Development of an Introductory Seminar to help utilize patients' waiting time at a MHC – A qualitative study of the user perspective

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Abstract

Background: In Norway, mental health disorders are the second highest cause of people on disability pension and the highest cause of lost working years. Due to this continuous increase in the number of psychiatric patients, MHCs struggle to meet demand, thereby, resulting in long waiting times for the treatment. This study tries to find what information is necessary for patients to cope with their problems while waiting for the actual treatment to start. It will be done by developing a pre-therapy introductory seminar, aimed at providing patients with the relevant information and prepare them for active participation in the treatment.

Method: A qualitative method with semi-structured individual interviews was applied in this study. Participants were strategically chosen in relation to the research question and data was collected by interviewing 10 patients in two rounds of interviews at Trondheim and Haugesund, respectively. Two rounds of interviews were conducted for achieving saturation of data and to gain better insight information pertaining to the research question. The interviews were audio taped and transcribed and were analyzed in four steps: (a) from raw data to topics (b) from topics to codes (c) from codes to sense-carrying units (condensation) and (d) from condensation to descriptions.

Results: Following three main themes are highlighted in results:

1. First topic describes why participants want information or why they think information is necessary during waiting time. Participants felt that information during the waiting time will lead to better control over their own ailments with more insights and better understanding of their situations
2. The second topic describes how information should be conveyed or how the introductory seminar should be organized. Participants preferred oral information than written and the information should be presented and exhibited in such a way that they can make optimal use of the seminar. The participants also wanted information about the institution and the personnel
3. The third topic describes what information the participants want or in other words what should be the content of the introductory seminar. It was important for the participants to receive information about the mental health in general, the course of treatment, what types of treatment methods are available and how they could get these treatments. This information can make the treatment choice easier and will help them understand the benefits and side-effects of various available treatment methods. The

main findings in this study corresponded largely with previous research and literature. In addition to this, most participants thought that user involvement is important and it is necessary to know how to be an active participant. Some of the participants wanted to know what they can do themselves and how and wanted to understand their patient rights at a MHC. Most participants also wanted to get information about various user organizations that can help them cope with their problems.

Conclusions: This study shows that teaching / education is regarded as useful for patients waiting for their treatment at a MHC. This could increase patients' knowledge about making choices about their treatment and to be more active in their treatments. Most of the participants wanted information about mental health disorders or general mental problems, treatment methods and the outcomes. It was important that they had a role in their treatment, including wanting more knowledge with regards to user involvement. Also, the necessity of information about patient rights and user organizations emerged clearly from the participants during interviews.

Keywords*:* In the search for literature for this study the following keywords were used: *'Patient education and patient participation'* on Cochrane data base of systematic reviews; *'User involvement, education, patient education, self care and psycho education'* on Pubmed; *'Patient involvement, patient planning and development'* at BMJ; *'Decision making, mental health, participation views education'* on Kunnskapssenteret.

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1. Introduction

Mental health problems are quite widespread in the population these days. Persons in need of care and treatment for mental health problems increase every year[1]. About one-sixth of the adult population has at any time a mental illness and/or substance abuse problems[2]. According to the World Health Organization, mental illness will be the main cause of disease burden in industrialized countries in 2020[3]. Due to continuous increase in the number of psychiatric patients, MHC struggle to meet demand, thereby, resulting in long waiting times for the treatment[4]. Longer waiting times at MHC results in additional problems related to initial appointment nonattendance or patients missing appointments[5-7] and high patient drop-out rates[8, 9]. In addition to this, long wait times may result in prolongation of physical and emotional distress and social dysfunction at home, at school, and in the community at an individual level. At a systems level, increased rates of non-attendance lead to reduced efficiency of MHC[4, 10]. So, it is important to figure out how to effectively utilize this waiting time and also take steps to minimize the related problems[11, 12].

