Stigma, Self-stigma and Resistance:

Life Stories of people with Type 1 diabetes in Belgrade

by

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Abstract

The central topic of this thesis is the stigmatization and resistance to it in the context of a chronic health condition. It focuses on experiences of people living with Type 1 diabetes in Belgrade, more accurately, activists of Plavi krug, through analyzing whether and how they were stigmatized, whether stigma led to self-stigma, and how they resisted it. More specifically, the thesis examines the factors and fields of life where stigma was most experienced, gender roles in relation to stigma, role of community-support in creating resistance to stigma, and activists relation to the concept of neoliberal entrepreneurial subjects. Methodologically, answers are derived through life-story interviews and autoethnography. Interviewees discussed stigma in relation to educational attainment, personal relationships and employment. Interviewees' answers were mainly interpreted through the prism of Goffman's and Link and Phelan's theory of stigma, while the analysis was also informed by Parsons' 'sick role', Foucault's notion of 'docile body', Rose's view of neoliberal entrepreneurial subjects, Hughson's theory of gender roles in Serbia and Shih's models of resistance to stigma. The thesis ultimately attempts to outline the mechanisms interviewees used in resisting stigma since the moment of their diagnoses until present day. By tracing the paths of their resistance, which were observed in relation to the adoption of either coping or empowerment model of resistance, the thesis managed to categorize interviewees into six different types of resistors, highlighting above all the importance of community support in the development of resistance to stigma.

Key words: stigma; self-stigma; resistance; type 1 diabetes; community-support, Belgrade.

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DAS – Diabetes Association of Serbia

PK – Plavi krug

PWD – People with diabetes

T1D – Type 1 diabetes

1 Introduction

> *Once stigmatized, you become other, always other. This othering is not so much my own activity as it is a process of distancing that others deploy as a strategy of containment and control in their relations to me. In declaring the other other, people claim, "I am not that."*
>
> (Taylor 2009: 207)

Type 1 diabetes (from here on T1D) is an autoimmune disease, which occurs as the result of the destruction of beta cells[1], leading to the inability of the pancreas to produce and distribute insulin throughout the body. With the lack of hormone insulin, the blood sugar rises and if not treated daily, leads to life-threatening complications and finally death (JDRF n.d.).

I have been living with T1D since the age of five and have gotten to know and understand all the ways in which diabetes is not only a medical condition, but a social one as well, same as any other acute or chronic illness. One of the social aspects of diabetes is *stigma*, a gap between virtual identity (who one is supposed to be) and real social identity of an individual (who one is) (Ricer 2011). What has changed since the daily treatment for T1D was first used in 1922, is not only the number of people affected by the condition, but the visibility of it. The type of insulin has changed and is injected more than three times per day, people can prick their fingers or use sensors for glucose monitoring and insulin pumps or pens[2]. The visibility, of course, has a great impact on stigma.

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[1] Betta cells are the cells that produce insulin. More information: https://www.diabetes.co.uk/body/beta-cells.html.

[2] By pricking of a finger with a needle, a small amount of blood is put on a test strip: https://www.diabetes.co.uk/blood-glucose/how-to-test-blood-glucose-levels.html. Blood sugar meters are small devices, of various shapes and sizes, not bigger than a mobile phone, that measure the amount of sugar in blood by pricking a finger and putting a small amount of blood to a test strip, connected to the meter. For example, the one I currently use is: https://www.diabetes.ascensia.com/our-meters/contour-plus-one-meter/.
Insulin pens are devices for injecting insulin, measured in insulin units (1ml of insulin is 100 units). They look the same as pens, hence the name. When injecting insulin, a small needle is attached to the head of the opened pen, which is removed after every injection. For example: https://www.novonordisk.com/patients/diabetes-care/pens--needles-and-injection-support/flexpen.html.

The importance of studying social aspects of T1D lays in the fact that there is a growing inclination to stigmatization because of the lack of information/necessary infrastructure to deal with the needs of people with diabetes, who are getting diagnosed at an alarming rate. According to the *International Diabetes Federation Diabetes Atlas* from 2019, there are 463 million people currently living with different types of diabetes around the world. It is estimated that by the year 2045, the number will rise to 700 million. In 2019 alone, it is estimated that over 4 million people died because of diabetes. In Europe, the number of people affected are currently 59 million, with an increase of 15% until 2045 (Malanda et al. 2019). The estimations for Serbia (whose capital, Belgrade, is the field of this study) show that there are 773.7 thousand people aged 20 to 79 living with diabetes, meaning 11% of the country's population, estimated to rise up to 13% by the year 2045 ("Serbia Diabetes Report 2010 — 2045" n.d.). Generally, more than 90% of people who have diabetes are diagnosed with type 2[3], leaving type 1 in the minority, which is why more research has been done on the lives of people with type 2 diabetes and certain aspects of it. Therefore, T1D is less popular to study, as it is less common than type 2, which, on the other hand, means it is also less written about. Furthermore, there are no public records of diabetes related stigma research being done in Serbia. In a society that differentiates between "normal" and deviant people (in this case through a life with chronic condition), such

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In Serbia, there is only one type of insulin pump available: https://www.diabetes.co.uk/diabetic-products/pumps/medtronic-paradigm-insulin-pump.html. It can only be received for free from the health insurance of Serbia, if a person fits the very strict criteria – e.g. having complications, high blood sugar, uncontrollable diabetes... It acts as an insulin pen, however, the basal – 24-hour dose is injected all the time, in very small amounts. When having a high blood sugar or eating, a person manually adds insulin through the pump, by pushing a few buttons.

Flash glucose monitoring sensors (such as *Freestyle Libre* which people with T1D in Serbia use, is a device connected to the body via plastic needle and an adhesive tape in the shape of a circle. It measures glucose in the inter-cell fluid beneath the skin. On the surface of the body, there is a small circular „head" of the sensor that, when a sensor meter or smart phone is leaned on it, sends radio-waves of the data about the glucose. A person can perform this action as many times as they want during the day. For a more depicting explanation: https://www.freestylelibre.co.uk/libre/.

[3] Type 2 diabetes is a condition where the betta cells produce insulin, however, not in full capacity as the pancreas is slowed down. More on type 2 diabetes: https://www.diabetes.org.uk/diabetes-the-basics/what-is-type-2-diabetes.

as Serbian, it is of great importance to give people with T1D a voice, which this study aims to achieve.

The main focus of this study is to identify how people with T1D in Belgrade are stigmatized and how they handle and/or resist stigma, through life stories and autoethnography. Life stories have been 'collected' from people who are, just as me, activists of *Plavi krug* – 'Blue Circle' (from here on PK), a citizen organization for battling against diabetes in Belgrade, Serbia. On the question of methodology, I am of the opinion that a universal study of stigma and self-stigma of people with T1D should incorporate both quantitative and qualitative methods, in order to have a strong number-concerned basis, with a more personal and strong individual-level superstructure. Although I have very limited time to use both methods, my research will qualitatively focus on many social aspects of life of a person with T1D in Belgrade – chronologically since the time of diagnosis until now, therefore painting a very clear and comprehensive picture of stigma-related experience from the times of socialization, through different educational levels, employment and social and romantic relationships, something other studies have not done.

2 Theoretical and conceptual framework

The purpose and the main research question of this thesis is to identify and understand how people with T1D are (who are volunteers at a patient organization in Belgrade) stigmatized and self-stigmatized and how do they handle the experiences.

The first scholar many think of when hearing the word "stigma" is Erving Goffman. His book *Stigma: Notes on the Management of Spoiled Identity* was first published in 1963 and was a stepping-stone for studies concerning mental and physical conditions, illnesses and disabilities – among them, diabetes. Goffman writes about the different types of stigma a person can possess. He defines stigma when he refers to the discrediting attributes that appear as the result of human interactions and meanings created by the individuals participating in them. Discrediting attributes on their own do not possess positive nor negative connotations. Instead, the connotation is made through interactions. In other words, stigma is a gap between virtual identity (who one is supposed to be) and real social identity of an individual (who one is) (Ricer 2011). Goffman emphasizes that stigmatized individuals are seen as less human and are therefore entitled to be discriminated against and labeled, making their chances of a normal life minimal. The nature of interaction between "normal" and stigmatized individuals depends on the type of stigma the stigmatized possess. People who are *discredited* have a visible stigma, which is known to other actors (such as race, ethnicity). People who are *discreditable* have a stigma not visible at first glance (such as chronic and mental conditions, sexual orientation – these are Goffman's examples). For the discredited, a tension exists specifically because other actors know about the stigma, while the discreditable fear and feel uncertainty about their stigma being revealed and how to hide it most effectively (Goffman 1963).

This brings us to the second important concept of the research – self-stigma, since internalizing the visible, discredited stigma leads to "the prejudicial attitude wherein individuals develop negative attitudes toward themselves because of their condition" (Kato et al. 2016: 2). The internalization of stigma effects people's identities, physical and psychological well-being and has social consequences (avoidance of public places, limited social interactions) and economic ones (loss of employment, worsening of economic situation and income) and finally, worsening of diabetes self-control (J. L. Browne et al. 2014; Schabert et al. 2013). However, testimonies of activists of *PK* indicate that self-stigma can be overcome, mostly with support and help from family and close ones, as well as the confidence gained thanks to local and national patient associations.

Goffman's theory can very well be applied to the study of PWD. In my opinion, the situation with people who have T1D is inasmuch more interesting as they stand somewhere between the discredited and discreditable, or possess both stigmas. Often, their stigma is not visible, however, certain attributes do reveal it. Goffman's theory will be used in this research to help identify the discrediting and the discreditable individuals, whether they influence their stigma and how, as well as the leading factors to developing self-stigma.

I define the visible attributes that contribute to the stigmatization of people with T1D as: the dependence on medication (insulin) that has to be injected through an insulin pen/pump several times per day; frequent monitoring of blood sugar glucose levels, performed by pricking a finger; symptoms of light or heavy episodes of hypoglycemia[4]. I have chosen the above-mentioned attributes because they lead to the stigmatization due to the ignorance of other actors. Stigmatization in this case manifests as: identification of injecting insulin in public places as taking psychoactive substances; wrong impression that someone possesses a lower intellect since lighter hypoglycemia affects concentration and supply of oxygen to the brain, while heavier hypoglycemic events might seem as if the person is under the influence of alcohol and behaving repulsively (Liu et al. 2017). Due to the stigmatizing attributes, children,

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[4] Extremely low levels of blood sugar, a potentially life-threatening state. For more information see: https://www.nhs.uk/conditions/low-blood-sugar-hypoglycaemia/.

adolescents and adults often have problems with self-confidence and socialization, which can also affect their relationship towards their condition.

Bruce G. Link and Jo C. Phelan, contemporary social and health stigma scholars have written about health-related stigma in a way that can be very well applied to many cases of mental and physical conditions and disabilities as their theory is very general and comprehensive. Namely, Link and Phelan use the term stigma in a situation where labeling, stereotyping, separation, loss of status and discrimination occur together in a power relation situation. The authors claim that the process of stigmatization consists of four parts: (1) people identify and *label* differences (the label connects an individual with some negative characteristics which form a stereotype), (2) people oriented towards the dominant system of beliefs label with the help of negative characteristics, which become *negative stereotypes*, (3) labeled individuals are *separated* into specific categories, so the differentiation between "us" and "them" can be established, and finally, (4) labeled individuals experience the *loss of status* and individual and structural *discrimination* (Link and Phelan 2001).

