Sakari Halonen

"Sharing is Healing"

Experiences of Communality and Participation in OCD- and Tourette's Peer Support Groups

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The purpose of this thesis is to highlight and analyse the different experiences of participation and communality of people in OCD- and Tourette's syndrome peer support groups. The Finnish Tourette's and OCD Association STOY works in an informative way to raise awareness in these topics. The goal of the thesis is to work as a theoretical examination of the experiences who have participated in these groups hosted by the association.

The research material came about through thematic group interview. The interview was held during a regular session of the support group. This was due to making sure that the members could have the sense of safety talking about their experiences like in regular meetings. Four people including the counsellor, who acted as the interviewer, participated to the interview. Two of the interviewees were long time members and one of them was there for the first time. The interview consisted of themes which were gone through with each member.

The research highlighted several experiences from the people who participated. The experiences were analysed through the theoretical viewpoints of participation and communality. These were chosen due to the preliminary understanding about the concepts. The concepts were assumed to appear in the material and the goal was to create new understanding about them with research.

The overall experience of peer support groups in this case was found to be positive. The members highlighted safety and the importance of sharing their experiences. The members feel like peer support groups allow unique relationships to form, where meaningful discussions can be had, without knowing the other people in the 'regular' everyday life.

Keywords	participation, communality, OCD, Tourette's syndrome, peer support, peer support group

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Tämän opinnäyteyön tarkoitus on tuoda esiin ja tarkkailla kokemuksia, joita OCD- ja Touretten syndrooma vertaistukiryhmissä käyvillä on. Suomen Tourette- ja OCD yhdistyksen STOY:n tavoitteena on lisätä tietoisuutta näistä aiheista. Tämän opinnäytetyön tavoite on kuitenkin toimia teoreettisena tutkielmana yhdistyksen ryhmätoimintaan osallistuvien ihmisten kokemuksista.

Tutkimusmateriaali saatiin temaattisen ryhmähaastattelun kautta. Se toteutettiin yhden vertaistukiryhmän normaalin tapaamisen aikana. Tämä sen takia, jotta jäsenillä olisi sama turvallinen olo puhua kokemuksistaan kuin muissa tapaamisissa. Neljä jäsentä mukaan lukien ohjaaja, joka toimi haastattelijana osallistui haastatteluun. Kaksi haastateltavaa olivat pitkäaikaisia jäseniä, kun taas yksi oli ensimmäistä kertaa ryhmässä. Haastattelu koostui teemoista, jotka käytiin jokaisen haastateltavan kohdalla läpi.

Tutkimus toi esiin monia kokemuksia haastateltavilta. Kokemukset analysointiin yhteisöllisyyden ja osallisuuden teoreettisessa viitekehyksessä. Näihin käsitteisiin päädyttiin aiemman ymmärryksen pohjalta. Oli oletettua, että ne esiintyvät tutkimusmateriaalissa, mutta niiden pohjalta olikin tarkoitus luoda uutta ymmärrystä.

Pääpiirteittäin kokemukset ryhmässä olivat positiivisia. Jäsenet toivat esiin turvallisuuden tunteen ja kokemuksien jakamisen tärkeyden. He kokivat, että vertaisten välille muodostuu uniikki yhteys, jossa voidaan keskustella syvällisistä asioista tuntematta toisiaan ulkomaailman 'normaalissa' arjessa.

Avainsanat	yhteisöllisyys, osallisuus, OCD, Touretten syndrooma, vertaistuki, vertaistukiryhmä

Contents

1   Introduction

The goal of this thesis is to look at and highlight the different experiences of people in peer support groups. The peer support groups in this case are for people with obsessive compulsive disorder (OCD) and Tourette's Syndrome. The research focuses on the experiences of participation and communality. The purpose of the research is to work as a theory-based information packet for the working life partner.

The motivation to research this topic comes from experience of working as a counsellor for OCD- and Tourette's support groups. The theoretical analysis of the experiences of the group members was lacking from the counsellor work. Since, these mental health conditions are also quite rare, it was topical and important to look at the phenomena through the individual experiences of the people dealing with these issues.

1.1   Obsessive Compulsive Disorder - OCD

Obsessive compulsive disorder, more commonly known as OCD, is an anxiety disorder in which as the name implies, it is typical for the person with the disorder to have obsessions and compulsions. The obsessions can be about various things, or present themselves in different ways (intrusive thoughts, ideas, impulses), but the main element is the feeling of anxiety that they cause for the person dealing with these obsessions (Abramovitz, McKay and Taylor, 2008, p.15). The obsession- name refers to the re-occurrence of these intrusive factors whereas the compulsions are the repetitive actions or behaviours to try to diminish the feeling of anxiety these obsessions cause (The American Psychiatric Association, 2013 cited in Öcal, et al., 2019, p.2).

1.2   Tourette's Syndrome

Whereas OCD is about involuntary thought patterns and compulsions, Tourette's syndrome is associated with tics. Tics are defined as noticeable abrupt movements or sounds of a person. To the outside, tics can be seen as irregular pulses of 'normal' behaviour. As they often are repetitive for the person suffering from them, they can be interpreted as purposeful behaviour to someone who does not know about the person's condition. (Martino and Leckman, 2013, p. 4.) Tourette syndrome is diagnosed and defined through these tics. For this diagnosis, the person must have had multiple tics that

occur through a longer time. Also, they cannot be caused by substances or other medical conditions. (Freeman, 2015, p. 9.)