In recent times, models like shared decision-making (SDM) and patient participation (PP) are being promoted in health care process, as these incorporate user involvement and patients' perspectives on their treatment and care[13]. The models represent an important ideological counterpart challenging paternalism and disease-oriented models of care, where patient is a passive recipient of care and all treatment related decisions rely entirely on the knowledge of the health care worker[14]. SDM enhances patient participation, by setting the person at the center of care and the process of treatment decisions[13]. Sharing of information is a pre-requisite for SDM. Both European and US mental health policies aim to include these models as a core value to reduce institutional forms of care, developing community-based mental health services and integrating people with mental health disorders in the community. To support this, involvement of users, and their families is seen as an important strategy[13]. The focus of this present study is also to incorporate the concept of patient or user involvement during waiting period and provide patients with information and strategies for their treatment early on[12, 15, 16]. By receiving necessary information, it can enable patients to participate in decisions about their own treatment and thus, may provide independence and improve their participation in the health care delivery process[17]. Several studies examined the effects of waiting-list interventions for preparing the patient for treatment. Results have been positive in terms of PP, however, still no link has been established between the interventions and the treatment outcomes[12].

The concept and philosophy related to patient/user involvement is quite new in mental health services[18, 19]. Mental health services are being oriented towards recovery in terms of focusing on integration of people with mental disorders in the community, provision of flexible in and outpatient mental health services and continuity of care. Although sharing of information, PP and user involvement are applauded, there are concerns regarding implementation of patient-oriented care models in the clinical mental health field, especially in relation to inpatient mental health care[13]. There are challenges related to inpatient care, and tensions between the patient and provider perspectives on treatment and care. It is reported that patient or user perspective is a necessary contribution for continuing development of services[13, 20]. This forms the basis of this study and patient or user perspective is included for better understanding on utilization of waiting period in a MHC. Since, only a few educational interventions[17, 21, 22] have been developed so far to improve PP before treatment at a MHC, additional patient educational measures such as educational seminar development are explored as part of this study.

1.1 Concept of SDM

‘‘No decision about me without me’’ encapsulates the ambition of a more patient-centered healthcare system that promotes SDM[23]. There are common features and overlaps between the concepts of SDM and PP[13]. SDM is a tool to enhance PP and help tailor general care to the needs and preferences of the individual patient[13]. Shared decision-making aims to increase patients’ knowledge and control over treatment decisions that affect their well-being and sharing information with the patients is the main goal of SDM. Both patients and health care providers contribute to the process of SDM[13]. The provider must provide information and lay out treatment options, their potential consequences and also explore the patient’s potential expectations. To support this, the patients must bring their experiences, values and opinions. Various types of decision aids (or educational tools) are often used in SDM.

In general health care, despite some successes with SDM implementation, efforts still face considerable difficulties. It is concluded that implementation work has not considered the patient perspective in detail. It has been reported that individual capacity to participate in SDM depends on two key factors: knowledge and power[23]. Knowledge refers to both knowledge about the treatment options available and of personal preferences and goals. Power refers to the patients’ perceived capacity to influence the decision-making encounter.

In the context of mental health there is growing attention to SDM, emphasizing that SDM is an important part of the person’s recovery process. SDM is suggested as an approach to medication management and to support decision-making in psychosocial matters such as work, housing, psychotherapy and other service provision[13]. Despite these arguments there is limited empirical knowledge about the associations between SDM and clinical outcomes for patients with mental disorders. A recent Cochrane review by Duncan, Best & Hagen[18] conclude that SDM interventions may not improve patients' health outcomes, but do increase PP in decision-making and satisfaction with care, without increasing the need for resources. Studies reported that since hardly any studies are available, it is, to date, impossible to make an evidence-based judgment as to whether SDM is feasible in psychiatry[18, 19]. However, if evidence suggests that SDM could be successfully implemented in psychiatry, a key role will be played by the development of decision aids, with the help of which patients are enabled and encouraged to participate in decisions in an informed manner. Only through the use of such aids will it be possible to supply patients with information. It is also reported that interventions aimed at changing long established behaviors are most likely to be effective if they are based on evidence from patients rather than what researchers or clinicians think is likely to work. Early work suggests that interventions should be delivered in two stages: preparation, followed by enablement[24]. At first, patients need to be informed about SDM — what it is, what to expect, and why it is appropriate. Finally, once the patient has made an informed decision to be involved, the focus should move on to enablement, which includes offering appropriate decision support tools.

