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ORIGINAL PAPER

Between 'there' and 'here': individual perception of diabetes mellitus among post-Soviet immigrants in Germany

Sigrun Simolka[1,2], **Antoinette Conca**[3,4], **Wilfried Schnepp**[†4]

[1]*Diabetes-Schwerpunktpraxis F. Mederacke / Dr. med. F. Graupner, Chemnitz, Germany*
[2]*Department of Nursing Science, University of Applied Science Dresden, Dresden, Germany*
[3]*Department of Clinical Nursing Research and Development, Kantonsspital Aarau, Aarau, Switzerland*
[4]*Department of Nursing Science, Faculty of Health, University of Witten / Herdecke, Witten, Germany*

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Abstract

Aim: Individual experiences shape perceptions of illness. Post-Soviet migrants have different expectations of chronic disease treatment than German patients. This study aimed to delve into perceptions of diabetes mellitus, a topic of increasing importance in global migration. *Design:* Qualitative, semi-structured interviews were conducted with 26 post-Soviet migrants with diabetes and three Russian-speaking diabetes counselors, mainly recruited through a snowball system. *Methods:* The research data were analyzed using a hermeneutic approach. The categories of the common-sense self-regulation model and developed subcategories were scrutinized by means of content analysis, ensuring a comprehensive understanding of the data. *Results:* The perception of diabetes mellitus varied depending on the country where the diagnosis was made. This included the individual recording of symptoms, the expected time course, and the allocation of different competencies. Opportunities for access to the local healthcare system in the former Soviet Union influenced these expectations. *Conclusion:* The study's findings underscore the importance of healthcare access in the country of origin and the patient's knowledge of diabetes mellitus in shaping their perception and treatment. These factors, influenced by the social environment and the patient's level of education, continue to play a role even after immigration to Germany.

Keywords: communication, diabetes mellitus, perception, post-Soviet migrants, subjective theory of illness.

Introduction

After the collapse of the former Soviet Union in 1991, approximately 2.7 million late resettlers and repatriates (terms used synonymously) and their relatives (own calculation, according to Federal Office of Administration, 2023), as well as about 211 000 Russian Jews, immigrated to Germany (Federal Ministry of the Interior and for Home Affairs / Federal Office for Migration and Refugees, 2023). This group of post-Soviet migrants, a term coined by Panagiotidis in 2017, is diverse, with members predominantly hailing from the Russian Federation, Ukraine, and Kazakhstan (Federal Statistical Office, 2020). Their decision to leave their country of origin was intended to be permanent, marking a significant shift in their lives.

Repatriates are descendants of German emigrants who lived as a minority in Eastern European states and later migrated back to Germany. The term was introduced in the Federal Expellees Act in 1953 (Federal Ministry of Justice and Consumer Protection, 2015). In the former Soviet Union, being Jewish was considered a nationality and was documented in passports (Kessler, 2003). This designation was not linked to the Jewish religion – the previous association with religion was considered undesirable and sanctioned by the ruling socialist system (Bernstein, 2021). Nor was it dependent on having a Jewish mother, as required by halacha (Ehrenberg, 2012).

Different ideas of diagnostics and therapy between healthcare professionals and patients often lead to discrepancies (Boll-Palievskaya, 2005, 2009; Dimova et al., 2019; Van Son & Stasyuk, 2014). Patients' perspectives must be included in therapeutic considerations if interventions are to be effective (Berger, 2018; Brua, 2009; Kavelage & Kofahl, 2011; Şat et al., 2020). A detailed literature review on subjective theories of illness in diabetes mellitus

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Corresponding author: Sigrun Simolka, Diabetes Schwerpunktpraxis F. Mederacke / Dr. med. F. Graupner, Matthesstraße 72, Chemnitz, Germany; email: sigrun.simolka@uni-wh.de

among people from the former Soviet Union has been published (Simolka & Schnepp, 2017).

In the former Soviet Union, healthcare provision depended on the local healthcare system. Access to the system was granted through relatives with varying levels of education. The best treatment options were available to well-educated people living in metropolitan areas. Conversely, the lower the level of personal education and that of the relevant social network, the more limited the access to adequate care, particularly in the case of diabetes mellitus. Access to the healthcare system was most difficult in rural residential settings (Aronson, 2011a; Aronson 2011b; Kühlbrandt et al., 2012; Rusinova & Brown, 2003).