In the case of OCD and Tourette's syndrome, the symptoms can be related to regular behaviour in a way that makes them hard to talk about in an everyday context. A person with OCD can talk about how they have the feeling of obligation to carry out a compulsion, but can a person without OCD understand the feeling of inner obligation that the compulsion and obsession presents? Same goes for Tourette's. If a person has multiple tics in a situation, for example yelling a curse word, it can be misunderstood or in the worst-case scenario it can cause annoyance or even despise at the person having the tic. The symptoms may seem like a 'average' person is just acting differently, because the symptoms do not need to be grandiose or noticeable immediately in relation to these conditions.

2 Working Life Partner

2.1 The Finnish Tourette- and OCD- Association

The Finnish Tourette- and OCD- Association better known as STOY, is a non-profitable organization that in their own words works as a bond between people with OCD and/or Tourette's syndrome and their close ones and others who are interested in the subject. The association works in many areas to improve the awareness on OCD and Tourette's syndrome and offer support for people. Some of these areas are for example, offering general information about different issues, hosting, and facilitating events and offering peer support groups around Finland. (STOY, 2022.)

The association consists of over 600 members. The association is funded by STEA (Funding Centre for Social Welfare and Health Organisations). Also, the members pay an annual membership fee which is also a part of the funding of the association. This plays into the idea of the members being a part of the community in a way of funding. The money that the association gets from the members, is put back to the association to benefit the members.

The association hosts peer-support groups in eight cities around Finland. Groups are for people with Tourette's syndrome and/or obsessive-compulsive disorder. The groups have one or two volunteer peer-counsellors, who act as facilitators in the group's meetings. Groups schedule meetings to talk about their experiences and stories with OCD

or Tourette's. The thesis focuses on the interview held in one of the groups and on the information received from the other groups. One of the peer-support groups, the one held in Tampere, is also co-organized by OmaVoima in co-operation with STOY. This is the group where the interview on the thesis's topic is held.

2.2 Facility: OmaVoima

The thesis is in co-operation with STOY, and the research implementation is held in OmaVoima Tampere. OmaVoima is a part of a large multi-professional social service organization Setlementti Ry. It is based in Tampere, and they focus on supporting adults with neuropsychiatric characteristics, such as ADHD, autism spectrum, and more notably for this topic OCD and Tourette's. The organization's support, however, is vaster than these conditions. The organization offers low threshold services free of charge to, in their own words, better the overall welfare of the clients and support communality and citizen activity. This is achieved by offering information and support through diverse services. The organization offers one on one work in the form of consultation, open activities such as community theatre and hosts and facilitates peer support groups for different people. This association is where an interview for the thesis research is held, and they work with STOY offering the facilities to hold one of the peer support-groups in. (OmaVoima, 2022.)

2.3 Client Centred Services

According to a multi-associational project facilitated by the Finnish Mental Health Society Mieli and other associations (Hietala, 2018, p.52), to be able to offer sufficient and affective mental health- and substance abuse related services in Finland, as an addition to working public services, it is crucial to have non-profitable associations and experience-based help available. This way people even in the most vulnerable situations get the most out of the services. To reach this goal, the services also must be client centred.

To be able to develop an association's services in a client centred way, we need to ask, what really is client centred? Client centred services have been described in many studies. Corring (1996) and Glenister (1994), highlighted the importance of mutual respect of the clients and professionals and the feeling of being valued. This combined with the nature of the service being managed in a fashion where the client chooses what is their need and what they want to do, rather than someone telling what to do or

referring them into a service, makes the service in client centred. (Sumsion, 2005, p.13.)

In their definition of themselves as an associations, both associations STOY and Oma-Voima highlight support and the welcoming nature of their services. The associations fit into the definition of client centred services by Sumsion (2005, p.13), where the client chooses what they want to do. No one refers people with OCD to STOY' s website or support groups, rather people can recommend that one who might find the information in their website useful, can themselves find out what they are looking for. This is the bond between people-aspect of the association. To be able to carry out these client centred services one of the key aspects of the association's actions is peer support groups.

3   OCD and Tourette's Syndrome in Society

3.1   Loneliness

Since OCD and Tourette's syndrome are quite rare, can misinterpretations about their symptoms lead to feelings of loneliness and exclusion. Loneliness can be defined as a situation where one's social environment and -network is not adequate to their own preference. (Jones, 1981; McWhirter, 1990; Nilsoon, Lindstrom & Naden, 2006; cited in Bevinn, 2011.) Weiss (1985 cited in Rahikka, 2020,) divides loneliness into social- and emotional loneliness. Social loneliness is about feeling left out of a social group. In the case of people with OCD or Tourette's this can be the different things that the person for example is not capable of doing due to the condition, such as school or work. Emotional loneliness is the person's negative feelings about relationships or the lack of them. For example, not having an intimate partner or a lack or a loss of a loving parent. In the case of people with OCD or Tourette's syndrome this could be also the lack of people who to talk to about their condition. To summarize, the problems people face with these conditions can also lead into the feelings of loneliness.

3.2   Statistics

Tourette's is diagnosed to approximately 1,0- percent of young boys and 0,3-percent of young girls. For older people it is harder to diagnose, since there are no accurate numbers. (Leivonen et al. 2015, p.1059). OCD is diagnosed to 1-4- percent of children depending on the research (Puustjärvi and Asikainen, 2010). In total 0,6- to 3- percent of

people in total have this condition (Chong et al. 2012, cited in STOY). Since the numbers for both conditions are low, one can think about the risks of not being able to talk to people with similar experiences. The rarity of these conditions opens room for discussing the importance of being able to share or relate to other people.