1.2 Overview on Patient Participation

Patient participation (PP) pertains to the patient's involvement and role in decision-making in matters relating to their own treatment and care[13]. Concepts and theories related to PP are quite widespread and various PP definitions are available with different content and focus[25-33]. No single definition exists and various terms such as patient collaboration, patient involvement, patient empowerment or patient-centered care are used interchangeably[14]. For example, McEwen et al[34] defined PP as patient's activities related to maintenance and promotion of health, disease detection and treatment and adaptation to the disease if it is not curable; Tritter et al[33] described PP as a change in the patients' role from passive recipients to active participants; Florin et al[28] and Cahill et al[25] linked PP to patients' past experiences in their current treatment and Stringer et al[32] and Hickey et al[30] correlated PP to the fact that it is the patients' right to be involved in decisions that finally affect them; Rise et al[31] related PP to three main aspects: respect, dialogue and shared decision making between patients and service providers; Most of these definitions point to the fact that PP should be considered as a patient's statutory right and therefore, the patient should have an impact on the design of the health care services. It has been reported that PP can enhance the therapeutic alliance between patient and doctor[35] and can have overall positive results in health care[36-38]. There are also several proposed benefits of patient involvement in health care such as better services and production of improved sources of information for patients[37], reduced medical errors and improved patient safety[14], better coordination of care in chronic diseases[39] and improved clinical decision making[40]. Research has shown that PP, either at the system level or at the individual level is important and the patients should involve themselves in designing services along with health professionals[41, 42]. Patient-related factors that influence PP and can hinder the process are: acceptance of new patient role, level of health literacy and extent of knowledge, confidence in own capacities, type of decision making required, stakes of the proposed outcome, type of illness, age, sex, socioeconomic level, ethnic origin and use of alternative medicine[14]. Similarly, health care worker-related obstacles to PP are: desire to maintain control, time required to educate and respond to patient, type of illness, personal beliefs, professional specialty, ethnic origin and insufficient training in PP[14].

PP is a central concept in the Norwegian health policy. According to the Norwegian health authorities, PP is a major goal in mental health[43] and is made mandatory in hospitals (Hospitals Act §34 and § 35), and is emphasized with highest priority. "Patient participation must occur at all levels, from policy development and organization of services for the involvement and individual patients in their own care planning" (citation from Aim in the budget for the Norwegian Department and Health). Strengthening user's knowledge, their rights to be involved in their treatment and their education are also responsibilities of an MHC, based on the Norwegian legislation and the guidelines from the management of Norwegian outpatient clinics (§3.8, specialized health care services law). It is necessary to improve patient outcome, health status and quality of life[44, 45] by increased PP in outpatient community mental health centers (MHC). In spite of these measures by Norway, national surveys done in MHCs in 2002-2007, have consistently found that patients who seek help are dissatisfied with the information they receive, and their opportunity for real impact in their treatment[46].

1.3 Patient Education – a way to increase PP

It is likely that PP can improve if the patients have more information and education about their treatment options and ways to improve their health behavior and status before the start of the actual treatment. In general, patient education includes planned activities aimed at providing information on coping with symptoms, problem management, basic facts about mental illness and its treatment and community resources[27, 43, 47, 48]. The purpose of patient education is to maintain and improve health and in some cases to slow or reduce deterioration. Through patient education, patients' opportunities to participate in decision making concerning their own care might be enhanced[49] and their feeling of being involved in the management of their own care will be supported[50].

Research has shown that preparatory educational interventions for psychotherapy have provided some promising results relating to overall effectiveness on processes and outcome[51]. It is reported that as the educational interventions are brief and inexpensive, they can be very suitable for the managers and policy makers. Also, evidence suggests that pre-treatment education of psychotherapy clients may decrease fearfulness, anxiety, and role confusion[52, 53]. Overall, patient education can be an effective way to support psychiatric patients' capacity for independent living, compliance and insight and has a positive effect on patients' well-being and ability to cope more effectively with their illness[51, 54]. There are some studies that have looked at how patients can be prepared for treatment to prevent drop-out and increase attendance by means of educational interventions. For example, educational interventions, also referred to as pre-therapy preparation, are normally aimed to prepare patients for participation in psychotherapy prior treatments and involve education about assessment, aim of therapy, patient rights, roles and responsibilities[55]. These pre-therapy educational interventions may also have positive effects on patients' mental health and can improve their psychotherapeutically behavioral skills[15, 52, 56, 57].