Immigrants with diabetes mellitus are influenced by their past experiences, which may lead to behaviors that differ from healthcare providers' expectations (Bachmann et al., 2014).

Aim

The present study aims to capture the individual perceptions and required therapies for immigrants from the former Soviet Union. It focuses on the perspectives and subjectively perceived social realities (Steinke, 2019) of post-Soviet immigrants affected by diabetes mellitus and includes findings from the first author's doctoral thesis (SS). SS conducted all interviews while working as a diabetes educator and doctoral student. The results were discussed in a peer group at the University of Witten / Herdecke doctoral college.

Methods

Design

A qualitative study design was used. The common-sense self-regulation model (CSM) (Leventhal et al., 1992) and Mackenbach's (2006) models of socioeconomic inequalities in health served as the theoretical framework. The CSM defines five dimensions: identity (perceived symptoms), expected consequences of illness, assumption of time course (acute, cyclical, or chronic), suspected causes, and perceived control (Leventhal et al., 1992). Social risk factors can cause health disparities. For instance, education, occupation, and income directly influence behavior and indirectly affect health (Mackenbach, 2006).

Sample

Twenty-six post-Soviet immigrants with type 2 diabetes (7 men and 19 women) from different federal states in Germany participated in the study. Most of the interviewees immigrated to Germany between 1995 and 2010. At the time of the interviews, they were between 43 and 86 years (mean age: 67.1 years). The interviewees had known their diabetes mellitus status for an average of 15.3 years (0.5–40 years). Exclusively, ethnic German repatriates lived in a rural area before immigration. Of these, older German women had the lowest educational attainment. All Jewish immigrants had previously lived in metropolitan areas and were generally academics (see Table 1).

Three diabetes educators (experts who care for Russian-speaking patients and work in diabetes-specialized practices or hospitals) were selected for the expert interviews. They were also immigrants from the former Soviet Union (time of migration between 1994–1998, age of migration between 25 and 37 years). They had an enormous wealth of experience that could be used to explain the statements of those affected by diabetes. Two experts had already been trained as nurses in the former Soviet Union. All experts had received further training as diabetes educators in Germany. The experts were able to compare the two different healthcare systems based on their own experiences.

Inclusion and exclusion criteria

The study participants were required to be affected by type 2 diabetes mellitus and to have immigrated to Germany after the collapse of the Soviet Union (1993). Although an intended age limit of 40–75 years was set, it was not strictly adhered to by the participants. Anyone who felt able to participate was interviewed.

Depression requiring therapy and other manifest mental illnesses disclosed by participants were exclusion criteria. The diagnosis of mental illness was heavily stigmatized in the Soviet Union (Weinhold & Gurtner, 2014) and often went unnamed. Therefore, to minimize pathological psychological reactions triggered by the memory, a follow-up call the next day and contact information for local psychologists and therapists were always offered, although neither was taken up.

Data collection

All interviews were conducted between August 2016 and January 2018. Recruiting people from the former Soviet Union for studies is always challenging (Asikainen, 2021; Bachmann et al., 2015). Therefore, various methods were employed to access potential participants in the study (general practitioner and diabetes-specialized practices with a high proportion of Russian-speaking patients, language courses for immigrants from the former Soviet

Union, meeting places for Russian speakers, Russian-speaking nursing services, and diabetes educators). The 'snowball system' proved the most effective: after the interviews, respondents were asked about other potential participants within their network of acquaintances. The diabetes educators, who were members of the Migration Working Group of the German Diabetes Association, were also approached as interview partners.

The presence of the interpreters necessary for this study (themselves post-Soviet immigrants), was helpful. As people with the same life experiences in the Soviet Union, they were perceived as 'one of us' who could, therefore, be trusted. They were familiar with the diagnosis, as they were employed in diabetes practices or involved in diabetes counseling in clinics. An information sheet outlining the aims of this study was provided to potential interview partners in both German and Russian.

Depending on their wishes, the interviews were conducted in the Russian-speaking community's meeting places, clinics, or participants' homes.

