabetes, irrespective of age. Certain clinics offer outdoor treatment alone while other hospitals provide indoor care as well. Though some diabetes centers house allied specialties such as ophthalmology, physiotherapy and psychology under one roof, many limit their services to clinical diabetology. Many health-care facilities are manned by a team of diabetes health-care professionals, but often, a single Diabetologist has to wear multiple hats (and ensure that they fit!). This harsh reality creates challenges for CwD, who may or may not receive adequate attention and care. This is especially true in resource challenged set ups, where the same provider and the facility, is expected to care for both children and adults.

Multiple guidelines are available to provide advice regarding various aspects of diabetes. These include guidelines related to children and to biological as well as psychosocial aspects of the disease.^[1-4] Diabetes care, however is much more than correct prescription of life-style modification and drugs. CwD need to be provided appropriate care in optimal surroundings, which are perceived to be friendly.

Access this article online

Quick Response Code:



Website:
www.joshd.net

DOI:
10.4103/2321-0656.115303

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CWD-FRIENDLY STANDARDS

It is surprising therefore that no standards have been set for health-care facilities, which deliver diabetes care. The vast, heterogeneous characteristics of diabetes care act as a deterrent to the laying down of versal, yet cogent guidelines for diabetes care facilities. The differing economic environment in various countries also makes drafting of such guidelines a challenge. Calls have been made to ensure child-friendly services, both in general^[5,6] and specifically for CwD.^[7] Suggestions have also been made to improve pediatric diabetes care, focusing on a developing country perspective.^[8] The need for collaborating with children in health-care research has also been highlighted.^[9]

Children across the world in spite of contrasting socio-economic backgrounds and various quality of health-care share many similar characteristics. This is true of CwD as well. All CwD require appropriate care for their condition, delivery by competent caring diabetes care professionals, housed in good quality diabetes care settings. Through this communication, we try to highlight the need for standards in CwD-friendly health-care facilities. The standards mentioned below are suggestions and are not dictates, and are voluntary measures of improving care for CwD. They have universal applicability, irrespective of resources.

IMPORTANCE OF BEING CWD-FRIENDLY

Diabetes, including diabetes in children, is an eco-sensitive disease, sensitive to the environment.^[10] This implies that the condition is modulated by the physical and human (social) environment of the person with diabetes. The CwD who is provided ample opportunity for physical activity, healthy eating options and social scaffolding to cope with stress, will have better glycemic control than a peer without such exposure. His analogy extends to health-care or diabetes care facilities as well. The quality of the health-care system or facility and its perceived quality or child-friendliness is equally important in determining response to diabetes therapy. The same is true for quality and perceived quality of diabetes care providers.

A CwD-friendly health-care environment, both physical and social will enhance the health-care seeking experience and improve future health-related behavior. Better patient satisfaction will translate into customer evangelism, which will improve the behavior of the family and community as well. This will promote utilization of curative, as well as preventive health-care services; have a positive impact on therapeutic outcomes.

THE EIGHT A'S OF CWD-FRIENDLINESS

A CwD-friendly health-care facility should exhibit the eight A's [Table 1]

- Available: Provide 24 × 7 contact, either in person or on the phone
- Accessible: Geographically accessible by road/rail/other means of transport
- Acceptable: Acceptable to the socio-cultural environment it is located in.
- Affordable: Affordable according to the economic environment
- Affectionate: Offer friendly service, which does not alienate CwD
- Accurate: Provide scientifically correct treatment
- Appropriate: Provide treatment appropriate to the CwD's needs
- Answerable: Be answerable to children, their needs, wishes and requirements.

CWD-FRIENDLY ENVIRONMENT

The environment of a diabetes care facility can be classified as physical and human. The physical environment can be divided into hard and soft infrastructure. The human element of care involves “soft” skills of staff as well as the quality of medical care that is provided.^[11] As the diabetes care facility does not exist in isolation, but is a part of the community it serves, community outreach is an important component of CwD-friendliness. Similarly, a will to improve one's services as observed by self-audit, is a sign of being CwD-friendly. These attributes, listed in Table 2, are described below.