4   Peer Support Groups

It could be generally said that the main goal of mental health services or mental health work in general is recovery or simply feeling better. This calls for the exploration of different methods of services and methods to reach this goal. In the case of this thesis, the method in discussion is peer support, more accurately, peer support groups. Studies have shown that peer support groups have been an effective help in the recovery processes of long-term mental health issues. (Strand et al. 2020.)

4.1   Definition of Peer Support Groups

Risen from the alcohol abuse- and schizophrenia community in the 1930's United States, peer support group activities landed to Finland later in the 1960's. Peer support can be defined as the act of people with similar backgrounds or people suffering from similar issues sharing their experiences with one another. It can be implemented through organizations, municipalities or by people in communities by themselves. (Rissanen & Juvansuu, 2017.)

Whether peer support is implemented as pair work, in groups or in other environments, it is often based around voluntary work. Peer support groups are relationships that aim towards helping one another in similar crisis or difficult life circumstances (Hyväri 2005, cited in Männikkö 2011). Peer support groups are targeted to not only help the clients or group member, but also the counsellor or facilitator. The mutuality of peer support in this case means that the group counsellor supports the members and the other way around. Therefore, traditional volunteer work is usually not mutual. In that case the worker supports only the client. (Mikkonen, Saarinen 2018, p.26.)

4.2   Peer Support Activity

However, often concepts of being a peer, peer support and peer support activity can be interpreted as a single entity. For example, if someone is talking about the peer support for people with OCD, they perhaps imagine a support group or a support mentor right

from the start. They are then talking about peer support activity, not necessarily about peer support. Firstly, peer support is defined as experience-based support between people and is the umbrella-term that the other two concepts live in. Therefore, being a peer as a concept is simpler and is about the relationships. For example, in the case of OCD, a peer-relationship can form between two persons with OCD, or even between the parents of two children with OCD. Experiences and relations make two people peers to one another. Finally, the different actions that organizations or persons implement in the form of support groups highlight peer support activity as a separate thing. (Mikkonen & Saarinen, 2018. p. 9 & p. 20).

5   Participation

5.1   The Opposite of Exclusion

Is participation something that society or individuals ought to be going towards? This question could be looked at through the viewpoint of what society should not be going towards. Similarly, participation can be looked at from the definition of exclusion since, it can be defined as the opposite. Exclusion is defined as comprehensive accumulation of disadvantage and lack of participation. Thus, participation is then also the lack or the opposite of exclusion. (Hämäläinen 2008.), (Hämäläinen, 2002.)

5.2   Three Part Model

Isola, et al. (2017), present that participation turns up in three levels. Firstly, in person's own life, it is about possibility or ability to make their own decisions and actions and as an environment that is sensible, in control of the person and somewhat anticipable. Secondly, it is also about the process of being able to affect others and other environments around oneself. Finally, it is about the local relations where one can effect on the common good and creating meaningful things and relationships. This definition and these levels can be put into the context of the support-group environment.

Participation in the context of a support group, for example is about the relations of acting, participating the feeling of belonging in the support group. This is a key factor of developing and maintaining the sense of participation in a community (Nivala, Ryynänen, 2019). The meaning of acting as an active actor in the support group participation is to keep the peer- nature alive where the mutual respect of both members and

counsellors needs to have (Mikkonen, Saarinen 2018, p.26.) This links also to the second level of Isola et al' s (2017) model of where participation turns up in.

The support groups' idea is also linked to the final and third part of the model (Isola et al 2017.) The idea of the groups is to allow the members to contact and connect with others who have similar experiences and therefore, offer ways to make these meaningful relationships. As earlier mentioned, the peer support context is about common good in a way that the members enter to the group in a mindset, where they are expected to be support, but also that they are expected to do so for others.

6   Communality

6.1   Sociology's Definition

Communality refers to the idea of certain people having a subjective feeling of belonging together, sharing goals and ideas, and sharing responsibilities with others (Pooley, Cohen, Pike, 2005). Kananen et al. (2015), found out that communality highlights the community's reciprocity and the individuals' personal investment in the community. Therefore, it also furthers communication and cooperation between the community members.

In sociology, community is based around Aristotelean philosophy. People have a natural drive to communality, communal activity and common good. The definition of community has developed from family- to status- and later to agreement-based relations to communities. Family-based community is based on biology and primitive relation to community. Status-based relation is about on status or other position in a community. Finally, agreement-based relation means that communities are based on people's own decisions of being a part of communities. (Kangaspunta, 2011.)

6.2   Societal and Communal Relations

Communality describes the relations and commitment of individuals to a community (Kananen et al. 2015). It is based on a social bond which thrives from the sense of belonging to something with an emotional experience. Tönnies (1988), divided the communal relations to communal (Gemeinschaft in German) and societal or 'market' (Gesellschaft) relations. Communal- or Gemeinschaft- relations are about individuals work-

ing together towards a common goal. Societal- or Gesellschaft- relations are about individuals working towards an individual goal using other members of the community as instruments to get to the goal. (Aro, 2011.) (Kurki, 2002.)

Both Communal- (Gemeinschaft) and Societal- (Gesellschaft) relations are important for an individual. A person who works together towards a common goal (Gemeinschaft) has a natural drive to be in a relationship where they have the sense of belonging. However, it is important to see individual goals and consciously work towards something even though the relations might seem like instruments of one's own individualistic goals. (Kurki, 2002).

7 Implementation

7.1 Research question

The point of the thesis is to be theoretical analysis for the working life partner of experiences in peer support. Since peer support as a phenomenon is not as simple as it may seem at the first glance, it is important to discuss the experiences of the members in a peer support group. The research question for the thesis is: what kind of experiences people with OCD or Tourette's syndrome have of communality and participation in their support group?