The data were collected using a sociodemographic questionnaire. This included age, gender, year of immigration to Germany, country of origin, education, occupation, and diabetological data such as the last glycated hemoglobin (HbA1C) and existing long-term complications.

The interviews were audio-recorded and conducted using a semi-standardized questionnaire based on Witzel (2000), integrating the previously presented models' themes and the literature review results (Simolka & Schnepp, 2017). The complete method has been described in a previous article (Simolka et al., 2019).

Data analysis

Both translations during the interviews and the second translation after the transcriptions considered the context of statements, the comprehensibility to readers, and the cultural background of the interviewees (Wettemann, 2012). Based on Kuckartz's (2014) content analysis, content structuring was chosen to analyze the interview data. This method includes both inductive and deductive evaluation steps. MAXQDA 12.0 was used for the study.

At the conclusion of the study, all participants received a summary of the results presented in plain language.

Results

To preserve the anonymity of the interviewees, all quotations are used without reference to the transcripts, as Morse (1998) recommended. The participants themselves repeatedly distinguished between 'there' and 'here': 'That helped very well there, but then I moved to Germany. None of these medications were available there, so I got others.'

The key factor that helped to manage diabetes was the experience with the local healthcare system in the former Soviet Union (the country where the diagnosis was communicated; see Table 2). The CSM explained the results (Leventhal et al., 1992).

Table 1 Setting of origin and nationalities

	Nationality	Metropolis / large city	Town	Village	Total
Interview participants	German	2	5	7	14
	Russian	3	2	0	5
	Jewish	5	0	0	5
	Georgian	2	0	0	2
	Total	12	7	7	26
Experts	German	1	0	2	3

Table 2 Country of communication of diabetes diagnosis

	Total
Country of origin	7
Known in the country of origin but not treated	3
Germany	11
Germany, but diabetes was probable in the country of origin	5
Total	26

Identity

In the country of origin, the patients often noticed the first signs of diabetes and discussed them in their social networks. Only then was a physician consulted, who verified the diagnosis with a blood sugar test: '[...] he had heard from other people, and then the family doctor came and made the test in a laboratory [...]'.

Participants who had lived in a metropolis exclusively reported diabetes that did not yet present any of the known symptoms. The decisive factor then was access to high-quality medical care, which was always through acquaintances: '[...] my doctor, our friend, had already called a professor [...]'.

However, only respondents and their family members with academic degrees reported these opportunities.

Some of the participants had already been diagnosed with elevated glucose levels by their physicians in their country of origin. However, since the physicians never referred to diabetes as a disease and those affected did not notice any signs that they were aware of, the disease was perceived as nonexistent to those affected. Conversely, in Germany, the diagnosis was often made during the initial visit as part of a screening or differential diagnosis of other diseases. The participants were surprised, as they had not observed any of the known symptoms.

Causes

For the category of causes, no significant differences were found between the countries where the diagnosis was communicated. Predominantly, external causes were generally considered to be responsible for diabetes. The burden of immigration, old age, other diseases, or inappropriate treatment in the Soviet Union were mentioned as suspected causes. In a few cases, participants described their illness as self-inflicted due to personal behaviors: eating the wrong diet (too much, too much fat) or engaging in less physical activity in Germany compared to their country of origin. This behavior seemed to reflect an internalization of blame previously assigned by medical staff in the Soviet Union. Both participants and experts described the drastic and hurtful language used by healthcare professionals. When confronted with the interviewees' statements, the experts interpreted this as either a defense mechanism or an acceptance of blame. According to the respondents' narratives, the hypothesized causes of diabetes were usually present as a problem simultaneously.

Time course

Regarding diabetes mellitus already diagnosed in the former Soviet Union, physicians sometimes promised that the disease could be cured if the person followed their dietary recommendations and reduced their weight: '[...] but I should be able to eliminate it with dietary changes.'

If blood glucose levels improved, the person was removed from the diabetes registry and no longer received diabetes-related screenings, medications, or social support services. Some participants reported that buckwheat was prescribed like a drug and used therapeutically in hospitals. Buckwheat was available by prescription only if the person was enrolled in the diabetes registry. Participants from a village or urban environment in the Soviet Union, who had only limited access to healthcare, said that they were offered a possible cure for diabetes. Healing was, therefore, also the declared goal of these respondents. Participants who had access to high-quality healthcare in metropolitan areas never questioned the chronicity of diabetes. If the initial diagnosis had been made in Germany, the physicians would have stated that long-term complications should be avoided. At the time of the interviews, all participants had accepted the chronicity of diabetes.

