**ARCADA**

# Estonian mental health service users' experiences regarding autonomy

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Abstract:

A significant number of qualitative studies and autobiographical perspectives of people who are living with severe mental illness show that a growing sense of agency and autonomy is considered as the key aspect of recovery. The aim of this research was to explore how the Estonian mental health service users experience receiving mental health services in relation to their sense of autonomy. The research was carried out by using qualitative content analysis. The sample involved 5 adults with different mental health issues, with whom semi-structured interviews were conducted. The results show that respectful, genuine, emphatic and inclusive treatment that follows horizontal expertise creates trust and safety which results in better collaboration and enhanced autonomy. At the same time, providing insufficient information, not taking the service users' opinion into consideration and overuse of coercion by medical staff can be seen as hindering the service users' autonomy. The community based mental health center enhances the service users' autonomy by providing tools to cope with everyday life and by supporting the person regarding the accomplishment of their personal goals. Simultaneously, paternalistic pressure in order to complete goals that do not actually belong to the service user but to the service provider themselves, can harm the person's autonomy. The study also revealed that even though people with severe mental illness have more limitations, they can still be autonomous and sense that they direct their lives. The findings confirm the idea, that autonomy should be seen as a process of individual growth in interaction with the environment and that it might not be an "all-or-nothing" right but a shifting state. The role of the care provider is to actively facilitate the service users' ability to exercise control over their lives as much as it is possible. The main limitation of this research was the wide scope of the study, which included the service users' experiences regarding both psychiatric and community based mental health services. The author recommends conducting a research in Estonia focusing on either psychiatric or community based mental health services in order to go deeper into the subject of service users' autonomy.

| Keywords: | Autonomy, self-determination, mental health care, psychiatric services, community based mental health services, lived experiences of mental health service users, coercion in mental health care, practices that support autonomy, mental health ethics, qualitative research, Estonia |
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| Number of pages: | 46 |
| Language: | English |
| Date of acceptance: | |

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# 1  INTRODUCTION

This thesis seeks to explore the subject of autonomy through the lived experiences of Estonian mental health service users. The concept of autonomy has different meanings in different contexts but in this paper, autonomy is seen as the person's ability to make decisions regarding their own life and exercise control over it. This involves the ability to take an active role in the recovery process by participating in treatment planning and rehabilitation but also having the general ability to decide upon how to live one's life according to their own preference.

According to Drake and Whitley (2014), a significant number of qualitative studies and autobiographical perspectives of people who are living with severe mental illness show that a growing sense of agency and autonomy is considered as the key aspect of recovery. The ability to speak for oneself and to be taken seriously enables a person to become self-determined and take responsibility in life.

A study done by Myers et al. (2016), found out that a community mental health service program that encouraged independence and personal responsibility for wellness improved the overall autonomy of the participants. The ability to participate in the treatment planning and having it tailored according to their personal needs, gave many participants also a greater sense of self-worth (Myers et al., 2016).

In their autobiographical narratives, people with mental illnesses note that empowerment can come through a mental health system that provides "choices, options, information, role models, opportunities for bettering one's life" (Drake and Whitley, 2014). The mental health system with its rules, regulations and procedures as well as the professionals with their knowledge, values and attitudes can have a great influence on the person's health and recovery. By showing empathy and helping the service user and their family to make informed decisions about the treatment, mental health workers can provide tools to cope with difficult life situations and provide a sense of control over one's life.

Simultaneously, negative experiences that decrease one's sense of autonomy, such as being subjected to involuntary treatment, paternalistic attitudes on behalf of the professionals, lack of respect, superficiality or indifference regarding the service users' preferences and experiences can in the long run cause unwillingness to seek help or

cooperate with mental health professionals which might result in more frequent relapses and a general worsening in the service users' health condition.

According to a study done by Chambers et al. (2014) in England, patients who were involuntarily hospitalized expressed the feeling of lacking autonomy and powerlessness while detained which contributed to the diminishing of their self-worth and the feeling of not being treated as human beings. The same idea was already expressed by Kant in the 19th century who characterizes autonomy as "the ground of the dignity of the human and every rational nature" (Kant, Wood and Schneewind, 2002). Therefore, it can be concluded that a decrease in autonomy makes a person feel less of a human being.

The reason for choosing this topic stems from the author's interest in the subject of mental health ethics and wish to draw attention to the subject of supporting the service users' autonomy. Currently, there is a lack of studies done in Estonia that focus on listening to the service users' perspective and experiences on the matter of autonomy. This in concordance with Shields et al. (2019) who note that while the service users' voice has been gaining in legitimacy and value, policy initiatives and system development continues to lack input from the target group whose situation it is supposed to improve.

The author hopes that through giving voice and listening to the personal stories of the service users it would be possible to explore the themes that can be seen as either supportive or diminishing to the service user's autonomy in Estonian context. Hopefully the results can be used to further research this subject and possibly contribute to improving the situation of people with mental illnesses in Estonia.

The following chapters provide a background to the study area by introducing the concept of personal autonomy in the context of mental health from an ethical and philosophical standpoint followed by describing principles and approaches that support service users' autonomy, as well as practices and attitudes that restrict autonomy. The paper then moves on to stating the aim and research question as well as describing the choice of research methods, data collecting and analysis procedure. After that, the study results are presented and discussed. Finally, the ethical aspects and issues of trustworthiness of the research process are considered and a conclusion is given to the work.

## 2   BACKGROUND

## 2.1 The concept of personal autonomy in mental health care

### 2.1.1 Personal autonomy from the negative rights perspective

Negative rights are seen as the rights that entitle a person to be left alone from the interference of another person or a group of persons. It means that if someone has a negative right, they are free to do some action or not to do some action without anybody forcing or inhibiting them (Capone, 2011).

*I wish my life and decisions to depend on myself, not on external forces of whatever kind. I wish to be the instrument of my own, not of other men's, acts of will. I wish to be a subject, not an object; to be moved by reasons, by conscious purposes, which are my own, not by causes which affect me, as it were, from outside (Isaiah Kant).*

In bioethics, the subject of autonomy is one of great importance. Preservation of the patient's autonomy is seen as the cornerstone of respect for patients (Atkinson, 2007). Hence, autonomy is acknowledged as the guiding principle, a state to be preserved or a goal for patients to be reclaimed. Usually, it is regarded as the assumption that patients' wishes in relation to the treatment they receive need to be protected and respected in the form of informed consent (Atkinson, 2007).

According to Brendel (2015), people have the right to be free from intrusion by the state and others—whether rational or irrational, the only exception being the state's legal responsibility to protect those who are unable to protect themselves when there is a risk of harming oneself or other people. From the mental health perspective this means that people should be left alone and any kind of restriction of autonomy in the form of compulsory treatment or hospitalization is justified only if a person appears likely to, due to mental illness, do something which will destroy or seriously harm either their own autonomy or that of others (Lesser, 2013).

Breeze (2001) states that according to different ethical theories of deontology and utilitarianism, the prerequisite for autonomy is rationality and the absence of it is considered as a justification for "weak paternalism". The problem with this approach is

that the assessment of rationality can be very subjective (Breeze, 2001). For example, although often it might seem obvious that the benefits of medical treatment outweigh the disadvantages, some patients might still decide not to take medication because the side-effects that they are experiencing are worse than the suffering that comes from the mental illness (Lesser, 2013). In this case, although it might be difficult to understand for the people surrounding the patient, the decision can still be seen as rational. People, even if not perfect, are normally still the best judges of their own interests (Lesser, 2013).

Lesser (2013) adds that the mere fact that a person's decision is unwise or even seriously unwise, is not enough to determine incapacity. Only after all the steps have been taken to help the person, particularly by providing the relevant information in a way that they can understand it, can such assessment be made. Also, sometimes a person might lack autonomy in one area but possess it in another area. For instance, a patient might not be capable of making decisions about their finances but is perfectly able to make competent decisions regarding their health care.

Another principle that should be followed is that the decision of compulsive treatment or hospitalization should not be made on punitive grounds, no matter how unpleasant the person is behaving (Lesser, 2013). This requires self-awareness on behalf of the staff because these kinds of motives are often rejected on a conscious level but they can affect the decision-making nevertheless. Neither should anybody be coerced to treatment for the convenience of somebody. Most often it is the family, who might plead that their close one would be hospitalized. Lesser (2013) emphasizes that the family's point of view and concerns should be taken seriously but in order to detain someone in hospital compulsorily or to administer compulsory treatment, there needs to be good evidence that the person indeed has a mental disorder and is dangerous to themselves or others because of it.