7.2 Research subject's safety

As the association's groups work in eight places in Finland, the logistic nature of the research is taken into consideration. Since not all the groups are going to be visited, the research method needed to be such that it can be done face to face. The research was done with support group members and the -counsellor in one of the groups in Tampere.

Each group member attending to this study was handed an information (Appendix 1.) form as well as a consent form (Appendix 1.). In these forms the attendees were informed about the implementation of the study as well as their rights as attendees. The study does not use other personal information about the subjects, rather than in the interview recording may contain the first names of the subjects, which are however not used in the final thesis. This information was handed out in the consent form as well as in the information form.

7.3   Qualitative research

Qualitative research pursues to understand the viewpoints of the subjects through interpretations and contextuality. Since the research question highlights the demand of studying the different experiences of the research subjects, qualitative research was chosen for the thesis. Qualitative research offers the room for subjectivity: every person has their own reality and experience. This works directly with the research which discusses experiences. (Glesnen & Peskin 1992, cited in Hirsjärvi & Hurme, 2015.)

In the implementation of this thesis, the interviewer is a part of the interview. And since the interviewer is a member and a counsellor for the support group, it can be said that the researcher is a part of the research. Typically, in qualitative research, the researcher is in interaction with the subjects. This means that the results of the thesis also in a way thrive from the co-operation of the subjects and the researcher. (Hirsjärvi & Hurme, 2015.)

7.4   Thematic group interview

The research is carried out through a semi-structured thematic interview. Eskola et. al. (cited in Valli, 2018) summarized the meaning of using interview as a research method as such: If you want to know what someone thinks about something, shouldn't you ask them? This links to this thesis theme of discussing experiences: the members should be asked. Also, since the topics of OCD- and Tourette's are personal and can be emotional, thematic interview seems more lucrative way of asking about these issues than handing out questionnaires. The interview was carried out in a group interview format, since it seemed topical for the research question. The thesis is about groups, so it was natural to have the interview in a group discussion rather than in one-on-one setting.

Thematic interview is a method of semi structured interview. In structured interview, the questions and the structure of the interview are premade and in a structured planned setting (a form typically). Unstructured interview is the complete opposite. The goal of it is to rely on the interviewee's information completely. Semi-structured interview lies between these two options. Some parts of the interview structure are pre-settled, but room for flexibility is left. For example, questions can be same for all subjects, but asked in a different order. (Hirsjärvi & Hurme, 2015.)

In thematic interview, the themes work as the pre-settled questions. The goal is to go through the themes with each subject. However, the themes are gone through in a semi structured manner, where the order or structure can vary between subjects. In thematic interview, the interviewer can deepen their understanding of the themes by asking more questions about the themes as the interview goes on. The starting point of the thematic interview is to assume people have experienced something similar or topical. Themes are formed based on what is already know about the subject. In this case people with OCD and or Tourette's to have some experiences of participation and communality in the peer group setting. To be able to create the interview themes, the situation and environment has been in a way analysed beforehand. It would be impossible to think about any themes if person carrying out the interview would not assume anything about the interviewees. (Tuomi & Sarajärvi, 2018.)

The themes of the interview come from the literature and theory presented in the thesis. Rather than asking discussing communality and participation and having the members define these in context of their life, the themes and questions are drawn from the definitions and theory collected to the thesis. The interview discussions on the questions or themes are then reflected to the theory. With this operationalized way the results are more analysable in context of the theory, still having the interview situation to be more a discussion rather than an interview, which is more relevant to the peer support setting. (Eskola et. al. cited in Valli 2018.)

7.5   Theory-Bound Content Analysis & Abductive Reasoning

When qualitative research is analysed, one method that can always be used is content analysis. Eskola (2001; 2007, cited in Tuomi & Sarajärvi, 2018), divides content analysis into three different methods based on the relation of the data to theory used in the analysis. In data driven analysis, theory and formerly known data is not relevant when analysing the new data. On the other hand, theory driven analysis thrives from the former data, theory, and knowledge about the issue. Between these two, there is theory-bound analysis.

The problem with data driven analysis in the context of this thesis is that data driven analysis does not consider the former data and theories relevant for the research's analysis. It conflicts with the thesis' idea of making assumptions during the creation of interview themes. In the research question, the theory base is already analysed clearly, which would make the use of this method difficult. However, the other end of the spec-

trum is theory driven analysis. This method is based on testing former data and theo- ries. The analysis starts from the preposition of looking for theory in the data. Theory driven analysis does not resonate with the search of experiences in the data since, in theory driven analysis the analysis should be based around information from other in- terviews. Old information is not tested in this thesis. (Eskola 2001; 2007, cited in Tuomi & Sarajärvi, 2018.)

For this thesis theory bound analysis is used. Theory bound analysis differs from theory driven analysis in a way that the analysis is more inductive. Inductive reasoning refers to reasoning where the theory is analysed based on the data, not the other way around (deductive reasoning). Theory bound analysis can be looked at as inductive data driven analysis but with the concept of bringing in the theory as part of the analysis at some point of the analysis. Abductive reasoning is associated with theory bound analysis. In abductive reasoning, analysis can be done if there are former thoughts or theories be- hind it in this case theory and themes. (Eskola 2001; 2007, cited in Tuomi & Sarajärvi, 2018.)

8   Result analysis

8.1   The Interview

The interview was held during a meeting of the support group. The point was to have the interview to be held as part of one group meeting. It was a way to make sure that the members would have a safe environment to discuss their experiences. However, the members were informed about this beforehand.

The interview was recorded as an audio file and later transcribed to be able to analyse. The interview lasted around forty minutes and the transcription was four pages long. The themes can be found in the appendixes. (See Appendix 2.)