Control

Most participants had high self-efficacy expectations and internalized control beliefs, believing they could successfully manage their disease through diet and exercise. Participants reported their experiences or those of relatives and friends with successful changes, especially in nutrition. Communication was also a crucial factor in these experiences.

However, participants described their inability to control high glucose levels or resist daily temptations as external control beliefs. Regular visits to fitness studios were not necessarily related to high levels of physical activity in their country of origin. In Germany, the need to improve financial resources was noted.

With acceptance of the chronic nature of diabetes, personal goals changed. The interviewees highlighted their ability to continue fulfiling their roles within the family or social environment despite their illness. Women first took care of the well-being of family members before turning to their own needs. Conversely, men were expected to exhibit physical strength and engage in outwardly active roles. Particularly for those from rural backgrounds with limited education, making changes to traditional cooking recipes seemed impractical.

Role conflicts were described when the dietary needs for diabetes did not align with their husbands' expectations or when men undertook tasks traditionally associated with women. Concepts such as 'supporting each other', 'doing something for others', and 'togetherness' were central to their role allocation and motivation: For myself, I am a bit lazy.

Respondents termed the opportunity to fulfill one's role expectations as quality of life. When one's expectations of oneself, the demands of the social environment, or healthcare professionals' expectations cannot be met, some describe negative control beliefs. Weight was not reduced despite a drastic calorie reduction, and diet and exercise did not seem to influence metabolic parameters. Increasing medication was considered a personal failure, and the patients had poor self-efficacy expectations. The ability to achieve one's goals with the available options (diet and exercise) determines the sense of controllability of diabetes.

Consequences

Personal goals and one's ability to achieve them influence perceptions of the expected consequences of illness. Interviewees described 'feelings' / emotional goals: having the strength for everyday demands, being able to integrate familiar kitchen recipes into life with diabetes, or not experiencing any of the known symptoms of long-term complications: 'Diabetes is not so bad, after all, if you pay attention… uncomplicated.'

Negative consequences were more likely if one's goals could not be achieved through behavioral changes. Communication of treatment goals and negative experiences in the social environment determined expectations of the consequences of the disease: 'I think, with diabetes, you do not live very long [bitter laughter].'

Attributions of competence

The decisive factor for the participants' behavior was which topics were discussed and which advice was accepted. There was a clear separation in the attributions of competence, which does not constitute a category in the CSM. Drug therapies were assigned to the physician's domain. At best, the participants wanted to be informed but rejected shared decision-making due to a lack of medical knowledge. Respondents made independent decisions regarding their competence (diet and physical activity), which they discussed in their social environment but never with medical staff. They also reported paternalistic language when physicians prescribed something. This appeared to be an overstepping of the doctors' assigned area of competence.

Discussion

This qualitative study highlights the importance of individual disease theories to diabetes mellitus treatment adherence. The results revealed that the perception and management of the disease depend on healthcare access in the country of origin and knowledge of diabetes; for relatives, both were dependent on their educational level. Even after immigration to Germany, communication channels continued to be used as before.

The social environment and healthcare access

Respondents' perceptions of being affected by diabetes mellitus were influenced by the different healthcare systems of the countries (Soviet Union versus Germany). It was essential to know the situation and country in which the diagnosis was made. Knowledge of the social network was decisive. In the former Soviet Union, the first symptoms were discussed with relatives and friends. This group of people then arranged contact with the healthcare system. Diabetes was then usually treated by endocrinologists in polyclinics located in cities or metropolises (Bartlett, 2000). The affected who lived in a village were also treated there. In the local environment, further care was then provided by a more highly trained nurse, a so-called feldsher / Фельдшер. This term originates from the German or Swiss military of the 17th / 18th century, and it still referred to the less trained military surgeons (Berlin-Brandenburg Academy of Sciences) or 'village doctor' (Sapozhnikova et al., 2016). However, individuals with a higher social status (university graduates) described higher-quality medical care and standardized treatment (Rusinova & Brown, 2003). Through their social contacts, they were primarily cared for by professors. Even when blood glucose levels were elevated, the disease sometimes went unrecognized by the participants since physicians did not specifically label it as 'diabetes', and no well-known symptoms were noted.

