

International Diabetes Federation – Putting Women and Diabetes on the Global Agenda

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Abstract

Eighty per cent of the 300 million people with diabetes live in low- and middle-income countries and women represent half of this worldwide diabetes community. Gender roles and power dynamics shape vulnerability to diabetes, affect women's health-seeking behaviour, access to health services and influence the impact of diabetes on women's health. This creates a set of concerns that are specific to women. In addition, as the prevalence of type 2 diabetes in women of reproductive age has increased, so has the prevalence of gestational diabetes mellitus (GDM), a form of diabetes with onset or that is first recognised during pregnancy. GDM is a major cause of maternal and infant morbidity and mortality and a major factor in the intergenerational transmission of diabetes. The International Diabetes Federation (IDF) is responding to this aspect of the global diabetes epidemic by launching a new programme on women and diabetes. This programme will build the evidence base, promote awareness and political commitment, support gender-responsive health systems and empower women to take a leading role in diabetes prevention.

Keywords

Diabetes, women, low- and middle-income countries, International Diabetes Federation (IDF), gender differences, gestational diabetes, maternal health, diabetes prevention, global advocacy

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The Indian economist Amartya Sen wrote in 2001 that, 'gender inequality has many faces'.¹ Despite rapid progress in many parts of the world, the many faces of inequality between women and men, girls and boys remain widespread and have critical implications for the spread and management of diabetes. Sixty per cent of the world's poor are women,² two-thirds of illiterate adults are women³ and twice as many women suffer from malnutrition than men.⁴ These are important contributors to the social and economic determinants that are perpetuating the global diabetes epidemic and challenging global development. Investing in gender equality is a proven catalyst for achieving a range of health and socioeconomic development goals at the top of the international agenda.⁵ As gatekeepers of household nutrition and lifestyle, women are the main agents of change at the household level and beyond.⁶ Today, 80% of the 300 million people with diabetes live in low- and middle-income countries (LMICs).⁷ Women represent half of this global diabetes community, numbering 143 million.⁷ Diabetes is the seventh leading cause of death in women worldwide⁸ and diabetes-related complications result in disability, reduced life expectancy and health costs for virtually every society.

The International Diabetes Federation (IDF) is responding to the global diabetes epidemic by launching a new programme on women and diabetes. The programme will take a broad life-course approach, facilitating understanding of how diabetes affects a woman's health over her own life and that of others across the generations. Interventions at each stage of a woman's life will be focused upon; during childhood, adolescence, the reproductive years and beyond. The interplay of biological, sociocultural and socioeconomic determinants

throughout these stages will be examined. They shape a woman's vulnerability to diabetes, her health-seeking behaviour, access to health services and health outcomes. IDF is in a unique and powerful position to promote the women and diabetes agenda. As a federation of more than 220 member associations representing over two million members in more than 160 countries and territories, IDF has a global reach and significant ability to leverage support for women living with diabetes. IDF has attained its position as an influential player in global health and development, following the success of UN Resolution 61/225 on diabetes in December 2006 and the recent decision by the UN General Assembly to hold a UN Summit on Non-communicable Diseases (NCDs) in September 2011. The *IDF Diabetes Atlas*⁷ is the authoritative source of information on diabetes prevalence, mortality and healthcare expenditure. It also provides information on IDF's work to enhance the education and skills of healthcare professionals and demonstrates its multidisciplinary strength and capacity to deliver on this important agenda. At the local level, IDF's member associations boast extensive knowledge and capacity in diabetes management, care and prevention. This will inform and strengthen IDF's approach to women and diabetes.⁸

Programme Development Methodology

IDF used a rigorous collaborative exercise to develop the women and diabetes programme. It consulted over a period of four months with a group of 50 experts from all regions of the world, drawing on IDF's existing network of diabetes experts, as well as reaching out to a broader group of gender and health experts for the first time. The logical framework approach was used for programme development. This has

been used in international development,⁹ but the process was adapted to enable online consultation during each stage of the programme design. This collaborative exercise provided a valuable online platform for knowledge exchange and the prioritisation of concerns. Through this, IDF has developed a comprehensive five-year programme. It has also fostered an important network of experts and partners to draw on and collaborate with.

Programme Overview

This new programme will build the evidence base, awareness, political commitment and health systems capacity for the 143 million women currently living with diabetes and the 222 million expected to have diabetes by 2030.⁷ The programme is predicated on four major outputs that are interlinked and mutually reinforcing:

- building the evidence base;
- global awareness and commitment;
- gender-sensitive health issues; and
- empowering women to prevent diabetes.

