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SUBJECTIVELY PERCEIVED QUALITY OF LIFE OF PATIENTS WITH MENTAL AND BEHAVIOURAL DISORDERS

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Abstract

The scientific article analyses the subjectively perceived quality of life of adult patients with mental and behavioural disorders, and its relationship to the certification of day care institutions according to the EQUASS quality implementation system and the links with health services provided to adults with disabilities. The aim of the research is to investigate the correlations between the subjectively perceived quality of life of patients with mental and behavioural disorders and the health services provided. The article presents a research study involving 13 respondents (seven men and six women) with mental and behavioural disorders. Qualitative research with the in-depth interview method was applied. The respondents ranged in age from 20 to 48 years (the mean age was 32), all of them had attended the day care centre for from one to 20 years (the average attendance was 7.5 years). The research data were processed using narrative analysis. The research results revealed that adults with mental and behavioural disorders perceive the health system integratively. The essential triangulation that influences the assessment of their subjectively good quality of life was identified: the characteristics of the person himself/herself, the efficiency of services provided, and the professionalism of the employee. It was also found that for respondents receiving inpatient services for ten years or more, the subjectively perceived quality of life is related to social participation in the community. It was also identified that adults with mental disabilities still face stigmatisation; therefore, it is necessary to legally ensure the context of their social participation and valorisation. The research revealed that medical and social services for patients with mental and behavioural disorders require closeness: a person after in-patient treatment and receiving additional psychosocial rehabilitation services focuses on the valorisation of his/her role in society and social participation.

KEY WORDS: mental disability, social participation, stigma, quality of life, integrative healthcare, health care service.

Anotacija

Moksliniame straipsnyje analizuojama suaugusių pacientų, turinčių psichikos ir elgesio sutrikimų, subjektyviai suvokiama gyvenimo kokybė bei jos sąsaja su dienos globos įstaigų atestavimu pagal Europos socialinių paslaugų kokybės sistemą (angl. *European Quality in Social Services* – EQUASS) bei suaugusiems žmonėms su negalia teikiamomis sveikatos paslaugomis. Tyrimo tikslas – ištirti pacientų, turinčių psichikos ir elgesio sutrikimų, subjektyviai suvokiamos gyvenimo kokybės ir teikiamų sveikatos paslaugų tarpusavio sąsajas. Straipsnyje pristatomas tyrimas, kuriame dalyvavo 13 respondentų, turinčių psichikos ir elgesio sutrikimų (septyni vyrai ir šešios moterys), taikytas

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kokybinis tyrimas giluminio interviu metodu. Respondentų amžius svyravo nuo 20 iki 48 metų (amžiaus vidurkis – 32 metai), visi jie dienos centrą lankė nuo vienerių iki 20 metų (vidutinis lankomumas – 7,5 metų). Tyrimo duomenys apdoroti taikant naratyvinę analizę. Tyrimo rezultatai atskleidė, kad suaugę asmenys, turintys psichikos ir elgesio sutrikimų, sveikatos sistemą suvokia integratyviai: nustatyta esminė trianguliacija, daranti poveikį jų subjektyviam geros gyvenimo kokybės vertinimui – paties asmeninės savybės, teikiamų paslaugų efektyvumas bei darbuotojų profesionalumas. Be to, nustatyta, kad respondentų, kuriems teikiamos stacionarinės paslaugos dešimt metų ir ilgiau, subjektyviai suvokiama gyvenimo kokybė susijusi su socialiniu dalyvavimu bendruomenės gyvenime. Nustatyta ir tai, kad psichikos negalią turintys suaugusieji vis dar stigmatizuojami, tad būtina teisiškai užtikrinti jų socialinio dalyvavimo ir valorizacijos kontekstą. Tyrimas atskleidė, kad medicininių ir socialinių paslaugų pacientams, turintiems psichikos ir elgesio sutrikimų, teikimas neatsiejamas nuo empatiškumo, jautrumo, individualios prieigos, žmogus, po gydymo stacionare gavęs papildomų psichosocialinės reabilitacijos paslaugų, orientuojasi į savo vaidmens visuomenėje valorizavimą ir socialinį dalyvavimą.

PAGRIDNINIAI ŽODŽIAI: psichikos negalia, socialinis dalyvavimas, stigma, gyvenimo kokybė, integrali sveikatos priežiūra, sveikatos priežiūros paslauga.
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Introduction