The definition of stigma by Link and Phelan is adequate as it brings together important elements of stigma, which can be studied separately or together and therefore show which element of stigma is more common than others in the context of people with T1D. However, I am of the opinion that not all factors Link and Phelan introduce in their theory are applicable or important to this study. For instance, although discrimination, labeling and stereotyping are important and experienced by people with T1D in Belgrade, separation is not commonly experienced, as they are not completely disapproved, rejected and excluded, while loss of status in not applicable to those who get diagnosed with diabetes in their childhood or adolescence. Therefore, I plan on using the three particular elements of stigma the two authors introduce and in a chronological order, the one they use to explain the process of stigmatization of an individual.

One of the labels by which people with T1D are called is – sick. The term sick role was introduced by functionalist Talcott Parsons. Parsons believes that when a person is diagnosed with an illness, she gains a new role in society – the social role of a sick person, which has to be fulfilled since it is expected by the rest of society. Parsons argues that there are four aspects of institutional system of expectations with regards to the social role of a sick person: (1) the person is free from the previous roles she was fulfilling, (2) the person needs help from others, (3) the person has to wish to get better – that is her responsibility, and (4) the person has to seek professional help for the illness (Kecmanović 1978). Although more fitting for acute illnesses than chronic conditions, such as T1D, the label of a sick person is interesting to study from Parsons' perspective, as it presents the way some people get labeled and stigmatized and told they cannot fulfill certain roles. In other words, due to the societal expectations from a sick person, which people with T1D do not fulfil, they get stigmatized.

Michel Foucault's concept of the *docile body* is important for understanding the positionality of a person with T1D in society. For Foucault (1977), the body is the object and target of power, the central location of power relationships. He argues that: "A body is docile that may be subjected, used, transformed and improved" (Foucault 1977: 136). As Dellinger and Williams) write: "Through self-surveillance and everyday disciplinary practices, individuals internalize and reproduce hierarchies of social status and power, transforming their own bodies into "carriers" or representatives of prevailing relations of domination and subordination" (1997: 152). The docile body is considered to be healthy and an embodiment of power of regulation. It is the way it is naturally supposed to be (Corbett 2010). The type of power Foucault connects to bodily discipline is biopower, social control manifested through daily routines docile individuals perform – self-surveillance and self-discipline, especially with regards to health, hygiene and sexuality (Pylypa 1998). Who is considered to be a "normal" individual, as opposed to a deviant one, is regulated through the power of medical doctors.

However, individuals as active and knowledgeable agents can resist the oppressive power (in this case biopower) relations. I would hypothesize that people with T1D do resist stigma, resulting in a re-organization and re-distribution of power towards PWD. I would attempt to discover their strategies and channels of support in overcoming the oppression and gaining power. Foucault famously said that "knowledge is power". Applied to this study, I would hypothesize that the knowledge people with T1D have about the condition and its' political, institutional, economic and social surrounding gives them power to resist stigma. That knowledge is provided through the support of volunteer organizations. Nevertheless, as "concepts of normality and deviance are manufactured so as to create the types of bodies that society needs" (Pylypa, 1998: 26), the task of normalizing T1D is a harrowing one.

Resistance from stigma by Shih, is characterized through two models – coping and empowerment. In the coping model of resistance, individuals lean towards prevention, meaning they "adopt strategies to cope with stigmas to avoid negative consequences... rather than to create positive ones" (Oyserman and Swim 2001, as cited by: Shih 2004: 180). On the other hand, model of empowerment is adopted by individuals who see themselves as active participants in the society, who create positive stigma for themselves and fight back (Shih 2004). My hypothesis is that my interviewees are currently using the model of empowerment, however, had used, at certain points in their lives, the coping model as well.

The problem with the existing body of literature on stigma and diabetes specifically, is that it is mostly done by medical scholars, and not by sociologists, anthropologists or psychologists, therefore, lacking the theoretical depth and multifaceted approach of a social science. However, taken all together, they are contributing and could be seen as specific aspects or parts of a broader theme about stigma and diabetes. The existing literature is mostly based on Goffman's theory, Link and Phelan's, or sometimes both at the same time.

For example, Chatterjee and Biswas (2012), in their medical journal article titled "Psycho-social stigma among T1D mellitus patients" studied stigma among children and young adults in India, focusing on the psychological phases young people go through since early childhood until the end of adolescent period, while also providing guidelines for lowering the effects of stigma. They barely touch upon Goffman's theory of stigma and do not apply it in practice. Nishio and Chujo (2017) relied much more on Goffman's theory in their article "Self-stigma of Patients with T1D and Their Coping Strategies" in which they conducted 24 in-depth interviews with patients in a Tokyo hospital. The biggest flaw of the study is the fact that the interviews were conducted before or after a doctor's consultation, in the hallway, and not in a space interviewees felt safe and relaxed. Nevertheless, what can be picked out from the study are the three dimensions of dealing with stigma the authors identified: physical, psychological and spiritual.

An interesting study by Abdoli, Abazari, and Mardanian (2013), titled "Exploring diabetes type 1-related stigma" uses the definition of stigma by Link and Phelan and focuses on 26 people in Isfahan, Iran – 8 people with T1D, 5 people who are family members of a person with diabetes and 13 who do not have T1D, nor know someone with it. It is a highly interesting study as it deals with what people get labeled as, helping me to realize existence of further dimensions to labelling and stereotypes. Another study, although dealing with type 2 diabetes, seemed helpful for a broader construction of this thesis – the 2013 Jessica L. Browne et al. "'I call it blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes", where Link and Phelan's theoretical approach was used to discover how people blamed themselves for having diabetes and the contexts in which they experienced discrimination – from the media and popular culture, to everyday conversations. Stigma surrounding T1D is closely linked to type 2, as they are often mistaken to be the same condition and therefore, leading to even more stigmatization, meaning that most of the insights from the above-mentioned study are applicable to type 1 as well. Finally, both Goffman's and Link and Phelan's theory are used in a quantitative study of the Swiss context, which identified the number and frequency of people getting depressed due to stigmatizing experience (Gredig and Bartelsen-Raemy 2017), successfully painted a general picture of the stigma influence on mental health. Kato et al. (2016) conducted a qualitative research on people with type 2 diabetes in Japan, focusing on self-stigma and connecting it with a bad self-control, as well as the overall health. Despite set in different contexts, both studies have provided significant insights for this study of Serbia, where hitherto such research has not been conducted.

One of the problems I identify in the existing literature on diabetes and its' stigma is the language used. Coming from a person who lives with diabetes for four fifths of her life, being called a person with diabetes is what I, as well as many other people around the world, feel comfortable with. Above all, I am a person, meaning that T1D is just one part of my personality. I do not see myself as a patient in my daily life, only the 15 minutes I spend a few times per year at my doctor's. Furthermore, I do not feel as a 'diabetic', as diabetes is not the sole definer of my personality. However, many, although not all studies, use these exact words. Link and Phelan wrote about this type of labeling in their 2001 article, explaining that if a person is called 'epileptic', they are put into the 'them' category. However, if they are called 'a person with epilepsy', they are a part of 'us'. "Incumbents are thought to "be" the thing they are labeled" (Estroff 1989, as cited by: Link and Phelan 2001: 370) but if "a person *has* cancer, heart disease, or the flu—such a person is one of "us," a person who just happens to be beset by a serious illness" (Link and Phelan 2001: 370).When medical doctors write about stigma, it only seems logical to use the word patient. Despite this, these authors should have in mind that the studies are not read only by other medical doctors and researchers, but PWD as well.

Therefore, in my study, as I am of the belief that language matters[5], my interviewees as well as the general population of affected, will be called PWD.

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[5] More on why language matters in the lives of PWD: https://diabetogenic.wordpress.com/2019/05/02/revisited-tangled-and-complicated/.

3 Contextual framework

In order to place the problem of stigmatization and self-stigmatization into wider social relations, meaning, on the macro level, this section will describe the relevant systems and institutions in their relation to and treatment of PWD in Serbia and specifically Belgrade. Belgrade has been taken as the place of my research since it is the city I was born and raised in and spent almost all of my life. It is also the city of my organization for citizens battling against diabetes, *PK*.

Serbia is the country of semi-periphery (Hughson 2017) of Europe. Although under influence of local structures, it is also influenced by transnational processes and is positioned not only against the center, or 'lagging-behind' it and never being able to catch up, but also characterized by de-development (Hughson 2017). This de-development means rising levels of poverty, rising social differences and inequalities, rising social insecurity and a reduction of social protection, corruption, a lack of rule of law, anomy, feeling of hopelesness of citizens, barbarization through war conflicts, population crisis, closing of social structures, reduction of quality of life, re-patriarchization and re-traditionalization and a demolition of educational, health and scientific institutions (Hughson 2017). Thus, the support that institutions are supposed to provide to PWD is insufficient, meaning that the burden falls on existing citizen-volunteer organizations. This inadequacy will be addressed thoroughly. However, the context given here is of the present time, therefore not explaining the institutions and their relationships towards PWD during, for example 1970s or 1980s, when some of the interviewees were diagnosed. Interviewees' life stories will be of most help for understanding the relationships from that time.

In the most general sense, any kind of discrimination towards individuals is forbidden by the Constitution of the Republic of Serbia (*Ustav Republike Srbije* 2006). Legal status of PWD is not established in a more specific sense, as diabetes is not classified as a disability in

Serbia. The specific classification of PWD is dependent on institutions alone, meaning, if a certain institution has rules for people with chronic conditions, they should implement affirmative measures, or positive discrimination to the cases of those individuals with diabetes.

3.1 Educational institutions' stances towards people with diabetes

Educational institutions, although supposed to diminish the effects of stigmatization during the period of socialization, often do quite the opposite. The law does not oblige kindergarten headmasters and teachers to take care of children with diabetes (*Uredba o Zdravstvenoj Zaštiti Žena, Dece, Školske Dece i Studenata: 49/1995-1816* 1995). It is thus left upon their good will whether they will let a child with diabetes into the group or not. In other words, informal testimonies of parents of children with diabetes who live in Serbia (obtained through Facebook groups of my organization for a practicum class) show that kindergarten children are often stigmatized and marginalized as a result of difficulties in "training" teachers to provide adequate care. Although throughout my socialization, I thought it was normal that I had fantastic teachers in kindergarten who knew me a year before diagnosis and devoted themselves to diabetes completely afterwards, it seems that my experience was an anomaly. While people with T1D in general are not classified as disabled in Serbia, as mentioned above, children with T1D are classified as having development impediments (Mitić 2011). However, they do not receive any kind of care or treatment directed to help their parents, who often have to come to kindergartens during breaks and treat their child's diabetes, therefore being in danger of, or in actuality, losing their employment. The issue then is the broader structural framework which does not address the particular needs of those with diabetes. If observed from an institutional perspective, it appears that there is a specific role of a "normal" student, which a child with diabetes does not always fulfill, and which can have an effect on the child internalizing stigma and self-stigmatizing itself. The question that arises is this: can the kindergarten or school as an institution be changed in order to fully accept a child with diabetes? The only way that is currently being done is by special training of teachers at hospitals, which is completely voluntary and rare.

