Original Article

People with diabetes in Estonia: Standard of living, aspects of health, and coping behavior

Virve-Ines Laidmäe, Tarmo Tuisk[1], Ulvi Tammer-Jäätes[2]

Institute of Social Work of Tallinn University, Uus-Sadama 5, 10120 Tallinn, Estonia, [1]Department of International Relations of Tallinn University of Technology, Estonia, [2]President of the Estonian Diabetes Association, Tallinn

ABSTRACT

Objective: The objective of this study is to analyze the factors that aggravate everyday life, health status, living conditions, economic coping, medical rehabilitation, and training needs of people with diabetes. **Materials and Methods:** In 2001, in cooperation with the Ministry of Social Affairs of the Republic of Estonia and the Institute for European Studies, the Estonian Chamber for Disabled People conducted a survey among people with different disabilities. The survey also included people living with diabetes. A total of 974 people were surveyed; 86 of them had diabetes. The data were analyzed using frequency tables. The results reflect the subjective opinions of the people surveyed. **Results:** There are more women (64%) among people with diabetes than men. The disease is more frequent among the older population (74% in the age group of 26-45 years). Persons living with diabetes display a variety of health complaints (vision problems, high blood pressure, osteoporosis, tooth decay, etc.). Of the people surveyed, 75% are satisfied with the medical care they have received. Of the people with diabetes, 63% were hospitalized for 6-30 days during the past year. The need for a helper was often (63%) cited as something that would facilitate coping with everyday life. Catering services are especially important for persons living with diabetes (30%), but the need for a conversation partner was also highlighted (21%). **Conclusions:** The efficiency of the impact of adjustment courses should be considered more. There is an apparent contradiction — although they are of working age, not everyone can find work. People with diabetes rarely have the courage to talk about the difficulties they are faced with in their everyday life. Help and financial support from the state are needed to solve the problems. The organization itself could do a lot more favorable conditions for its activities, which were established.

Key words: Coping, health, living conditions, need for help, people with diabetes

INTRODUCTION

In Estonia as well as in other countries, the life of people with disabilities is characterized by a fight for independence and self-sufficiency. Reaching these goals is often hindered by the limitations of everyday life and the negative attitude prevalent in society. In Estonia, there have been very few studies to determine the living conditions of people with disabilities. People with rheumatism are one of the more thoroughly researched groups in Estonia;[1] however, they are only a part of people with chronic ailments. This gave rise to the need to include other disability groups — people with diabetes among others. There are 70,000 individuals with diabetes in Estonia; they are united by the Estonian Diabetes Association established in 1992.

The number of persons with diabetes is growing as the population is aging and becoming more urbanized, the number of overweight people is increasing and the overall level of physical activity is decreasing.[2] It is important to note that diabetes increases the risk of other diseases such as heart diseases, stroke, arthritis, depression, and high blood pressure.[3,4] Therefore, it is extremely necessary to describe the situation of and shortcomings in the coping of persons living with diabetes. After all, diabetes significantly impairs normal everyday life (frequent visits to

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Corresponding Author: Virve-Ines Laidmäe, Researcher at the Institute of Social Work of Tallinn University, Uus-Sadama 5, 10120 Tallinn, Estonia. E-mail: ines@tlu.ee

the doctor, daily administration of medications, checking blood sugar levels, a strict diet). The possibilities for changing this situation are best seen and described by the patients themselves. Stuckey[5] emphasized that unless we understand the living conditions of diabetes patients and their social and behavioral limitations, we cannot know how to treat them. In order to understand the context of the life of diabetics outside medical indicators, qualitative research is very helpful; however, a general overview is also provided by sociological questionnaires that rely on quantitative data. And this is despite doubts whether it is possible to research and present the opinions of patients in a quantitative manner.[6] Still, several studies have been conducted about the quality of life and coping of people who suffer from rheumatism, heart conditions, stress, and other illnesses[7-10] These studies are necessary in order to gain insight into the daily life of such people so that their opinions and problems could be presented to the relevant authorities. This information enables to design measures in order to plan services (including rehabilitation) and social support and other support programs.