One of the most vulnerable groups in society is adults with mental and behavioural disorders. The World Health Organization (WHO, 2019) states that people with mental disorders often experience stigmatisation and discrimination, which can also lead to lack of access to health and social services. A study by Vaes and Muratore (2013) shows that even in medical institutions, employees need emotional detachment, and employees who experience an emotional relationship with patients are more likely to be at risk of burn-out. Experiencing stigmatisation, the limitations of social participation and an individual perception of disability presuppose the opinion that people with mental disabilities themselves can best identify the subjectively perceived context of quality of life (Connell, O'Cathain, Brazier, 2014; Mattila, Määttä, Uusiautti, 2017). According to Eurostat (Eurostat Statistics Explained), in 2017 there were 3.9 million in-patients with mental and behavioural disorders who were discharged from hospitals in the EU. Relative to population size, Germany, Austria, Latvia, Lithuania, Romania, Finland and France recorded the highest number of in-patient discharges for those treated for mental and behavioural disorders in 2017, some 1,200 to 1,700 per 100,000 inhabitants, more than ten times as high as the equivalent ratios for Cyprus and the Netherlands, where the lowest ratios were recorded. According to the WHO (2019), people with mental disabilities are at higher risk of stigmatisation and human rights abuses in institutions and in access to health care service, such as long-term confinement in institutions. Also, in some countries, up to 85% of people with mental disabilities have no access to health care (Vaes, Muratore, 2013). Research on patients' quality of life shows that the patient's functioning and quality of life depend to a large extent on reducing stigma and family education (Choo et al., 2019), social functioning, and general mental and physical well-being (Comer et al., 2011). Despite the WHO (2020) definition of quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns, in the case of mental disability, scientific studies have generally shown that the subjective quality of life of patients with mental disorders depends most on their social participation and psychological factors (Borsbo et al., 2009; Barker et al., 2009; Narvaez et al., 2008), and the social, psychological, economic, medical and other parameters of a 'quality' life (Parish-Plass, 2013), for example, in schizophrenia, may have extremely low compatibility between objective and subjective QoL (Narvaez et al., 2008). Patients with mental disabilities have a better quality of life through integrative health care (Choo et al., 2019). One of the key strategies for the well-being of people with mental disabilities of the European Pact for Mental Health and Well-Being (2008) launched by the EU is education and combating stigma and social exclusion. In Lithuania, due to the growing number of people suffering from mental illness every year, the health care service is facing challenges (Urbonienė, 2017). Social participation and combating stigma are essential factors promoting the return of people with mental disabilities to society (Urbonienė, 2017; Pundžiūtė, Stankuvienė, 2011). To improve the situation of people with mental disabilities in Europe, the European Quality in Social Service (EQUASS) project funded by the PROGRESS Programme was launched in 2014 with the aim of contributing to the improvement of working conditions and of quality of personal care and household services in 11 EU member states, and to establish criteria for trends for success and transferability of good practices including mental health services. The main task of this accreditation is improved services. One of the countries implementing this political transformation is Lithuania. For this reason, the article presents a study conducted in an institution that is experiencing the transition to the EQUASS system for patients with mental disabilities from the perspective of their so-called subjective well-being: 'happiness and well-being' (Greve, 2008).

1. Materials and methods

Qualitative research was conducted from September to February. The study included 13 respondents (see Table 1) receiving psychosocial rehabilitation services due to mental disability, seven men and six women aged 20 to 48 years, with a mean age of 32 years. The respondents received services for from one to 20 years; the average duration of services due to mental disability was 7.5 years.

Interviews were conducted with the respondents in an environment that was convenient for them, where they felt comfortable with building an alliance and a trusting atmosphere (Campbell et al., 2002). An open-ended semi-structured in-depth interview was used. The respondents were coded R1, R2, etc. During the organisation of the research process, non-probability targeted sampling of respondents was performed, after selecting four respondents; others applied to the researcher themselves with the aim of participating in the qualitative research. Researching in this way, it is important to realise that it is not the disorder that creates a person's disability, but the social system that creates the barriers (Watson, Kieckhefer, Oshansky, 2006). Presenting the respondents' disorders is especially important in terms of 'giving them a voice', i.e. it should not be considered as somatophobic, as well as the aspiration to discard everything relating to body and biological origin (Williams, 1999).

Table 1. Respondents' demographic data

Code	ICD-10 disorder code	Disorder description	Sex	Age, years	Psychosocial rehabilitation services provided (years)
R1	*F02.8, F07.2, T90.5*	Dementia, with hypothyroidism, acquired; post-concussional syndrome; sequelae of intracranial injury	M	33	3
R2	*F71.9, F45*	Moderate intellectual disability; somatoform disorder	V	20	1
R3	*F70.1, G80*	Mild intellectual disability; cerebral palsy	M	32	10
R4	*F72.1, F33.1, G80*	Severe intellectual disability, recurrent depressive disorder, cerebral palsy	V	26	4
R5	*F72.1, F33.1, G80*	Severe intellectual disability, recurrent depressive disorder, cerebral palsy	M	30	5
R6	*F70.1, G24, G40.2*	Mild intellectual disability, dystonia, localisation-related (focal)(partial) symptomatic epilepsy	V	48	3
R7	*F72.1, F33.1,G80*	Severe intellectual disability, recurrent depressive disorder, cerebral palsy	M	40	20

Code	ICD-10 disorder code	Disorder description	Sex	Age, years	Psychosocial rehabilitation services provided (years)
R8	*F70.1, G24G40.2*	Mild intellectual disability, dystonia, localisation-related (focal) (partial) symptomatic epilepsy	V	31	3
R9	*F71.0*	Moderate intellectual disabilities	M	39	14
R10	*F 71.0, Q90.2-21*	Moderate intellectual disability, Down syndrome-trisomy 21, translocation	M	34	12
R11	*F 71.0, Q90.1-21*	Moderate intellectual disability, Down syndrome - trisomy 21, translocation	V	20	1
R12	*F72.1, F33.1, G24.4, G80*	Severe intellectual disability, recurrent depressive disorder, idiopathic orofacial dystonia, cerebral palsy	V	43	20
R13	*F70.0, G80.3, H53.0*	Mild intellectual disability, amblyopia ex anopsia, dyskinetic cerebral palsy	V	22	3

The transcribed research data were analysed using narrative analysis. Thus, the researcher conveys not only the symbols but also the subjective interpretation of reality of the person's quality of life (Jones, Brader-Araje, 2002). This allows us to analyse the spoken representation as a meaning of communication (Henwood, Pidgeon, 1994), and reality is constructed 'here and now' (Jones, Brader-Araje, 2002). The reality experienced by the respondent is replicated verbally again, and takes on a specific form: expressions, descriptions, and being silent encode important information. The respondent presents his/her perceptions of various events or social interactions (Martz et al., 2010). The interview was conducted according to a semi-structured questionnaire (see Table 2) with the following constructed conversation topics about the subjective quality of life.