At school level, children with T1D can feel left out of their peer groups (which can occur later in life as well), are afraid of how their peers might react, behave or talk about diabetes, and whether their condition might affect their academic performances. Many times, they are excluded from social groups because of the stereotype that diabetes is contagious. Studies in India show that children with diabetes are anxious, depressed, unsure of themselves and have a difficulty socializing (Chatterjee and Biswas 2012).

Although no affirmative measures exist for children in kindergartens or schools, they are able to enroll into high school of their choice with a lesser number of points than other students. They are also, via affirmative measures, seen as invalids by the University institutions in Serbia and as such can enroll via a special ranking list, which makes them eligible for free housing in a student dorm (if not from the city where the university is based) ("Stručno uputstvo za sprovođenje upisa u prvu godinu studijskih programa osnovnih i intergrisanih studija na visokoškolskim ustanovama čiji je osnivač Republika Srbija za školsku 2017/2018. godinu," n.d.). After finishing their first academic year, they can sign up for the student stipend of the Republic of Serbia. They are classified in the 'sensitive' group, where they belong as 'chronic patients'. The criteria is much more lenient, as they can get the stipend if they have not lost an academic year, no matter their ECTS number and average grade (*Konkurs Za Dodelu Studentskih Stipendija Studentima Visokoškolskih Ustanova u Republici Srbiji Za Školsku 2019/2020. Godinu* 2019). On the other hand, when I was studying, the criteria for the sensitive group was more strict – needing at least or more than an average grade of 8.5 (out of 10) to qualify for the stipend, indicating a change in recent years.

3.2 Diabetes and workforce

The financial and other arrangements that enable Serbian citizens to participate in the capitalist market presume a certain idea of the ‘normal’. Therefore, certain jobs are forbidden for people with T1D. Those are usually the ones where a person can jeopardize their own or others’ safety due to hypoglycemia, such as: professional truck, train, car, lorry or other drivers, pilots, firefighters etc. Additionally, night shifts are not recommended since they change the usual lifestyle of PWD and can lead to complications. Furthermore, PWD are unfit for military service (“Diabetes and Employment – Getting a Job” 2019)[6]. However, through informal testimonies from people from my organization, I learnt that people with T1D sometimes have problem finding employment, even for the office-work positions. The activists say they are often exclusively disqualified on the basis of their health condition when interviewed.

In order to understand how people with T1D fit inside the labor market, a neo-Foucauldian view of neoliberalism will be used. Power, by Foucault, is seen as “the creation, shaping and utilization of human beings as subjects” (Rose 1989: 2). This means that power exists on micro as well as macro levels, ruling the lives of individuals, holding them in check, guiding them and their actions, making them regulate themselves. Enterprising, calculative, independent, successful individuals are governed by competition on the labor market, but also in school, university, hospitals, family, business and social welfare (Rose 1989). Work is seen as the most important element of self-realization, while health is “ensured through a combination of the market, expertise and a regulated autonomy“ (Rose and Miller 1989, as cited by: Rose 1989: 16). In other words, if an individual is healthy she is also an entrepreneurial self, and vice-versa. Since healthy bodies are seen as a public value and political objective by neoliberalism, where does that leave people with T1D? If their stigma is not

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[6] This information was also available on *Diabeta.net* – the official website of the DAS, however, informational pages are currently under construction and inaccessible, therefore, I am providing information from the biggest UK diabetes-related blog.

visible, they may seem to the public as healthy and act as enterprising individuals, forever hiding their true selves. However, if their stigma is visible, my hypothesis is that they are not accepted as “normal” entrepreneurial selves. In addition to this, I will examine how are people with T1D different and how much do they ‘stray’ from Rose’s definition of entrepreneurial individuals.

3.3 Diabetes and gender roles

Depending on the culture, there is difference in ways of distinguishing male and female bodies, their role in reproduction, cultural attributes of the feminine and masculine (Pine 2007) and finally, gender roles.[7] In Western societies, now less than before, gender roles are traditionally divided into feminine and masculine, assigned to males and females at birth and nurtured throughout socialization and growing up (Siegetsleitner 2006). Masculine is strong, independent, powerful, aggressive etc. Masculine is into politics, sports, economics (Mukhopadhyay, Blumenfield, and Harper 2017). Feminine, on the other hand, is good, emotional, expressive – same as Parsons’ ideal woman; sacrificing, taking care of others. What is considered to be masculine and feminine is defined and controlled by gender regimes. Hughson (2017) defines gender regimes as not only relations between genders as concrete social actors, but a system of power, expectations, roles, behaviour, discourses, visualiation, attitudes and hierarchization of gender differences (and producing gender gaps).

Hughson goes on claiming that, in the semi-peripheral Serbia, women are powerful on the micro level – the private sphere, where they take care of the household, while also being employed. They are, since after the fall of Yugoslavia, strong, sacrificial and wiling to do anything for their country. However, they are also subjects of violence against women and

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[7] A great part of this sub-chapter has been taken from my final paper for *Key Issues in Anthropology* course at CEU.

strong misogyny, due to the crisis in masculinity (happening as a result of men as well as women being a ‘surplus’ in the workforce) (Hughson 2017).

Analogous to other traditional societies, boys and girls in Serbia are also taught specific gender identities and attributes through socialization and popular culture. The gender differences in relation to diabetes and stigma include how the condition is experienced, what is the treatment-seeking behaviour, care, opennes, support and general stance of society on health-related problems (Vlassoff 2007). When boys or men are diagnozed with diabetes, they can develop the attitude to recover from the diagnosis, as one of the traditionally imposed attributes of masculinity is problem solving. In contrast, they are also more likely to hide their diabetes and not let it affect their daily lives, which could be the reason for less experienced stigmatization than girls. On the other hand, girls are more likely to fully adapt their life to diabetes (Charmaz et al. as cited by: Siddiqui, Khan, and Carline 2013), making their diabetes more visible. Thus, they can be stigmatized to a greater extent, as people in their community are aware of their condition, as opposed to boys. Girls and women tend to be more depressed, stressed and anxious than boys and men as their stigma is visible. In addition, “any characteristic that might interfere with men's ability to fulfill that traditional gender role, including being chronically ill, may be perceived by men with diabetes to be a potentially stigmatizing attribute” (Brooks and Roxburgh 1999: 404). That explains why being and staying healthy is very important for men in Serbia, as for 56% of the informants in the *Men in Serbia* study, getting sick is their worst fear (Hughson 2017) which is highly correlated to their gender function of being breadwinners.

3.4 Support towards people with diabetes

Different types of support – informational, emotional, psychological, health-related, educational, are essential for all PWD. Until 2005, state-owned and regulated counseling in primary care units in Serbia was performed by medical specialists such as: diabetologists, cardiologists, surgeons, dietitians etc. Since 2005, the counseling has been stopped because of the law that prevented specialists to continue their work in the primary care units, leaving the heavy burden to general practitioners, who were over-working already and could not provide more services (Popović 2016). PWD started founding their own volunteer organizations to help those in need and provide any kind of support.

3.4.1 Institutional support today

Due to the number of appeals from patient organizations and medical professionals, the Health professional board of the Republic suggested that state-counseling be brought back in 2007. Until 2014, the appeal was not taken under consideration by any of the four Ministers of Health that were on the position (Popović 2016). In 2015, 34 of 40 counseling places were re-opened around the country ("Domovima zdravlja vraćena savetovališta za dijabetes" n.d.). Since then, PWD are able to get proper counseling from medical professionals, however, what these counseling stations often do not offer is psychological and definitely emotional and legal help, empowerment and overall understanding. This exists only in citizen volunteer organizations, such as *PK* in Belgrade.

3.4.2 Alternative support

As a result of complete invisibility of PWD, volunteer patient organizations started emerging around the country in the 2000s, enabling patient's voices to be heard and represented. Those organizations that have no broader political agenda except for fighting for rights of PWD, are under the umbrella of the *Diabetes Association of Serbia* (DAS), a major volunteer organization gathering 13 local organizations from all around Serbia. All organizations deal with representation, awareness activities and public lectures for all citizens, provided by educated activists, doctors, nurses, pharmacists and others.[8]

In 2010, *PK* emerged from the previous *Society for the battling against diabetes of the city of Belgrade* ("O Nama" 2013) and organizes weekly lectures about diabetes, different complications, psychological support, the importance of self-management, counting carbohydrates etc. It is a donations-based organization which participates in all annual healthcare festivals in Belgrade, where they provide information and advice about diabetes and check citizens' blood-sugar. From the data obtained from the president of *PK*, from 2010 until 2018 there were 85 thousand blood-sugars checked, and over a thousand new people diagnosed by the organization at different manifestations. One of the main campaigns of *PK* is the importance of sport, both for people with and without diabetes. The main event is the annual marathon "Blue Circle around Ada lake" the second largest marathon and support race in the last five years in Serbia. *PK* also organizes humanitarian football, basketball and tennis tournaments to raise awareness and gather resources for the organization to continue its work. An important part of *PK* is Plavi kružić (Blue Circlet), a support group for parents of children with T1D, that helps mediate between institutions and individual excluded cases.

In the later parts of the study, it will be clear that *PK* played and still plays a very important role in the lives of people who are its volunteers and activists. *PK* is the reason my interviewees and I know each other and became friends. It is also the reason behind many changes in our individual stances towards diabetes, self-management and advocacy. It is a place of freedom, safety, understanding and family.

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[8] All the information about the DAS and *PK* were available online up until a year ago, when the Association's website started changing and the pages have not been restored, and the web page of *PK* was shut down for some time. Therefore, the information I provide was double checked with the President of the Association and the President of *PK*, before writing it here. However, my references are, therefore, from the knowledge I have, as an activist and patient representative on the local and national level. A very limited amount of information can be found on *PK*'s website: https://www.plavikrug.org/index.php/o-nama.

4 Research questions

The topic and focus of this research are the possible experiences of stigmatization and self-stigmatization of people living with T1D, which leads to the general research question: How are people with T1D in Belgrade stigmatized and self-stigmatized and how do they handle it?

Specific, sub-questions, derived from the main one are the following:

- Which factors of stigma are experienced the most (labeling, discrimination, stereotyping)?
- In which field(s) is the stigma experienced the most (e.g. education, social connections, romantic relationships, employment etc.)?
- How are the effects of stigma and self-stigma determined in relation to expected gender-roles?
- How does the experience of stigma impact self-identity and do self-beliefs constrain the individual’s actions?
- Do the individuals with T1D question the conventions of “healthy” people in Serbia and resist stigma?
- Do people with T1D fit into the concept of neoliberal entrepreneurial subjects?