The interview themes which worked as the interview questions came from the theory base of the thesis. They were drawn from the definitions of participation and commu- nality. As the interview was semi- structured, some of the questions were drawn from the discussion and the interview itself. (Hirsjärvi & Hurme, 2015.)

For the session three people showed up. The session was voluntary, so no invitations were sent, or prescheduled interviewees were present. This comes back to the implementation plan for the interview. To be able to have a regular peer support meeting and discussing these topics during it. Two of the three interviewees were long time members and one of them was there for the first time. This opened a good possibility to have both experiences from regular members and from the newcomer.

8.2 Results

The point of the thesis was to find out what experiences people with OCD- or Tourettes's Syndrome have of communality and participation in the peer support group setting. The interview is analysed, and direct translated quotes are presented to have an idea about the topics. The interview was held in Finnish and later translated to English for the purpose of this thesis.

The interview material is analysed with the theory bound analysis. Theory bound as in the material was analysed with the theory already guiding what to look for in the material. Also, the interview questions were already formed based around theory. In this way the material was searched for themes that resonated with the theory base of participation and communality and then thematized to make further analysis. (Tuomi & Sarajärvi, 2018.)

The themes that rose from the material were openness and safety, comprehension between the members and the lack of comprehension. Mentions of these themes were looked at from the material and collected as groups. In this thematization, the goal is to look at what is said about said theme.

8.2.1 Openness and Safety

The interviewees were asked about coming to the peer support group and how they see the other peers. This brought up the first theme of analysis; openness and safety. It seems that the peer support group as and environment is something that people feel safe in and are therefore willing to talk about things.

> "Normally one lives alone with compulsions."

> "Here its open to talk about. It diminishes the shame around it."

"This is a safe space."

"You can come with any mood."

"You don't have to pretend to be normal."

8.2.2 Comprehension between peers

Asking about why to come to the peer support group the comprehension between members rose as well. Also, the members reflected peer support groups to other information sources such as online support. It seemed that the primitive need of a human to be around other people is seen in this context as well.

"It is valuable to have people that know how it feels."

"It can help that you read online, but actually seeing people with similar experiences makes you realize that other people actually have obsessive thoughts. It feels real."

"On the internet there is no human contact that one needs in their life anyway."

When asked about sharing experiences and what aspects work in the group, this theme was highlighted. The act of sharing is seen as difficult in itself but the importance of letting things out and reflecting on them with others who have similar experiences is seen as important.

"It is scary to share, but it feels liberating because they are the kind of things that you don't want to share with everyone."

"Sharing is healing, even though it does not remove the thoughts. You just don't need to be alone with them anymore."

"We are combined by the fact that differs us from others in the regular life."

8.2.3 The Lack of Comprehension of Others

One of the themes that rose from the material was the lack of comprehension of others. This theme could be seen as a negative thing, but in this context, it seemed to be more of a uniting factor. The group feels connected, when other people outside the group do not understand what they are going through.

> "It seems that others have a hard time to understand if they don't have OCD. The thoughts seem absurd to me. So, it is hard to understand if one doesn't go through them themselves."

The lack of comprehension of other people was highlighted when asked about what the members expect for when they share their experiences in the group. This brought up the difference of sharing in other environments such as traditional psychotherapy against sharing in peer support groups.

> "I hope that here my thoughts wouldn't sound so absurd. When you have anxiety about what is in your head, you wouldn't like to hear that don't talk about that or worry about it. That doesn't help."

> "This world is inexplicable to most people."

> "Peer support is the best, since you know that others know the same. It works differently than talking to a therapist, even though there is also dialogue, but it is not the same."

> "When sharing to a therapist about obsessive thoughts, it felt analytical and empty."

These themes were chosen from the interview transcription by choosing them through theory. These themes could be analysed in the context of the theoretical base of the thesis. Theory bound analysis in this case meant that the theory was brought to the analysis in the choosing of the themes. Abductive reasoning was used, when choosing the themes according to what was known about the theory and what in the material could be associated with it. (Tuomi & Sarajärvi, 2018.)

9   Conclusions

After reviewing the material, the interviewees seemed to have similar ideas about the peer support group. The openness and safety, mutual comprehension, and the feeling of others (society and other people without OCD or Tourette's) not understanding their situation were the main points that rose from the group interview or -discussion. The first conclusion that can be maid is that every member seemed to gain something from the support group. Not a lot of negative things were said during the interview. This could be traced to the voluntary nature of the group; the members would not go to the group meetings if it would have a negative effect on them.

9.1   Choosing the Theoretical Concepts

For the thesis, the concepts of participation and communality were chosen as the concepts that guide the implementation. This is due to the preliminary understanding of the concepts and the assumptions made while choosing them. Therefore, implementation of the thesis was carried out assuming that these concepts will present themselves in the materials in some way.

It can be seen in the title and the research question as well. Asking what experiences people with OCD or Tourette's have of these concepts is an assumption. However, the point of the thesis was to look at these subjects from the theoretical viewpoint. Therefore, in its core, the research question and ultimately the thesis is about developing the preliminary understanding of the concepts towards new understanding. Thus, the preliminary understanding changes as well. (Varto, 2005.)

9.2   Experiences of Participation

The interviewees had similar experiences about participation in the group. They felt that they feel safe and are welcomed to share their experiences without judgement. They highlighted that they are not expected to do anything or be like someone they don't identify with.