The data obtained in the research were divided into subcategories, which were expanded into categories. The reliability of the narratives was constructed through the description of methodological procedures (Merriam, 2009; Creswell, 2009). According to Moilanen (2000), the presented narratives do not reflect the whole truth, but the world subjectively experienced by the respondents, their subjective quality of life and the factors influencing it, events that cannot be generalised. Newton (2009) describes this possibility: constructing research reliability through the creation of respondents' realities. Representations of people with mental disabilities in conveying their subjectively perceived quality of life exist in the middle between naive realism and radical constructivism in seeking research credibility (Feldman, 2007). The research findings were presented to the respondents, thus achieving verification and insight (Johnson, 1999). Habermas (1973, 215, cited in Moilanen, 2000, 384) writes that in gathering feedback, it is meaningful to construct an unforced dialogue, so that participants can evaluate and strengthen their arguments.

Table 2. Interview topics

Thematic block of personal well-being in the process of psychosocial rehabilitation
It is about understanding the meaning of the life of a person with a disability in the rehabilitation process: spiritual and material well-being, future prospects, social participation, employment, opportunities for participation in the centre (cf. Narvaez et al., 2008; Greve, 2008; Borsbo et al., 2009; Barker et al., 2009; Parish-Plass, 2013; Choo et al., 2019)
Thematic block of the component of psychosocial well-being: internal properties.
It is about the person's state of health, psychological state, self-esteem and self-acceptance, social contacts, relationships with close people, family members (Campbell et al., 2002; Watson et al., 2006; MacConville et al., 2012; Connell, O'Cathain, Brazier, 2014)
Thematic block of meeting individual external factors and needs in the context of rehabilitation services
It is about friendship, meeting the need for belonging, the context of valorisation, the need for being alone, meeting the need for attachment and love, the need for affiliation, the feeling of joy, freedom, happiness, security (Newton, 2009; Comer et al., 2011; Scorsolini-Comin et al., 2013; Ruggeri et al., 2001; Lehman, 1983; Van Dongen, 1996; Eack et al., 2007)

Results

The research results are summarised in Table 3. According to the respondents, their subjective quality of life is highly dependent on the severity of the disorder itself, as it largely determines the degree of social participation and inclusion in public life. A visually noticeable disorder is more often a sign of bullying and stigmatisation in society. According to the respondents, the perception of their subjective quality of life requires mutual interaction: the readiness of healthy people to accept a different individual and the activity of the respondent himself/herself. All the respondents mentioned integrity when talking about health-care services. According to the respondents, when receiving psychosocial rehabilitation services, it is important to take into account their efficiency, their effectiveness due to a specific disability, and the creation of conditions for self-realisation. When it comes to the reform of the implementation of the EQUASS system, the respondents mention that the changes allow them to be approached and ‘give an opportunity to have a say’ about what services they lack. The respondents mention that they are most empowered by integrative health care, which they describe as team self-expression sessions organised in addition to medication, the opportunity to relax, a friendly environment for patients, good services, and an excellent relationships with staff.

Table 3. Research categories, subcategories and illustrative statements

Category	**Subcategory**	**Frequency**	**Illustrative statements**
Thematic block of personal well-being in the process of psychosocial rehabilitation			
Meaning of life	Spiritual well-being	3	‘First of all, it means faith. Yes, it’s more important to communicate with loved ones and friends, but it’s most important to communicate with God…’ [R10] ‘…Well, if the weather is good, let’s say, and mum works, I always go to church’ [R12]
	Material well-being	5	‘Living cool means having money for everything and not counting money, and working and having when to relax’ [R1] ‘The flat is in order, the repairs are done. Now I have everything I want: a washing machine, a computer. When you have a car – it’s a good life then…’ [R8]
	Future prospects	12	‘I want to work and relax […] to walk as before the accident to improve my physical condition’ [R1] ‘I would like to be as happy as I am now […] I don’t think I know – to be with my loved one. I don’t like to daydream too much. I pursue goals […] I am now pursuing goals to improve walking. That my A. would still be beside me…’ [R5]

