

Report to the World Diabetes Foundation

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Based on the Master thesis in Global Health:

Living with a chronic condition in an unstable conflict

A qualitative exploration of women's experience of living with diabetes in Palestine.



Introduction

Following up on a grant received from the World Diabetes Foundation, we hereby deliver a short report on our thesis project with the title “Living with a chronic condition in an unstable conflict - A qualitative exploration of women’s experience of living with diabetes in Palestine”.

This paper encompasses the executive summary of our thesis as well as five policy recommendations emerging from our thesis. In a separate file, we have shared the full thesis.

The grant from the World Diabetes Foundation was allocated for an 18 days field work in Palestine with the purpose of gathering empirical material for the thesis. The field work was carried out with support from World Diabetes Foundation, Augusta Victoria Hospital, and DanChurchAid in Palestine and we owe them great gratitude.

Executive summary

Background

Palestinians are experiencing a dramatic rise in non-communicable diseases, and are finding themselves in the midst of an epidemiological transition. Diabetes is new to the political agenda but with prevalence rates forecasted to reach 21 % in 2020, urgent attention by policy makers and programme managers is needed. Women are at excessive risk of non-communicable diseases and poor adherence to diabetes management, but the literature on Palestinian women's experience of living with diabetes is scarce. Moreover, women's vulnerability towards diabetes management primarily results in an intensified focus on gestational diabetes without acknowledging that women could have specific challenges in living with type-2 diabetes. This study seeks to fill this gap by taking a user-perspective to unfold how Palestinian women comprehend and manage type-2 diabetes and assess diabetes services as meaningful to them.

Methods

The thesis is built on fieldwork in two cities in the Qalqilya Governorate in the West Bank of Palestine: the Ministry of Health-driven clinic in Azzun and the UNRWA-driven clinic in Qalqilya. These interviews were supplemented by field observations at the Diabetes Clinic at Augusta Victoria Hospital in Jerusalem, as well as at the two clinics in Qalqilya and Azzun. These study sites were chosen as they constitute venues for rolling out the Diabetes Comprehensive Care Model in this current project phase of the collaboration between World Diabetes Foundation, Augusta Victoria Hospital, DanChurchAid and the health NGO Juzoor.

The empirical material was analysed using a thematic network analysis and an abductive methodology. We employed Antonovsky's Sense of Coherence theory to analyse the empirical material. This theory is based on the belief that a person with a high sense of coherence will have a better ability to cope with external stimuli in this case diabetes. A person's sense of coherence encompasses three dimensions namely comprehensibility, manageability and meaningfulness. We adopted Antonovsky's theory as an analytical framework to shed light on women's perspective on diabetes and ability to overcome the stress it brings. Building on the analytical framework employed, we analysed how the 10 Palestinian women comprehend, manage and engage meaningfully in diabetes.

Results

The women comprehended the cause of diabetes through various explanatory mechanisms. Whether they prescribed the cause of diabetes to stressful life events, the living circumstance in Palestine, family disease history or God, they used these explanations to make predictions for why they got diabetes. To structure an understanding of diabetes, we found that many women used bodily manifestation of symptoms with a need to perceive diabetes as something visible. By comprehending diabetes as very normal in the context of Palestine, some women were found to be more likely to accept diabetes as a condition of life.

The women relied on both personal and external resources at disposal to meet the demands diabetes brought. While some found use in a personal strategy of engaging relatives as social support, others felt most confident in their diabetes management by being independently in charge of their diabetes. The context was pinned out as significant for the choice of personal strategy as feeling in control of diabetes was for some women depended on their ability to deal with the stress posed by the living circumstances. A few women were unsuccessful in identifying personal strategies leaving them either with a sense of loss of control of diabetes or accepting the disease as an inevitable

circumstance of life. In terms of external resources, we found that the women counted on regular check-up with blood sugar test and insulin measurements as a resource at disposal. Services such as group education, psychosocial support, and treatment of complications were on the other hand regarded as extraordinary and thus not considered as an external resource to rely on.