Thomas Szasz (cited in Lesser, 2013) argues that compulsory admission is not a medical question, but a moral and political one. According to Szasz, if someone injures other people, it is a matter of law, and if they injure themselves, it should be their own business. Whether there should be any intervention or not if someone supposedly could harm someone else or themselves, is a political question. If freedom is believed to be the

supreme political value, then there should be an intervention only on the ground of what someone is actually doing rather than what they might do (Szasz, cited in Lesser, 2013)

## 2.1.2 Personal autonomy from positive rights viewpoint

In contrast to the individual's negative rights that focus on *freedom from* something, Berlin defines positive rights as *freedom to* (Berlin, 2002). Personal freedom is the possibility of acting — or the fact of acting — in such a way as to take control of one's life and realize one's fundamental purposes (Carter, 2019). One can think of freedom as the existence of control on the part of the agent. To be free, one must be self-determined, which means that one must be able to control their own destiny in regards to their interests. Rather than the liberal-individualist concept of liberty -   the protection of the individual from unwanted "interference", the positive freedom understands freedom as a form of "self-mastery". According to this view, a person is positively free only if their true or autonomous self is in control and if they have the essential resources and abilities to fulfill their plans and desires (Wertheimer, 1993).

Wertheimer (1993) adds that if we were to consider mental illness as an "internal" or "intrapsychic" coercion, then it might be easier to justify "external" coercion. According to this view, people with mental illnesses will be coerced either internally or externally in any case but only external coercion has the potential of relieving the person from both internal and external coercion in the future (Wertheimer, 1993). In other words, if mental illness causes the loss of autonomy, then external coercion can be justified on the basis that it has the possibility of providing future autonomy.  For example, someone who is experiencing psychosis, might speak of thoughts which are not theirs or having thoughts put in their head. In that case they might feel that they are not in control of their thoughts or actions and as a result, their own life in general (Atkinson, 2007). From this point of view providing involuntary treatment to that patient, although restrictive to one's autonomy from one hand, could on the other hand be seen as a mechanism to strengthen *future* autonomy of the patient (Lesser, 2013).

Agich states that the liberal or classical concept of autonomy as a right, has a number of limitations (Agich, cited in Le Granse, Kinébanian and Josephsson, 2006). It does not sufficiently take into consideration that humans are social beings and that the decisions

that are made during care provision have a significant effect on the person's life. Agich sees autonomy more as a process of individual growth in interaction with the environment (Agich, cited in Le Granse, Kinébanian and Josephsson, 2006). Similarly, Atkinson (2007) states that considered developmentally, autonomy might not be an "all-or-nothing" right but a shifting state.

Wilken (2010) adds that from the narrative study, it is apparent that autonomy and dependence can exist at the same time. Due to their disability some people might trust part of their autonomy to others and autonomy is realized in connection to other people. According to Wilken (2010), the main feature of autonomy is that the person is (finally) in control of the decisions made regarding their life. This is something that the care provider should actively facilitate through finding the strengths and vulnerabilities of the client in order to restore the ability to exercise control as much as possible.

According to Munetz, Galon and Frese (2003), the arguments on individual human rights, and people's rights about their own lives provide a powerful position against coercive treatment. Nevertheless, they point out that such a purely rights-based approach could leave "revolving door" patients in unacceptable circumstances, leaving them unable to improve their lives. The decision to not practice any compulsory interventions may contradict mental health practitioners' main obligation to help people. (Munetz, Galon and Frese, 2003). Wilken (2010) refers to Andries Baart according to whom "autonomy should not result in a situation in which one is allowed to die all alone due to loneliness, drugs, madness and an untamable temper, because one chooses so oneself".

Entwistle, Carter, Cribb and McCaffery (2010) state that a more relational understanding on autonomy should be applied. Namely, that independence should be de-emphasized and instead the patient-clinician communication style should be in focus to understand what supports and what undermines the patient's autonomy.

Entwistle, Carter, Cribb and McCaffery (2010) add that if practitioners are overly focused on offering patients freedom of choice rather than enabling them to make informed decisions, then they might fail to properly help those who are basically "competent" but due to lack of confidence are having difficulties choosing between different health care options. From this perspective, if a clinician is only willing to inform the patient about

health care options and insist that they themselves need to choose, the patient might instead feel abandoned (Entwistle, Carter, Cribb and McCaffery, 2010).

Wilken (2010) refers to Baart according to whom the nowadays widespread notion that all people are capable of being autonomous, know how to be independent, live their lives and develop, is an ideal (or even ideology) that for many seems to be out of reach. Simultaneously, inability to comply with this social norm excludes these people from mainstream society. Wilken (2010) concludes that instead of the idealization of individuals as self-sufficient and self-reliant, the neediness, vulnerability and interdependence of all human beings should be recognized and, in this context, people who depend on care and support can also be autonomous.

## 2.2. WHO's principles for supporting patient's autonomy

Out of WHO's ten basic principles for mental health care law (1996), three cover directly the subject of self-determination and autonomy. These principles are:
- Provision of the least restrictive type of mental health care. Persons with mental health disorders should be provided with health care which is the least restrictive.
- Self-determination. Consent is required before any type of interference with a person can occur.
- Right to be assisted in the exercise of self-determination. In case a patient merely experiences difficulties in appreciating the implications of a decision, although not unable to decide, he/she shall benefit from the assistance of a knowledgeable third party of his or her choice.

WHO's (1996) recommendations for implementing self-determination are:
1. Presuming that patients are capable of making their own decisions unless proven otherwise;
2. Making sure that mental health care providers do not systematically consider that patients with a mental disorder are unable to make their own decisions;
3. Not systematically considering a patient to be unable to exercise self-determination with regard to all components (e.g., integrity, liberty) because the patient was found to be unable with regard to one (e.g., authority for involuntary

hospitalization does not automatically include authority for involuntary treatment, especially if the treatment is invasive);

4. Giving verbal and written information (in an accessible language) to patients about the treatment; detailed verbal explanations should be provided to patients unable to read;

5. Calling for the patient's opinion regardless of his or her ability to consent and giving it careful consideration prior to carrying out actions affecting his/her integrity or liberty; asking someone deemed unable to decide about his/her own good to explain the motives behind a given opinion may unveil legitimate concerns for consideration and, as such, promotes the exercise of self-determination;

6. Abiding by any wishes expressed by a patient prior to becoming unable to consent.

## 2.3 Open Dialogue and Need-Adapted Approach

Open Dialogue and Need-Adapted Approach are integrated mental health treatment systems that engage families and social networks from the very beginning of their seeking help. Both approaches can be seen as examples of approaches that enhance mental health service users' autonomy by emphasizing the service users' involvement in the health care process.

One of the core principles of Open Dialogue and the Need Adapted Approach is the use of dialogism in which the patient, the social network of the patient and the staff all openly discuss the current situation focusing primarily on the relation between the patient and the family members (Seikkula et al., 2003; Piippo and Aaltonen, 2008). Everybody, including the staff, reflects openly about their thoughts and feelings about what is heard in the meeting which as a result provides the patient and the family members several reflections to their story and creates a shared understanding of the issues. All plans and decisions regarding the treatment are also made with everyone present (Seikkula et al., 2003). This sort of open discussion can be a powerful tool in order to make the patient feel that they are heard and understood and as a result increase their agency in their own lives. A study done by Piippo concluded that the consequence of versatile interchange of knowledge and understanding leads to the experience of wholeness and autonomy (Piippo and Aaltonen, 2008).

According to Piippo and Aaltonen (2008), the patient's experience of autonomy, safety, trust and honesty are interdependent in the treatment process. Through honesty and openness trust can be increased, which as a result creates autonomy and the feeling of safety.

Additionally, an important aspect in creating trust between the patient, their social network and the staff is practicing horizontal expertise. This means that the staff consciously share the power and show that the patient's and their family members' ideas and knowledge of the situation are as highly valued as the views of the professionals. (Pippo and Aaltonen, 2008)

Furthermore, if the patients experience autonomy, they might as a result feel more responsible for their situation and its further development (Piippo and Aaltonen, 2008). This gives them the power to improve their lives with less intervention from the professionals. This sort of treatment which treats patients as individuals and enhances their autonomy also creates more trust towards the treatment system and as a consequence the patients are more likely to seek and accept help from the professionals. (Piippo and Aaltonen, 2008).