Category	Subcategory	Frequency	Illustrative statements
	Social participation	11	‘Active participation is when you are invited to kind of, well there, to be among other people…’ [R4] ‘I participate everywhere now, no matter how much I succeed: whether I succeed right away or later. Now I don’t say ‘I don’t know how, I don’t succeed’ […] I succeed, I just need self-confidence…’ [R5]
	Occupation	9	‘When I was working – making candles, I was happy […] And I also want to work that way. I would like to do like A. (visitor) – to work three days and attend the centre two days. But constantly. As O. said: ‘so that it would be good for them and for me too […] And it’s better, because I’m constantly waiting for a call from K. [the project manager] […] Maybe she will call and tell me, hopefully say: go to work!’ [R12]
	Participation opportunities at the centre	12	‘With all your mind, all your ability, all your health, participate in what you like best. There is a desire to do it and it doesn’t matter to me how much effort or health it would cost me. I will do it until I succeed…’ [R10] ‘I participate in town celebrations and events […] it also happens when my father and I go somewhere’ [R13]
Thematic block of analysis of the preconditions for ensuring the psychosocial transformation of a person in the context of the services provided in the rehabilitation centre			
Components of psychosocial well-being: internal qualities	Psychological state	10	‘Sometimes it’s hard, there’s a lot of anger. Then, so to say, sometimes it’s interesting […] it’s in every way […] life is good now. All kinds of moods come to me. Then they pass…’ [R4] ‘After mother’s death, in fact, I was very broken, blaming myself for a long time. It was hard […] now I can say that I really recovered, I believed in myself […] I’m satisfied just because I live in Klaipėda. Because if I didn’t live in Klaipėda, I’d definitely break. I wouldn’t be me’ [R5]

Category	Subcategory	Frequency	Illustrative statements
	Health status	5	'I'd just like to walk even better, keep my balance…' [R5] 'My head is not working well. So I make something not the way it should be. I have to redo everything then. Not everything works […] I would like to reach the working level. To be capable […] and then to be able to work' [R6]
	Self-esteem, self-acceptance	10	'That I'm already a little stronger […] that I'm already so satisfied' [R4] 'I'm interesting, handsome. I like to work […] I'd like to work with wood' [R13]
Thematic block of preconditions for the efficiency of services provided by a health-care institution			
Components of psychosocial well-being: external factors	Social contacts	8	'I keep in touch with former classmates on Facebook…' 'I participated more everywhere when mum was alive, we went everywhere, I wasn't stuck between four walls, as someone thinks that with a disability, only home […] I really didn't expect everyone to love me so much, to wait for me, that someone cares for me, despite the loved one that he's waiting for' [R5]. 'I communicate with friends […] it's bad being alone, there is no one to talk to […]' [R8]
	Relationships with close people, family members	10	'I'd like our family to live together all in the house […] so that my brother is always near me […] I communicate with my brother the most' [R3] 'When I am sad, I call my brother, my loved ones, I communicate with them. Then it's easier for me. Psychologically easier. Better with loved ones than with friends…' [R9]

Category	Subcategory	Frequency	Illustrative statements
Meeting needs	Meeting the needs of friendship and belonging	9	‘Discover happiness in simple things, not to be afraid to tell dear people that you love, soothe them, advise, caress…’ [R5] ‘Because that person is a friend you are safe with in every sense. If you feel bad, he will hug you, if you feel good, he will be happy…’ [R10]
	The need to be alone	6	‘I like being alone more. Yes, yes. Because I’m used to being alone. It is safer for me then…’ [R9] ‘I want to be alone, because of fatigue, and sometimes people start to make me nervous. I want to relax, to be alone’ [R10]
	Meeting the need for attachment and love, affiliation	8	‘I enjoyed it when mum was alive. I could spend the whole day with her. We went to the sea. When we did lessons together, we wrote together with my mother’s hand…’ [R5] ‘To have a second half is the first condition of a good life. That she will understand me. And that I’ll understand her. She understands me well and I understand her […] And that mum will understand me…’ [R12]
	The feeling of joy	3	‘To me, from the whole school, the principal gave a certificate: “To the girl who did not give up, who wanted to study, who pursues her dream,” that is, to me. And my dad told me about it, and my heart almost stopped for joy…’ [R5] ‘I enjoyed life when mum was still alive…’ [R6]
	The feeling of happiness	4	‘I want to have a girlfriend to be happy…’ [R6] ‘I was happy when I discovered my parents, loved ones. I realised then that I’m not alone. I realised this […] When my relatives come to me in Lithuania. Then I’m happy’ [R9]

Category	Subcategory	Frequency	Illustrative statements
	The feeling of freedom	4	'I want no one to regulate, no one to explain, no one to command, no one to "mess up my mind"' [R4] 'I'd like to make friends without the supervision of relatives, but M. doesn't let me go. Calls, looks for me. Says, "Come here quickly, I'm worried about you"' [R6]
	The feeling of safety	4	'There is no safety for me without my mum [...] I have fears, my mum's friend gets drunk, I don't know what will happen to his mind […]' [R2] 'If with a family, it's better alone. Because with family, I don't feel like myself, completely. I have fears. I'm not even allowed to talk on the phone […] when my family used to say so cruelly that I'll never find a friend, that I have a disability, that I won't be loved, who needs you like this, who will want to help you, you are pitiful […]' [R5]

Subjective quality of life, according to the authors Diener and Lucas (1999), and Diener (2006), shows how objective conditions are assessed and felt by the person. Summarising the answers of the respondents, it can be stated that the majority of the respondents spoke about the components of the image of their subjective quality of life in the process of rehabilitation through the context of their freedom and happiness; meeting the needs of friendship, security, and love; life satisfaction; the activity and its meaningfulness insofar as it helps to realise oneself. According to the respondents, the complexity of psychosocial rehabilitation services helps people with mental disabilities to integrate into society and develop their daily life and work skills. Meanwhile, participation in occupational activities increases self-esteem, encourages them to feel needed, and opens up opportunities for communication, which is especially important for people who have complicated relationships with their nuclear family.