The regular check-up was something that most women were satisfied with and it was successful in meeting their expectation to services. We found that their motivation to engage in treatment was highly related to the medication with a trust that the medication, the “magic pill”, could ensure a pain-free life with diabetes. Many women did not find the doctor’s services meaningful as he did not engage in their personal concerns and take into account the women’s comprehensibility of diabetes. Screening and treatment for complications was desired by most women, whereas psychosocial support and group counselling was not seen as meaningful to engage in as the women drew on personal resources to meet the need for support.

Conclusion

This qualitative study shed light on their comprehensibility and manageability of diabetes and their sense of meaningfulness of health services. We sought to amplify the voices of women with diabetes in underserved communities in Palestine. By taking a user-perspective to diabetes care, we illuminated how Palestinian women in the Qalqilya governorate experience living with diabetes.

A life with diabetes is shaped within the complex reality of managing both the disease and the stress from an unstable humanitarian situation. We found, that their expectations to health services were embedded in the way they comprehend a life with diabetes. We also found, that these expectations emerge from the social resources or health services they believe are available to them. To meet the challenge of an increasing burden of diabetes in Palestine, our findings emphasises the importance of delivering comprehensive care in a dynamic manner with respect to the user’s individual experience.

Policy recommendations

Our thesis project ought to shed light on the transferability of the Diabetes Comprehensive Care Model into the Palestinian setting. Based on our project, we have the following recommendations for future practices of the World Diabetes Foundation and organisations alike initiating diabetes interventions in settings similar to Palestine:

1. Women appreciate and expect structured health services with a sense of regularity.
2. Screening for diabetes complications are important and can be prioritised even greater.
3. Services offered can to a higher extend take its starting point in the patient's understanding of diabetes.
4. The Diabetes Comprehensive Care Model should allow for a more dynamic approach to the individual patient.
5. Psychosocial support should be integrated into all health services.

1. Women appreciate and expect structured health services with a sense of regularity.

We find in our thesis that the women have many issues they need to balance throughout the day, and throughout their life under occupation. This means that for some diabetes is not something they allow to take up all their resources. Therefore, they express great satisfaction with the regularity of there being a monthly visit to the clinic. This structure is to be built upon in future interventions, where it should be taken into account the value of somebody else taking care of their treatment.

2. Screening for diabetes complications are important and can be prioritised even greater.

Diabetes complications pose a great fear among the patients. We have described, that the women feel their actions related to diabetes management do not have a significant effect. Despite that, the fear of wounds not healing well, the risk of amputation of a diabetic foot or losing eyesight motivate them to sustain these actions anyway. Introducing regular foot and eye screening will therefore be a significant improvement to the current practice.

3. Diabetes services should be offered with a starting point in the patient's understanding of diabetes.

The women's expectations to treatment are rooted in their understanding of diabetes. Adherence to treatment and health promotion efforts could be improved if the health staff incorporate the women's comprehensibility of diabetes in the advice given. Health awareness initiatives should focus on the preventive effects for future generations considering the strong family ties and belief that uncontrollable factors can cause diabetes. Along this line, we suggest to actively involve the target group when planning health promoting activities, as to secure both ownership and an appropriate format that suits the user's needs.

4. The Diabetes Comprehensive Care Model should allow for a more dynamic approach to the individual patient.

A patient-centred approach to diabetes is much welcomed as women comprehend diabetes differently. The Diabetes Comprehensive Care Model should not be approached as a checklist of services to be given to the women. Health staff must possess the technical capacity to deliver care with respect for the individual's comprehensibility, manageability, and meaningfulness. This even though such prioritization is difficult to make in a health system short of both resources and staffing. Quality of care should be at the centre to increase women's meaningfulness in engaging in diabetes services and self-care. We suggest, that the daily implementation of the Diabetes

Comprehensive Care Model will be seen less as a check-list of services and more so as a palette of opportunities, that at every visit will be tailored the patient's needs.

5. Psychosocial support should be integrated into all health services.

There is a need for the health care providers to see diabetes in everyday life of the patient. They need to take the effect of the living situation into account acknowledging that diabetes might be the lesser of the women's challenges today. Instead of offering psychosocial counselling as a standalone activity, we recommend that these are integrated into all health services. Building on this, we suggest that group counselling sessions are conducted in a peer-to-peer approach between diabetes patients. In this way, the group counselling session builds on the sense of community feeling and the women will share experiences and be inspired to adopt new strategies for diabetes management.