The voluntary nature of the support group means that they are not even expected to join if they don't want to. The subjects felt that they can have an impact on others by sharing their experiences, which is a key factor in participation. It was pointed out that

peer support groups form unique relationships, where people share very deep and personal things without having any other contact with the people outside the group. It can strengthen the feeling of belonging in the group since only group related issues are discussed in the sessions. (Isola, et. al. 2017.)

The members felt that sharing their stories and experiences helps them as well as the others. This comes through from understanding each other and the whole situation in the peer support group. This is linked to the second part of Isola's model of participation (2017), where the feeling of acting as someone who's actions influence others is highlighted.

9.3   Experiences of Communality

When it comes down to the second main subject of the thesis; communality, there were multiple experiences of it in the interview material. Comprehension between members can be equated to the sense of belonging and common goal aspects of communality. The members felt that they are heard, and they have a deep emotional understanding of their peers' situation, which is not found anywhere else. This came from the fact that they can share thoughts with people in similar situations. They felt like peer support groups offer unique experiences of comprehension, which for example the internet cannot offer. (Pooley, Cohen, Pike, 2005.)

What was interesting was that the experience of being different from the people outside the group, was seen as positive in the group's context. The members felt that they feel exclusion from others, but in the group that exclusion brings comprehension and through that brings them closer together. That can be seen as a common goal which is part of the different definitions of communality. The members could be seen as working against their exclusion from others by coming to the group and feeling connected.

For Tönnies' (1998) two-part communality definition, where on the other hand people have a natural drive to work towards a common goal together and on the other hand using others as instruments to reach individual goals, both are valid experiences for the members. It can be said that the members felt that they are there to feel better about their own situation (societal relations) as well as helping others at the same time (communal relations). This makes the divide of the definition of communality irrelevant, since in either side they are working or acting in the group, in the context of communality (societal or communal), the other way is valid and important too. (Aro, 2011.) (Kurki, 2002.)

10 Further discussion

10.1 Ethical discussion & Own Learning

Since the support group's counsellor in this case is the researcher, their role needs to be examined. In this case, it is impossible to say that the research is not affected by the fact that the interviewer is a part of the group. However, this was informed to the group. Also, the nature of the research in the first place was to have the material be more of a discussion had in the group's meeting. This resonated well with the topic of experience. It can be argued that a member of the group asking about the issues can get deeper responses than a stranger who does not have similar experiences with the topic.

This in mind, the interview was held in a way that the interviewer didn't answer the questions, even though they were a part of the peer support group. This mixture of member and researcher made up a proper challenge for the research but worked out in the end. Professionals in peer support groups is spoken about, but it can be an asset and is used a lot in substance abuse work for example (experience experts). Why not in the mental health field as well?

10.2 For the Working Life Partner

When looking at the different webpages and social media of The Finnish Tourette- and OCD- Association, where their information is mostly given out on, one might say that the information given is mostly about raising awareness about the two mental health topics. This is understandable since that is one of their key objectives as an association.

However, maybe the most concrete action the association takes every week is the hosting of the support groups. There are flyers for the groups and the association sends out forms regularly for the clients, group members and group counsellors to send feedback to the association about the groups, but perhaps more of the information about why peer support is offered in this association is needed to the different media of the association. (STOY, 2022.)

The point of this thesis is to focus on the aspects of communality and participation in the groups, not the groups' functionality. The goal is to hear and evaluate the actual experiences in limited topics, which offers the topic in question a more thorough cross-

section. The information about the experiences of the group members on communality and participation can be guided towards the public, to the funders and the board of the association.

10.3 Further research

Since this interview was held only in the support group in Tampere, further similar research could be done. The challenge was to get different results out from the group. The group in Tampere has been the same for over a year. This affects surely to the conclusion about the experiences. This research can be looked at as biased, since the person carrying out the research has been a part of the support groups, but the point was to reflect and introduce experiences in the context of theory, not to argue directly, should the support groups be used more. Also, as a critique, the interview material was limited, but it can be argued that it explained the group members' experiences of these theoretical topics adequately. It could also be argued that every experience is valuable for this research question.

In the future, through the findings of this thesis, perhaps a questioneer form could be made to ask about these experiences more directly. That way it could be distributed nationally to all the support groups that STOY hosts. The themes that rose from the interview and were analyzed in the results, could be used as questions for the form. It would be important to hear from the other groups in Finland as well to get a better grasp on the support group situation in the country.

Another interesting point of view could be that if there are different experiences, especially negative experiences, in the peer support groups around Finland, what influences or causes that? It would be more about the group functionality, which was something this thesis didn't consider, but would be important to discuss as well. Since, in this research all the members had positive experiences about communality and participation, the possible negative side was not discussed.

10.4 Preliminary Understanding

Like inferred before, the preliminary understanding of concepts changes due to research. In the case of this thesis, the preliminary understanding on the topic suggested that people that go to these support groups have positive ideas about going to the groups and that they can present anecdotes that discuss their experiences of these concepts. This was strengthened by having this research, but not necessarily in the

ways that was clear in the preliminary understanding. The concept of a peer support group was highlighted as a unique safe place that brings people together with the thing that separates the people in it from others. (Varto, 2005.)

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Research Information Form & Consent Form

TIEDOTE TUTKIMUKSESTA

OCD and Tourette's Syndrome Peer Support Groups - Experiences of Communality and Participation

Pyyntö osallistua tutkielmaan

Teitä pyydetään mukaan tutkielmaan, jossa tutkitaan OCD- ja Tourette vertaistukiryhmissä käyvien osallisuuden ja yhteisöllisyyden kokemuksia. Olemme arvioineet, että sovellutte tutkielmaan, koska olette osallistuneet vertaistukiryhmään. Tämä tiedote kuvaa tutkielmaa ja teidän osuuttanne siinä. Perehdyttyänne tähän tiedotteeseen teille järjestetään mahdollisuus esittää kysymyksiä tutkielmasta, jonka jälkeen teiltä pyydetään suostumus tutkielmaan osallistumisesta.