Another core principle of Open Dialogue that can be seen as enhancing the service users' autonomy is tolerance of uncertainty. This guiding principle is applicable to crisis situations where instead of "quick fixes" like prescribing high doses of neuroleptics or involuntary hospitalization of the patient, a different model is used. In case of a crisis, mental health professionals try to create an adequate sense of safety through meeting the network on a daily basis at least for the first 10-12 days. The goal is to support the network during the crisis while avoiding premature conclusions or decisions about the treatment. Especially when it comes to neuroleptic medication, it is discussed at least during three meetings before introducing it. By being present and constantly evaluating the situation together with the network, it is possible to go deeper, get a better understanding of the situation and find more resources within the network, instead of just reacting to what is happening. Because this kind of approach gives the patient and their family the opportunity to live through the crisis while still feeling relatively safe, they acquire knowledge and tools on how to cope and make informed decisions in its true sense, which as a result supports the patient's autonomy (Seikkula et al., 2003)

## 2.4 Shared Decision Making

Another patient-centered model is Shared Decision Making (SDM), which is a collaborative and dynamic process that recognizes patients both as individuals and as equal partners in their care. Reflective listening and sharing of options and choices is used and, in this way, patients are empowered to participate actively in their treatment (Velligan, cited in Walsh Tulley, 2017).

According to Velligan, patients often do not understand their treatment and want more information and choice options. The SDM approach is especially suitable in order to clarify the patient's preferences when there is no clear best option for the treatment (Velligan, cited in Walsh Tulley, 2017). The tools that are used are Controlled Preference scale, which provides the clinician information on how involved the patient wishes to be in the treatment decisions. The Elwyn Shared Decision-Making model offers the service provider behavioral strategies to promote patient involvement in treatment choice, options and decisions. Finally, the Tell-Ask-Choose-Review program aims to give patients advice on what their role is in the treatment process and how to get the most from their visits in order to be more positively engaged.

A study done in Australia researched the patients' perspective on SDM in "real world" hospital sample (Nott et al., 2018). The results showed that SDM leads to more positive attitudes towards medication and may improve adherence with treatment. The results also showed that patients that were involuntarily hospitalized had experienced lower levels of SDM.

A study done in Germany by Hamann et al. (2009), evaluated the opinions of 352 German psychiatrists towards using SDM with patients who have been diagnosed with schizophrenia. The results showed that over half of the psychiatrists use SDM regularly, but decision-making styles were adjusted depending on the individual patients and decision topics. For example, SDM was seen as beneficial for well-informed and compliant patients and for those who are currently not satisfied with their antipsychotic medication. SDM was not seen as suitable for patients who potentially lacked decisional capacity. Psychosocial matters such as future housing, psychotherapy and work-therapy were considered more suitable for SDM than medical and legal decisions, such as hospitalization, prescription of antipsychotics or questions regarding legal guardianship. This study, as well as the previous, concluded that patients who are seen as lacking in

decisional capacity are often not involved in SDM. Then again, studies show that although people with schizophrenia have indeed shown poorer decisional capacity when compared to people without any mental or physical conditions, in most cases the results became equal when they received an additional educational intervention that allowed them to think through the information necessary to accept the treatment (Hamann et. al, 2009).

These two studies, from the perspective of patients and psychiatrists, show that even when the patient is involuntarily hospitalized or not compliant regarding the treatment, an effort should be made to give them as much information as possible about the treatment and try to involve them in the decision-making process. Nott et al. (2018) concluded that this method could be especially beneficial in treating this type of patients because, contrary to the belief of many psychiatrists, openly sharing information regarding medication side effects does not negatively impact medication adherence. Due to the fact that SDM makes patients feel valued and empowered, it is likely to enhance patient's autonomy (Nott et al., 2018)

## 2.5 Psychiatric Advance Directives

Psychiatric Advance Directives (PADs) are documents that enable patients with severe and chronic mental illness to notify their treatment preferences for future mental health crises and to appoint a proxy decision maker for the period that they themselves are incompetent to make decisions (Nicaise, Lorant and Duboise, 2012). The aim of PADs is to enable self-determined treatment for patients who lose decisional capacity and, in this way, reduce coercive interventions such as the use of police transport, involuntary hospitalization or involuntary usage of psychiatric drugs during mental health crises (Swanson et al., 2008). According to Swanson et al. (2008), less use of coercion should lead to increased autonomy and self-direction for people who experience serious mental health problems.

A study done by Swanson et al. (2008), examined whether the use of PADs can be associated with reduced frequency of coercive crisis interventions (CCIs) mentioned above. The study revealed that in the presence of incapacity, the predicted use of CCIs was 43-49% among patients without PADs, whereas among patients with PADs it ranged from 20-28%. CCI rates were overall much lower among patients who had completed

PADs whereas they had not lost decisional capacity during a mental health crisis (Swanson et al., 2008).

Then again, a systematic view on PADs done by Nicaise, Lorant and Duboise (2012) analyzed 38 research papers that covered the subject of the PADs and found that the use of PADs cannot be associated with enhanced patient autonomy. According to the authors, their main finding was that instead of having a positive effect on patient autonomy, PADs are more efficient as tools to improve the therapeutic alliance between the patient and the clinician (Nicaise, Lorant and Duboise, 2012).

It might just be that PAD as a legal document does not have a significant effect on patients' autonomy *per se* but more so the process of completing it. Swanson et al. (2008), state that the experience of legally documenting one's future treatment preferences might motivate the service user to be more actively engaged in the treatment planning, which as a result might result in a lower occurrence of mental health crises (Swanson et al., 2008). Secondly, the above-mentioned improvement of therapeutic alliance and trust that happens when the clinician and patient together discuss and prepare a PAD, can result in better handling of future crisis situations. For example, if the clinician is familiar with the patient and their PAD, then she might also be in a better position to advocate for the patient's preferences during a crisis (Swanson et al., 2008).

## 2.6 Coercion in mental health care

Coercion in mental health care is a term that is used to describe a range of practices which aim to make a person accept treatment that has been refused. It includes compulsion and other treatment pressures like interpersonal leverage and persuasion (Szmukler, 2015). Molodynski, Rugkåsa and Burns (2010), state that even though the subject of coercion in psychiatry has traditionally focused on the question of formal mechanisms of compulsion, such as compulsory hospitalization, it does not represent the overall picture, as there are many other (informal) strategies that are widely used in order to pressure service users to accept treatment. Szmukler and Appelbaum (2008) have described different types of pressure as a hierarchy, ranging from "persuasion" as the least coercive and "compulsion" as a last resort, when nothing else works (see Figure 1).
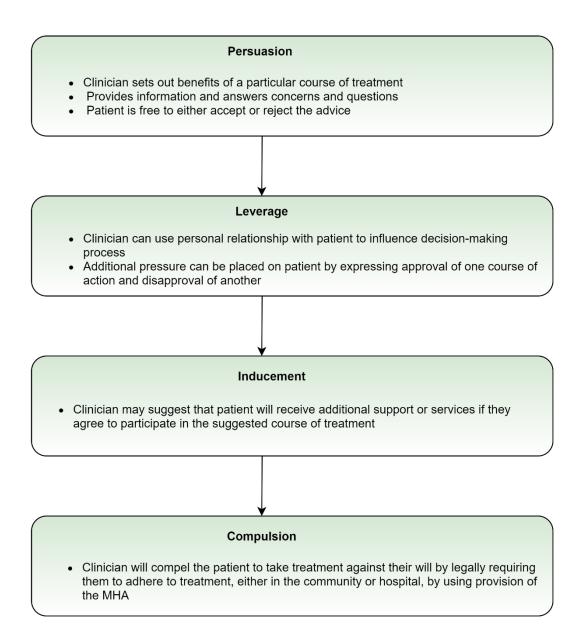
**Persuasion**

- Clinician sets out benefits of a particular course of treatment
- Provides information and answers concerns and questions
- Patient is free to either accept or reject the advice

**Leverage**

- Clinician can use personal relationship with patient to influence decision-making process
- Additional pressure can be placed on patient by expressing approval of one course of action and disapproval of another

**Inducement**

- Clinician may suggest that patient will receive additional support or services if they agree to participate in the suggested course of treatment

**Compulsion**

- Clinician will compel the patient to take treatment against their will by legally requiring them to adhere to treatment, either in the community or hospital, by using provision of the MHA

*Fig 1. Hierarchy of treatment pressures.*

These types of treatment pressures are widely used by mental health care professionals and are considered necessary for the benefit of the patient's health and general well-being but at the same time can affect the patient's autonomy negatively.

Wertheimer (1993) describes coercion as "threats". When a person is "threatened", they will be in a worse state regarding some relevant moral baseline if they do not accept the proposal. For example, sentences like "If you don't start taking your medicine, you will be involuntarily hospitalized," can be seen as coercion".  In this case, the moral baseline that is compromised is liberty, which they would be deprived of, should they not accept the proposal (Wertheimer, cited in Szmukler, 2015).