Various patient education methods have been developed and evaluated[58]. Patient education with informational elements is a way to enhance PP in decision making concerning their own care[49, 59, 60]. Various patient education interventions have been developed to ensure that patients receive information. The most popular being low-cost, informative brochures that are often available in the waiting room[40]. Interventions also include pre-therapy interviews[61], audio[62], videotapes[63], group exercises and training on group therapy[64, 65] for administering pre-therapy preparation. The complexity of patient education has already been revealed in previous studies[47]. There is still a lack of understanding into how patients with psychiatric problems experience patient education on psychiatric inpatient wards. To assure high-quality patient-centered patient education, the content, possible problems and how patients want to develop the area of patient education should be identified[66, 67]. Asking patients themselves as to what information they want can be an effective way to improve effectiveness of education based interventions[47]. Similar attempt is made in this present study with a focus on the application of educational approaches, in the form of developing an introductory seminar, aimed at better utilization of waiting time for the new patients at an MHC. Patients will be asked themselves as to what information would they like to see in the introductory seminar that can help them deal with their illness during the waiting period.

1.4 What type of information do patients want about treatment?

Based on detailed literature search, it was found that although there are examples of interventions, there is limited literature available on what type of information patients themselves think should be provided before the start of the treatment at a MHC (during the waiting period). Results from a study about Patients' Views on Psychiatric Patient Education suggest that patients retain much of the information they have learned and they appreciate being given information about diagnosis, prognosis, treatment, and their own role[68]. The study also stated that the patients make constructive plans for changes in their behaviour after discharge and it can prove very useful for them if information about alternative treatments and how to deal with the waiting time is provided to them at the very start of the treatment[68]. Another similar study has also found that the patients with serious mental disorders want high quality information about care and a role in decision making concerning their own care[69].

1.5 Aim

No study was found that has investigated what type of information patients want while waiting for a treatment at a MHC. This study tries to overcome this deficiency by development of a pre-therapy introductory seminar aimed at providing patients with information that will help them during the waiting time at a MHC and prepare them for active participation in the treatment. The aim is to explore what patients want from such an introductory seminar. The seminar will help educate the patients on the available treatment options and can enable them to cope with their problems by means of greater participation in their own therapy. This can lower the risk of patients dropping out from the treatment and can be a platform for increased contact between patients and service providers. By way of the seminar, large numbers of patients are reached at a time and can offer additional help to them.

2. Methodology

The study's aim is to produce context for an introductory seminar, where the patients will get information about topics arising from interviews with the participants. This study is part of a larger project that has an overall aim of developing and evaluating the effect of an introductory seminar for patients on the waiting list in a community mental health centre (MHC). The larger project will be conducted in a way that allows for a combination of qualitative and quantitative data, and it is useful for creating a broad understanding of practical side of the participants experience and the effects. More specifically, it firstly aims to educate patients, so as to enable them to choose among available treatment options. Secondly, it aims to enable patients to cope with their problems while they are waiting for treatment, giving information to increase self-help and providing contact with primary health care and user organizations during the waiting time.

The intention of the introductory seminar is to provide patients with information while they are on the waiting list in a MHC and this study will produce context for developing the seminar. In order to address the problem, it is necessary to clarify one's scientific starting point and selection of method. By methodology, we mean knowledge about methods. According to Thornquist[70], *"it is about making connections to basic questions about the relationship between theory and empiricism, what scientific knowledge is and how one reaches valid knowledge"*. The method is a necessary pre-condition so that the results found in this study will provide a good and necessary understanding of what the study is seeking knowledge of[71]. A method is, in other words, a method of approach in order to attain new knowledge.