Discussion

The research results obtained are summarised in Figure 1. The subjectively perceived quality of life of a person with a mental disability is strongly related to the holistic model. The same is confirmed by other authors' studies (see Connell, O'Cathain, Brazier, 2014; Lehman, 1983; etc). In the psychosocial rehabilitation

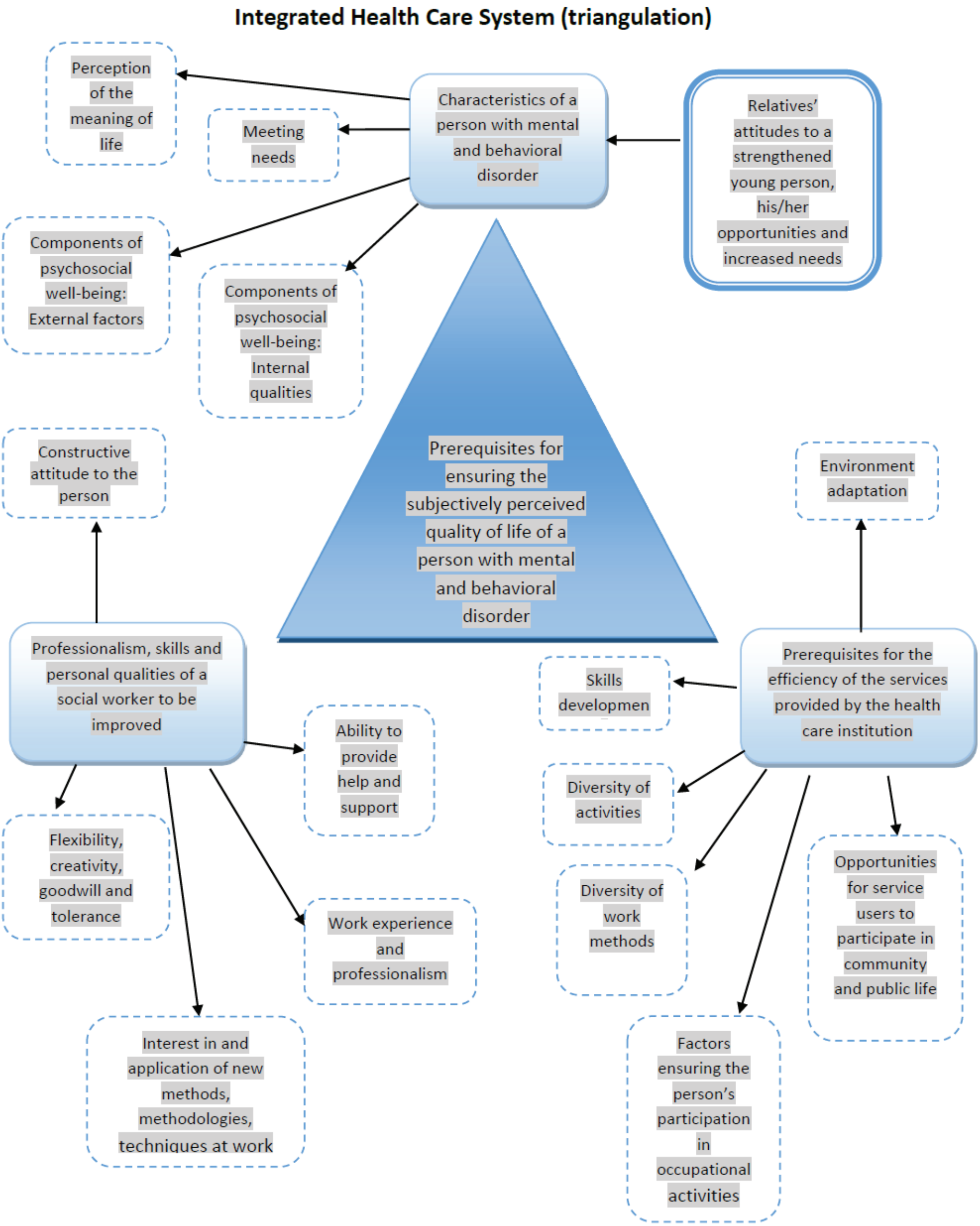

Figure 1. The perception of an integrated health system

health system, patients place the greatest emphasis on their individual feelings, the context of relationship building, and valorisation through the use of integrative services. We will discuss three essential topics, the narratives of which were analysed: well-being in the process of the psychosocial rehabilitation of the person himself/herself, prerequisites for ensuring the individual's psychosocial transformation in psychosocial rehabilitation, and an evaluation of the effectiveness of the services provided.

The well-being of people with disabilities in the process of psychosocial rehabilitation

When talking to the respondents about how they assess the process of psychosocial rehabilitation, people mostly talked about and emphasised what is important for their well-being, and what gives them meaning in life. Three respondents mentioned spiritual bliss:

'Faith in God – then it is better, the years are meaningful…' [R11].

As many as five respondents talked about material well-being, which can also be created in the rehabilitation process: various work projects are mentioned, which involve people with disabilities by the institution itself, then people feel a greater satisfaction of the need for affiliation and the meaning of valorisation as a person in a broader context:

'…I want a car […]' [R3]. '[…] so that I could live independently, earn money and pay for the flat' [R12]; '[…] that I stood on my own two feet. Life changed the other way. I started to work. Everything has changed since August, materially improved…' [R8].