5 Methodology

The fieldwork included life stories, which demand equal relations of power between the researcher and informant (Megías, García, and Arcos 2017) and autoethnography. The life story approach "emphasizes the experiences of the individual that is how the person copes with society" (Abubakar and Abdullah 2008: 2), through "stories of ordinary people living out their lives within wider political and social contexts, and whose lives are "moulded by policies, structures, prevailing beliefs and attitudes" (Bathmaker and Harnett 2010: 165). It allows the interviewee's voices to be heard in a way they choose and feel comfortable to do so. Life story interviews also paint a picture of individual's identity and changes that happen through their life, as well as the factors that influence them. Since the stories alone are subjective, they will get complete meaning through my interpretation and analysis (Atkinson 2001).

Autoethnography, although often criticized for being too non-academic, trivial and subjective, is highly cathartic, truth-telling and healing (Giorgio 2013). I found autoethnography to be a very important addition to the life story interviews because of a number of reasons: with doing autoethnography, we embrace vulnerability, disrupt taboos and, most importantly, "reclaim lost and disregarded voices" (Adams, Holman Jones, and Ellis 2015: 36); we go beyond academy and become activists (Doty 2010) or, in my case, already are activists and are only strengthening our existing positions. Writers are a part of their work always, however, some are a part of their work more than others. I believe I fit into the second group. Autoethnography "wants the reader to care, to feel, to empathize, and to do something, to act" (Ellis and Bochner 2006, as cited by: Giorgio 2013: 470). It fills a gap in the existing research on the topic, it shows how objective can subjective experiences actually be. It breaks stigma.

On another note, given the fact that I myself have been living with T1D since the age of five and am an activist in *PK*, the *DAS*, as well as a European and global youth patient advocate for *International Diabetes Federation*, I have a so-called ‘halfie position’, meaning that at the same time, I am a researcher as well as a part of the community I am researching. I cannot be only one with the people I call a second family. As Abu-Lughod writes – halfies write for and answer to multiple communities (Subedi 2006). And again, the great part of being a ‘halfie’ lies in the fact that there is less (or in my case, from the way I see it, no) power relation between me and the informants. Because of my halfie position, I have a double consciousness – as an insider and an outsider (academic) at the same time.

5.1 Interviewees

The units of research are people who live in Belgrade, have T1D since childhood or adolescence, are over 18 years old and are volunteers/activists of the organization *PK*. This means that the results of the study will only be interpreted and connected with a certain group of people, more knowledgeable about their condition, and not the society’s average. They are perceived as agents of their own lives, whose life stories shape their individual identities. Most of them occupy the lower or upper middle-strata, therefore analysis will not tackle with class differences in stigma experience and perception.

During the interviews, my interviewees and I constructed the meaning of certain situations and experiences together (Devault 1990), without misunderstanding and set-backs. While talking to the informants, if an idea that connected their experience to mine arose, I wrote it down as part of my autoethnography. I compared my experience in certain fields to those of the informant and thought about why we had some differences or similarities.

Excluding myself, there are nine interviewees, out of which six are female and three male. Their names have been changed. All except one interviewee have achieved at least a BA level of higher education, and all except two – me and the youngest, Goran, who is a student, are employed. Two female interviewees are married and one of them has two children, while four interviewees and I have romantic partners. All of the interviewees who were born in cities other than Belgrade, moved there for higher education (and one because of the war in Bosnia) and continue to live in Belgrade.

Table 1. General information

Name	**Gender**	**Age**	**Age at diagnosis**	**Place of birth**	**Education**	**Employment**	**Marrital status**
Simonida	F	50	5,5	Belgrade	BA diploma	journalist, company manager	/
Mirko	M	37	12	Belgrade	Applied studies College diploma	IT programmer	relationship with a person with T1D
Biljana	F	42	11	Belgrade	Highschool diploma	hostel owner	/
Andrej	M	31	8	Stara Pazova	BA diploma	journalist, sports commentator, TV editor	relationship
Goran	M	23	13	Zaječar	BA diploma	/	/
Lea	F	30	7	Požarevac	PhD student	DNA scientist	married, pregnant
Nela	F	34	5	Belgrade	BA diploma	PR manager	relationship
Andrea	F	24	8	Belgrade	BA diploma	call center agent, folklore teacher	relationship
Sara	F	36	4	Sarajevo	BA diploma	co-owner of car mechanics shop	married, has two children
J.F.	F	24	5	Belgrade	BA diploma	/	relationship

6 Analysis of life story interviews

Generally speaking, all interviewees were familiar with a broader concept of stigma, or more often discrimination as its factor. All but one of them were labeled, or made fun of in primary or secondary school. Only one interviewee, Sara, had a highly manifested self-stigma, while shorter instances of self-stigma were experienced and overcome, by other interviewees as well. Only one interviewee, Andrea, found trouble talking about a stigmatizing experience, being on the verge of tears, while I tried to ask more about that period of her life.

All of the interviewees now possess high levels of resistance, therefore leading certain path-dependent lives. Due to the interesting and various trajectories of resistance the interviewees have taken since diagnosis until present time, I have categorized them, as well as myself, in six different types and created descriptive names for them. The types wary – from complete resistance towards stigma from the moment of their diagnosis until today, to those who experienced high levels of stigma and self-stigma at the beginning of their trajectories, while resisting it more and more over time. Type one are *leaders* – those who had high levels of resistance from the start, had a certain attitude on stigma and talked back. Biljana and Andrej are leaders and, curiously enough, they also have high positions in *PK* and the DAS. Biljana was diagnosed with vitiligo[9] before getting diabetes, therefore learning how to fight a different type of stigma first. She was encouraged to fight back by her mother and, although experiencing stigma over time, her attitude towards stigma and high level of resistance have not changed. She used diabetes for her gains while growing up. Andrej did the same thing, however not only while growing up, but also in the present. He has a very strong opinion about how much stigma can impact a person's life and can therefore understand why they would hide their stigmatizing attributes. Mirko is a *warrior*, a type or resistor with an (intense) experience that set him back,

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[9] A chronic condition of skin depigmentation. For more information, see: https://www.nhs.uk/conditions/vitiligo/.

although having an attitude towards stigma and defying it. The third type are *subtle warriors*, Nela and Lea, who did resist stigma throughout time, however, not always confronting directly the source, but finding other channels of reaction. Goran is a *neutral* – having experienced no cases of stigma. Fourth type are *pioneers* – Simonida and myself who, although experiencing a certain level of stigma and set-backs, overcame them and used the knowledge and experience to impact lives of PWD. Simonida created the first Serbian website for PWD and became a highly respected person in the field, while I am hoping to become a researcher in the field of stigma and health. Finally, the last type are *climbers*, who achieved something unbelievable – went from an extensive amount of stigma and self-stigma, to high resistance levels. The types are created from my impressions and knowledge about the interviewees at interviews, their experience, thoughts and emotions, making them highly normative.

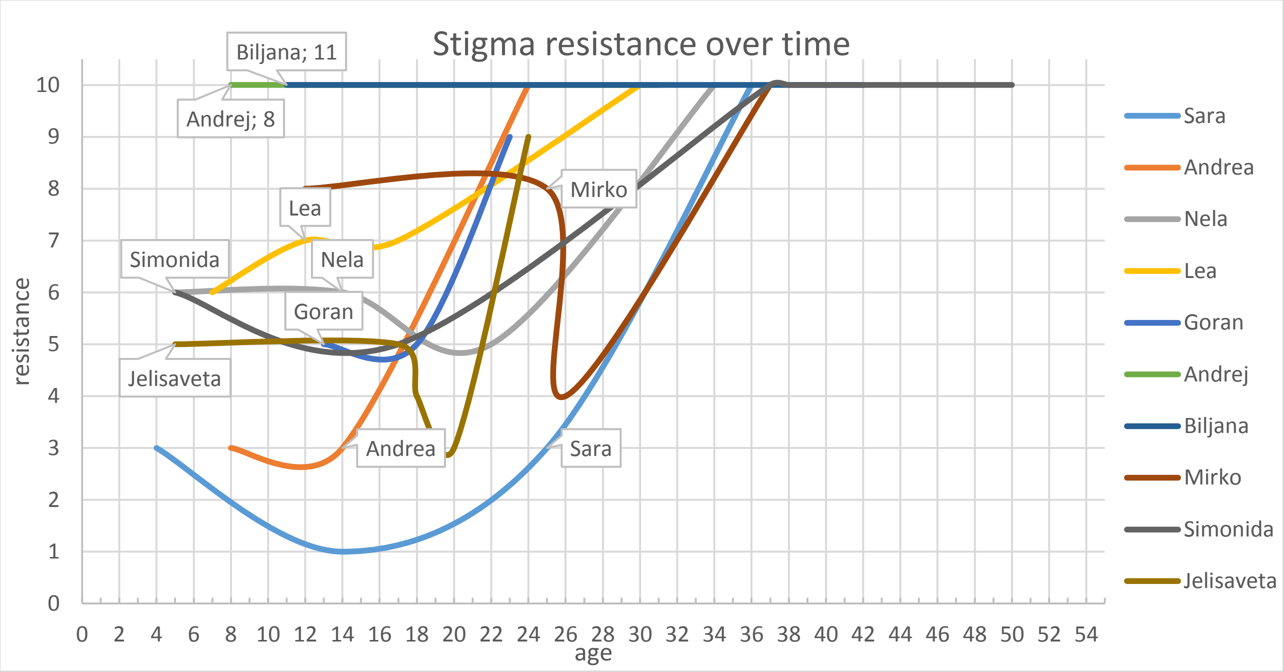
Table 2. Types of resistors

Type of resistant	**Characteristics**	**Name**
leader	high levels of resistance from the start, attitude on stigma and talked back, positions	Biljana Andrej
warrior	an attitude towards labeling one experience setting back	Mirko
subtle warrior	resistance to stigma not always confronting directly the source	Nela Lea
neutral	no stigma	Goran
pioneer	stigma overcoming and achieving in the field of diabetes	Simonida J.F.
climber	from extensive stigma to resistance	Andrea Sara

The below-shown graph helps to envisage six types of resistors by tracing trajectories of interviewees' resistance to self-stigma from the age at diagnosis until present time. Number

0 on the vertical axis presents complete self-stigma, 5 is neutral, while 10 is complete resistance. The level of resistance is measured by how much support the interviewees had upon diagnosis from family, friends and the community, as well as their experiences. These levels are assigned by me and are normative, extracted from the life story interviews.