Publications on diabetes mainly analyze the medical aspects of the disease and the possibilities of improving treatment.[11,12] Even if, among all else, studies take into account the links between diabetes and heart conditions, stress, and depression.[2,10] there is still very little data to characterize the daily life of persons with diabetes or analyze their satisfaction with life.[12-14] We also found an interesting study that researched the level of knowledge that social scientists have about diabetes (whether diabetes is treatable, is diabetes characterized by high blood sugar levels, what are the symptoms of diabetes). The prerequisite was that professionals who work in areas related to social sciences, health, sociology, demography, and psychology should be "agents of change" by increasing the society's awareness with their research, thus improving attitudes towards people with diabetes.[15]

Based on all of the previously mentioned factors, we believe that this publication could provide additional information to improve the living conditions of people living with diabetes and to satisfy their vital needs; after all, apart from the medical aspect, patients would need significant changes in different areas of daily life as well as someone to counsel or help them.

Sample and Goal of the Study

The data of this article was gathered during the project *Quality of Life of People with Chronic Conditions and Disabilities in Estonia* [*Kroonilise haigusega ja puudega inimeste elukvaliteet Eestis*];[1] in order to conduct this project, in 2001 the Estonian Chamber of Disabled People, which is established under the Ministry of Social Affairs, gathered a large amount of data. The project was financed by the Ministry of Population and Ethnic Affairs and the data from the survey was processed and analyzed by the staff of the Institute for European Studies. A total of 974 respondents were interviewed. The selection of the sample was conducted as follows: a selection with a ratio of 1:2:1 from I, II, and III category of disabilities, respectively, were made from county registers, which differentiate between people with different categories of disabilities. The goal of the project was to study and provide an overview of the situation of people with chronic conditions and disabilities who were in the age group of 16-45 years in Estonia.

Respondents were selected randomly from the following categories of disabilities: people with vision impairment, people with allergies, people who are deaf, people suffering from multiple sclerosis, people who are hard of hearing, people with mobility disabilities and people with diabetes, rheumatism, heart conditions, epilepsy, and psoriasis. Among this vast amount of information, we decided to concentrate on people with diabetes in this article. The purpose of this publication was to ascertain how people with diabetes cope, how many need help and support, what is their level of involvement in the society and working life and their rehabilitation and training needs.

For this purpose, we separated the response forms of people with diabetes from the general sample (which included people with all conditions) and analyzed their quality of life and coping and sometimes drew comparisons with groups of people with other disabilities. Out of the 974 people with illnesses or disabilities, 86 had diabetes.

Results

Living conditions, economic coping and professional activity of persons with diabetes

Among the respondents with diabetes, 36% were men; two-thirds were single and 28% were married. Among the respondents, 41% had children with an average of 1-2 children. Among the respondents, 26% were in the age group of 16-25 years and 74% were in the age group of 26-45 years.

Living conditions and apartments

Over a half of the respondents had standard conditions for personal hygiene and access to warm water; however, many used water from a well or had to fetch water from a source away from their home. Of the respondents, 69% lived in apartments that had indoor plumbing while 19% lived in apartments where the toilet was in the hallway or outside, or used a pit toilet; 56% had a bathroom. Every

second respondent used an electric stove; 34% had a wood stove. In questions about other persons living in the household, the majority of respondents reported living with their parents (38%) or spouse (24%).

The apartment of 13% of the persons living with diabetes has been adapted to their disability. This percentage is remarkably lower in this group of people compared with people with other disabilities — for example, in case of people with heart conditions, it was 43%.

Of the respondents, 94% have a phone and 51% of the people with diabetes have a bicycle. They mostly miss owning a car, followed by a separate home, a computer, and a bicycle [Table 1].

People with mobility disabilities have the greatest problems with heating their homes (24%), closely followed by people with diabetes. People with diabetes are also dissatisfied with the lack of storage space; however, compared with the other groups of people with disabilities, they also cite a lack of privacy [Table 2] very frequently.

Economically, almost every second respondent is coping well or reasonably; however, 39% of the respondents with diabetes are in an economically dire situation. The rest were not able to evaluate their economic coping. Of the persons with diabetes, 82% receive a pension or support payments.

Almost every second respondent has a job. The majority (89%) wish to work. Of the respondents, 9% would be primarily interested in a part-time job and 67% claimed that they handle work assignments well. At the same time, every second respondent emphasizes the need for additional training. The majority (97%) claim that their colleagues value them. Among people with diabetes who work, 68% are satisfied with their lives while only 48% of the unemployed feel the same.