According to Wertheimer (1993), the distinction between coercion and inducement or persuasion is connected to the different kinds of psychological stress that one experiences when having to make a decision as in contrast to the feeling of constraint. Then again, if a person sees the proposal as a threat, then they might feel more resentful than if they see it as an offer. How they see it depends on their moral beliefs. For example, if a person believes that the doctor has a *right* to propose a treatment, in contrast to a family member (what do they know), then the person will most likely feel less constrained by the doctor than by the family. In Wertheimer's (1993) opinion, coercion is a constraint on freedom, whereas inducement and persuasion do not threaten one's freedom or autonomy (Wertheimer, 1993).

Valenti et al. (2015) point out that while formal coercion in psychiatry is regulated by legislation, other interventions that are referred to as informal coercion, are often less regulated. Their research aimed to find out which way these interventions are used by mental health professionals in ten different countries with different sociocultural contexts. The results showed five common themes: (1) a belief that informal coercion is effective; (2) an often-uncomfortable feeling using it (3) an explicit as well as (4) implicit dissonance between attitudes and practice - with wider use of informal coercion than is thought right in theory; (5) a link to principles of paternalism and responsibility versus respect for the patient's autonomy (Valenti et al., 2015).

A systematic review done on the subject of informal coercion by Hotzy and Jaeger (2016) revealed that the prevalence rates of informal coercion were 29-59%. The results revealed the majority of the health professionals and one third of the patients had a generally positive attitude towards informal coercion. The subjective evaluations of positive outcomes were described as enhancement of adherence, promotion of clinical stability, and avoidance of relapse. The negative consequences of informal coercion were increasing stigma of psychiatric services, weakening of the therapeutic relationship and consequent avoidance of mental health care (Hotzy and Jaeger, 2016).

Hotzy and Jaeger conclude that similarly to formal coercion, ethical and clinical guidelines should be applied to using informal coercion. Coercive interventions should only be used if less invasive interventions are not applicable and the expected advantage

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outweighs the potential harm by the intervention itself. Hotzy and Jaeger (2016) add that in order to apply informal coercion ethically, legally and therapeutically, there needs to be awareness on behalf of the professionals that leverage and other types of treatment pressures are very common in daily mental health care. Mental health professionals should be competent to realize when they are using informal coercion, what is the impact of it as well as the ethical guidelines of using this intervention (Hotzy and Jaeger, 2016).

# 3 AIM

This thesis aims to study Estonian mental health service users' experiences regarding autonomy. The research question is:

1. How do people with mental health problems experience receiving mental health services in Estonia in relation to their sense of autonomy?

The table below shows the research process as well as the steps that are taken to reach the aim of the thesis.

**RESEARCH QUESTION**
- How do people with mental health problems experience receiving mental health services in Estonia in relation to their sense of autonomy?

**RESEARCH SUBJECT**
- Mental health service users

**DATA COLLECTION METHODS**
- Semi-structured interviews, open-ended questions

**RESEARCH DATA**
- Voice recorded and transcribed interviews
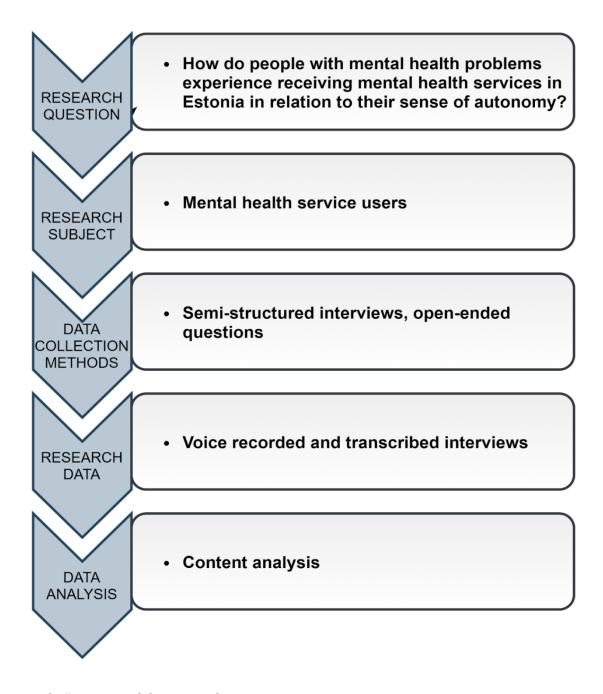
**DATA ANALYSIS**
- Content analysis

*Fig 2. Summary of the research process*

# 4 RESEARCH METHODOLOGY

## 4.1 Description of research method

In order to study Estonian mental health service users' experiences, qualitative content analysis method was chosen. Qualitative research is suitable when the primary interest is what meaning people attach to the things in their lives (Taylor, Bogdan and DeVault, 2015). The central idea is to understand people from their own frames of reference and experience reality as they experience it. In order to understand how the people, they are studying see the world, qualitative researchers try to empathize and identify with them. At the same time, the researchers must attempt to stay neutral and set aside their own perspectives and taken-for-granted views of the world (Taylor, Bogdan and DeVault, 2015). This does not mean that the researcher cannot have their own pre-understanding about the matter or no preconceived knowledge of the area of investigation but that there needs to be self-reflection and awareness in order to minimize any bias of their influence (Bengtsson, 2016).

According to Hsieh and Shannon (2005), qualitative content analysis is a flexible research method for analyzing text data that has recently been widely used in health studies. It is suitable for the subjective interpretation of the content of text data and uses the systematic classification process of coding and identifying themes or patterns (Hsieh and Shannon, 2005). The focus is on the characteristics of language and communication while focusing on the content or contextual meaning of the text (Bengtsson, 2016). According to Bengtsson (2016), content analysis examines the language intensely in order to classify large amounts of texts into an efficient number of categories that represent similar meanings. Through presenting thorough descriptions of specific settings or phenomena, the results of qualitative content analysis can help to develop new theories and models as well as validate existing theories (Zhang and Wildemuth, 2005).

The study design includes conventional content analysis, which allows the categories and names for the categories to appear directly from the text (Hsieh and Shannon, 2005). The absence of preconceived categories allows the material to speak for itself. This type of category development where the categories emerge from the data through the researcher's careful examination and constant comparison follows the inductive reasoning (Zhang and Wildemuth, 2005).

Instead of testing any theory or hypothesis, inductive reasoning is based on learning from experience (Dudovskiy, 2021). According to Dudovskiy (2021), in order to reach conclusions or to generate theory, patterns, resemblances and regularities are observed.

## 4.2 Sampling and recruitment

The sample involved 5 adults with different mental health issues. No specific diagnosis, age group or sex was targeted because the focus was on exploring the experiences rather than making generalizations about the sample group. The sample group consisted of three women and two men whose age ranged from 27 to 51 years. The mental health issues that the interviewees had experienced were primarily psychotic disorders such as schizophrenia and mood disorders such as depression and bi-polar disorder. The inclusion criteria were that the participants had to have at least one year experience of using psychiatric and rehabilitation or special care services in a community based mental health organization. The time factor was considered important because it allows to present a broader view to the subject. In reality, all of the participants had been using both psychiatric services and community based mental health services 5 years at minimum.

This type of sampling technique, that identifies and selects individuals or groups that are especially knowledgeable about or experienced in the subject of research, is called purposeful sampling (Cresswell and Plano Clark, 2011). According to Palinkas et al. (2013), purposeful sampling is a technique widely used in qualitative research as it allows the identification and selection of information-rich cases for the most effective use of limited resources. This involves identifying and selecting individuals or groups of individuals that are especially knowledgeable about or experienced with a phenomenon of interest (Palinkas et al. 2013).

The participants were contacted through Tallinn Mental Health Center which is a community based mental health service provider in Tallinn offering a wide range of services to adults with different mental disorders. Rehabilitation services offered in Tallinn Mental Health Center include the services of a personal psychologist, art and music therapist, occupational therapist, social worker, physiotherapist and a nurse. The special care services include daily life support services (personal support worker, day-care centers) and an assisted living service (with housing).

The author works in the same organization but avoided interviewing persons who she works with. Other staff members of the rehabilitation team helped to choose the participants who met the inclusion criteria of the research and were willing to share their experiences. The author then contacted the potential participants via phone or e-mail, briefly introducing the aim of the research. Six persons agreed on participating in the interview, out of which one later cancelled due to health problems.

## 4.3 Data collection

Data was collected through conducting semi-structured interviews. According to Jamshed (2014), semi-structured interviews are widely used in the research of different health care professionals. This method of data collection was chosen because it allows the researcher to gather open-ended data in order to examine the interviewee's thoughts, beliefs and experiences about a certain topic and to explore subjects that might sometimes be rather personal and sensitive (DeJonckheere and Vaughn, 2019). Additionally, this type of data collection is suitable when the interviewer only gets one chance to interview someone (Cohen and Crabtree, 2006). It provides structure but also allows flexibility.