The problems that existed at the time of becoming aware of the disease were considered causative, regardless of the country in which diabetes was diagnosed. For participants, achieving their therapeutic goals (such as fulfilling social roles and meeting self-defined parameters of quality of life and health) within their behavioral capabilities (their area of competence) determines their sense of control over the disease. Communication about treatment goals in social networks and experiences in one's environment determined expectations about potential consequences. In Germany, the diagnosis was often made during the initial examination or diagnosis of other diseases. Since none of the known symptoms had yet appeared, the designation 'diabetes' was a complete surprise.

The overarching goal of all interviewees was to maintain their usual daily routine while adhering to social norms. Attention to role attributions in the social environment was also crucial for adherence in a study among Turkish immigrants in Germany (Yilmaz-Aslan et al., 2014). In Lenzen-Schulte's (2016) study, German patients rated maintaining roles in their social environment and preserving a self-defined quality of life under various disease conditions significantly more highly than physicians did.

Knowledge of and communication with healthcare professionals

The narratives assessed the physicians' knowledge of diabetes mellitus. This was not the aim of this study, but respondents discussed this topic in the context of the different therapies they had received, resulting in apparent differences. Respondents highly respected professors in the metropolises of the former Soviet Union for their expertise. In contrast, respondents who had previously lived in an urban or village environment and had been treated in polyclinics expressed a more critical stance towards their doctors. They cited misdiagnosis, incorrect therapies, overestimation of healthcare professionals' competence, and late referrals to specialists as contributing factors to their diabetes management issues. Social inequalities in medical staff knowledge have also been found in health care in metropolitan areas, cities, and villages (Aronson, 2011a; Rusinova & Brown, 2003). In polyclinics (standard care), endocrinologists were often overwhelmed by the number of affected patients and could not provide adequate education and treatment for diabetes mellitus (Aronson, 2011a; Kühlbrandt et al., 2012). People who lived outside an oblast (i.e., a municipal administrative unit in Russia) center were more likely to be treated with non-evidence-based therapies. HbA1C was measured regularly in only about 15% of those affected, requiring more frequent inpatient treatment (Sapozhnikova et al., 2016). Worse outpatient care in urban or village areas was associated with increased direct (2.36–fold) and indirect costs (2.77–fold) to the medical system (Sapozhnikova et al., 2016).

The healthcare system in the former Soviet Union did not include diabetes counseling (Kühlbrandt et al., 2012). If any counseling took place, it was provided by doctors. With the exception of the feldshers in rural areas, nurses also had a subordinate status. One expert, therefore, described her profession as a diabetes educator to Russian-speaking patients as: "консультировать вапрос диабета" (i.e., a consultant on diabetes issues). Moreover, this underlines her level of training.

However, even in metropolitan areas, whether an expert was consulted or standard care was provided in outpatient clinics often depended on the participants' relatives. When participants and their relatives were academics, the interviewees described receiving treatment from a professor. Rusinova and Brown (2003) referred to this group of individuals as 'established intelligentsia' (i.e., Russian term for people with a university degree for at least two generations within one family) (Rusinova & Brown, 2003). The 'new intelligentsia' group (comprising individuals with only one generation of academic degrees) typically used the conventional healthcare system, even if better care could have been provided locally (Rusinova & Brown, 2003). Among participants with low levels of education who had previously lived in a large city, narratives seemed comparable to those of interviewees from village structures in terms of both the living conditions described and perceptions of diabetes or healthcare access.

All participants in the present study highly rated the physicians' knowledge in Germany. However, they were critical of time management and interactive communication. This criticism seemed to be more directed at German-speaking doctors than at the physicians from the former Soviet Union. This finding contrasts with Aronson's study (2011b) in which interviewees indicated a need for more confidence in the professional competence of doctors from their countries of origin. The difference lies in the assessment of various skills: Aronson's interviewees (2011b) focused on professional competence and possibly carried over expectations from their country of origin, while participants in our study evaluated doctors' communicative (verbal and non-verbal) skills. When available in Germany, Russian-speaking physicians were favored, as they were perceived as part of the social network. Participants could interact with them using familiar verbal and non-verbal communication rules confidently. A study by Mehler et al. (2004) using native speakers as physicians for Russian-speaking patients in Denver, US, noted an improvement in metabolic parameters. The authors attributed this success to linguistic and cultural concordance with the patients.