Similar results were obtained in the study by Connell, O'Cathain and Brazier (2014), which states that people with mental disabilities are highly focused on holistic psychosocial rehabilitation, and its effectiveness should be assessed on the basis of qualitative parameters, including their recognition in society, sense of value, and relationship of friendship. According to Narvaez et al (2008), the subjective indicators of life satisfaction include the degree of life satisfaction. As in the study by Connell, O'Cathain and Brazier (2014), the data in this study were also similar, in that loneliness, isolation and a degree of stigmatisation have the greatest impact on subjective quality of life, and well-being in the rehabilitation process. It is observed that these topics, as well as love, belonging, affiliation with friends, family and employees, are among the most important ones. Almost all (12) respondents stated that when attending the psychosocial rehabilitation centre, they feel the impetus of life, movement, change, better mental health, and the opportunity to improve themselves:

‘At the centre, I improve myself to be stronger. Resurrect […] improve my condition, more independent […]’ [R9]. ‘Being able to communicate gives me a meaning to life […]’ [R3]. ‘[…] when you feel support from the other part, you can move mountains. And those difficulties that were, our difficulties, they are not easy. Surely we are together and it is easier for us to overcome them, indeed’ [R5].

Van Dongen’s (1996) study comparing the quality of life of working and non-working people with mental disabilities also showed that there were no statistically significant differences between groups, but occupational activity shifts people away from symptoms of mental illness and improves mental health.

In terms of future prospects and opportunities for social participation, people with mental disabilities place a strong emphasis on being ‘among people’, ‘being able to communicate’, the need for ‘compassion’ and ‘love’:

‘When you are invited to kind of, well there, to be among other people […]’ [R4]. ‘[…] it means with all your mind, all your ability, all your health, you participate in what you like best. There is a desire to do it, and it doesn’t matter to me how much effort or health it would cost me. I will do it until I succeed […]’ [R10].

This study also confirmed the same findings as the study by Mattila, Määttä, Uusiautti (2017), that love, friendship and communication with other people are a fundamental need for a subjective quality of life. This study also shows that people with mental disabilities are more prone to finding their other half, and building relationships, although they may not always be able to explain or describe this:

‘I’d like to be with my girlfriend. To be able to walk everywhere together’ [R6].

‘To be able to realise myself […] so that I could live separately […] to meet my beloved and marry him. That’s how we would live. We would both go to work. It doesn’t matter whether in the flat or in the house. It’s important that it is separately from the parents’ [R10].

The aspects of love, belonging, social support and occupation provide an opportunity for people with disabilities to establish themselves in society, and foster society and culture. These are some of the most important variables that affect subjective quality of life (Lehman, 1983; Eack et al., 2007). During occupational activity, the rehabilitation centre focuses on how a person with a mental disability consciously perceives himself/herself, without criticising or interpreting (Watson et al., 2006; MacConville et al., 2012).

Prerequisites for ensuring the individual’s psychosocial transformation in the context of services provided in psychosocial rehabilitation

When talking about prerequisites for ensuring psychosocial transformation in psychosocial rehabilitation, people talk mainly about their internal intra-psychic qualities, the importance of relationships with the institution's staff, and meeting needs, the extent to which attendance at the institution and psychosocial rehabilitation provide opportunities to restore relationships, feel happiness and joy, and meet needs.

The respondents talked mainly about their subjective sense of quality of life through the complexity of their physical and mental health status, insofar as it affects their social participation and the degree of stigma in society, psychological condition, and self-acceptance/self-esteem. Research shows that self-esteem/ subjective well-being is reflected in the person's subjective state, and in the assessment of the response to their individual needs (Campbell et al., 2002; Watson et al., 2006; MacConville et al., 2012). According to the respondents, when assessing psychosocial services, their psychological condition in the rehabilitation centre and self-assessment are very important. As many as ten out of 13 respondents emphasised this:

'My life is a real anecdote indeed. I'm doing well and having fun…' [R10]. 'I'm fine here. I found my other half. When I found a girlfriend, I became more polite, better […] I used to be nervous, angry…' [R8].

Assessing their psychological condition, the respondents mentioned that they understand the complexity of their condition, and that they would like to change in a positive direction, and would like the symptoms of the disability to be easier:

'I wish I was a little calmer, psychologically calmer for my mum, aunt, godmother. I wish I wasn't hysterical. I would like to have an emotional balance, I would learn to control myself…' [R4].

Similar research results have been obtained in other scientific studies (see Ruggeri et al., 2001; Lehman, 1983; Eack et al., 2007), as well as in the assessment of human health status:

'I'd like to change my leg for a new one. The leg gives up. I wish my leg would be healthy and I would live with E' [R12].

'Not everything works […] I would like to reach a working level. To be capable […] and then to be able to work' [R6].

These respondents' narratives show their desire to improve their physical and mental condition, to achieve a higher level of working capacity, for greater opportunities for self-realisation, wider employment opportunities and affiliation with the community, and a lower degree of stigmatisation.

Regarding the respondents' self-esteem and self-acceptance, it is confirmed that being loved and dear to someone is one of the essential things, as is repeated in several topics:

'You always need to tell people your loved ones that you love them. Maybe not everyone values it, but I do know that I am not valued by my family…' [R5].

‘I’m a simple person who does everything he wants to do. I’m a normal person who has equally negative and positive qualities…’ [R10].

