Policy Brief

Diabetes self-management and Social media: Experiences of children and young people in Kyrgyzstan

1. Background

In 2022, a multi-country study "Target product profile of non-invasive and minimally invasive glucose self-monitoring devices for low- and middle-income countries: a qualitative study in Kyrgyzstan, Mali, Peru, and Tanzania" was conducted, with participation of FIND, ACCISS, and Health Action International (HAI).

It aimed to study the opinions of consumers and healthcare professionals on the available and desired characteristics of self-management devices, based on daily experiences of using the blood glucose measuring devices.

This study is a secondary review of the data set collected in Kyrgyzstan by the Health Policy Analysis Centre (HPAC) as part of the above-mentioned study. It synthesizes information on aspects of everyday self-management experiences that had been collected in interviews but were not the focus of the original marketing study.

This study focuses on self-management by children and young people receiving insulin therapy, information needs for self-management, and the role of social media.

The term 'self-management' refers to measures that patients and their relatives/caregivers take to maintain important vital parameters, primarily blood glucose levels, at target or controlled levels. These measures include blood glucose self-monitoring, insulin administration, healthy nutrition, physical activity, sleep, rest, and work. 'Self-management' is interchangeable with the term 'self-monitoring'.

2. Aim and Objectives

Aim

To explore information needs and self-management practices in diabetes patients, with focus on children, adolescents and young individuals receiving insulin therapy.

Objectives

1. Conduct a secondary review and analysis of transcriptions that contain qualitative data collected as part of the original (marketing) study.
2. Synthesize information to answer the research questions.
3. Develop recommendations for potential users of the research.

Research questions

What is patients' awareness of essential elements of diabetes self-management? How and to which extent effectively do potential sources of information on self-management tools function? Under what market conditions and social attitudes do patients exercise self-management and receive information on self-management tools? How do access to information and information needs change as children with diabetes grow up? What is the role of social media in meeting information needs for self-management?

3. Methodology

In the original multi-country qualitative study "Target product profile of non-invasive and minimally invasive glucose self-monitoring devices for low- and middle-income countries: a qualitative study in Kyrgyzstan, Mali, Peru,

and Tanzania", open-ended questions as part of semi-structured questionnaires were used to stimulate discussions. The data were collected and recorded in audio files and then transcribed.

For this study, the qualitative data subjected to secondary review and analysis using the MAXQDA program. The following keywords were used in MAXQDA to find relevant quotes and statements:

- blood glucose self-monitoring, insulin, self-management, information, social media.The quotes extracted from the software were collected into information blocks, which became part of the information synthesis to answer the research questions.

4. Study findings:

Psychosocial difficulties

The age at which diabetes is diagnosed plays an important role in accepting the diagnosis and learning self-management skills. Children perceive changes in their daily life after starting diabetes self-management less consciously.

For them, injection procedures gradually become part of the routine, and over time they get used to them, perceiving them as a normal part of life. For many adolescents, a significant change is that the need to carry out procedures at school or in public causes them shame and discomfort.

Parents, upon learning of the diagnosis, often face emotional shock, guilt, and anxiety for the child's health. Constant monitoring of blood glucose levels, regular injections, and the need to follow medical recommendations become a heavy burden, causing chronic stress and fatigue.

Mothers of children on insulin therapy are often forced to devote themselves entirely to caring for the child. Until adolescence, mothers serve the child, carrying out the necessary daily procedures. For many mothers, the daily care of a child with diabetes makes it difficult to find a job and pursue a career.

How does the health system promote diabetes self-management?

The Ministry of Health purchases insulin with government funds and ensures that patients have access to insulin by providing it free of charge. Under the subsidized drugs program, the diabetes patients can purchase test strips at a discounted price.

Diabetes Schools in healthcare facilities provide patient education and counseling. These efforts occur in the context of financial, personnel, informational and organizational barriers to access to self-monitoring devise and information about self-monitoring.

Information work in Diabetes Schools is quite effective in teaching patients and their families to basic knowledge and skills. In Kyrgyzstan, the Diabetes Schools operate only in some healthcare facilities.

However, these Diabetes Schools cannot meet the broader information needs of patients, especially at the local level. In particular, the widespread use of social media by patients as a source of information has become a challenge for existing Diabetes Schools, which currently lack trained personnel and educational materials.

On the other hand, with proper changes in their work, the use of social media can give Diabetes Schools the opportunity to provide more necessary information to patients and "keep up with time".

The extent to which healthcare facilities effectively create conditions and provide information for regular diabetes self-management significantly affects the motives and behavior of patients.

Physicians express concerns about the poor commitment of patients to regularly visit primary healthcare facilities for monitoring their condition, physical and laboratory parameters, or for education. Most patients visit healthcare facilities mainly to receive free insulin.

This situation is often due to the fact that there is a large gap between the needs of patients in medical services, information and education on self-management and what the healthcare facilities can actually offer.

Social media and diabetes self-management

There are already many studies globally about the impact of social networks on self-management of diabetes patients. Patients need social support and exchange of experiences. Patients' visits to doctors are often rare and irregular, while diabetes is a disease that requires constant monitoring.

Children and parents often seek answers to questions about specific situations - self-monitoring and insulin therapy at school, various sports, entertainment, travel, pregnancy and childbirth, etc.