Table 1: Desire to purchase different equipment/goods among people with diabetes

Goods/things	Purchase preferences of the respondents with diabetes (%)
Living space	20
Car	53
Computer	10
Bicycle	7
Mobile phone	4

Table 2: The relative importance of problems among diabetics that complicate coping with daily life in an apartment

Exacerbating circumstances	Percentage of the respondents with diabetes (%)
Heating is difficult	13
Not enough storage space	12
Inferior conditions for washing	12
No privacy	13

A third of the respondents claimed that they do not feel lonely, whereas 61% agreed with the statement that they have occasionally felt lonely. Parents or spouses were mostly listed as persons close to the respondents – 37% and 29%, respectively.

Social activity

Half of the people with diabetes are satisfied or very satisfied with their lives. The percentage of people who are dissatisfied could be explained by psychological factors, which might be caused by the stressful nature of health problems. Of the people with diabetes, 40% participated in a social event outside their homes once a month while 14% did so once a week. Three out of four respondents were well-informed about leisure and relaxation opportunities close to their homes. Generally, people with chronic conditions and disabilities demonstrate low public initiative. The same applies to people with diabetes who rarely have the courage to talk about their problems, especially in public — at school, at work, or in newspapers. Are they embarrassed or do they lack the courage?

Of the respondents with diabetes, 74% belong to the Estonian Diabetes Association. The reasons for not belonging in the association were equally reported as "do not care" or "difficult to participate". Only few people with diabetes had not heard of the organization.

Persons living with diabetes were the most active group in terms of participating in trainings and seminars for people with disabilities (60%), whereas they have not participated in sports events at all.

Health

People with disabilities or chronic conditions (including diabetes) were generally satisfied with the state of their health — every sixth reported good health and almost every second reported satisfactory health. About a half of the people with disabilities or chronic conditions must administer drugs regularly. Usually, administering medications is related to the peculiarities of the disability or condition: the majority of people with diabetes (96%) must use medicine on a regular basis (the average among people with disabilities is 49%). People living with diabetes use tranquillizers in order to calm down (14% administer them regularly and 19% occasionally).

Compared with people with other chronic conditions, people with diabetes demonstrate a significantly higher occurrence of other health complaints. Thus, problems with vision are more frequent than average among persons with diabetes; 12% have vision impairment, 28% have serious problems with vision, and 45% have some problems with vision. Diabetes is the primary problem of the people suffering from it (84% are disabled because of the disease). The other problems of people with diabetes include hypertension (every third has serious problems because of this condition); quite a few (41%) also suffer from reduced blood pressure. People with diabetes suffer from bone loss (every third) as well. Tooth decay troubles almost all people with diabetes. Circulatory problems are also the most frequent among people with diabetes (the majority have some or serious problems in this area).

In all groups of people with disabilities, the level of reported satisfaction with medical care exceeded 75%. Among the people with diabetes, 11% discovered their condition themselves, while 70-80% of the cases were discovered by doctors. There was also a very positive outcome — 74% of the respondents with diabetes claimed that they received immediate medical assistance as soon as their disease was discovered.

Many people with diabetes take care of their health using natural methods: they try to spend a lot of time outdoors, walk, eat healthily, drink medicinal tea, and follow health news in the media. The most unpopular measures were vegetarianism and having fast days. Disabled people do not consume excessive amounts of alcohol.

Compared with people with other disabilities, people with diabetes display the healthiest habits (more than a half of the respondents have a healthy lifestyle, 23% responded negatively and 20% have not considered it). People following a healthy diet can mostly be found among people with diabetes (59%). The greatest obstacle for people with diabetes in taking care of their health is financial difficulties — this reason was mentioned by three-quarters of the respondents.

Of the people with diabetes, 63% were hospitalized for 6-30 days during the past year. Compared with people with other conditions, people with diabetes had the greatest number of doctor's appointments per year: 67% went to 6-20 visits and 13% over 21 visits. Also, in case of people with diabetes, doctors make house calls more frequently than average: 65% up to five times a year; every third respondent received 6-20 house calls. Based on these facts, it can be suggested that doctor's appointments or house calls that take place so frequently indicate that diabetes significantly impairs normal everyday life.