Vapaaehtoisuus

Tutkielmaan osallistuminen on täysin vapaaehtoista.

Voitte myös keskeyttää tutkimuksen koska tahansa syytä ilmoittamatta. Mikäli keskeytätte tutkielman tai peruutatte suostumuksen, teistä keskeyttämiseen ja suostumuksen peruuttamiseen mennessä kerättyjä tietoja ja näytteitä voidaan käyttää osana tutkimusaineistoa.

Tutkielman tarkoitus

Tämän tutkielman tarkoituksena on osoittaa ja havainnoida osallisuuden ja yhteisöllisyyden kokemuksia vertaistukiryhmissä.

Tutkielman toteuttajat

Tutkielma toteutetaan Metropolian sosionomitutkinnon opinnäytetyönä, sekä yhteistyössä Suomen Tourette- ja OCD- yhdistyksen eli STOY:n kanssa.

Tutkimusmenetelmät ja toimenpiteet

Tutkielma toteutetaan ryhmähaastatteluna vertaistukiryhmän tapaamisen yhteydessä. Vertaistukiryhmän tapaaminen pidetään normaalisti, jonka lomassa haastattelija kysyy tutkielmaan liittyviä kysymyksiä. Tutkielma toteutetaan 1–2 vertaisryhmän tapaamiskerralla.

Kustannukset ja niiden korvaaminen

Tutkielmaan osallistuminen ei maksa teille mitään. Osallistumisesta ei myöskään makseta erillistä korvausta.

Tutkimustuloksista tiedottaminen

Kyseessä on opinnäytetyö, joka julkaistaan julkisesti Theseus-palvelussa, sekä STOY:n verkkosivuilla.

Lisätiedot

Pyydämme teitä tarvittaessa esittämään tutkielmaan liittyviä kysymyksiä tutkijalle/tutkimuksesta vastaavalle henkilölle.

Tutkimuksen tietosuojaseloste: Henkilötietojen käsittely tutkimuksessa

Tässä tutkimuksessa käsitellään teitä koskevia henkilötietoja voimassa olevan tietosuojalainsäädännön (EU:n yleinen tietosuoja-astus, 679/2016, ja voimassa oleva kansallinen lainsäädäntö) mukaisesti. Seuraavassa kuvataan henkilötietojen käsittelyyn liittyvät asiat.

Tutkimuksen rekisterinpitäjä

Rekisterinpitäjällä tarkoitetaan tahoa, joka yksin tai yhdessä toisten kanssa määrittelee henkilötietojen käsittelyn tarkoitukset ja keinot. Rekisterinpitäjä voi olla Metropolia Ammattikorkeakoulu,

toimeksiantaja, muu yhteistyötaho, opinnäytetyöntekijä tai jotkut edellä mainituista yhdessä (esim. Metropolia Ammattikorkeakoulu ja opinnäytetyöntekijä yhdessä).

Tässä tutkimuksessa henkilötietojen rekisterinpitäjä on

Metropolia Am-mattikorkea-koulu	☐	
Toimeksiantaja	☐	Toimeksiantajan nimi:
Muu yhteistyö-taho	☐	Yhteistyötahon nimi:
Opinnäytetyön-tekijä	☒	

Voitte kysyä lisätietoja henkilötietojenne käsittelystä rekisteripitäjän yhteyshenkilöltä

Rekisterinpitäjän yhteyshenkilön nimi: Sakari Halonen
Organisaatio: Metropolia Ammattikorkeakoulu
Puh. 0442510888
Sähköposti: sakari.halonen@metropolia.fi

Tutkielmassaa teistä kerätään seuraavia henkilötietoja

Henkilötietojen käsittely on oikeutettua ainoastaan silloin, kun se on tutkimukselle välttämätöntä. Kerättävät henkilötiedot on minimoitava, niitä ei saa kerätä tarpeettomasti tai varmuuden vuoksi.

Tutkielmassa noudatetaan Metropolian GDPR-ohjeita kaikissa vaiheissa!

Haastattelu äänitetään, josta voi käydä ilmi osallistujien etunimet.

Teillä ei ole sopimukseen tai lakisääteiseen tehtävään perustuvaa velvollisuutta toimittaa henkilö-tietoja vaan osallistuminen on täysin vapaaehtoista.

Tutkielmassa ei kerätä henkilötietojanne muista lähteistä.

Henkilötietojenne suojausperiaatteet

Haastatteluäänitteet varastoidaan Metropolian suojatulle OneDrive palvelimelle. Tämän käyttö on opinnäytetyön tekijän käyttäjätunnuksen ja salasanan takana. Äänitteet ja muut tiedot säilytetään salasanan takana ja hävitetään viimeistään puolen vuoden kuluttua.

Henkilötietojenne käsittelyn tarkoitus

Henkilötietojenne käsittelyn tarkoitus on helpottaa aineiston analysointia.

Henkilötietojenne käsittelyperuste

Suostumus

Tutkimuksen kestoaika (henkilötietojenne käsittelyaika)

Tutkimus kestää enintään joulukuuhun 2022 asti.

Mitä henkilötiedoillenne tapahtuu tutkimuksen päätyttyä?

Haastatteluäänitteet tuhotaan välittömästi tutkimuksen loputtua.

Tietojen luovuttaminen tutkimusrekiseristä

Tietoja ei luovuteta tutkielman ulkopuolelle.