Limitations

In more than half of the interviewees, therapy was coordinated in a diabetes-specialized practice in Germany. Nearly two-thirds of the participants reported attending training on the disease in Germany. It is possible that this study included a higher proportion of individuals who had already engaged with their disease more intensively and proactively. A significant number of interviewees had lived in metropolitan areas (n = 12) in their country of origin, while fewer had lived in cities (n = 7) or villages (n = 7). Additionally, more participants with academic professions (n = 10) were willing to be interviewed compared to those with a degree from a technical or vocational school (n = 6 each) or without any vocational training (n = 4). The number of male interviewees (n = 7) was significantly lower than that of females (n = 19). Due to the difficulty in accessing possible interlocutors, an equal distribution could not be achieved. All these limitations may have led to unequal assessments of health care, knowledge competence, or individual role attributions.

Conclusion

The perception of diabetes mellitus and its management are decisively influenced by the knowledge within the social network and healthcare access in the former Soviet Union. Healthcare professionals treating patients who are post-Soviet migrants should be mindful of these factors. The clear separation of specialties that emerged from the interviews could also be an opportunity to offer targeted guidance to these individuals. Developing coping strategies within their self-determined areas of responsibility is central to effective diabetes counseling. There is no need for a new training program in this regard. Professionals in this field should be aware of the individual perceptions and action-guiding backgrounds of this group of people (Brundisini et al., 2015) to be able to provide nondirective counseling (Rogers, 2007). This counseling should be accessible within the local community. Michalik et al. (2022) referred to the shortest possible distances as a ‘to-go structure’ in which information should be accessible in the residential environment. In this context, shared meeting places of post-Soviet immigrants can be used as a ‘shelter shared language’ (Kofahl et al., 2009) and a space for ‘cultural and communicative memory’ (Assmann, 1988). Ideally, native Russian speakers with medical training completed in the country of immigration should be favored, as they are familiar with the verbal and non-verbal rules of communication (Nekouei Marvi Langari et al., 2023) and can enhance therapeutic success (Mehler et al., 2004). In addition, they are often trusted more by the patients.

The question arises as to how access to healthcare in Germany could be structurally modified to remove individual barriers, particularly for migrants. Could the ‘Community Health Nursing’ model, as advocated by the World Health Organization (2017), offer new solutions as a structural approach to advising these individuals? An initial report has already addressed potential solutions (Expert council for concerted sction in health care, 2001). On December 15, 2023, a law was enacted in Germany to strengthen this nursing responsibility (Federal Ministry of Justice and Consumer Protection, 2023). The first community health nurses have recently completed their Master’s degrees and are available to the German healthcare market. This development has not yet been reflected in the funding structures of the healthcare system, which still regard these roles as model applications. It is crucial to draw on the broad experience from other countries (Bodman, 2019) and consider these insights in feasibility studies for Germany (Eberl & Schnepp, 2011).

The change in communication about patient-related quality of life as a treatment goal for diabetes in Germany is reflected in the current therapy guidelines (Haak et al., 2023; Landgraf et al., 2023) However, this aspect is still insufficiently addressed by healthcare professionals (Lenzen-Schulte, 2016). It is crucial to emphasize this focus in treatment concepts and counseling for individuals with diabetes mellitus and other chronic illnesses.

Ethical aspects and conflict of interest

Ethical approval was obtained from the University of Witten / Herdecke Ethics Committee on September 10, 2015, as an extension to the expert interviews, on October 24, 2017. The authors declare they have no financial or personal relationships with individuals or organizations that could inappropriately influence their work.

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Author contributions

Conception and design (SS, WS), data analysis and interpretation (SS, AC, WS), manuscript draft (SS, AC), critical revision of the manuscript (SS, AC), final approval of the manuscript (SS, AC).

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