There is reason to claim that the incomes of people with chronic conditions and disabilities only allow them to purchase the most indispensable pharmaceuticals. Obtaining technical aids and medical devices was also problematic. Of the people with diabetes, 27% can afford to buy technical aids with their own income.

Need for assistance

People with different disabilities mostly mentioned the need for a personal assistant (63%) to help them cope with daily life. However, persons with diabetes needed the help of an assistant less frequently (30%). Every fifth respondent with diabetes needed a special computer to cope with daily life and every tenth respondent needed transportation services. People with diabetes consider catering services (30%) the most important issue.

People with diabetes needed the following various domestic services: most needed meals delivered (26%) and also help in arranging medical care (22%).

Only 4% of the people with diabetes were interested in ordering and obtaining firewood; however, they need more help than people with other disabilities to saw or chop wood, take it indoors, and heat their home (13%). Also, more often than others, people with diabetes needed a service to help them organize correspondence (14%) and establish contacts with nonprofit organizations and movements (14%). At that, people with diabetes are more likely than others to express their wish to receive free-of-charge services (51%).

People living with diabetes also demonstrated higher levels of socializing needs (21%).

Of the people with diabetes, 31% were well-informed about adaption courses; they had also benefited the most from adaption courses for the disabled (93%).

What kinds of rehabilitation services are needed?

People with diabetes consider the following services the most important: rehabilitation, social services to improve coping, vocational training, and the availability of adapted working conditions [Table 3].

People with chronic conditions and/or disabilities expect the state and social workers to mainly provide material assistance; the number of people expressing this was noticeably higher among people with diabetes (77%).

Table 3: Assessment of the need for rehabilitation services among people with diabetes

Rehabilitation service	Percentage of the respondents with diabetes who considered the service necessary (%)
Rehabilitation	71
Training for coping with daily life	36
Vocational training	26
Vocational retraining	18
Possibility of working in a place adapted to the disability	39
Social services to increase the level of coping	51

Technical aids

When considering the percentage of people belonging to different disability groups who need technical aids or prosthetic appliances, it becomes apparent that while most belong in a group of people with mobility disabilities and vision impairments, the third largest group consists of people with diabetes (15%). In their daily life, people with diabetes use glucometers (91%) and test strips (79%) the most. Other aids used by the respondents with diabetes were spectacle magnifiers (9%) and blood pressure monitors (8%).

In the opinion of people with diabetes, the company that supplies technical aids should improve the availability of information (73%) and instructions on how to use technical aids (60%). Other important aspects were service culture and improving the quality of products — in the opinion of 23% and 19% of the respondents with diabetes, respectively. People with diabetes were also one of the groups to include the highest percentage of persons dissatisfied with the system of allocating technical aids and prosthetic appliances — 28% of the respondents.

Since 2007, the availability of diabetic supplies has significantly improved. The Estonian Health Insurance Fund has added a large number of new useful products to its list of discounted supplies and the availability of supplies to various groups of diabetics has expanded.

List of diabetic supplies covered by the Estonian Health Insurance Fund's benefits since January 1, 2013

- Glucose meter test strips in the following cases in the following extent:
  1. 1100 test strips per half-year for a child under 19
  2. 600 test strips per half-year for a type 1 diabetic
  3. 1100 test strips per half-year for a pregnant woman and mother until the child is one year old
  4. 300 test strips per half-year for a type 2 diabetic being treated with insulin injections
  5. 50 test strips per half-year for a type 2 diabetic being treated with pills
  6. 300 test strips per half-year for a patient with gestational diabetes who is treated with dietary management
  7. 600 test strips per half-year for a patient with gestational diabetes or someone pregnant with type 2 diabetes who is treated with insulin injections until the child is one year old.

Above-mentioned quantities can be purchased from pharmacies at 90% discount.