A study by Mattila, Määttä and Uusiautti (2017) confirmed that belonging and love in people with intellectual disabilities can significantly affect emotions and subjective feelings about quality of life. Meanwhile, Connell, O’Cathain and Brazier’s (2014) study proves that criticism, judgmental interrelationships, and not understanding, promote human isolation, reinforce stigmatisation in society, and impair a subjectively perceived quality of life.

When evaluating psychosocial rehabilitation services, as many as five respondents emphasised social participation and opportunities for integration into society:

‘I am accepted as I am. People here are tolerant…’ [R4].

‘With friends, yes, the surroundings are benevolent. Because, really, they’re amazing everyone, really. To love someone, to take care of someone…’ [R5].

‘Quite a good environment in the centre, benevolent […]’ The environment and the people who are here bring me joy and satisfaction…’ [R8].

‘I feel good, I feel I am at home’ [R9].

As many as six respondents emphasised the benefits of integrative psychosocial rehabilitation: that they can be themselves through the opportunity to express themselves regardless of disability; the possibility not to hide problems specific to a person with a disability; the opportunity to get acquainted with other people with disabilities:

‘I’m uncomfortable at home. I’m not safe. I don’t want to go back home […] I come to the centre feeling irritated…’ [R2].

‘I’d like not to be afraid to express my opinion and not to think that I will offend someone. Maybe I will offend someone, but next time maybe a person will think, because I think all the time not to offend […] Because if a person wants to see me in the activity, I feel I am needed…’ [R5].

‘My own person asked me what I would like to learn this year. So I replied that I would like to learn how to cook […] I want to gain new experience with new employees […]’ [R7].

‘I can express my opinion…’ [R13].

The integrative content of psychosocial rehabilitation services allows to provide people with significantly more services they need to meet individual needs. Some respondents see rehabilitation services as an opportunity to communicate, ensure safety and self-realisation. However, one of the essential aspects is non-judgment, being understood, social support. The importance of such social support was conceptualised by Eack et al. (2007) in their study on the subjective quality of life and symptom expression of people with schizophrenia.

Prerequisites for the efficiency of the services provided by the health-care institution

Regarding the effectiveness of the services, the respondents spoke mainly about and assessed the opportunities provided by the services for integration into society, adaptation to the environment, the variety of activities and methods used, and the opportunity to develop their skills. Nevertheless, it is interesting that when talking about these topics, people placed a strong emphasis on the links between these methods/skills and other forms with contexts of love, belonging, value, and valorisation. Such narrative speech actualises how the subjective quality of life is based on personal relationships and their value:

‘I really didn’t expect everyone to love me so much, to wait for me, that someone cares for me, despite the loved one that he’s waiting’ [R5].

‘People give me joy. Communication with them is important…’ [R10].

‘With other people I feel better, I’m not lonely then. I’m afraid alone, understand me. Mum went away (died), I started crying’ [R6].

Regarding meeting needs, the respondents also mentioned the possibility of improvement, some reinforcement, impetus, and its healthy development. This importance has also been actualised in other studies (Scorsolini-Comin et al., 2013; Connell, O’Cathain, Brazier, 2014). Talking about the prospect of meeting their needs in the provision of psychosocial rehabilitation services, the respondents mainly mentioned the need for friendship, belonging, and love.

‘…When you are loved, when you are among people who understand you, support you, who teach you something, who encourage you, who will never say anything bad to you, will not offend […] of course, it’s love as well, because without love it’s nothing. when you feel support from the other half, you can move mountains…’ [R5].

Research by Connell, O’Cathain and Brazier (2014) shows that the quality of belonging, social compliance, and relationships are important for quality of life. The narratives of many respondents confirmed this statement, by emphasising that they experience love, care, attachment and friendship, they have someone they can rely on and trust. The most common supportive relationships are with a partner, friends, family or health care professionals (Connell, O’Cathain, Brazier, 2014). As many as nine respondents described a good life when the need for friendship and attachment is also met:

‘Communicating with loved ones, friends, gives me a meaning to life…’ [R7].

‘When I have a problem, then there is no one to talk to. Friends are needed to talk, to share difficulties…’ [R9].

The respondents’ narratives confirm the findings of Mattila, Määttä and Uusiautti (2017) that good and close human relationships, love and friendship, communication with other people and social needs in general are the main sources of well-being. The feeling of happiness for the respondents is directly related to communicating with loved ones, the joy they experience, and its moments:

‘All is well for me, I have a mother […] to have a beloved friend, to be in a couple […]’ [R7]. ‘It is very important for me to have a friend. I want attention, to have friends. Then I feel security, joy, happiness…’ [R13].

The respondents’ statements about the feeling of love confirm Mattila, Määttä and Uusiautti’s (2017) statement that the social and emotional element of development includes social life and emotions. Therefore, love is an important part of social and emotional development, as concepts and experiences of love are related to overall development and well-being and quality of life. Nevertheless, some respondents face a dilemma between maintaining social contacts and the need for being alone when assessing independence. Four respondents said they like being alone because they feel they are tired of the effects of the surroundings:

‘I like being alone at home…’ [R7].

‘…I like going for a walk, to stay alone…’ [R13].