2.1 Qualitative research method

A qualitative research approach is well suited to explore what patients require from an introductory seminar by investigating and describing people's experience and by trying to understand their point of view[72]. Each individual has a starting point, a history, personality and experiences with significance in the process around information, wishes and involvement. Focus of this study is to try and find out what type of information patients would require before starting out-patient treatment at an MHC. Intention is to develop contents for a pre-therapy introductory seminar aimed at providing patients with information that will help them during their waiting time at an MHC and prepare them for active participation in the treatment.

Qualitative methods build on philosophical theories about human experience and interpretation of human opinion is considered as valid knowledge[73, 74]. Within this perspective, one is not concerned about finding objective truths, but in reaching an understanding of the individual's life, surrounding the topic. Through the depth interviews employed in this study, the participant's own experience is approached by trying to understand what the individual participant has perceived or experienced and the information that he or she would like to receive in relation to the introductory seminar. It was therefore natural to choose a qualitative approach as this is the approach best suited when one is looking for knowledge about human phenomena such as experiences, perceptions, thoughts and attitudes[74]. With this qualitative study, the intention is to develop new knowledge and not reproduce knowledge already found previously[74]. The qualitative method aims at understanding and not judging by describing what the situation is and not by preaching or writing about what it should be.

As opposed to quantitative methods, which focus on the incidence of a phenomenon, one seeks through qualitative methods to reach an understanding of social phenomena in the context of abundant data about people and situations[75]. Another way to clarify this difference is that this material consists of qualitatively representative conversations while the quantitative methods build on numeric data in the form of figures[74]. The researcher's insight, analytical skills and ability throughout the entire research process affect the quality of qualitative research[76]. This study seeks information about how the experience emerges for individual participants by understanding, interpreting or deconstructing the human experience qualities of every individual[77, 78]. The purpose of this qualitative study is to achieve understanding of the phenomena in the context of abundant data about people and situations in the participants' social reality. Efforts are made to understand the reality as understood by the participants studied by the researcher.

2.2 Qualitative interview

The qualitative research interview is selected as an approach to the problem and as a method of data collection because this study seeks holistic depth knowledge from the patents with experience and perceptions about the topic, as well as from the ones who are new to the system. The aim of qualitative interviews have been to gain an insight into the participant's own understanding and what they mean themselves by getting information before they start treatment. The interview is the most widespread approach to qualitative research and a usual method of acquiring knowledge about people's life situation, their attitudes and experiences, say Tanggaard and Brinkmann[78]. When an interviewer has an interview with an individual, it is called a depth interview or an "unstructured interview". Another term for this is a semi-structured interview. Semi-structured interviews are relevant to this study because we have the aim of getting to know something we didn't know previously and of carrying out a conversation, which will contribute to understanding the participants' viewpoint regarding the problem in the study. The depth of the conversation depends on the problem and what the researcher wants to get an answer to[74]. The aim of the research interview is to facilitate the conditions for a conversation about the participants' thoughts, opinions, attitudes, reasoning, feelings, motives, histories, life-world with relevance to our research question[79]. Therefore semi-structured interviews provide the opportunity for a certain degree of flexibility in interviews so that the data produced can steer the questions that eventually are asked[75].

Basis for the semi-structured interviews is that the researcher starts off with an open mind and by that it means that he or she has the knowledge about the topic while letting the participants speak freely[78], which allows a new point of view to emerge from the participants. It is therefore important for the researchers to understand the conversation between the participant and the interviewer and the significance this has for interpretation and findings, says Kvale[77, 80]. This has been an important framework for knowledge development during this study when the data was collected through conversations with the participants.

2.3 Participants and recruitment

Participants were strategically selected. The strategic sample refers to the select participants who have characteristics or qualifications that are strategic in relation to the research question [25]. According to Malterud[74, 81], the aim of using a strategic choice is that the material should have the best possible potential to shed light on the issue being studied. Based on this background, 10 patients were selected to ensure age and gender variation. This number of participants corresponds to the standards of qualitative research [73, 74, 82].

To be eligible for this study the participants had to be on the Trondheim MHC or Haugesund Psychiatric Centre (HPC) waiting list with an estimated waiting time for treatment between two and four months. Furthermore it was required that they were at least 18 years old, understood Norwegian and provided informed consent to participate in the study.