We have identified six functions that Social media in Kyrgyzstan perform for diabetes self-management:

- Participation in information campaigns about diabetes
- Promotion of patients' rights
- Exchange of practical advice
- Emotional and psychological support
- Access to information about new medical products, technologies, drugs.
- Resolving urgent issues

In international practice and literature, there are practically no significant and measurable effects of Social media on the quality of self-management. However, the use of social media for diabetes self-management will continue to grow. The growing importance of Social media among diabetics in Kyrgyzstan was facilitated by:

1) staffing and infrastructure limitations in government healthcare facilities;

2) the growth of Social media due to the COVID-19 pandemic;

3) initiatives from parents of children with diabetes.

Access to insulin as a driver for use of Social media for diabetes self-management

In Kyrgyzstan, the most visible and functional form of Social media and information exchange turned out to be groups of parents of children with diabetes on WhatsApp and Telegram. The main motive for creating such groups is mutual assistance in purchasing devices for glucose measurement and insulin administration, as well as insulins. Unfortunately, important elements of self-management that are not related to technology, namely healthy eating, physical activity, work and leisure, and others, remain outside the focus of Social media users in Kyrgyzstan.

An example of such a narrow use of Social media is the use of Social media for the purchase of insulins by type 1 diabetes patients after reaching the age of 18.

The current barriers in the country to obtain analog insulins after reaching 18 years, in some until reaching the age of 29 years, force most patients to buy analog insulins through Internet resources.

At the same time, they do not want to receive free human insulin and regularly visit a doctor to monitor the condition and learn self-management.

A similar situation, when patients with type 1 diabetes, due to restrictions in access to free analog insulins, need to change the type of insulin to human genetically engineered, causes dissatisfaction among most patients and their relatives due to the remaining preference for analog insulins, which are perceived as more comfortable to take and comparatively better tolerated.

Many patients with this preference continue to take analog insulins after 18 years and buy it at their own expense.

Due to the extremely limited availability of such insulins on the local pharmaceutical market and retail pharmacy network, such patients are forced to resort to purchasing and importing analog insulins from abroad.

Parents of children with diabetes and adult patients actively exchange information in WhatsApp and Telegram social groups about the availability of insulins in the pharmacies, import options, discuss prices and other elements of the financial access to insulins.

5. Recommendations

- **Diabetes Schools are recommended to allocate more financial support, provide up-to-date teaching aids and training materials.**
- **Nurses should conduct more training and allocate more functions for teaching patients with diabetes.** In conditions of limited access to Diabetes Schools in healthcare facilities and staffing difficulties, nurses have already become a source of diabetes information and counseling.
- **Programs to support diabetes patients should be intersectoral in nature.** Coordinated efforts from the government, educational institutions, social support agencies, NGOs, and the private sector are required.
- **Health authorities and professional associations are recommended to more actively engage in social media as a tool for interaction with patients.** Setting the agenda and monitoring the content of social media materials will help improve diabetes self-management and protect patients from possible negative influences of social media.
- To influence social media content on self-management, **health authorities are encouraged to work in partnership with social media participants.** The Ministry of Health, professional associations, and educational institutions can better adapt their capabilities by closely interacting with bloggers, influencers, and social media groups.
- **Social media could become a reliable source of information on use of insulins and glucometers, healthy eating habits, physical activity, and other attributes of self-management.** These effects of using the social media will contribute to implementing the digital patient registration, tracking and procurement of medicines and medical devices, e-procurement, and other ongoing reforms.
- **Conduct additional research on patient preferences for different classes of insulin, namely biosimilars, analogs, and genetically engineered.** Such research would make it possible to make insulin procurement more responsive to insulin preferences and needs.

6. References

1. *"Target product profile of non-invasive and minimally invasive glucose self-monitoring devices for low- and middle-income countries: a qualitative study in Kyrgyzstan, Mali, Peru, and Tanzania", FIND, Geneva (Switzerland), Health Action International (HAI), Amsterdam (Netherlands), 2022.*
2. *Ewen, Margaret, Molly Lepeska, David Beran, Aida Abdraimova, Karen Bonilla-Aguilar, Stéphane Besançon, Asel Dunganova, George Msengi, Moise Nguemeni, and Janeth Tenorio-Mucha, (2023) Monitoring Access to Insulin (MAIn) tool: Evidence from people living with diabetes is crucial to policy development.*
3. *Policy brief "Provision of services under the State Guaranteed Benefits Program at the PHC level and availability of glycated hemoglobin testing in diabetes patients", Center for Health Policy Analysis, Bishkek (2024).*
4. *"Rapid assessment of access to insulin and care for diabetes patients in Kyrgyzstan", Center for Health Policy Analysis, Bishkek (2010, 2018).*
5. *Government Resolution of the Kyrgyz Republic "State Guarantees Program for Providing Citizens with Medical and Sanitary Care", as amended on 30.12.2020 # 636, dated 27.01.2021 # 26.*
6. *"Assessment of the PHC service delivery to the population with specific conditions ", Center for Health Policy Analysis, Bishkek, 2023.*

The full version of the report can be found on the for Health Policy Analysis Center website: www.hpac.kg

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