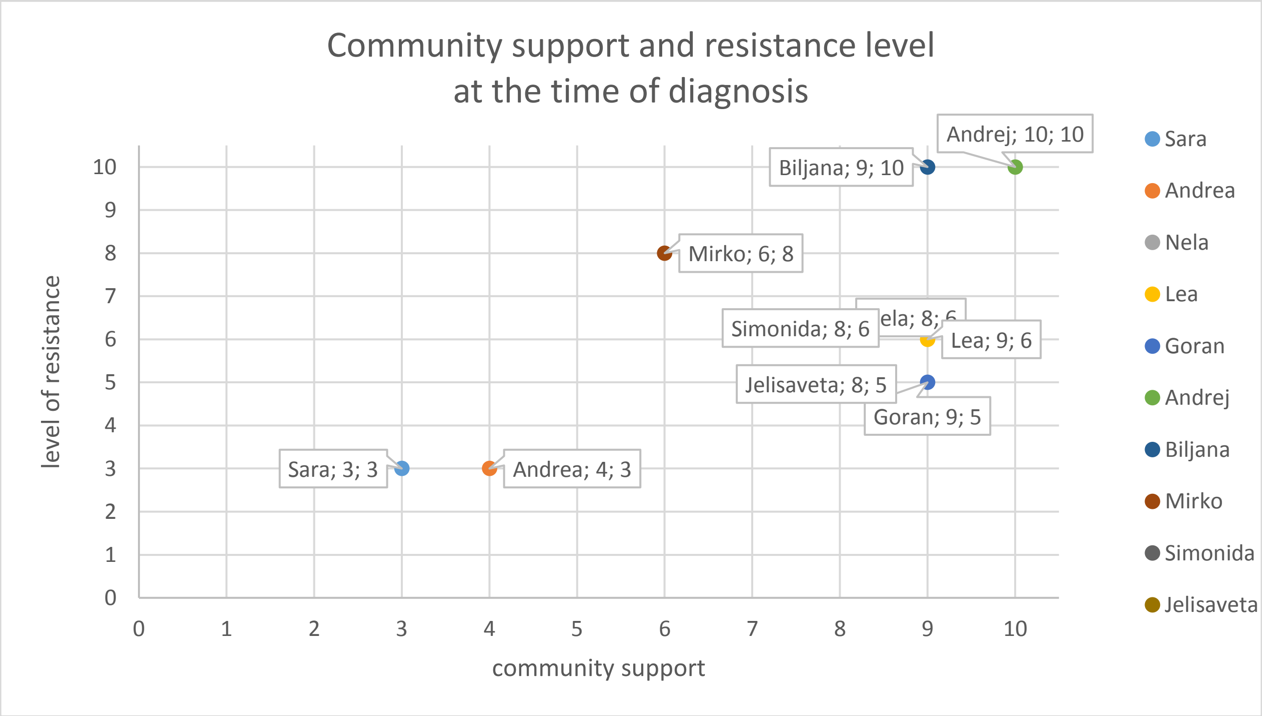
Graph 1. Stigma resistance over time



What is visible at the first glance is that, although having very different starting points with regard to the level of resistance, all of the interviewees at the present time have high levels of resistance - either 9 or 10. This is due to the often repeated feeling of contempt and understanding that the interviewees (and me) felt once they met other PWD (in *PK*), influencing their empowerment and rise of self-esteem. As *leaders*, Andrej and Biljana completely resisted stigma since diagnosis even before joining *PK*, either because of the overwhelming community support in Andrej's case or because of the earlier experience with stigma in Biljana's case. The *warrior* Mirko had a higher than neutral position towards resistance, however, an experience of discrimination at a job interview set him back for a little while, after which he came to the organization and not only returned, but raised his resistance level. Nela and Lea had very similar starting points, with a high level of support at the beginning, however both dropped on the resistance-level axe during teenage or young adult periods. Namely, having started attending high-school, university or having romantic relationships in that period, they increasingly experienced stigmatizing situations. Goran has had the value of five on the self-stigma resistance scale, which is valued as neutral, same as his type. After coming to the organization, thus altering his community-support, his level has risen. Simonida and I had similar levels of resistance at the beginning, same age of diagnosis. However, as she is 25 years older than me, meaning that she grew up in different period, her first 20 years with diabetes were much less visible than mine. It took more time for her to develop higher levels of resistance than me, presumably because she had no one with diabetes in her life in those years.

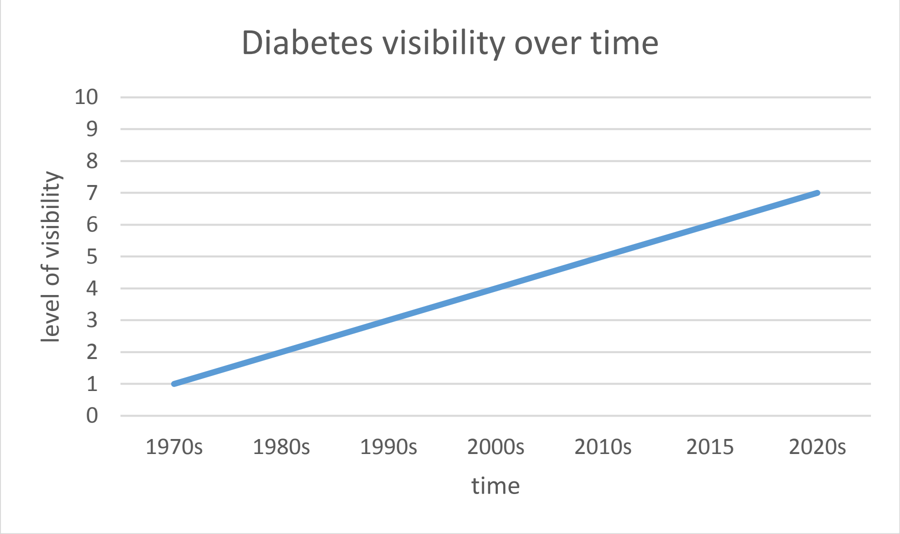
On the second graph, a micro-look of Graph 1. lines' starting points shows the amount of community support interviewees had individually (normatively measured) at the moment of diagnosis. Again, the numbers are induced from the life story interviews.

Graph 2. Community support and resistance level at the time of diagnosis



In addition to the certain amount of support, an important aspect of diabetes–related stigma is its visibility. Graph number 3. shows an overview of the visibility of diabetes in Serbia, with regards to medical aid available and used at a certain point in time.

Graph 3. Diabetes visibility in Serbia over time



The time frame shown on the graph depicts the period from the diagnosis of the oldest interviewee, Simonida, until present times. The level of visibility of T1D is highly important as it helps or minimizes stigma. During the period from 1970s until 1980s, the type of insulin used was still of animal kind, which did not induce many hypoglycemias, was injected twice per day (morning and evening) via glass syringes and there were no blood sugar meters, only at-home urine tests. The insulin taken in the morning and evening contributed to the non-visibility of diabetes for Simonida at the time. In the 1990s, humane insulin was invented and used, which causes more hypoglycemia, and thus have an effect on diabetes-related visible stigma. However, as Yugoslavia was under international trade sanctions in 1990s, those interviewees already diagnosed at the time (Simonida, Biljana, Lea, Mirko, Sara) used any kind of medical aid available from distant relatives or friends from Europe, as there was hardly any or, at certain points in time - no insulin in Serbia. In the 2000s, the interviewees had blood sugar meters, some used pens, some plastic syringes, while insulin pumps were also introduced. In 2015, first flash glucose monitors were invented for use, but are not available in Serbia until the present day. Thus, as they are available in almost all other European countries, people from Serbia acquire them from there. Along with the meter, pens or pumps, sensors too contributed to the higher visibility of T1D.

Having introduced firstly the types of resistors, then effects of community support and over-time condition's visibility on interviewees' levels of stigmatization, the following sub-chapters of the analysis will give answers to the main and sub-questions of the research. The analysis will include sub-chapters on different types of stigmatizing experiences and interviewees resistance against it, points on stigma and gender, self-identity and finally and how people with T1D fit into the neoliberal entrepreneurial life.

6.1 Stigmatizing experience

As stated in the theoretical and conceptual framework, life stories are analyzed through the concept of stigma (where labeling, stereotyping and discrimination occur) in relation to the visible stigmatizing or discrediting attributes of diabetes. Attributes include: the dependence on medication (insulin) that has to be injected through an insulin pen/pump several times per day; frequent monitoring of blood sugar glucose levels, performed by pricking a finger/using a sensor; symptoms of light or heavy episodes of hypoglycemia. Labeling, stereotyping and discrimination have been experienced by all but one interviewee. All of the factors, as well as the resistance towards them will be analyzed separately (except in cases where more than one have occurred) in order to create a more truthful picture of the experience. They will be shown chronologically and by types of resistors.

6.1.1 Labeling and resistance to it

Our physical appearance makes people give us certain comments – young, pretty, bright, healthy, lively... They have a hard time believing someone so young and healthy-looking can have diabetes. My interviewees and I have been in these kinds of situations and conversations numerous times. Many of them, when getting frustrated with people being surprised responded with: *well does it say that I have diabetes on my forehead?!* In the lives of people with T1D, labeling was manifested in the following name-calling: drug addict, druggie and other slang names of the same meaning, alcoholic, sick child, sick person and *šećeraš/ica,* (a pejorative name not seen as such by the general public) in Serbian meaning ~ sugary person. Experience of labeling differs in relation to the level visibility of diabetes, or to the medical devices and aid interviewees use.

Most experiences of labeling happened to *subtle warriors*, while less to the *warrior* and *pioneers*. *Leaders* and *neutral* did not put so much emphasis on it in the interviews, while *climbers* experienced labeling in combination with other factors (as will be shown later). The *subtle warriors* – Lea and Nela have been called *šećerašica* and sick in primary school, which made them angry and hurting, however, did not leave a permanent or long-lasting effect. Nela said: *I did feel bad in a sense that I'm different from other children, because every difference causes a distraction. And I was being put into some frames of a person who is sick, which I'm not...I mean I'm not, fuck it, I have a problem.*

In high school, Lea experienced labeling again. Lea's teacher told her class: *it's sad that parents let a sick child go to school, so I was shaken again* [thinking about the labeling in primary school]*, it was really hard for me, I still remember. And I went to the principal and psychologist and it ended with a schooling of that professor after which there were no more comments. I don't think we changed him but he didn't speak like that again*. She experienced labeling in a way close to what Parsons wrote regarding the sick role. As Lea did not fulfill one of the institutional expectations of being free from her previous role (Kecmanović 1978), meaning, she continued to be a (sickles) high school student, she was labeled and stigmatized by her professor. This experience lowered her resistance levels for a shorter period of time.

Finally, a few years ago, while in the primary care unit waiting room, Lea was called a *šećerašica* again, when she was not only labeled, but also stereotyped – about being nervous: *One nurse told me in a hospital: Oooh, so you are a šećeraš – which is the worst label for a person with diabetes for me. – You šećeraši* [plural] *are nervous, I know, my husband is also a šećeraš, come on, don't be nervous, we'll get you in next, you don't have to wait. And I mean it was cute because she wanted to help but I really do become a nervous šećeraš when they say something like that to me.*

Although not directly handling stigma on her own, the *subtle warrior* did take certain steps towards resistance, which became stronger throughout years. The last instance of labeling only made her laugh. The subtle warriors did not use the coping model of resistance, however, neither did they always use the empowerment model as categorized by Shih (2004). They did fight back, without creating a positive stigma for themselves, until joining *PK.*

Subtle warriors' experience is further emphasized by looking at a contrasting experience of a *leader* and an example of *pioneer* with lesser effects. For Andrej, a *leader*, nothing changed in school after his diagnosis: *I was a favorite in community...*[diabetes] *only contributed to me being more special ... Up until a year ago, I made you all laugh, but now that I'm sick, the teacher can't lecture me on anything. Being called a poor thing, I knew how to take advantage of. I was smeared for those situations.* This *leader* used the empowerment model as an active participant in the society who turned his visible stigma into a positive one.