In the first round, participants were recruited at MHC in Trondheim between May 2009 and July 2009 by sending a letter to all who met the inclusion criteria. The letter included information about the study and a return letter for the patients to use if they wanted to participate. Those who wanted to participate were invited to a screening interview where they received further information about the study. Of those selected seven were participants in the study.

In the second round, a letter was sent out to the departmental leader, at HPC in April 2014, about being able to interview some patients referred to HPC. In advance, the aim of the project and its criteria were put forward so that those who were eligible were included. The letters were sent on to relevant participants. Responses from five participants were received, of which just three turned up at the appointed time. Of those who participated, one was on the waiting list and two had finished with treatment at HPC.

The following exclusion criteria were applied: excluded were patients with a guarantee of a treatment start within less than two months, as well as patients who would not understand the consequences of their taking part in the study. Patients who were under 18 years old were also excluded. Patients with significant language or comprehension difficulties, severe dyslexia or cognitive impairment were likewise excluded from the study.

The distribution of participants is according to that they been treated in mental health care before or not are as follows: Three participants are new in the system (participants 2, 5 and 6). One participant has been examined, but is now on the waiting list (participant 8). One participant dropped out, and one is now waiting for new treatment (participant 4). Three participants are attending treatment, one of them dropped out earlier, but is now in for treatment again (1, 3 and 7). Two participants have completed treatment (participant 9 and 10).

2.4 Interview guide

In advance of the interviews, an interview guide was developed and there was an interview guide for each round. The main topic of the interview guides was: What type of information do patients require before the start of your treatment? Participants were also asked to elaborate regarding information on how to handle waiting time, choose the type of treatment and take an active part in their treatment. The interview guide contained key words and questions to relate to during the interviews. Malterud says that the guide will function as a flexible memory checklist with suggestions for questions[74]. This was no set template for what was asked about or for the order in which the questions were asked. According to Malterud[74], the interview guide may be used as a starting point for mental concentration with regard to the topic so that one can try to collect two or three main questions that frame the most important issues. An interview guide may more or less set the course for the interview and it doesn’t need to be detailed or theory driven. This would also depend on the understanding one has of what the interview will be about and what methodological frameworks one allows the interview be conducted within[78]. When it comes to semi-structured interviews the interview guide contains an overview of topics to be covered as well as suggestions for questions. In this study, the interviews have been flexible. The questions were not asked in a definite sequence. When the patient started to talk about a topic, the questions were then asked in relation to that topic and to obtain more depth information.

2.5 Conducting interviews

Interviews were started with the participants signing the consent form for participation in the study followed by a short a presentation about the interviewer and the intention of the study. The participants then received information about the confidentiality obligation, anonymity of participants in the study and the fact that they at any given time could withdraw from the interview and the study. The participants were also informed that the interviews were recorded on an audio tape recorder, and these will be deleted when the study is completed. The interviews were done by two different persons. First round was done by a student in Trondheim and she interviewed participants in MHC. The second round was done by the author of this master's thesis in Haugesund. There are advantages and disadvantages of getting data collected by two different persons. Advantages are that it saves time, and the collected data is from multiple cities and two MHCs instead of just one. Disadvantages are that the author didn't have possibility to ask participants from the first round of interviews any follow-up questions to clarify any misunderstandings.

The interviews progressed by asking simple questions, as a form of warm-up exercise. It was important to create a good atmosphere by being attentive and maintaining eye contact. Then the process continued with questions that invited reflection and full answers. Interviewer was careful not to interrupt or put words into the mouth of the participant. Follow-up questions were then asked based on the information provided by the participants. Interviewer was careful to show an interest in what was being said, by responding with nods or smiles and also by making encouraging comments such as "yes, aha, hmm" and "absolutely". The interview guide was a great help and it was used as checklist for which topics should be brought up, and was a source of good advice. The interview guide was not presented to the participants in order to make sure that the participants could give spontaneous answers[77]. Whenever a clarification was necessary for what the participants meant to say, follow-up questions were asked. In the end the participants were asked if they wanted to add something or something they had not been asked for that they wanted to tell.