Rekisteröitynä teillä on oikeus

Koska henkilötietojanne käsitellään tässä tutkimuksessa, niin olette rekisteröity tutkimuksen aikana muodostuvassa henkilörekisterissä. Rekisteröitynä teillä on oikeus:

- saada informaatiota henkilötietojen käsittelystä
- tarkastaa itseänne koskevat tiedot
- oikaista tietojanne
- poistaa tietonne (esim. jos peruutatte antamanne suostumuksen)
- peruuttaa antamanne henkilötietojen käsittelyä koskeva suostumus
- rekisterinpitäjän ilmoitusvelvollisuus henkilötietojen oikaisusta, poistosta tai käsittelyn rajoittamisesta
- siirtää tietonne järjestelmästä toiseen
- sallia automaattinen päätöksenteko nimenomaisella suostumuksellanne
- tehdä valitus tietosuojavaltuutetun toimistoon, jos katsotte, että henkilötietojanne on käsitelty tietosuojalainsäädännön vastaisesti

Jos henkilötietojen käsittely tutkimuksessa ei edellytä rekisteröidyn tunnistamista ilman lisätietoja eikä rekisterinpitäjä pysty tunnistamaan rekisteröityä, niin oikeutta tietojen tarkastamiseen, oikaisuun, poistoon, käsittelyn rajoittamiseen, ilmoitusvelvollisuuteen ja siirtämiseen ei sovelleta.

Voitte käyttää oikeuksianne ottamalla yhteyttä rekisterinpitäjään.

Tutkielmassa kerättyjä henkilötietoja ei käytetä profilointiin tai automaattiseen päätöksentekoon

Henkilötietojen käsittely aineistoa analysoitaessa ja tutkimuksen tuloksia raportoitaessa

Osallistujat anonymisoidaan tutkielmaa tehtäessä. Jos haastattelussa tulee ilmi jonkun henkilön etunimi, sitä ei käytetä tutkimuksessa itsessään, vaan jonkinlaista koodinimeä (esim. Henkilö 1). Nimet voivat siis olla vain alkuperäisessä haastatteluäänitteessä, josta ne eivät siirry mihinkään.

Tutkimusaineistoa ja tutkielman yhteydessä kerättyjä näytteitä säilytetään OneDrivessa ja puoli vuotta, jonka jälkeen ne hävitetään poistamalla kaikki tiedostot.

Consent form

Tutkielman nimi: **OCD and Tourette's Syndrome Peer Support Groups - Experiences of Communality and Participation**

Tutkimuksen toteuttaja: Metropolia Ammattikorkeakoulu Oy, Sakari Halonen (0442510888/sakari.halonen@metropolia.fi)
Ohjaajat: Jukka Törnroos (jukka.tornroos@metropolia.fi) Katja Ihamäki (katja.ihamaki@metropolia.fi)

Minua on pyydetty osallistumaan yllämainittuun tutkimukseen, jonka tarkoituksena on osoittaa ja analysoida osallisuuden ja yhteisöllisyyden kokemuksia OCD- ja Tourette- vertaistukiryhmissä.

Olen saanut tutkimustiedotteen ja ymmärtänyt sen. Tiedotteesta olen saanut riittävän selvityksen tutkimuksesta, sen tarkoituksesta ja toteutuksesta, oikeuksistani sekä tutkimuksen mahdollisesti liittyvistä hyödyistä ja riskeistä.

Minulla on ollut mahdollisuus esittää kysymyksiä ja olen saanut riittävän vastauksen kaikkiin tutkimusta koskeviin kysymyksiini.

Olen saanut tiedot tutkimukseen mahdollisesti liittyvästä henkilötietojen keräämisestä, käsittelystä ja luovuttamisesta ja minun on ollut mahdollista tutustua tutkimukseen liittyvään tietosuojaselosteeseen.

Minua ei ole painostettu eikä houkuteltu osallistumaan tutkimukseen.

Minulla on ollut riittävästi aikaa harkita osallistumistani tutkimukseen.

Ymmärrän, että osallistumiseni on vapaaehtoista ja että voin peruuttaa tämän suostumukseni koska tahansa syytä ilmoittamatta. Olen tietoinen siitä, että mikäli keskeytän tutkimuksen tai peruutan suostumuksen, minusta keskeyttämiseen ja suostumuksen peruuttamiseen mennessä kerättyjä tietoja ja näytteitä voidaan käyttää osana tutkimusaineistoa.

Allekirjoituksellani vahvistan osallistumiseni tähän tutkimukseen.

Jos tutkimukseen liittyvien henkilötietojen käsittelyperusteena on suostumus, vahvistan allekirjoituksellani suostumukseni myös henkilötietojeni käsittelyyn. Minulla on oikeus peruuttaa suostumukseni tietosuojaselosteessa kuvatulla tavalla.

_____,   _____   .   _____.   _____

Allekirjoitus: _____

Nimenselvennys: _____

Alkuperäinen allekirjoitettu tutkittavan suostumus sekä kopio tutkimustiedotteesta liitteineen jäävät tutkijan arkistoon. Tutkimustiedote liitteineen ja kopio allekirjoitetusta suostumuksesta annetaan tutkittavalle.

Interview Questions & Themes

Peer support groups

Why go to a peer support group?

Can one get similar information elsewhere?

Does talking in peer support group differ from talking in i.e., on the internet?

Sharing & Other members

How does it feel to talk about compulsions?

What are you expecting when talking about your experiences?

How do you see the other members?

The group

What makes a community? Is this a community?

What works in this group?

How does this differ from regular therapy?

What makes the sense of safety?