I, unlike Andrej, was not a person everyone wanted to be friends with and did not have a high level of self-esteem. When I was 17, I asked one of the school teachers, with whom I have had a good understanding, why he smokes so many cigarettes and is there a way to smoke less. Before having the time to respond, my good friend jumped in and asked me, without expecting an answer: "Oh I'm sorry, can you start taking less insulin? Oh, right, you can't because you'll die". I did not confront her, but only told my close friend, who argued with her later on. Even though it hurt in the beginning, I did not care later on. In short, I mostly used coping mechanism against stigma up until a few years ago.

6.1.2 Stereotypes and resistance to it

Link and Phelan describe stereotypes as undesirable characteristics (Link and Phelan 2001) that are applied to a person by those of the dominant value system. Lived experiences of stereotyping did not have a noticeable impact on interviewees and did not lead to self-stigmatization. It seems that this factor is the lightest of the three. Stereotypes such as being told they must not eat sugar, they should be obese, older and that they are contagious, have mostly irritated the interviewees, who often responded with curse words or doing the complete opposite, to spite the stigmatizers and create positive stigma, through the resistance model of empowerment.

Although my life with diabetes had a good start, as the money needed to buy my first blood sugar meter was collected by the parents from my kindergarten and my teachers were ready to take care of me and accepted the new situation, there was one bad experience. Namely, a grandparent of one of the children in my group approached my mother soon after I came back to kindergarten telling her that she has to withdraw me from the group. She said I will infect other children and that she had no intention of keeping her granddaughter in my group. My mother, was furious and shaken. She realized that our lives will be changed forever, that not only she had to start giving injections at least four times per day to her five-year old’s little body, but also that someone did not want me near their child. However, as I have found out about this only a few years ago, it had no impact on the level of my resistance during childhood.

As *leaders*, Andrej and Biljana were ready to fight back directly when being stereotyped in primary school, through the resistance model of empowerment. Biljana described a situation that left a mark on her as it was a time her mother taught her how to fight back: *Once, one woman pitied me, and the fact that I was eating a sandwich, like, I can't eat sweets. And my mom was with me and I think that was her test for me, to see how I will behave and defend. And mom was tough, especially when there was injustice and things like that, she poked people's eyes out. When the woman told me „poor you“, a volcano erupted inside me. Why am I poor? Am I missing something? I do everything others do so I am not poor, and mom said: That's the way, tsar* [a name for someone really cool, good etc.]. *And the woman said she was sorry.*

Andrej reacted to stereotypes by doing the exact opposite of what people told him he can or cannot do: *'Till today it gets on my nerves, that behavior. I would love to slap those people and not say anything because I am probably sick and tired of explaining again and again.* Both *leaders* resisted subordination of docile bodies by being knowledgeable on the stereotypes they were called. They used their knowledge as power to resist stigma. Nevertheless, Andrej noticed that stereotyping affects other PWD, who do not have such high level of resistance to fight back, leading to them hiding diabetes.

6.1.3 Discrimination and resistance to it

Discrimination was, along with labeling, the most frequently experienced factor of stigma, however, it left a much greater impact on interviewees than labeling or stereotyping did. Most of them experienced discrimination at different levels of education and when applying for employment. Seven interviewees (and I) experienced some level of discrimination, while Andrea – a *climber* was the only person with continuing discrimination all throughout primary school, from classmates as well as teachers, who bullied her, labeled her and restricted her actions. She adopted the coping mechanism of resistance, trying to avoid negative consequences. She describes one example: *I had a situation where a teacher didn't let me go to a shop to buy juice when I was low, 2,5 and I had nothing in my backpack. She* *argued with me and didn't believe so I left the class and that was it. So, I had no support from her. And there were no changes in how others behaved, it was even worse. ... Simply, I carry a very hard and painful experience from primary school.* Fortunately, she had no such experience in high school or any time after, which made her progress towards resistance faster.

An equally troubling experience happened to *pioneer* Simonida who, although she was not discriminated against during almost all of primary school, did have troubles in second and third year of high school. Her teachers showed no understanding for her situation*: I got dangerously stuck, I had dangerous complications with open wounds on my legs* [from bad diabetes management and animal insulin]*, I spent a lot of time in hospital, I didn't get final grades in many classes and, so, I was either not graded or got an F, and then I found, I mean my mom found a scheme in a school in Zvezdara* [different municipality] *for me to take all exams in August so I passed all classes with D's.* Although the discrimination she endured had an effect on her grades and education, it did not leave long-lasting effects on her identity.

A similar case of discrimination happened to Nela, when a University professor did not believe she was feeling unwell because of a hypoglycemia and told her not to fake it because she did not learn enough for the exam. Her father interfered and she was given a second chance, however, it left an impact: *After that, everyone apologized but I didn't feel better because it was injustice. I was glad they felt bad and I wanted them to suffer.* The *subtle warrior* felt that, after trying to talk to the professor about her condition and being ignored, the only channel of action was through her father – an obvious authority and a body with knowledge and power.

My experience also involved ignorance which produced discrimination. Namely, when I was signing up for the entry exam at my undergraduate University, I reported that I have an insulin pump that functions on radio waves, as I know radio-wave stoppers are used to end any kind of cheating via machines. The personnel probably got scared and thought the best option for me is to take the exam in the disabled persons' room, where no stoppers are used. I have never identified as a disabled person, as I am, by definition, able-bodied, no matter how much diabetes affects me mentally. I called my aunt, a professor, who organized a meeting for me with the three pro-rectors. I was scared but found the strength to speak for myself and demand what I thought was right. The pro-rectors agreed with me. It was the first time I directly fought back and with people I was scared of and implemented the empowerment model of resistance.

In the context of workplace and job interviews, Sara, Biljana and Mirko, different resistors, experienced discrimination. Sara was supposed to receive her first paycheck at her first job, but the boss told her she could not achieve what others did due to diabetes, which is why she did not deserve it. She said: *he used my naivety, age and the fact that I was an obedient child. ... And I was sorry that was my first job and first experience. After that, I toughened up and didn't let someone say something like that and worked a lot more than others* [like a true *climber*, who started embracing the empowerment model of resistance].

At Biljana's first job, after three years of working there, someone attributed her behavior to diabetes: *That was the first time I felt done. I racketeered so many curse words and everything. Because I was organizing everything there alone. And there was some problem, someone made a mistake, misread the program and the plan and for them it was my fault. And I told them so many things.* Afterwards, she quit.

Mirko experienced his first set-back at a job interview, more than ten years ago and I learned from Biljana it left an impact on his self-esteem as he stopped applying sometime after that. Mirko recalled: *...it was a long time ago, before PK, before life experiences, if something like that happened today I would be rich cause I would sue them, I would injure them. I passed the first round, at the interview everything nice, I was told there might be shorter trips inside the country. The psychologist asked if traveling is a problem, I said no, but if I could be told a day earlier because I have a need for a cooked lunch. –Why? – I have diabetes. But traveling is not a problem, I have a valid driver-license. And the woman starts raising her voice: Why* *didn't you write that on your CV?! –I asked what difference does it make, it doesn't affect my professionalism. She insisted I had to write it. I asked if we could go to the next question. – No. And she ended the interview and that was it. That was, I can freely say, the only ugly situation regarding diabetes. After that, I sometimes did, sometimes didn't write that I have diabetes. Now, every time I go to an interview I ask if they are recording.* From his own words, we can understand how much the organization meant to him and his resistance development. At the time, he did not possess enough knowledge to adopt the empowerment model of resistance, therefore behaving as a docile body. Mirko's case greatly presents what I wish to emphasize with regard to re-organization and re-distribution of power towards people with T1D. The power to resist stigma is gained through possessing and demonstrating knowledge, which Mirko lacked more than ten years ago. After gaining it, he would whole-heartedly resist discrimination with his knowledge.

6.2 Self-stigma and transformation to resistance

Self-stigma is defined by the internalization of discredited stigma, leading to negative attitudes of individuals towards themselves. It played a significant role in the lives of the *climbers* – Andrea and Sara who had negative experiences with stigma regarding diabetes from the start, which resulted in them hiding it while checking blood-sugar and giving insulin, or treating a low while also impacting their mental health. The visible stigma that led to them being discredited, was experienced through bullying, name-calling, isolation from peers, for which they used the coping model of resistance of hiding and self-stigmatizing. However, some interviewees, along with myself, although not having stigmatizing experiences from the start, still hid at certain points in life, because of the fear of potential discredited stigma. The crucial factor of overcoming self-stigma for all was meeting other PWD, which helped them develop the resistance model of empowerment.

The most by-the-book example of self-stigma was *climber* Sara's. When the war in Sarajevo started in the 1990s, she moved to Belgrade and started first grade. The teachers as well as classmates were informed about diabetes. The classmates stigmatized her by calling her names, acting as if she were contagious, not wanting to play with her or share school supplies. This led to her making a decision to, when she moved to another part of Belgrade and went into 5th grade, stay silent about diabetes. Her mother respected her wishes and only the head teacher of her class knew. Sara used the coping model of resistance against stigma by completely hiding diabetes, which could have led to serious life-threatening state. For the period from the fifth until eighth grade, she said: *So, I was living through personal traumas at the time, I wasn't bullied by kids, which was good enough for me, and I loved studying and being better than others. But then there were situations where I studied and wanted to get a grade for oral exam and I was going low, and I can't tell it to anyone. So I ate candy or juice while hiding it the best I can, and then continue the exam. I feel bad about it looking from this perspective, but in that moment, it was the best decision.*

High school was different for Sara as she had two other girls with diabetes in class, who were very open about it, however, she never felt like she could fit in with them. Therefore, in 2009, everything changed when she met Biljana [interviewee] after getting an insulin pump. Sara commented: *And she, with her attitude and stories, it meant a lot. The attitude that nothing can touch her. And so the organization was founded, that was a turning point for me. And meeting more PWD. And there, I really started to change, in my attitude towards myself, health. ...The organization means so much to me, where people talk normally about it* [diabetes].

I can completely relate to what Sara said about the organization. I was in my last year of high school when I came to *PK*. Since then, I have, gradually, developed self-confidence and had less of a problem to speak up about my health condition. Male interviewees never mentioned having fears for their looks for wearing an insulin pump, while Nela and I did. We both felt embarrassed for having something ‘medical’ on our waste, for everyone to see and judge. Will someone think I am gross? Nela told herself she must not feel that way: *Of what do I have to be embarrassed? And I was like: You can’t feel that ever again. And your friends should be proud, all the things I do while I have 10 hypoglycemia’s.*

For me, it was a much longer process of acceptance, concluded thanks to the organization. I stopped hiding my insulin pump, and even wear a pink skin over it as a fashion statement. In the end, my insulin pump turns out to be a great conversation starter.

Leader Andrej, who never experienced self-stigma, told me what he thinks about hiding: *I secretly wanted some cafe, restaurant to come to my table and say: Oh you can’t do that here* [meaning give insulin], *so that I can sue them and take a lot of money, like some woman did here in Mc Donald’s, but it never happened to me, no matter how often I went to that Mc* (laughs).

6.3 Friendships, romantic relationships and gender roles

Although some of the interviewees had experienced the loss of a friend because of diabetes, stigma was, to a much greater extent experienced in romantic relationships, directly or indirectly, from partners themselves, their friends or members of family.