According to Jamshed (2014), semi-structured interviews follow an interview guide, which is a schematic presentation of the questions and topics that are being researched. At the same time, the interview protocol is flexible, consisting of open-ended questions and the use of planned and un-planned follow-up questions that invite further clarification, exploration or elaboration (DeJonckheere and Vaughn, 2019).

Key features of semi-structured interviews according to DeJonckheere and Vaughn (2019)

- Loose, flexible structure
- Iterative
- Groups or individual participants
- Scheduled in advance
- Gathers information from key informants who can inform the topic
- Insight into participant perspectives
- Deep exploration of participant thoughts and experiences
- Often the sole data source for a qualitative study

*Fig. 3 Key features of semi-structured interviews*

The research design covered the areas of psychiatric treatment and community based mental health services focusing on different subjects that were considered relevant to the subject of service users' autonomy.

The interview guide (see Figure 4), consisted of open-ended questions that covered the subjects of obtaining information about different treatment options and mental health services, ability to participate in the planning of medical treatment and rehabilitation services, perceived effects of the services, experiences of treatment pressures, attitudes of staff and the feeling of being in control in one's life.
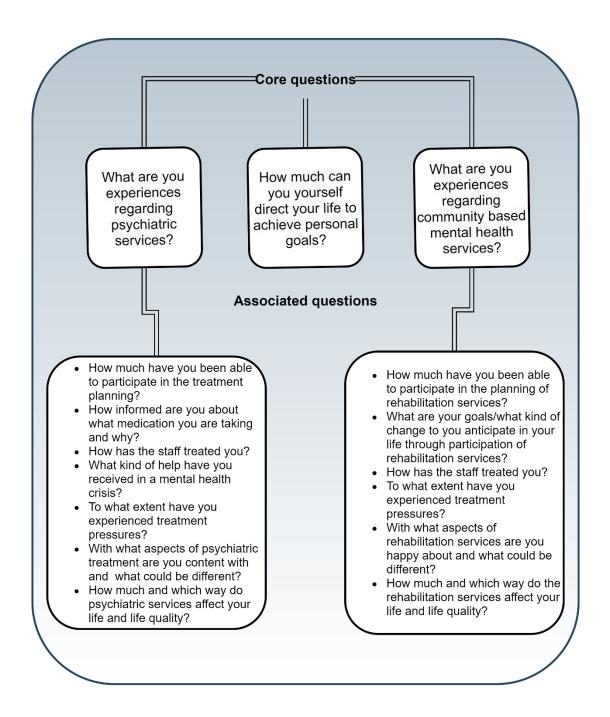
**Core questions**

What are you experiences regarding psychiatric services?

How much can you yourself direct your life to achieve personal goals?

What are you experiences regarding community based mental health services?

**Associated questions**

- How much have you been able to participate in the treatment planning?
- How informed are you about what medication you are taking and why?
- How has the staff treated you?
- What kind of help have you received in a mental health crisis?
- To what extent have you experienced treatment pressures?
- With what aspects of psychiatric treatment are you content with and what could be different?
- How much and which way do psychiatric services affect your life and life quality?

- How much have you been able to participate in the planning of rehabilitation services?
- What are your goals/what kind of change to you anticipate in your life through participation of rehabilitation services?
- How has the staff treated you?
- To what extent have you experienced treatment pressures?
- With what aspects of rehabilitation services are you happy about and what could be different?
- How much and which way do the rehabilitation services affect your life and life quality?

*Fig. 4. Interview guide*

## 4.4 Procedure

The interviews took place during the 26-27th of April 2021 in Tallinn Mental Health Center. This location was chosen because it is familiar to the interviewees and the facility has rooms that are both private and comfortable. This is the environment where the interviewees regularly meet with their psychologist and other professionals who offer

services to them in the community based mental health center and therefore was considered a safe space. All of the interviews were conducted in Estonian language.

The interviews started with introduction and expression of gratitude towards the participants that they had agreed to take the time to share their experiences. The author briefly introduced herself, the aim of the research and the process of the interview. The author then introduced the key features of the consent to participate in the research which was then followed by signing the document.

The interview was captured through using voice recording (permission was asked beforehand in the written consent) which allowed the author to actively engage in the conversation while capturing all the relevant information that would later be analyzed.

The recorded interviews lasted 50-80 minutes during which the author followed the interview guide flexibly, modifying the sequencing and wording of the questions to best fit the interviewee and the context. When the interviewee was open to discuss a certain question more in depth, the interviewer followed the pace and the other way around, if the interviewee did not want to discuss a certain topic, the interviewer moved on to the next question. As a result, not all questions presented in the interview guide were covered equally in each interview. This was not seen as a problem as it allowed the interviewees to express their thoughts on subjects that are relevant to them, which was valuable information for gaining a better understanding of the research topic.

During the interview, the author tried to use a warm and a respectful tone encouraging the interviewee to openly express their thoughts and feelings about their experiences regarding psychiatric and community based mental health services. According to DeJonckheere and Vaughn (2019), the interviewer should build trust quickly by listening attentively and respectfully to the information shared by the interviewee. The author also acknowledged the sensitive nature of the conversation, allowing to skip or move on when the interviewee showed too much emotional distress.

Due to the fact that the author works in the same organization and has regular meetings with the service users, it was important to be aware of the different role that the author was carrying during these interviews in contrast to the normal meetings. For example,

normally the author would probably react more to some of the experiences that were shared, trying to soothe or give an opinion, whereas in this case she had to use a more neutral tone, in order not to influence the answers or course of the interview too much.

After the recording had finished, there was a short exchange of thoughts and feelings regarding how it was to participate in the interview. The author, again, expressed gratitude and gave feedback that the participants did well, which clearly seemed to make the interviewees happy.

## 4.5 Data analysis

The data was analyzed in four stages*: transcribing and familiarizing with the text, coding, identifying categories, identifying themes*. In the analysis process, latent meaning was searched. According to Bengtsson (2016), in latent analysis the researcher seeks to find the underlying meaning of the text to understand: *what the text is talking about*. Although the process of the analysis is presented below, it must be stated that it was not a linear process – the author repeatedly went back and forth between codes, categories, themes and raw data in order to assure quality.

### 4.5.1 Transcribing and familiarizing with the text

After conducting the interviews, the audio recordings were transcribed into text by using a combination of an automated transcription program (Advanced Rich Transcription System for Estonian Speech) and manual transcribing. Firstly, the automated transcription program was used after which all of the transcriptions were corrected manually. The text was read and initial notes were taken in order to become familiar with the content and get a first impression of the ideas expressed by the interviewees. The material was read on paper as it seemed to provide a better overview.

### 4.5.2 Coding

After becoming familiar with the material, the open-coding process followed, during which fragments of texts that were rich with meaningful information relevant to the research question were marked and given a code inductively. Each code was also given an explanation. According to Bengtsson (2016), using a coding list that includes explanation of the codes minimizes a cognitive change during the process of analysis in

order to secure reliability. However, the codes did change during the analysis process as some patterns started to appear, therefore it was important to repeat the coding process several times in order to assure that the codes match the text.

Coding was done using the ATLAS ti web research software, which facilitated managing and organizing the extensive data (finding utterances and codes more easily).

| Text | Code |
|---|---|
| "With hospital there is this issue that you spend very little time together with the psychiatrist. And they take it superficially in my opinion." | Supercifial care |
| "I feel that the fact that I've been sewing there, makes me feel that I'm needed, that I have some obligation and I need to get out of the door and do something. I'm useful, not just sitting at home." | Feeling needed |
| Of course I'm always a little bit afraid about whether I am able to do it right, so that people would be satisfied. Whether I do everything correctly, so that I don't forget or ruin anything. I have these type of small fears. | Overcoming fears |

*Fig.5 Coding*

### 4.5.3 Identifying categories

After coding was done, the author found the similarities and differences between initial findings and identified the categories. According to Erlingsson and Brysiewicz (2017), a category is formed by grouping together codes that are related to each other through their content or context. The codes were repeatedly moved back and forth between categories. According to Bengtsson (2016), all categories must be rooted in the data which they arise. The categories were then compared and interconnected with each other.
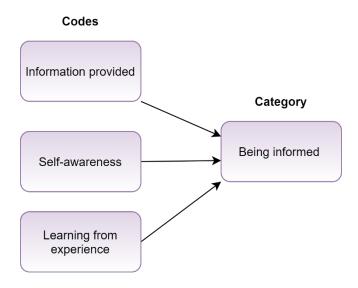
**Codes**



*Figure 6. Categorization*

## 4.5.4 Identifying themes

Finally, the categories were sorted into themes. All of the themes included at least two categories. Bengtsson (2016) describes a theme as an overall concept of an underlying meaning on a latent level. A theme should answer questions such as *why, how, in what way, or by what means?* The author then confirmed that the themes indeed covered the most important ideas and feelings expressed in the interviews and answered the main research question.