Building the Evidence Base

There is currently a severe shortage of sex-specific and gender-sensitive data on the global diabetes epidemic. Strengthening this evidence base is an important step towards ensuring world leaders and donor agencies commit to women and diabetes as an urgent priority. The evidence needs to be built in all regions, particularly in LMICs, which shoulder the largest numbers of people with diabetes. Analysis of the gendered patterns of the global diabetes burden at different levels is also essential. This will involve epidemiological, qualitative and health systems research. The under-representation of women in clinical studies and lack of gender-sensitive analysis conducted within studies are an underlying cause for the paucity of evidence on diabetes in women. This must be addressed. One priority area in this research agenda must be the prevalence of gestational diabetes mellitus (GDM). The increasing incidence of GDM reflects the rapid increase of type 2 diabetes in the background population.¹⁰ GDM is an important risk factor for maternal and infant morbidity and mortality.¹¹ It is associated with an increased risk of both mother and child developing type 2 diabetes later in life.¹¹ IDF will lead efforts to collect comparable GDM prevalence data from all of its seven regions. These data will be incorporated into future editions of the *IDF Diabetes Atlas*, thereby broadening the presentation of the global burden of diabetes of the Atlas and catalysing and shaping the global response required for GDM. Beyond prevalence data, the gendered dynamics and patterns of diabetes need to be analysed, from both patient and health services perspectives. Identifying the challenges and impact diabetes has on women's health, education and quality of life across all of IDF's regions will advance evidence-based interventions. Understanding the gendered patterns of diagnosis and health-seeking behaviour will facilitate the tailoring of health services to the regionally specific needs of men and women alike. IDF will be the intellectual driver behind this broad research agenda.

Global Awareness and Commitment

Campaigns for other diseases, such as HIV/AIDS, have demonstrated the effectiveness of evidence-based advocacy and awareness in establishing commitments at the global and national level and influencing donor funding. IDF has earned its reputation as an influential player on the international health and development stage for both diabetes and NCDs. It will build upon these successes within the women's health arena. By leveraging various communication

channels and collaborating with its member associations, IDF will disseminate the evidence and messages of the women and diabetes agenda from local to global level.

A matter of particular relevance to the global development agenda is maternal diabetes. With only five years left until the end date of the UN Millennium Development Goals (MDGs), the maternal health goal remains the most off track. New approaches are desperately needed to speed up progress. Improved care and treatment of diabetes in pregnancy has the potential to reduce maternal and infant morbidity and mortality, and the longer-term intergenerational prevention of chronic diseases such as diabetes. IDF will lead a global campaign to elevate this 'Cinderella' matter of maternal health to the attention of policy-makers and the general public. Work has already begun, presenting the evidence at high-level meetings and conferences. This will continue through to IDF's next World Diabetes Congress in Dubai from 4 to 8 December 2011.

IDF's women and diabetes advocacy and awareness activities will reflect its twin-track approach to tackling diabetes and NCDs. It will work with its sister federations in the NCD Alliance (the Union for International Cancer Control, the International Union Against Tuberculosis and Lung Disease and the World Heart Federation) to raise the profile of the wider gender and NCD agenda. It will harness the NCD Alliance's powerful voice, adding to its own, to influence international development goals and agendas, such as the MDGs and successors to the MDGs. It will also integrate gender into the preparations and outcomes of the pivotal UN Summit on NCDs in September 2011.

Gender-sensitive Health Systems

Diabetes care and management in many countries currently largely fails to respond to the specific needs of women living with diabetes. Sex-specific care for diabetes is in its infancy. This is reflected in diabetes clinical guidelines that recommend prevention and treatment of patients as if they are a homogenous group.¹² Little attention is being given to the different ways men and women experience diabetes within programmes and services. Insufficient consideration is being given to the way in which gender roles and power dynamics shape diagnosis and treatment. Through leadership development, training programmes and improved communication, IDF will develop gender-sensitive diabetes education, care and management. This will include improving diabetes education for women with GDM by supporting the development of regionally relevant educational tools. This is a gap that needs to be addressed, as women who develop GDM need immediate support to adapt their lifestyle to ensure optimal pregnancy outcomes and reduce their own and their infant's risk of developing type 2 diabetes later in life. The global diabetes epidemic provides an opportunity to strengthen health systems and catalyse reforms of benefit to patients with other diseases and conditions. Diabetes and NCDs need to be integrated into health systems, particularly at the primary care level and within maternal and newborn child health (MNCH) programmes. Pregnancy and early infancy offers a window of opportunity to provide services aimed at reducing maternal and infant morbidity and mortality, as measured in MDG 5.¹³ It also has great potential for the intergenerational prevention of several chronic diseases, such as diabetes. This is due to the concept of foetal programming, which proposes that the intra-uterine environment assumes great significance in determining the long-term prospects of the foetus.¹⁴ Through partnerships and collaborative

efforts, IDF will work to broaden the focus of MNCH programmes to both short- and long-term maternal and infant health outcomes.