With regards to friendships, only female interviewees experienced stigma. Namely, *climber* Andrea says she does not want to hear from anyone from school, because of the bad memories they caused her. Another *climber,* Sara, stopped being best friend with one girl in seventh grade: *my best friend liked one boy, and I guess he liked me, not her. And she told him about my diabetes. And he told me about that, saying: just so you know what kind of a friend you have. And we weren’t best friends anymore. I was really hurt but I was glad he was honest.* Despite being a *leader*, Biljana lost a friend in primary school too. She explained: *she* [friend] *told me her mom told her not to be friends with me because of diabetes and vitiligo. I had no* *intention to speak to her ever again.* However, as seen before, *leader* Andrej was a favorite among his friends, so much that his best friend explained to his mother in fifth grade how he will take care of him and his diabetes during a school trip to the seaside. This contrasting experience with friendships within *leader* type of resistors hints at gender being a crucial factor in the experiences regarding the private sphere.

Stigma in romantic relationships further supports that claim, as it happened to five women (including me) while only one male informant, Mirko, had a discriminatory experience on a first date. The women experienced discrimination, stereotyping and labeling from partners' parents and friends, not partners directly.

As my situation was somewhere in between, I will introduce this aspect with my own experience of stigma in a romantic relationship. Namely, when I found out I got 'awarded' with an insulin pump from the state in late 2013, I asked my then-boyfriend: *Will you still find me attractive now that I have an insulin pump stuck to my body?* Instead of being happy and crying happy tears for getting the best medical aid for T1D, I cried because I was afraid my boyfriend will not accept me with an additional thing stuck to my body all the time. I think he never truly accepted my diabetes and in fact wanted to change my behavior towards it. My fear was not baseless as in a study of the *American Society of Clinical Oncology* it was stated that depending on the health condition, men are five to ten times more likely to leave their partners than women, to what Michele Lent Hirsch added: "The way our culture demands that women be nubile and gyrating and luscious and fertile makes any hint of physical health issues – hint of moving toward death – a trigger for disgust." (Hirsch 2018: 7, 35).

When she was younger, *climber* Sara ended all her relationships first and, as she put it: *made a Chinese wall of isolation around* [her], *because of diabetes.* Then, with her husband, she decided to get married after being together for two months, which made her husband's family doubt her intentions: *his aunt was like: what do you need her for, so many girls, you* *could've chosen a healthy one to marry. And he said: look, she's healthy here* (pointing towards head) *and the fact her pancreas isn't great is not horrible. And my side of the family also said things like: Oh look, Sara got married, but healthy girls didn't. I look at all those things like this: ... A statement can either kill you or make you stronger.* It was one of those situations that indeed made her stronger and more resistant to stigma.

Mothers have a great influence on their children, at least in the stigmatizing experiences of *subtle warriors* Nela and Lea, as well as *leader* Biljana. Nela and Lea were very hurt by the situations they were in, while Biljana overcame it fast, same as other things in her life. Nela was 20 and started dating a guy from her building, whose mother loved her up until the point they began seeing each other romantically. Nela explained: *As he started talking more about me, his mom started influencing him to calm down. We grew distant, because of her ... And we lost touch ... I couldn't believe it all happened because of THAT. And when he came back we met, and I told him: I know this all started and was so stupid because of your mom. I was saying that and looking him in the eyes. He put his head down. – And to me, it's a problem that you didn't tell me. So his mom definitely had an influence on the relationship. And from the point of view of parents it's justified.* However, if looking from the point of view of partners, Nela says: *when someone is so important to you and you love him that much, to them it's not a burden because they want you to be well like we want that for them.*

Lea had a much more intense experience with an ex-boyfriend and his parents who did not accept her diabetes. She stated: *To them, it was unacceptable and horrible. And I know some of his friends talked how great he is because he's with someone who has the sugar. But when he told me all that, that he hid my diabetes from them for some time, it was devastating for me and the first time I dealt with that kind of discrimination – that someone writes me off and didn't even see me, because for all those years of our relationship I didn't meet them. That was horrible to me and I really felt it.* Having gained experience from this relationship, she was very honest with her husband, and asked him if he will accept diabetes fully, or if not, she would not bother being with him.

Leader Biljana, although being a very healthy influence on her ex-boyfriend who started exercising daily and eating vegetarian food, did not know he had a protective mother, who thought that, as she put it: *for her child, it was horrible not to have a family, not to have a descendant. And that was indirect, I mean, I felt that as I talked to him. And he said: she can talk whatever she wants, but I'm interested in you as yourself. And when we terminated the pregnancy, I was more important to him than the abortion and my health.*[10]

The only person that, again, used diabetes for his gains with girls, was *leader* Andrej. He said he would hit on girls in cafes: *I liked to give myself insulin in cafes on purpose. And often I frightened some girls. I turn to them and stab a needle in my stomach and they pay the bill and run away. And if they stay, weeeell then we're in game.* He also used it while being in relationships: *I knew how to act out in some situations, like: "Why did you yell at me?"* [imitating his girlfriend] – *Weell, fuck it, my sugar was high. And my sugar was four* [a very good level]. *So it* [diabetes] *was my ally.* With the experience he provided and his general stance, Andrej completely fits into the gender regime picture of masculinity – he is independent, strong and assertive.

It seems that the heteronormative culture played a decisive role in the lives of female interviewees, who are expected to be the carers – girlfriends, wives, mothers, however, not expected to be 'sick', which makes them inadequate to fulfill these roles. It seems as if women with T1D are excluded from the ideal of strong, sacrificial women in the semi-periphery. It is interesting to mention that one of the ways of getting an insulin pump for women in Serbia from the state healthcare system, is to *wish* to get pregnant. Does that mean that the state is not

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[10] Biljana did not know she was pregnant, it was not planned and because of the complications from diabetes she had at the time, the doctors decided she needed an abortion, as her life would be threatened with a pregnancy.

stigmatizing women with diabetes as long as they fullfill their role, even though society is? As family is the most important value for both men and women in Serbia (Hughson, 2017), should not they be equally stigmatized? Or is the current situation the result of men being looked down upon less than women in a patriarchal society? Perhaps the answer lies in the fact that, although relations between men and women are more egalitarian than before, it is still expected from a woman to be the sole carer in the family, where, if she also has to take care of herself, she is not good enough to take care of others as well, and is, therefore, stigmatized.

6.4 Stigma and self-identity

Does the experience of stigma impact self-identity, that is, how they see themselves? As seen in the chapters on the experiences my interviewees and I had with labeling, stereotyping and discrimination, stigma did have an impact on some of the interviewees. Stigma effected both those whose levels of resistance towards stigma were not high enough, as well as Mirko, who had high levels of resistance, even though he was completely derailed by the experience.

Afterwards, do self-beliefs constrain an individual's actions? None of the interviewees subjugated to Parsons' 'sick role', however, some interviewees did self-stigmatize themselves because of certain experiences, therefore constraining their actions. The influence of stigma on self-identity, as well as the stigma-less identity was discovered through the following questions: *How would you describe yourself?*, *How would you describe your life with diabetes?* and *Who helped you the most in resisting stigma?* In addition, the interviewees' feelings and thoughts at the time of diagnosis and at certain points in their lives were also used for this analysis. This way, I was able to see the changes in their stances and emotions regarding life with diabetes.

Leaders Andrej and Biljana had different stances on diabetes at their diagnosis (Andrej hated it, Biljana was rational – and three years older), however, they see themselves very similarly in the present. Andrej was angry when he got diagnosed, but never saw himself in a bad light: *I think that with my attitude and behavior, I showed them: Hey, you are more sick than me, even though you're healthy.* His opinion of himself today is: *I think everyone has a role in this life. ... My role is, I think, to help people in any way. Of course in the field of diabetes. ... I think it's a much greater pleasure when you do something while having diabetes. It's powerful.* Biljana also sees herself as someone who lives to help: *... People, animals, everyone. I am stubborn and persistent but I know that without other people, PK wouldn't exist.* On living with diabetes and if it stops her to do something she said: *I think diabetes is my life, not a part of it, I don't see it as a separate thing because it's here for so long. But I think it's great, how many people all of us met and all the things we did because of diabetes.* In short, both *leaders* see diabetes as a part of them that made them who they are today, alongside meeting others with diabetes.

However, that stance is not unique to *leaders*, as also Mirko, Lea, Nela, Andrea, Sara and I feel that way too now. For example, *climber* Andrea, who was in eighth grade when she came to *PK*, said: *it meant so much when I met other PWD* [in *PK*]. *And now I'm not ashamed or anything, I hold my pump at my chest because that's the way I feel comfortable, who has a problem with that, well, what can I do? But now, when I enter a bus, I check my blood sugar without a problem, I lick it* [her finger after pricking] *also* (laughs). Although stigma impacted her greatly in primary school, she is now very different, has strong self-confidence and independent. Another *climber*, Sara shared something similar about herself today: *Now, in this moment,* [I am] *finally at peace. Because all my life, I was running after an award, I mean, I didn't know how to live with sugar, and now I think I finally found a way. ... All my life was a drag, and now I am finally in control.*

For many of us, diabetes also meant discipline, order, thinking ahead and being analytical. On the other hand, Lea misses being spontaneous because of this lifestyle: *When I* *was younger, my friends and I would hang out and they would think of taking a bus somewhere, to have a little adventure. And I would always think how I can't do that, I don't have my long-lasting insulin, enough food and water to be able to join an adventure like that.* Goran said that he stopped playing sports because in the next few months after his diagnosis, whenever he would go to practice his blood sugar levels would drop, so he would spend more than half of practice on the bench, waiting for it to rise again.

During childhood, my interviewees and I often thought about fitting in. Some – like Andrej, Simonida, Sara and Goran would stop giving themselves insulin or checking blood sugar because they wanted to be the same as their peers. Nela went to a psychologist when she was eight because she ate candy: *... And the psychologist said: Nela only wants to be like other children. – And I hated her for saying that, although it was true, like, I AM like other kids!* However, on a better note, she also said that: *I never felt like I couldn't do something because of diabetes. And I think there's big difference if someone got it as really small or older. We* (meaning me and her) *learnt everything with diabetes. All the things we succeeded at, we did with diabetes, you know? And I say SUCCESS, because it really fucking is that.*

What Nela said here resonated with me as I have a similar stance on how we perceive diabetes in our lives and how we look at the world. I think that the relationship we have toward our diabetes is dependent on what we have experienced. There are many factors that influence the self-identity of people with T1D, and stigma is just one of them. If it were not for diabetes, would I have pursued swimming competitively and met so many good friends that helped me grow up? Would I also be disciplined, organized, persistent? I do see myself as a fighter, just as Nela and Andrea. I do fight every day to keep my blood sugar in target, I fight when I have a very bad low to survive, I fight against stigma, I fight for patient's rights. Thanks to diabetes, I have traveled around Europe and am in training to become the global young leader in diabetes.

In other words, diabetes is a big part of my identity, and precisely it pushed me to be more pro-active.