# 5 RESULTS

This chapter discusses the main findings of the research covering the service users' experiences of medical treatment and the services of a community based mental health center (MHC).

## 5.1 Wanting to experience care that is emphatic and respectful

The participants repeatedly expressed the relevance of the attitudes and behavior of the medical staff. The experience of being treated with genuine interest, empathy and respect created trust and better collaboration between the service user and the healthcare team, which at the same time resulted in better medical adherence.

*P.5 "…especially because I have the experience with my outpatient psychiatrist, with whom I see that they really care deeply. Like really care… and I feel it. And it makes me positive, because they are confident, and I trust the treatment they prescribe."*

Genuine and respectful care was sometimes considered even more important than the effectiveness of the prescribed treatment. Two of the participants distinguished the differences between mental health hospitals and units and the main aspect that attributed to the overall experience was how the staff's attitudes and behavior was perceived.

*P.5" The medical staff should treat this patient who is in a very acute state, as if they would treat a healthy person, humanely, respectfully…literally in a way that they would understand. Because no matter in what state the person is, you should treat them equally."*

Two of the participants expressed that they had very negative experiences with the attitudes and behavior of the staff while submitted in the psychiatric hospital. They felt that some of the staff members lacked sense of mission and acted in a degrading way by raising their voice, making nasty comments or criticizing when a patient was behaving in a weird way, being mean and angry and using physical force to hold someone down. The idea was expressed that when the patient is in a mental health crisis situation receiving treatment in a psychiatric hospital involuntarily, they are often feeling very vulnerable

and afraid because they are lacking control over themselves and their surroundings which is why they need the staff to make them feel safe by showing both empathy and respect.

On the other hand, two of the participants expressed positive experiences regarding the way they were treated in the psychiatric hospital. By acting humanely and showing genuine care, the staff made the patients feel respected and noticed.

*P.2 "She doesn't care (that you're a patient), you know, she's just a friendly person. Everybody who passes by this unit says she's amazing! Sometimes you need so little to lift someone up like that."*

*P1. "I was at the hospital on my birthday and the staff brought me a cake and a card. That was really nice and I liked it."*

Participants also expressed the need to be able to speak freely with their psychiatrist about their current health state. Reflective listening and attentiveness on behalf of the psychiatrist were considered important, however the level of emotional support that was expected, varied. Namely, some only expected to discuss health-related subjects, whereas others felt the need to also talk about general well-being.

*P.2 "I don't know, like emotional support or…maybe I expect too much but…being able to express how I'm doing and what's my current state, right. Maybe I can get some relief by being able to speak freely and get it out of my system. And also receive some feedback. Yeah, a little bit like a psychologist also, not just regulating the brain chemistry."*

Having enough time for the meetings was also considered an important factor. Namely, three of the participants expressed that they would like the mental health professionals to have enough time for the meeting. Especially in inpatient care, the participants had experienced that the staff had too much work on their hands and too little time, so the meetings were too short and too rare, which made the participants feel that the care that they received was either superficial and/or indifferent. One participant illustrated the lack of personal attention followingly:

*P.4 "In the hospital, it's like working on a factory line, you need products and then everybody is doing something."*

This utterance expresses the idea that the staff has very little time in the hospital ("like working on a factory line"), which makes the person feel like an object ("product") that needs to be produced quickly. It expresses the feeling of being subjected to other people's actions and a lack of autonomy.

## 5.2 Wanting to be included in the treatment/rehabilitation process

Another core factor attributing to the service users' autonomy was the way they were able to participate in the planning of medical treatment and services oh the MHC. One of the main aspects that influenced the service users' autonomy was how much the mental health professionals applied horizontal expertise and encouraged the service users' participation in the decision-making process. Another important aspect was how much and which way the service users themselves sought participation and took matters into their own hands.

### 5.2.1 Inclusion in medical treatment as an outpatient

Most of the participants expressed that they have participated in the planning of their treatment as an outpatient. This includes collaborating with their health care team in order to find a solution to a mental health crisis and giving their input by sharing their experiences with the medical staff in order to find a treatment plan that suits them best.

*P.5 "When **we** had this crisis situation here in February then **we** considered if I should go to the hospital. And then luckily, **we** got over it, the doctor increased the dosage of one drug. And then the two weeks after that were really hard but then it started to work and I felt better."*

In this example it can be seen that instead of referring to the psychiatrist as a decision-maker, the service user uses the form "*we*" which indicates active participation and agency in the process, which had a positive outcome for the participant.

Most of the participants expressed that the psychiatrist has taken their feedback regarding different medication into consideration and has changed the plan accordingly. The subjects that were mainly addressed were the side-effects and dosages of the psychiatric drugs (mostly neuroleptics) that had been prescribed.

All of the participants mentioned that with time, their awareness regarding their health condition has approved, that they understand what is their diagnosis and treatment plan and with self-awareness the participation in the treatment planning has improved. Often this type of awareness was reached by difficult experiences that involved experimenting with the drug administration.

*P.2" No…I don't dare to stop taking it (neuroleptic) completely, previously I always ended up in the hospital, when I stopped it. Then you're like up all night without being able to sleep, having compulsive thoughts over and over again. It's crazy."*

From this study it was revealed that one's own experiences and research has been the main source of health awareness. When asked about, how one has become aware about their health condition and the drugs they administer, the respondents mostly answered that they either learned it by trial and error and/or reading information about the diagnosis from the internet (or studying psychology in the university).

*P.4 "In the recent treatment planning, I participated the most and therefore it suits me the best. First, I tested this version myself and then I presented it to the doctor by saying it fits me and I want to continue that way. I did human testing on myself by myself, not like in the Frankenstein style that the doctors use! (laughter)"*

Three of the participants expressed that they wished that the treatment team would have provided more information about their health condition and suitable treatment, adding that the staff should have a more holistic approach to health and well-being. This includes sharing more information about how life-style affects mental health but also for example food supplements.

Two of the participants expressed that although they now partake actively in the treatment planning, this has not always been like this either due to inner difficulties or because some

mental health professionals, especially in inpatient care, just do not take the patient's opinion into consideration. One of the inner difficulties expressed was social anxiety, which affected the patient's ability to communicate with the staff as they were afraid to ask questions or share their thoughts. The second inner difficulty that was mentioned was the feeling of anger. Due to the inability to communicate in a diplomatic way with the medical staff, they experienced that their opinions and ideas were not taken seriously.

Regarding the subject of coercion and treatment pressures, most of the participants expressed that they had not experienced treatment pressures but collaboration as an outpatient. One participant revealed that they had experienced treatment pressures in the form of leverage and had initially agreed with the treatment plan but after leaving the meeting, reconsidered and decided not to comply stressing the fact that they knew best how they feel.

P.2 "I left the cabinet thinking, I'm going to take the 15 mg (that they suggested), but I haven't done it. I mean, I currently feel well and no, I…I don't want to."

The author has a feeling that the main reason for not recognizing different treatment pressures, is the fact that for example persuasion and leverage (see Figure 1), are especially in the case of the treatment of psychotic disorders very common in mental health practices. Participants generally consider the psychiatrist as an authority and question their suggestions mostly after the recommended treatment has proven not to be suitable.

### 5.2.2 Inclusion in medical treatment as an inpatient

The participants had different experiences with inclusion while they received care as inpatients. Regarding inclusion in voluntary inpatient care, one person stated that they had not been actively involved in the treatment planning process as an inpatient but neither did they expect to be included. The participant felt that when they are in hospital having a mental health crisis, they are there to receive help and they expect empathy and care, but not so much involvement in the treatment planning.

The author noticed that the feeling of not being included enough was mainly expressed by participants who had received involuntary treatment. This involved the feeling of not receiving enough explanations or information about why they have been submitted to the hospital, what kind of treatment they will be provided and what kind of actions will follow.

P.4 *"No, nothing was explained to me there. The doctor just listened to my story, didn't reply to anything and then I was just placed in the unit. After some time, a lawyer came, read out something, not in common language, asked whether I agreed and made me sign this paper."*

Another participant expressed that they felt that they wished the mental health care team would have had regular meetings with them providing information and support.

P.3 *" Well, firstly, I wish I would have had more information about why I'm here. I didn't exactly understand it myself. Yeah, more regular communication with the doctor. Of course, I understand, that's just the way it is but…It doesn't necessarily have to be just the doctor but like, let's say a team who comes and talks to me, everyone in their own way…approaches me somehow individually."*

One participant expressed that they were not asked about what they thought they needed in order to feel and become better. Neither were their opinions and suggestions considered, although they really felt they knew what they needed. The same person expressed that because the medication did not work, they were involuntarily submitted to electroconvulsive therapy which left her with a permanent memory damage.