Empowering Women to Prevent Diabetes

The world urgently needs women to take a leading role in the fight against diabetes. Girls and women are important agents of change in healthy lifestyle adoption and diabetes prevention. As gatekeepers of household nutrition and lifestyle habits, women have the potential to drive prevention from the household and beyond. It is in the interest of diabetes prevention and the broader development agenda to harness women to promote political commitment and awareness of diabetes at local and regional levels. Extending out from IDF's membership base, it will be possible to establish a strong and dynamic network of women leaders who will provide a powerful voice for the 143 million women living with diabetes. Diabetes prevention strategies need to utilise women as agents of change but also need to be sensitive to the gendered dynamics of the risk factors of diabetes, particularly during childhood and adolescence. The World Health Organization (WHO) estimates that 70% of premature deaths among adults are largely due to behaviour initiated during adolescence.¹⁵ For girls in many LMICs, adolescence is a time when gender disparities become pronounced.¹⁶ A girl's low social status equates to low nutritional status, and cultural dress and mobility codes restrain physical activity. Promoting physical exercise opportunities to the 600 million adolescent girls in developing countries must be a priority for diabetes prevention. It will also provide a valuable channel through which to inform and educate the future gatekeepers of household nutrition and lifestyle patterns. Education will strengthen the capabilities of girls to become active members of their communities. IDF has both the regional sensitivity and global reach to take this important task forward, working through governments, education systems, local member associations and women's groups. Finally, IDF recognises that in order for girls and women to play a leading role in the fight against the global diabetes epidemic, broader gender and development concerns need to be addressed. For this reason the programme will work towards strengthening the health, education and economic development of girls and women. By establishing strategic partnerships with relevant organisations and coalitions, such as maternal health and girl-focused coalitions, IDF will bring significant weight to the broader gender equality agenda.

Programme Implementation

Implementation of this ambitious programme will be split into two main phases. The first phase will run from 2010 to the end of 2011. It will predominantly focus on evidence and advocacy activities. This is in order to use the current international development climate as a springboard for the women and diabetes agenda. In May 2010, the UN General Assembly unanimously voted to hold a UN High-Level Summit on NCDs in September 2011. The lead-up to and immediate aftermath of the UN Summit are critical, and provide a once-in-a-generation

opportunity to raise the profile of diabetes onto the global agenda. This is soon followed by IDF's World Diabetes Congress in Dubai, December 2011, which will continue the momentum and pressure. With only five years to go until the MDG deadline, pressure is mounting to make progress and find innovative answers to persistent development matters. It is crucial that the evidence is built for these high-level advocacy events in order to make the case for increased political commitment and funding for diabetes. Both the preparations for the UN Summit on NCDs and the countdown to the MDGs offer great opportunities to elevate and embed women and diabetes into the outcomes and shape the development agenda going forward. Phase two of programme implementation will run from 2012 to 2014. It will expand upon the evidence and advocacy activities of phase one by catalysing and implementing gender-sensitive diabetes management and prevention. These initiatives will provide best practice for mainstreaming gender into diabetes programmes. This will build momentum for the incorporation of women and diabetes in the international development agenda beyond 2015.

Investing in Women and Diabetes to Stem the Global Diabetes Epidemic

IDF is excited to be launching this new programme on women and diabetes. It believes that this is an important matter, not only for diabetes, but also for promoting gender equality and empowerment and contributing to wider socioeconomic development in LMICs. Investing in girls and women as agents of change must remain a priority on the global development agenda. IDF is ideally positioned to be taking this agenda forward as the legitimate global advocate for people with diabetes. It has the international reputation to leverage real change for women living with diabetes around the world. This five-year programme will foster new partnerships and collaborations for IDF and extend its reach into new arenas. IDF looks forward to reader support and to sharing results that will make a positive difference to women. ■



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