According to Connell, O’Cathain and Brazier (2014), both leisure and work activities give people with mental disabilities a sense of belonging to the community through social interaction, and raise the person’s self-esteem and feelings of pride and achievement. This finding is confirmed by the research participants. Four respondents attributed a sense of happiness to subjective psychological well-being. When talking about what a good life is for them, the respondents emphasised factors that determine happiness: the social environment, the opportunity to attend events, close people:

‘…I am happy when I go to the centre, to the concerts. There are many cameras at concerts. The singers kindly agree to take pictures with me […] [R4]. ‘I am happy: it means that I have everything a person may need. I have very nice parents, I have a puppy, I have fish. I have a very nice and warm house. I have enough to eat. In a word, I have all the pleasures I can have…’ [R10].

Regardless of disability, eight respondents said that it was important for them in life to meet the need for joy in the process of psychosocial rehabilitation:

‘When it’s never boring. When we talk about something, laugh. There is no time to be sad…’ (R3).

The narratives of the respondents revealed the importance of safety and a positive environment in the rehabilitation centre. Lehman’s (1983) research showed that universal well-being was most consistently associated with personal safety, social relationships, finance, leisure and health care variables. As many as nine respondents said they felt safe and unrestricted at the rehabilitation centre:

‘I don’t want to go home at all. I want to stay here […] I am safe here. I feel very safe…’ [R3].

‘I feel safe. No one here commands me […] they calmly explain, and calm me psychologically’ [R4]. ‘[…] safe. There are many good people around […]’ [R5]. ‘[…] safe. Because the staff supervise, and there is a good environment here’ [R8].

The study by Connell, O’Cathain and Brazier (2014) highlighted the difficult moment of social support and maintaining independence: support and assistance while maintaining one’s independence is a complex task. Meanwhile, the respondents’ narratives also revealed that in the psychosocial rehabilitation centre some feel constrained, forced to do what they do not want to do:

‘When you are forced to do it, when you don’t want to do it. Sometimes when you want to do something, you do it, when you don’t want to…’ [R3].

‘I don’t like all the rules here. I would like to change this order to allow people to leave during leisure time without staff outside the institution […] When I want to get out and can’t, it’s frustrating…’ [R9].

‘It makes me nervous that there are too many rules. It unbalances and bothers me. Sometimes I even forget the rules and want to scream. I’d really like fewer rules…’ [R10].

A study by Connell, O’Cathain and Brazier (2014) found that people valued their activities more and actively sought greater independence especially where it was hampered by physical health and mobility difficulties. For them, independence was important for dignity, pride and privacy, and dependence led to feeling of guilt and being a burden. This finding is also confirmed by the statements of ten respondents:

‘I am free, really, unrestrained […] When I ride that wheelchair, I have freedom in the day centre, and with a walker it is the same…’ (R4).

‘…I feel an inexplicable freedom, desire […] Maybe give myself to an audience when I act. I feel good…’ (R10).

From the respondents’ answers, it can be stated that by participating in occupational activities at the rehabilitation centre there is an opportunity to ‘discover’ oneself, increase self-esteem, and change interrelationships. All ideas aimed at meeting the employment needs of people with mental disabilities help them to participate in socio-cultural life and respond to the need for social integration. Occupational activities enable a person with a disability to meet the need for self-esteem, which gives him/her a sense of self-confidence, self-worth, strength, capacity, adequacy, and being useful and needed in the world. It can be said that the psychosocial rehabilitation centre provides an opportunity to cultivate the openness of people with mental disabilities to new experiences.

Conclusion

The research confirmed that commonly used measurements of quality of life with EQ-5D or SF-36 are too complex; consequently, the method of in-depth interview used in the research with the approach of narrative analysis allowed us to reveal representations of the people themselves about their subjective experience of quality of life in the health system. One of the key findings of the research on the subjective perception of the quality of life of people with mental disabilities is the need for love, belonging and freedom. According to all the respondents, their self-esteem and need for security are most influenced by the realisation of love and belonging. People with mental disabilities who have a life partner were most concerned with the desire that their biological family members, mother or father, recognise their boyfriend/girlfriend, and allow them to continue their friendship. According to the WHO (2019), the determinants of quality of life of people with mental disorders include not only individual attributes such as the ability to manage one's thoughts, emotions, behaviours and interactions with others, but also community support. The research also revealed that people with mental disabilities constantly experience a need for association and valorisation with the community; the vast majority of the respondents mentioned their poor physical and mental health, thus emphasising their difference from 'healthy' members of society. They also mentioned the perceived constant control of relatives or psychosocial rehabilitation workers, and the lack of freedom, as the most influential factor negatively affecting their quality of life.

The research revealed that for people with mental disabilities, in terms of valorisation of improving their subjective quality of life, occupation and rewarded work are essential symbols that strengthen assimilation in the community and personal identity. Meanwhile, occupational activities of psychosocial rehabilitation serve the development of friendliness, friendship and a team spirit. Targeted occupation in activities allows people to restore lost skills and improve new skills; to apply their creative powers; to be beneficial to society; to increase their self-esteem and feel a sense of dignity. The research found that people with disabilities who had used these services for ten years or more were more focused on occupational activities as a potential source of income, and on the valorisation of their role, than other participants in psychosocial rehabilitation, and sought greater assimilation with the community than those who had just started using rehabilitation services. It was observed that targeted occupational activities increased a person's involvement in community life through the holistic implementation of the concept of health, meeting individualised needs, highlighting strengths, and support from the immediate environment of the person with a disability.

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