 Overall, the experiences of involuntary treatment were described with words like: *traumatic, tense, stressful or difficult.* One person shared that being in a situation, where they had to be so dependent on staff's decisions and plead to be able to go home, was very hard for them.

P.3 *"There was this moment, that I remember, it was at the end of the hospital stay. I just didn't want to be there anymore and then I went and somehow pleaded that I'd like to go home soon. That took quite a lot of strength and courage from me."*

One participant expressed that due the trauma they had from their first involuntary treatment (which was also their first contact with psychiatric services), their willingness to collaborate with medical staff regarding their health problems was very low for a long time.

### 5.2.3 Inclusion in the of services of MHC

When asked about the experiences regarding MHC, all of the participants expressed that they had been included in the planning and decision-making process of rehabilitation and everyday support services. One person stated that the first times they participated in the rehabilitation services, they did it because other people pressured them to do so. Therefore, their own motivation to participate was low, neither did the staff in their opinion explain sufficiently what was the aim and outcome of the services. As their own motivation to receive services grew, their involvement also improved. All of the participants said that they could choose which services they wished to participate in, the case manager being the primary person with whom to discuss which services would be suitable. The participants thought that the services were flexible and they could participate as often as they wished. The goals were set together with the mental health professional considering the participant's needs.

P.3 *"Sometimes the goals are set but the goal changes and then…well I think I've been able to have a say quite a lot."*

All of the clients were able to state their current motivation and goals for participating in the services of MHC.

P.3 *"Right now I want to get my driving license done. That's one thing I've always wanted. That's like a bigger goal I have right now. Then finding a job, but that's on the long run. I want to find a good job that fits me. At first a part-time job but then may-be even 75% of a full-time job. Then a smaller goal is that I wouldn't experience social anxiety and that I am able to express myself as an individual and be able to interact in a group for example".*

The common reasons for participating were related to socializing and overcoming social anxiety, learning ways how to cope better with everyday life, stabilize health, gain self-awareness and finding a suitable work or path for education.

## 5.3 Supporting the service users in recovery and accomplishment of goals

Almost all participants expressed that the services offered in MHC had supported them in accomplishing their goals and/or recovery. The support that the participants mentioned can be divided into two main categories: providing tools and motivation to cope with life and accomplish goals.

### 5.3.1 Providing tools to cope in life

The participants mentioned that through participating in the individual and group services they had gained knowledge and practiced socializing. By learning how to express oneself, how to start a conversation and listen actively, two of the participants experienced that their social anxiety had either reduced or become minimal. The groups also provided the opportunity to discuss different subjects with other people who are in a similar situation, which helped to reach some clarity of thought. Another thing that was also mentioned was gaining new knowledge about health and a healthy lifestyle. For example, one person mentioned that they were really happy with the information that the physiotherapist provided because they learned how to strengthen their weaker parts. Participants also mentioned that their ability to be in the moment, self-awareness and analytical skills had improved and the variety of services that all had a different angle had strengthened the personality as a whole.

P.3 *"It has affected me very positively, really…It has strengthened my personality, at least I kind of feel this way, and analytical skills. I've been able to analyze myself and learn how to express myself. I like to go to therapies, its's constantly providing me with a new perspective or understanding."*

P.3 *"For example art therapy gives me a feeling that I can express my creativity or in the group the social part, which is helpful as well. Let's say that all of the therapies have aspects that somehow bring all of my personal life together. Yes…it's this variety."*

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### 5.3.2 Providing motivation to accomplish goals

A common thing that was mentioned was that the services provided motivation to improve oneself and/or accomplish one's goals. For example, it was mentioned that the services had helped them to find more motivation to be physically active. The participants also felt that the services had provided them motivation to get out of their house and do something useful. Just the obligation to go somewhere and do something productive, motivated two of the participants to take care of their self-hygiene and dress well. Seeing the psychologist was mentioned as the time and place where one made the effort to look into themselves and analyze aspects of their life that they would not commonly do on their own. Also, living independently was something that the workers had encouraged. Another theme that was brought up was the support in accomplishing work and study related goals. Participants said that the services had helped them to keep their job or finish their studies at moments when they were about to give up.

P.1 *"When I was finishing school, then I wanted to quit in the end. It was so hard and I couldn't do this calculating part, I'm not so good at it. I couldn't complete my final work. I took a study break and I thought that I'm not going to finish it. Then everybody supported me so that I would finish, telling me that it's not good to quit. And yeah, then I made an effort, completed the courses and somehow managed to graduate. It was a very good feeling."*

When asking about whether they have experienced pressure on behalf of the workers the common answer was that they had not experienced so much pressure but advice and motivation. One person felt that a bit of pressure was good so that one wouldn't give up so easily.

P.1 *"May-be a little bit of pressure is good. Like this example of finishing the school, may-be I would have quit if they wouldn't have told me: come on, you've got so little still to do, try to finish it. Sometimes I do think, why are they pushing me, I wish they felt more sorry for me."* (laughter)

Another person felt that sometimes they wished there was even more pressure in order to keep pushing harder (in physical training). Third person said that they had experienced some pressure but they did not consider it a problem as they felt they were always able to discuss this issue with the professional. On the other hand, one participant felt that they had sensed some pressure by some of the housing unit workers to choose a career that was not suitable for them and felt that this had set them on a wrong path.

P.4 *"When I proposed two potential university options and one hobby-idea, then they thought that I should go study to become a chef, telling me that I'm so good at it. Well…now we're back to square one where these options started to diverge. Oh well, if I wouldn't have tried, I wouldn't have known."*

Some of the persons mentioned that the MHC is in a way like a haven to them. It provides safety that allows them to get out of their comfort zone and achieve goals. One person for example stated that they had not so much received direct help and advice when experiencing problems, and that family members had been the primary supporters but that the MHC has been like a place to retreat: a place where one can clear one's head by being able to express one's thoughts and participate in activities that help to unwind.

## 5.4 Directing one's life as much as possible

When analyzing the subject of how different mental health services affect their users' autonomy, one of the subjects that was addressed was how much the participants in general feel that they have the power to direct their life. The idea was expressed that recovery is possible and when it comes to their own life, they feel that they are the ones who are in control.

P.2 *"And then I understood, that when you're active, when your body is active then maybe then the brain will follow. No…that's for sure, I haven't lost the battle…I mean, the whole war yet. So yes…I can (direct my life) very much."*

Some of the participants mentioned that even though there was the need to monitor their health state, reduce stress and use medication, they felt that they have as much autonomy as it is possible under the conditions. The autonomy was sensed through being mentally

stable and adequate, making choices regarding where to live and who to interact with, selecting career paths, being able to choose how to spend spare time and what goals to follow.

*P.5 "When it comes to my own life, I don't feel as if I'm somehow pushed or pulled…or somehow uncontrollable or like a stray of society. On the contrary, I feel that I can lead my life and I'm the only one who I'm supposed to lead."*

One person also expressed that it is difficult to lead their life the way they wanted because they lacked the tools to do so. The ability to direct one's life seemed to be relative, depending on the day. The external forces that constrained from leading one's life that were mentioned were the influence of other people and the society. For example, one person felt that their current living conditions that involved living with a controlling family member inhibited their autonomy. Some of attitudes that prevail in the society, seemed to negatively affect the participants' sense of autonomy. For instance, the notion that if you don't work, then you're a nobody and the stigma and labelling that comes with having a mental illness. One person experienced that their GP somehow mistrusted or did not take them seriously due to their psychiatric diagnosis and two persons mentioned that they do not trust to talk about their mental health issues at workplace because they feel that people would not understand. Also, the idea was expressed that the current perception of mental illness and diagnosing is stigmatizing. It was suggested the psychiatrists should perceive the diagnosis as a description of the current health state, not like a life-sentence and that recovery and living without medication would be considered as a possibility.

# 6 DISCUSSION

The research aimed to answer the question, how do mental health service users perceive and experience the psychiatric and community based mental health services in relation to their sense of autonomy.

The research revealed that one of the core attributes to the experience of autonomy was how the service user perceived the attitude of the medical staff. The feeling of being respected and treated with empathy was seen as contributive to the overall sense of autonomy. At the same time, indifferent and superficial or even hostile attitudes were seen as diminishing to the service users' autonomy. Most of the service users are currently content with the way their outpatient team treats them, whereas as an inpatient, especially during involuntary treatment, some of the participants also had experienced negative attitudes on behalf of the staff.

