Thriving, Not Just Surviving:
Empowering Persons with type 1 Diabetes

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Disclosure to Participants

• Notice of Requirements For Successful Completion
  - Please refer to learning goals and objectives
  - Learners must attend the full activity and complete the evaluation in order to claim continuing education credit/hours

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  - Presenter: Jason Baker MD – Founder, Board Chair Marjorie’s Fund, Lilly/BI: speaker, Insulet: speaker
  - Presenter: Susan Weiner MS RDN CDE CDN – Advisory Board Diabetessisters, Medical Advisory Board dLife, Medical Advisory Board healthline.com, Board of Directors ProjectREAL

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What we will cover today

• The importance of reaching the resource poor in their own communities
• Vocational and educational training methods to improve diabetes self-management
• What we can do “now” to help the resource poor with diabetes

Learning Objectives

1. Identify specific educational programming resources aimed at preventing health complications
2. Describe three specific ways for a young adult with type 1 diabetes (with limited resources) to increase access to sustainable sources of insulin and glucose testing supplies
3. Discuss the research on understudied populations with the goal of advancing the epidemiology of type 1 diabetes globally

Our Mission
To empower adolescents and adults living with type 1 diabetes in resource poor settings to not only survive their diagnosis, but to effectively control their diabetes and to thrive into adulthood.

www.marjoriesfund.org
Need in the Developing World

- Type 1 diabetes affects 15-30 million people globally
- A type 1 diabetes diagnosis is made every hour
- Incidence is increasing by 3-5% per year
- Means of diagnosis is limited

Need in the Developing World

- Despite often adequate access to resources control is still poor.  
  - Most adults and children with T1D do not achieve goals for glucose control set by the American Diabetes Association (T1D exchange, https://t1dexcahnge.org/pages/t1d-exchange-clinic-registy-top-10-findings/)
- Why?
  - Gaps in education
  - Lack of adequate support structure
  - Lack of adequate understanding of T1D
  - No Centralized database of T1D

Diathele.org USA Tour

- 7 Manhattan Marathons in 7 Days
- Then to: Minneapolis, Miami, San Diego and San Francisco!
- Sponsored by Marjorie’s Fund and Dexcom

Where We Work

Marjorie’s Fund works in resource poor settings worldwide where:

- Blood tests, medications, ongoing education and medical oversight are severely lacking; and
- Type 1 diabetes is frequently a death sentence.
- For those who survive, the quality of life is poor.

How We Work

For patients to survive and thrive, we work to reduce rates of diabetes complications by:

- Educating patients and their supporters in self-management
- Training healthcare providers in type 1 diabetes
- Ensuring sustainable access to treatment and testing supplies
- Assessing outcomes, conducting research

Rwanda Diabetes Education Center (RDEC)
The RDEC Curriculum

**Audience:** 20 PWD type 1, age 24 and older

- Diabetes Diary will be kept by all students
- Includes logs of glucose levels, food, insulin doses, and exercise
- Discuss weekly in group sessions
- Fingerstick/glucose testing log

Curriculum Topics

- Diabetes self-management
- Business skills & vocational training
- Nutrition and agriculture

Outcomes Assessment

Outcomes of the program will be measured using:

- Monthly quizzes on lecture topics
- Final Exam at the end of the program
- HbA1c measurements taken at baseline (start of the program), 3 months (mid program), and 6 months (program completion)
- Diabetes Questionnaire assessing quarterly HbA1c levels, complication rates, status of employment, housing, and food security
“Actions do not speak louder than words...they save lives.”
- Tom Karlya, AKA DiabetesDad

Well-child care diabetes education

- 16-month old Reagan
- North Carolina, pending legislation: Each physician, physician's assistant, or certified nurse practitioner who provides well-child care is encouraged to educate parents and discuss the warning signs of Type 1 diabetes.

We have to meet our patients where they are...

Meghan Jardine, MS, MBA, RD, LD, CDE

Native Lifestyle Balance - Curriculum based developed for the Native American Communities.

Reaching the Community

- Navajo Special Diabetes Project (SDP)
- Gallup Indian Medical Center (GIMC)
- REACH (Racial Ethnic Approaches to Community Health)

Bridge the gap

Resource Poor with T1DM
Areas of Need in the United States
1. Lack of a cohesive support network for adolescent and older individuals and their caregivers
2. Inadequate preparedness strategies for managing type 1 diabetes during times of emergency (such as hurricanes or natural disasters)
3. Inadequate training of school staff on type 1 diabetes care
4. A limited epidemiological database on type 1 diabetes

Resource Poor in the United States
- High rates of poverty
- Limited access to health insurance or poor coverage
- Lack of specialty medical care and emergency services
- Minimal exposure to diabetes education

All of which contribute to lack of diabetes diagnosis or treatment of complications

Goals
1. Identify areas of need for T1D patients in resource poor settings
2. Enhance the network of T1D patients
3. Expand the knowledge base of caregivers for people with T1D, including school nurses
4. Implement better emergency preparedness strategies for managing T1D during times of emergency
5. Improve the T1D epidemiological database

Translating Evidence Based Practice into Practical Application
- Not an easy task....
  - Distance from the healthcare professional
  - Financial limitations
  - Cultural barriers
  - Mistrust
  - High rates of illiteracy

Possible Solutions
- Telemedicine (limitations: privacy and security, digital divide, reimbursement issues, availability, lack of physical diagnosis)
- Web Based Efforts (limitations: digital divide- lack of technical skills, no internet, limited literacy and health literacy, lack of manual dexterity)

Possible Solutions (continued)
- Telephone Help Lines (limitations: funding, availability of phone lines)
- Community Health Care Workers (limitations: adequate support system, follow up and communication, training, professional support to prevent CHW burnout)
**Community Health Worker (CHW)**

- Advocate for PWD
- Identify resources in the community
- Attend appointments with patient
- Trusted and respected by patients
- Improve patient focus
- Identify home safety issues
- Report patient concerns to CDE’s

**CHW = “Eyes and Ears”**

- Identifies struggles: such as alcohol abuse
- Observes kitchen and living facilities in the home
- Assists with obtaining food from food pantries
- Patients confide and share info easily
- Helps pt’s with disabilities obtain services (ie deaf, blind)

**Collaborate with Existing Groups**

- Government agencies
- Health care providers
- Patient support groups
- JDRF
- ADA
- AADE
- DRI
- GWD
- Life for a Child, International Diabetes Federation

**Summary**

- Our current model for diabetes education may not work for the resource poor population
- Meet the people in their communities
- Explore more methods of communication
- Get involved!

**Questions? Comments?**

**References and resources**

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