2.6 Method for analysing data

The meaning of qualitative data is to find the information content in the text. Through the analysis process, it is presented that how the categories were formed and how these contribute to highlighting central topics of the collected data. The information that was produced from the interviews drives for what have been considered important to focus on in the analysis. Qualitative analysis must be carried out in such a way that others can later follow the procedure one has taken, recognise the structure of the argument and understand the conclusions[74]. The analysis was carried out by systematic text condensation[74]. The approach that was applied for the analysis consisted of the following four steps:

1. **From raw data to topics:** All the ten interviews were carefully examined, to get an overall impression of what was said in the interviews, and to start a thought process around any main topics. Then the preliminary topics were written down. Those topics represented a first, intuitive, data-based step in the organisation of the material[74].
2. **From topics to codes:** Each interview was then reviewed again to identify what Malterud[74] calls sense-carrying units. The text which in some way carried information about one or more of the topics from the first step was selected. Simultaneously while the sense-carrying units were noted in the text, these were also organized by coding. According to Malterud, the codes are developed and adjusted with a basis in the preliminary topics one had from the first step[74]. While new codes emerged continuously during the process, the texts were reviewed repetitively to capture all the sense-carrying units that have something to say about a particular code. Malterud says that such flexibility in the process is a condition to be able to pick out something new and capture it systematically[74]. After the code work was complete, codes were reviewed to check if some can be combined or restated. The codes are just a means and a structuring principle during the analysis part, and not a goal[74].
3. **Condensation – from code to sense:** This entails that each condensed sense-carrying unit in the code groups is rewritten so the concrete text content is translated into abstract sense and put in different sub groups under associated main topics. First round of interviews were utilized to theoretically understand the possible sub groups. Once the sub groups were evident, relevant information was placed under them by reviewing all the interviews from both the rounds.
4. **Summary, from condensation to descriptions:** In this phase the bits are reassembled, that is re-contextualisation as Malterud calls it[74].

The sub-groups were described and illustrated with associated quotes and are summarised in the results section of this study. Quotes from the data are used to illustrate and elaborate on the results. The analytical process was experienced as quite demanding with respect to time and keeping track of everything. A total of 82 pages transcribed data was analyzed as per the four steps mentioned above.

2.7 Ethics

Malterud[74] says that '*Qualitative studies involve meetings between people in which norms and values make up important elements of the knowledge that is exchanged and developed. That's why it is important that the researcher is familiar with some of the special ethical challenges that this entails.' p. 201*

This study is approved by the Regional Committee for Medical Ethics for Research. The main project protocol has been reviewed and approved by the Regional Committee for Medical Ethics for Research in medicine and was conducted according to the Helsinki Declaration. Protocol for this master's study was approved by Aslak Steinsbekk. All participants were informed orally and in writing. Written consent was obtained before participating. Participants had a choice to decline taking part in this study.

3. Results

In total there were ten participants: eight women and two men, aged between thirty and fifty, with different work backgrounds. Results are presented as three main themes based on what participants want with respect to an introductory seminar before treatment at an MHC. The first section is the participants' reason as to 'why' they want information during the waiting time. The next main topic is organisation, which describes 'how' participants want the information to be provided during introductory seminar. The last main topic is 'what' information participants want as part of the content of the introductory seminar. Sub-topics are presented for each main topic, and some of the sub-topics have further sub-topics.

3.1 Information during waiting time

It was clear from the interviews that most participants wanted information while they are on a waiting list. They said that as they had experienced discomfort in terms of mental health problems, which to varying degrees had impacted their daily lives, they have certain expectations and hope from the treatment in the near future. They felt that information during the waiting time would make it easier for them to handle situations during waiting time. If the waiting time got longer than expected, some experienced it as intolerable and it created uncertainties, since they didn't know what would happen next and when it would happen. One participant expresses it like this:

> *"Because it is always worse when you do not know what is happening. Because something happen in your mind. So I think people have a need to get concrete information about the service they will get, where they are going to go and what is going to happen."*
>
> *(Participant 9, female)*