Secondly, the research indicated that inclusion in the planning and process of the services significantly influences the experience of autonomy. Regarding outpatient care, there were different aspects that the service users experienced as inclusive. For example, all of the participants considered their current treatment plan more or less suitable for them and that they had been able to have a say in it. Additionally, in different mental health crisis situations, the service users had had positive outcomes through collaborating with the health care team which had created more trust towards the psychiatric services. The fact that with time and experience, the service users have gained self-awareness and confidence regarding their health condition has also increased autonomy because it allows them to express their thoughts more freely with the medical staff and has resulted in taking more responsibility for one's own health.

At the same time, there were experiences in outpatient care which indicated that not enough information is provided on behalf of the staff regarding one's health condition and medical treatment and most of the knowledge about one's health condition came from personal experience or research.

When comparing outpatient care to inpatient care, less information is provided to a person who is having a mental health crisis. When information is too scarce and/or presented in

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a way which is difficult to understand, then the patient is left in the darkness and it can create fear and mistrust. With knowledge comes power: when one has a better understanding of what is happening to them and how to proceed, then the feeling of being in control in one's life increases which contributes to the overall sense of autonomy.

Another finding was that in inpatient care, the patient's opinion was not really asked for nor considered. For some participants, this was not an issue because due to their health condition, they did not feel they were in a position to make suggestions. It seemed that for them, the caring and friendly attitude of the staff was more important than the ability to participate in the treatment planning, whereas for others it was seen as damaging to their autonomy. When receiving involuntary treatment, one person expressed the feeling of being stripped of their personal freedom as they were subjected to actions that were against their will causing them what they perceived as permanent health damage and trauma. Overall, the experiences of involuntary treatment were perceived as quite traumatic and potentially damaging to the person's self. These findings show that some of the principles of WHO for supporting the patient's autonomy are not always followed. Namely, the suggestion that involuntary hospitalization does not automatically include authority for involuntary treatment, especially if the treatment is invasive (WHO, 1996). Also, the suggestion to give patients verbal and written information (in an accessible language) about the treatment, is not always provided. Neither is the suggestion to consider the patient's opinion regardless of his or her ability to consent and giving it careful consideration always followed.

If the impact of formal coercion to a person's autonomy was clear, the informal coercion in the form of treatment pressures was not really something that was recognized or considered that problematic. The service users expressed the idea that no matter what the doctor says, at the end of the day, they are the ones who make the decision to either take or not to take the medication. Also, the author feels that the cultural aspect might have had an influence in this study, as the doctor is in Estonia generally considered an authority from whom some persuasion is expected. This finding is in concordance with Wertheimer's findings, who stated that whether or not the person sees the medical proposal as a threat or an offer depends on their moral beliefs. If a person believes that a doctor has a *right* to propose a treatment, then they will most likely feel not that constrained.

Regarding community based mental health services, the attitudes of the staff of MHC were not brought up so much, the participants simply stated that everyone has been friendly and respectful towards them. It was found that the service users generally felt that they had been involved in the planning and process of the services that they received and that there was awareness and motivation to participate.

The research indicated that by providing tools, a sense of safety and by supporting motivation, the services of MHC have influenced positively the service users' ability to cope with the difficulties of everyday-life and accomplishment of personal goals. Some of the service users had experienced some pressure on behalf of the staff of MHC, which generally was considered a positive thing but on one occasion it was seen as something that potentially influenced the person in an unwanted way. If the service users' own goals are kept in mind and the professionals motivate in areas and questions that the persons truly consider important, then some pressure can be considered as empowering. From this it can be derived, that when the person experiences that they themselves (with a bit of help from the others) are able to overcome obstacles and accomplish their goals, then this strengthens the service user's autonomy. At the same time, if the professionals are not careful enough, become paternalistic and start to pressure the service user regarding goals that belong to the staff and not the person in question, then this can affect negatively the service user's autonomy.

Moving on, the research also revealed that the ability to direct one's life depended on the perceived opportunities and obstacles. The inner opportunities and obstacles were related to the health state and to the acquired tools that one had to cope with everyday life. The external opportunities and obstacles were related to other people that surrounded the person and the attitudes regarding mental illnesses that prevailed in the society. All in all, most of the people felt that even though there are some restrictions that come from their health state, they are still the ones who direct their lives.

Both psychiatric services and community based mental health services can influence the service users' autonomy. The research confirms the findings of Piippo and Aaltonen (2008), according to whom the patient's experience of autonomy, safety, trust and honesty are interdependent in the treatment process. When the psychiatric and MHC services provide help that includes the service user as an equal partner (horizontal expertise) in the

planning and process the of services with an attitude that is both empathic and respectful, it creates a foundation for trust, safety and motivation. Trust, safety and motivation can result in better collaboration with the healthcare and rehabilitation team.

The psychiatric services provide the primary information about the treatment options, whilst the community-based MHC provides tools to overcome obstacles in life and accomplish one's goals. Effective collaboration with the medical team can help the service user to reach a better health condition whereas collaboration with the community-based MHC can result in better coping with everyday life. Then again, a stable health condition and better coping with everyday life allows the person to be more independent and autonomous in their life.
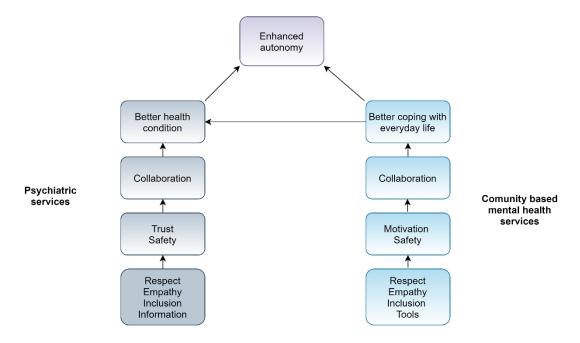


*Fig. 7 The effect of psychiatric and MHC services on autonomy*

In conclusion, the findings of the current research confirm the idea, that autonomy should be seen as a process of individual growth in interaction with the environment (Agich, cited in Le Granse, Kinébanian and Josephsson, 2006) and that it might not be an "all-or-nothing" right but a shifting state. A person might have a mental illness and occasionally have moments where they trust part of their autonomy to other people but they can still perceive themselves as autonomous persons because they sense that they are in control of the decisions made regarding their life (Wilken, 2010). The role of the care provider is to

actively facilitate the service users' ability to exercise control over their lives as much as it is possible (Wilken, 2010)

# 7 ETHICAL CONSIDERATIONS

This research touched subjects that are very personal and delicate for the participants, therefore, ethical considerations had to be taken particularly seriously. An ethical approval was retrieved from Tallinn Mental Health center that provides mental health services to the participants. The interviewees were informed about the subject of the research through their social worker and the participation was voluntary. The consent to participate in the research was given both orally and in written form. The participants were explained that they can stop the interview whenever they wish to and that they can avoid answering certain questions if they feel so.  The written consent included information regarding the use of voice recording and confidentiality. The anonymity of the participants was granted through removing all data that would enable the identification of the person who is sharing the information. Two of the participants also expressed the wish to read the thesis after it has been presented which the author intends to fulfil.

# 8 CONCLUSION

The study revealed that there are aspects of mental health treatment and services in Estonia that influence the service users' autonomy both positively and negatively. Respectful, genuine, emphatic and inclusive treatment that follows horizontal expertise creates trust and safety which results in better collaboration and enhanced autonomy. At the same time, not providing the service user sufficient information about their health condition, not taking the service users' opinion into consideration and overuse of coercion in psychiatric services can be seen as hindering the service users' autonomy.

The community based mental health center's services influence the client's autonomy positively by providing tools to cope with everyday life and by supporting the person regarding the accomplishment of their personal goals. The center also provides motivation and a feeling of safety that helps the person overcome the fears in order to become more independent. Nevertheless, when the professionals start to pressure, push and pull the client in order to complete goals that do not actually belong to the service user but to the service provider themselves, it can harm the person's autonomy.

The service user's overall sense of autonomy depends on how much one feels one can direct and make decisions about their life and the perceived inner and external opportunities and obstacles of doing so. This study revealed that even though the mental illness and the stigma related to it that prevails in the society hinders the sense of autonomy, most of the persons who participated in this study still feel that that they are the ones who are in control in their lives.

The main limitations of this research lie in the scope of the study, which was too big and the researcher's lack of experience in qualitative methods. The array of questions that were discussed was too wide, which resulted in large quantities of raw material but inhibited a more profound analysis on each topic. The author recommends a study that would focus more narrowly either on psychiatric or community-based mental health services in Estonia. Another potential limitation was the fact that the author currently works in the community-based mental health center she was studying, which might have somehow influenced the service users' willingness to openly share their more sensitive or negative experiences regarding the mental health center.

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