Table 1: The eight A's of CwD-friendliness

Availability
Accessibility
Acceptability
Affordability
Affection
Accuracy
Appropriateness
Answerability

CwD: Children with diabetes

Table 2: Components of CwD-friendliness

Physical environment
Hard infrastructure/architecture
Soft infrastructure
Human environment
Medical system environment
Quality environment
Community outreach
Audit

CwD: Children with diabetes

PHYSICAL ENVIRONMENT

Hard infrastructure/architecture

CwD-friendly facilities should be optimally designed to be safe for children. Rooms and corridors should be airy, with no chance of communicating air-borne disease. Stairs should have low steps and hand railings while ramps should not be steep. Restrooms should be designed for the convenience of children, both girls and boys. Playrooms or open spaces for playing should be provided, in a pollution-free environment. Clean drinking water and electricity should be available.

Soft infrastructure

The interior design must be child friendly and should be changed at regular intervals, being upgraded wherever possible. Chairs and tables should be of appropriate height for children, especially in examining rooms and laboratories. Colorful posters and visual aids, in vernacular language, written in large font, with pictorials, help convey a feeling of CwD-friendliness. A canteen located within or near the facility, which serves healthy, tasty, diabetes-friendly foods for children, is of help. Biomedical hazard disposal amenities must be in place in a CwD-friendly clinic.

HUMAN ENVIRONMENT

The diabetes care providers are the backbone of any diabetes care facility. These professionals need to be child-friendly if the facility is to be considered CwD-friendly. Qualified, trained and sensitized staff who are tuned to the needs of the pediatric age group, are an essential part of the CwD-friendly environment. They should welcome the child, as well as her/his family, to share doubts and concerns. Facilities for explaining diet, physical activity, insulin technique, monitoring, stress management and complication management, should be available. CwD-friendly staff should ideally work for extended hours on school holidays to ensure that education of CwD is not hampered. For trouble shooting, staff should be available 24 m × 7 m telephone or via SMS/E-mail.

MEDICAL SYSTEM ENVIRONMENT

Basic clinical and laboratory services must be provided by every CwD friendly health-care set up. While it is not expected that every CwD-friendly facility will have indoor wards, it should have tie up with nearby hospitals for admission. There should be collaboration with adult diabetes care providers and a transition clinic should be in place. Facilities for providing expert psychological care should be available.

QUALITY ENVIRONMENT

Every CwD-friendly diabetes care center must provide quality non-pharmacological and drug therapy. This includes maintenance of cold chain, ensuring availability of drugs (including insulin) and ancillary supplies, without break, using available educational tools and record keeping. Quality of care must be monitored by appropriate means, including biological parameters such as hemoglobin A1C and psychometric instruments.

OUTREACH

Family outreach

The family is an active and essential stakeholder in providing diabetes care to the CwD. The CwD cannot take care of herself or himself without the active participation of her or his parents, siblings and other relatives. A CwD-friendly health-care center must welcome parents and family members to join the fight against diabetes as equal partners and ensure that their concerns and doubts are addressed adequately.

Community outreach

The CwD is not an isolated entity, but is an integral part of her/his community. A CwD-friendly health center; therefore, should actively engage in community awareness activities, school health work and patient advocacy. This will help modulate the social environment of the CwD and improve long term outcomes.

AUDIT

Self-audit is a central pillar of CwD-friendliness. Health facilities that claim to be CwD-friendly should be engaged in a continuous, dynamic, self-improvement exercise. This is possible only with a formal system of self-audit and self-appraisal. Each facility should select indicators from the above mentioned aspects and monitor itself on a regular (perhaps quarterly) basis to assess improvement. Audit should also be performed by the CwD, who are the actual users of the facility. A formal or informal method of taking feedback from CwD and their family members must be put in place. Equally important, this feedback must be acted upon, to ensure better quality of care for CwD.

SUMMARY

This communication has tried to highlight the concept of CwD-friendliness, of health-care facilities, which provide diabetes care to CwD. This is an important, yet neglected issue and needs to be taken to center stage of health politics. Focusing on providing a friendly physical as well

as human environment, which delivers quality individual care and community support in a medical system subject to audit, will certainly help improve the health of our CwD.

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How to cite this article: Kalra S, John M, Unnikrishnan AG, Sahay R, Baruah MP, Bantwal G. Children with diabetes friendly services: A blueprint. *J Soc Health Diabetes* 2013;1:75-8.

Source of Support: Nil. **Conflict of Interest:** None declared.

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