- Disposable insulin pen needles at 90% discount
  1. 700 needles per half-year for a child under 19 years
  2. 700 needles per half-year for a type 1 diabetic
  3. 200 needles per half-year for a type 2 diabetic being treated with insulin injections
  4. 500 needles per half-year for a patient with gestational diabetes or someone pregnant with type 2 diabetes who is treated with insulin injections
- Insulin pump and its accessories in the following cases in the following extent:
  1. 1 insulin pump for a child aged up to 4;
  2. 1 insulin pump within a 5-year period for a person aged 5-18 who has started pump therapy aged under 5 or who has a glycosylated HbA1 above 8.0 or who has experienced frequent hypoglycemia or who has large swings in blood sugar level
- The Estonian Health Insurance Fund will assume the payment obligation for insulin pump accessories from an insured person aged under 19 undergoing insulin pump therapy in the following extent:
  - Medtronic pumps (Paradigm and Veo):
    1. Quick-set and Silhouette cannula 120 units per year, Sure-T cannula 180 units per year;
    2. Up to 100 reservoirs per year.
  - Accu-Chek pumps (Spirit):
    1. Up to 120 cannula and 70 catheters per year;
    2. Up to 75 reservoirs per year.
- Insulin pump glucose sensors
  1. 48 glucose sensors for a child up to and including 4 years of age per calendar year;
  2. 12 glucose sensors per calendar year for a person aged 5-18 who is undergoing insulin pump therapy who has a glycosylated HbA1 above 10.0 or who has experienced frequent hypoglycemia or who is measuring their blood sugar level over 10 times per day.

In order to buy diabetes supplies, a doctor must issue a medical device card for the needed devices. One card is issued per supplies group, that is, a general card is valid for glucose meter test strips and the patient is able to choose

which manufacturer's test strips to buy and if necessary, test strips from several different manufacturers could be bought within the provided quantity limit. The same is valid for insulin pump cannula — the patient must choose a suitable cannula type, needle and tube length, and different cannulas may be bought.

Conclusion and Suggestions

People with disabilities have become more active over the past few years and they are more actively involved in different organizations. They have realized that organizations are used to distribute information, organize different courses and various events and provide support and help for their problems. However, people with disabilities lack in political activity and the courage to express their problems. Of the respondents, 71% stated that they have not been involved in discussions over the situation of the disabled. The greatest problem faced by the organizations is a lack of both finances and staff. As people work there on a voluntary basis, everything is based on voluntary work. In Western countries, larger organizations employ people to actively research and analyze the needs of their members and shortcomings in their coping with daily life in order to make suggestions to ministries and governments, but in Estonia, they have no counterparts. The project *Quality of Life of People with Chronic Conditions and Disabilities in Estonia* was one of the first to provide an overview of the circumstances of the disabled and forward this information to the relevant authorities.

Organizations are perfectly capable of forwarding information, counseling, teaching coping skills, holding adaption courses, coordinating the work of support persons and personal assistants, etc. A great need for the above mentioned services was demonstrated by research data – 59% of the people with diabetes needed adaption courses and various social services in order to increase the level of their daily coping (36%); it was also important to them to receive counseling on different issues (57%).

Medical circles only consider rehabilitation in a narrow medical context; they also underestimate the importance of adaption courses, teaching daily coping skills and other kinds of rehabilitation activities in improving the independent coping of people with disabilities. Yet, the respondents considered adaption courses to be extremely useful (93% of the diabetics).

The system of allocating technical aids and medical devices was also problematic. Possibilities must certainly be found to increase funding and partially also add new items to the list of technical and medical aids. The remarkably high propensity (77%) of people with diabetes for material assistance is largely caused by the proportion of own contribution to the cost of aids and devices, which is too high.

The situation would be greatly improved if people with diabetes who study or work had benefits for an Internet connection, if personal computers were included in the list of technical aids, and if more educational materials and programs were available.

Work is as important for people with disabilities as it is to those who are healthy. Since all disabled people belong in the risk group of poverty and exclusion, it is important to apply all the possible measures to ensure that people with disabilities found suitable employment. At the moment, employment is unfortunately not available to everyone.

Of the respondents with diabetes, 45% were working while 89% wished to find employment. This is a sensitive issue as many of the respondents were in the age group of people who are normally involved in working life.

Many of the results of our work coincide with the results of other researchers. Our findings indicated that the majority of people with diabetes are women.[16] And, although a chronic condition such as diabetes could develop at any stage of life, it mostly occurs among older people.[10] Another statement confirmed was that diabetes causes an overall deterioration of the state of health and there is a high risk of developing hypertension, heart attack, and other similar conditions.[4] Concurrently, our study also pointed to many other aspects, which could help to improve the level of coping of people with diabetes. We hope that by increasing the awareness of the society about the disease and by helping to establish conditions to improve the situation of diabetics, we would be able to fulfill the role of "agents of change".[15]

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