6.5 People with Type 1 diabetes as entrepreneurial selves

By the neo-Foucauldian view of neoliberalism, an individual is an entrepreneurial self. She is enterprising, calculative, independent, successful and governed by competition on, among others, the labor market (Rose 1989). Work is the most important element of self-realization. Health is “ensured through a combination of the market, expertise and a regulated autonomy“ (Rose and Miller, 1989, as cited by: Rose 1989: 16). Therefore, a healthy body is a public value and political objective of neoliberalism. Since T1D is a chronic condition, it is incurable and cannot fit into the neoliberal concept of health. Thus, are PWD seen in a different light from those considered to be ’healthy’? Some of the interviewees definitely were. As mentioned above, Sara’s first employer did not give her the first paycheck, thinking she works much less than others because of diabetes. Mirko was discriminated at a job interview solely on the basis of his health condition. However, the interviewees see themselves as almost equal to others on the labor market. They have to think in advance and strategize, calculate, choose jobs they do not wish to do but need the higher salary, modify some goals.

Many of the interviewees have shown their calculative side. Goran said how he wanted to study medicine in high school, but was talked out of it by his parents. He is an example of what I would call an ‘entrepreneurial self for the future’: *My mom was like: what if you want to be a doctor and you’re supposed to operate on someone and you have a hypo, what then? And it was logical to me not to do it then. But I liked natural sciences, but there was parent’s influence. ... Life demands you have enough to keep you covered for everything you need for diabetes, so I chose law.* Not only did he change his high school wishes, he also thought about having enough finances to live a ‘good’ life with diabetes, meaning having enough to buy more expensive food, supplements, medical aid not provided by the state etc.

Pioneer Simonida had the same statement. She studied to be a librarian, however: *I went into economy, foreign trade, because I saw I can earn more, my whole life was a race for money, never in my life have I seen a book except in classes.*

During the 1990s sanctions and hyperinflation in Serbia, it was very hard for Simonida to find healthy food and insulin. She was not only calculative and independent but determined and persistent. She explained: *From one salary, we buy one egg, since nothing happened then, it won’t anytime soon* [meaning her death due to diabetes]. *You know, as a person with diabetes you eat bread and fat and those soapy bacons and sour cabbage and you’re happy you have even that, and mom and I work and in total have 3* [Deutsche] *Marks, and the insulin costs 60, one box. And then I find one more job, at a private firm, so then it wasn’t 3 Marks it was 200, so that I can have two boxes for 120 Marks*.

Goal modification, as with Goran, happened to Nela and Andrea as well. Andrea, the *climber*, said diabetes stopped her from nothing except becoming a stewardess. She slightly modified her goal and now works as an agent in a foreign airline company.

Lea, a *subtle warrior*, and I incorporated diabetes in our interests – she is a PhD student of molecular biology, which she chose because of interest in the way her body functions. I on the other hand, although uncertain of what my future will look like, would love to do research in the field of sociology of health.

The only interviewees who, although never hiding diabetes at workplace, were not calculative and did not modify their goals, were leaders Biljana and Andrej. Andrej said: *I never thought of diabetes and professions, not like ‘will I be able to because I have diabetes’, it didn’t exist in my head, only what I’m interested in*.

7 Conclusion

Generally, stigma was experienced by all interviewees and me apart from one – Goran, however, with a difference regarding factors of stigma and fields of life. Firstly, I have shown that stigma exists in all areas of an individual's life – from socialization and different educational levels, through friendships and romantic relationships to employment and insignificant encounters with strangers. Although having different resistance trajectories over time in their lives, all interviewees are now using the empowerment model of resistance. They behave as active society members and turn the received stigma into a positive one, which made their transitions path-dependent, meaning that, based on their type of resistor, they have implemented this model either since their diagnosis or later in life. Secondly, I have shown that self-stigma, unlike stigma, was not experienced by the majority of interviewees, but played a significant role in the lives of *climbers*. However, although not experiencing stigma that led to self-stigmatization, many interviewees hid diabetes at certain times in their lives, because of the need to fit in or fear from getting stigmatized.

From the three factors of stigma regarding the first sub-question of the research, discrimination was experienced the most. It happened to interviewees on different levels of educational attainment as well as employment and had impacted the identity and level of resistance of *climbers*, *subtle warriors* and *warrior*. In the second place, labeling was also experienced to a great extent, but had a less powerful effect, affecting only *pioneers* and *subtle warriors,* who fought back indirectly. In the third place, stereotypes mostly irritated the interviewees and were not experienced by everyone. Regarding the second sub-question of the research, which discussed fields of life where stigma was mostly experienced, various levels of education stood out – in kindergarten, primary and high school and University, by peers as well as professors. Furthermore, stigma was experienced in romantic relationships, coming from partners or family and friends, by five out of six female interviewees and me. Only one male informant, Mirko experienced stigma in connection to romantic relationships, on a first date. Finally, stigma was experienced at work – at a job interview, after first month of work, by colleagues and employers. A few interviewees lived through stigmatizing experiences regarding friendship.

Gender roles appeared as important factors leading to stigma in romantic relationships of female interviewees. As stated earlier, these women were thought to be unable to fulfill their traditional roles of wives, mothers and overall carers, because they had to take more care of themselves. On the other hand, this was not the experience of male interviewees who, although not fitting the profile hegemonic masculinity entails, experienced almost no stigma. It seems that the traditional, patriarchal Serbian society values men with diabetes more than women.

Stigma had an impact on some of the interviewees – depending on the level of their resistance or the intensity of experiences. Stigma affected their self-esteem, feeling of self-worth and in the cases of *climbers*, led to self-stigma. Self-identity is for most interviewees determined by them having diabetes, among other factors. They are proud of what they have accomplished and how far they have come, mentioning the impact *PK* had on their lives. Action restriction has a very limited influence on the lives of my interviewees, as it is mostly determined by them having less 'freedom' to be spontaneous. However, instead of being spontaneous, my interviewees are analytical, organized, resilient, humane, understanding, empathetic and strong.

With every instance of resistance towards stigma, the interviewees are questioning the conventions of healthy people. Many times when being stigmatized, through knowledge acquired after decades of living with diabetes, they do not only resist stigma by fighting back, but also by educating their stigmatizers. Although having different starting points regarding the levels of resistance, their transformation throughout the years led to high levels of empowering resistance in the present, as activists of *PK*.

Although not having ‘ensured health’ (Rose and Miller 1989, as cited by: Rose 1989), people with T1D fit into the concept of entrepreneurial individuals. They are not only calculative, independent and successful, but also, as mentioned before, analytical, organized and resilient. Most of them modified their preferred employment and professions, because of the need to be financially stable and have enough savings to finance any medical aid for diabetes and a healthy lifestyle. Only *leaders* left diabetes out of their job preference, giving it no significance.

The ultimate purpose of this study, as I think should be of all academic work, was to ameliorate people’s lives. More concretely, with stigma being the huge obstacle to people’s normal social life, and thus accordingly resistance to stigma being the way forward, I have highlighted the community support as the condition most bracing for the development of person’s resistance to stigma. With the classification of types of stigma-resistors, I have shown the importance of community support from the moment of diagnosis, as the afterward stigma-resistance depended on it, more than on any other factor. Thus, this study can have various applications: from social scientists, via policy-makers and healthcare workers, and over to very individuals with T1D. In other words, now they can focus their efforts to finding best strategies of achieving/creating community support. Hearing experiences of people who have fought stigma and have had different paths of overcoming it has often been neglected by both social scientists and policy-makers. This study will hopefully contribute to the field by giving voice to these experiences. What such bottom-up approach entails is not that the focus of a research should not be on the people who stigmatize or on their re-education, but solely highlights the emancipatory potential of the focus who *are* stigmatized and on their empowerment. Developing community support is not a simple act of aiding an individual, but has much deeper consequences, as it creates and strengthens later ‘entrepreneurs’ who can much more successfully combat stigma.

The limitations of this thesis lie in the perhaps narrow focus on a particular group of PWD. As an addition to this existing study, a broader study should be conducted on people who are not a part of an organization and perhaps live outside of the capital. In other words, in line with the conclusion of this thesis stressing the importance of community-support (most successfully in the form of local organizations) on raising individual's resistance level, developing strategies for such community support would be hugely advanced with experiences of people outside of organizations.

To conclude, the study contributes to the potential later research on strategies of developing community support, by, through relying on the experiences of my interviewees, showing the importance of organizations. On the one hand, organizations themselves should increase their focus on supporting people who get diagnosed with T1D. On the other hand, and more importantly, the state and healthcare system should inform children, their parents or adults of local organizations, so that they would be able to develop high-levels of resistance from the start. Lastly, social scientists should focus on providing organizations with tactical toolkit for increasing the scope of their independent activity. Ultimately, with stigma against diabetes being yet another injustice created by the system, nurturing resistance against it is a tactical decision.

> *For it wasn't only suffering: it was also learning through suffering. I know my awareness of people has deepened and increased, that those who are close to me can count on me to turn all my mind and heart and attention to their problems.*
>
> [Excerpt from the writing of a mother permanently disabled by polio]
>
> (Henrich and Kriegel 1961, p. 19. as cited by: Goffman 1963: 11)

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Appendix 1:

List of useful knowledge resources on diabetes used in footnotes

Betta Cells: https://www.diabetes.co.uk/body/beta-cells.html

Example of a blood sugar meter: https://www.diabetes.ascensia.com/our-meters/contour-plus-one-meter/

How to Test Blood Sugar: https://www.diabetes.co.uk/blood-glucose/how-to-test-blood-glucose-levels.html

Example of insulin pens: https://www.novonordisk.com/patients/diabetes-care/pens--needles-and-injection-support/flexpen.html

Example of insulin pump: https://www.diabetes.co.uk/diabetic-products/pumps/medtronic-paradigm-insulin-pump.html

Low blood sugar (hypoglicaemia): https://www.nhs.uk/conditions/low-blood-sugar-hypoglycaemia/

Freestyle Libre sensor: https://www.freestylelibre.co.uk/libre/

Type 2 diabetes: https://www.diabetes.org.uk/diabetes-the-basics/what-is-type-2-diabetes

Why language matters (tangled and complicated): https://diabetogenic.wordpress.com/2019/05/02/revisited-tangled-and-complicated/

Plavi krug official website: https://www.plavikrug.org/index.php/o-nama

Appendix 2: List of questions for interviews

1. Diagnosis: Tell me about the time you were diagnosed with diabetes – how old were you, what do you remember, how did it effect you and your family/friends?
2. Different fields questions: Tell me about your life with diabetes with regards to how you were treated and how you behaved towards others in kindergarten, school, high school, (university), at your work.

   + depending on the story: Did you hide diabetes from someone? Did someone give you a label of a ‘druggie’, sick person? Were you stereotyped (e.g. diabetes is contagious, getting diabetes because you ate too much sweets...). Did the diabetes technology have an impact on people’s behavior towards you?

   What are your employment experiences? Do you think employers see and treat you differently?
3. Tell me about your life with diabetes with regards to how you were treated by friends and people you know, romantic partners, family. Was everyone accepting?
4. Self-identity: How would you describe yourself, and how your life with diabetes?
5. Resisting stigma: Who has helped you most in overcoming stigma?