

A conversation with the International Diabetes Federation's Life for a Child, February 7, 2018

Participants

- Dr. Graham Ogle – General Manager, Life for a Child, International Diabetes Federation
- Emma Klatman – Health Systems Reform Specialist, Life for a Child, International Diabetes Federation
- Chelsea Tabart – Research Analyst, GiveWell

Note: These notes were compiled by GiveWell and give an overview of the major points made by Dr. Ogle and Ms. Klatman.

Summary

GiveWell spoke with Dr. Ogle and Ms. Klatman of Life for a Child (LFAC), a program of the International Diabetes Federation, to learn about LFAC's work on type 1 diabetes in children. Conversation topics included how LFAC might allocate additional funding, the costs to LFAC to provide insulin and medical care, potential treatment gaps in LFAC's countries, and long-term patient outcomes.

Potential uses of additional funding

Additional funding could allow LFAC to:

1. Newly provide basic care to prevent type 1 diabetes deaths in young people in places where LFAC doesn't currently have a presence (e.g. many African countries). Basic, "survival-level" care involves providing insulin and some limited medical support.
2. Improve type 1 diabetes care for young people in areas that already have life-saving capacity, but where patients' quality of life is generally low (e.g. Ethiopia, many Latin American countries).

The proportion of LFAC's country-level spending that goes towards basic life-saving care vs. more comprehensive care to improve quality of life varies between countries. Ideally, LFAC would want to focus on both dimensions if it had sufficient funding.

LFAC might allocate additional marginal funding at approximately 30% toward introducing basic care to new countries and 70% toward improving the quality and consistency of existing care. Introducing care to a new country generally doesn't cost as much as improving care. The need in a given country might also include both new support and improving treatment for existing cases. For example, in Ethiopia, where LFAC already has a presence, there are hundreds of new cases each year; building capacity to be able to take those new cases would fall under the 30% side, while improving care for existing cases would fall under the 70%.

Entering new countries

In new countries it might enter, LFAC would be the main actor providing core commodities to manage type 1 diabetes. There might be some people with type 1 diabetes whose families could afford supplies to some extent in the absence of LFAC to provide them (though, in general, those families would likely have to forego other important things to afford this).

LFAC always partners with existing local services, e.g. national diabetes associations, local charities, mission hospitals, and, where possible, Ministries of Health. For example, before LFAC entered Rwanda, the Rwanda Diabetes Association was providing care to 33 young people but didn't have capacity to operate outside Kigali; it approached LFAC for help expanding to other cities and taking on more patients.

LFAC is confident that people generally know how to access the existing health services that it partners with in a given country (e.g. in countries with public health systems, to go to the hospital when symptoms are noticed). Some people with access to private health care do go to private doctors instead, expecting better care, though LFAC thinks that in practice, patients often receive better care at public hospitals due to higher levels of expertise.

Improving existing care

Improving care would involve, e.g., aiming to bring patients' average HbA1c levels down to better levels (e.g. 9% or less), which would both improve current health and reduce the risk of longer-term complications. (HbA1c is a measure of how “sticky” a patient's hemoglobin is; poor blood glucose control causes more glucose to become stuck to hemoglobin.) In an adequately-resourced health system, patients with type 1 diabetes have their HbA1c levels measured about every three months.

LFAC believes it is less cost-effective to only provide insulin (which just allows children to survive) than it is to also provide blood glucose test strips and other assistance (which, by allowing self-monitoring of glucose levels, allow children to carry out daily life much better in general and reduce the risk of later life complications).

Effects of poor blood glucose control

Children with poor blood glucose control are particularly prone to episodes of high blood glucose, feel constantly unwell, and have difficulty going to school. They are also at much higher risk for long-term complications. LFAC is doing a health economics analysis of 30 years of HbA1c data from Pittsburgh, and looking at long-term outcomes including complications. This information will help LFAC estimate the cost-effectiveness of care in different countries where it operates. LFAC expects to have those results in three or four months.

Longitudinal studies tracking people over many years have shown that poor blood glucose control (as measured by an HbA1c test) is associated with much greater risk

of complications like kidney failure, blindness, amputations, and neuropathy, which can lead to death or serious disability. In particular, a period of poor blood glucose control soon after diagnosis can have detrimental long-term impacts even if glucose control later improves, whereas good control soon after diagnosis (even if followed by a patch of poor control later) is associated with much better outcomes. The data showing the outsized importance of early glucose control are clear, though the reasons aren't fully understood.

Costs per child

The insulin LFAC uses is donated in most countries. Previously, LFAC was paying for air freight for insulin at a cost of \$30 to \$40 per child per year. LFAC expects other organizations to cover freight costs going forward, such that insulin will only cost an average of \$10 per child per year (plus the cost of LFAC staff time in Sydney). The other components of care, beyond insulin, cost about \$120 per child per year (though this varies somewhat between countries).

Treatment gaps

It's difficult to estimate how many children in a country need care but don't receive it, either because of a lack of treatment resources, because they haven't been identified, or due to undiagnosed deaths. Longitudinal studies (as have been done in, e.g., Mali) can help produce better estimates of treatment gaps: for instance, if 10 cases were diagnosed in some previous year and 50 were diagnosed this year, that suggests that a significant proportion of cases might have been missed in the past. LFAC suspects that significant treatment gaps exist in, e.g., Ethiopia and India, but it's difficult to estimate the size of those gaps.

Overall mortality rates and treatment failure

Deaths of patients who are in LFAC's program are relatively rare (under 2% each year, and potentially up to 10% over a 10-year period, depending on the country).

LFAC monitors diabetes mortality rates and has published mortality data for, e.g., Ghana and Uzbekistan. LFAC measures mortality in terms of deaths per 1000 patient-years. In Rwanda, the mortality rate for people with type 1 diabetes is about 40-50 deaths per 1000 patient-years; the rate is much lower in Bolivia and rapidly decreasing in Mali. LFAC believes that in some countries (e.g. Nigeria), the rate may be more than 500 deaths per 1000 patient-years.

Patient outcomes after leaving LFAC

LFAC provides care for patients up to age 25 (LFAC wouldn't have the capacity to enroll new children if it continued beyond that). LFAC focuses on young people in part because good glucose control early on appears to be especially important (see above).

A study in Bolivia found that people who graduate from LFAC's program have good outcomes overall — while they're generally not receiving full treatment, they do

typically survive. In Rwanda, some people who have left the program have died (though far fewer than would have otherwise).

Some countries (e.g. Rwanda, Tanzania, Uzbekistan) are becoming more able to sustain support for patients after they graduate out of LFAC's program. LFAC encourages vocational training programs in some countries (though these are difficult and expensive for LFAC to foster). LFAC also partners with Insulin for Life, which distributes supplies donated by the public, hospitals, etc., and is able to help care for some patients who have left LFAC.

All GiveWell conversations are available at <http://www.givewell.org/conversations/>