Some of the participants felt that they received too little information during the waiting time. *"I think that generally there is too little information before you start" (Participant 4).* They had been told that they were on the waiting list, but apart from that they did not know much about what awaited them. Furthermore, some participants expressed the feeling that little information can lead to impatience. One participant expressed it like this:

Well, I guess I feel – I am very impatient and tense, I am on edge. And maybe I would have been calmer if I had known … what was going to happen.
(Participant 2, female)

Participants said that having knowledge before they go in for treatment influences the help they will receive, so it is important to receive good information. During interviews, the participants said that it is important to them to know what expectations the system has of them and what they can expect of the system:

"Yes, because when you know what is expected of you it is easier to cooperate"
(Participant 9, female)

"Yes, it's very tough. Being on a waiting list is a difficult situation to be in, and you encounter attitudes that make it worse."
(Participant 5, female)

3.2 Organization

Under this topic it is categorised how the participants want the information communicated during the introductory seminar. This means details on what participants think how many participants should take part in the seminar and how the communication should be structured. Participants said that this can be of great importance in relation to having meaningful information during seminar. The participants also wanted information about the institution and the personnel. This is described in more detail under the sub-topics.

3.2.1 Number of participants

Most participants emphasized organising the introductory seminar so there were not too many participants. Some said that up to 10 people might be appropriate.

"Yes, I would feel more secure with fewer people there. Only 10, I think".
(Participant 5, female)

The reason they wanted few participants is to pay attention in a better way to the information given. Some participants said that they experience anxiety when there are too many people in the room. Other arguments for having few participants is that it can make them feel more secure, and it felt more relaxed and reassuring to the participants when there were not too many people in the room, and they would not be distracted.

" No, I would not have very many people at seminar, but maybe 10".
(Participant 4, female)

3.2.2 Communication

Several participants mentioned that the introductory seminar should be organized in such a manner that it provides specific information related to individual topics that directly relates to the participants. One of the participants argued that it is more reassuring to gain knowledge and understanding about their own role and participation in what is going to happen to them. The participant felt that this aspect disappears when there is too much general information. Most participants did not spontaneously say anything about this, but some of the participants just answered “yes” when the interviewer asked directly if the information should be “straight and to the point”.

> *”Because it gets so – it gets so general that … that you cannot take in the fact that it is relevant to yourself […]. But if all the information related to you directly – then there wouldn’t be all sorts of general information that passes over your head, and by the time you get to what’s important, you’re no longer paying attention […]. Yes, and to talk about things that you know are relevant to the group.”*
>
> *(Participant 1, male)*

Some of the participants emphasized the importance of oral information compared to the written one, because they cannot concentrate and understand enough to get anything out of written information. The reason why the participants want oral information is also to feel reassured and get an understanding of their own role.

> *” I feel that getting information in written help, but it can also be quite tiring. For you must think properly and understand, and if you do not understand it, then it becomes very difficult.”*
>
> *(Participant 7, female)*

3.2.3 Organization of the institution

None of the participants spontaneously mentioned that they want information about the institution itself. When asked directly they answered that it is desirable. They wanted to know how a MHC works and what are the stages of the system, not the least how people work at the institution. In particular, participants who had some experience with the treatment mentioned the desire to obtain information on this topic. They gave the reason that it would make them feel more reassured during the waiting time because they will get a sense that they know the place. They also wanted this information because it can prevent confusion when they arrive for treatment.

”Yes, I would have liked a bit more information about how the DPS system works [.…] *how they work. And some superficial explanations about what they do at this DPS”*

(Participant 8, female)

One participant wanted information if the staff wore white clothes or a uniform and how the staff worked at the institution. This is related to getting familiar with the procedures at the institution and to feel prepared and reassured with regards to what is going to happen.

"Yes, do they wear white coats or normal clothes? That sort of thing means a lot.”

(Participant 9, female)

Participants with experience from previous treatment wanted the introductory seminar to be organised so that participants gain more knowledge on the practical part of the treatment, and things such as the duration of the treatment. In addition, there was one participant who wondered if the people admitted to MHC could get a leave for a day or so, if necessary.

”I guess it is mainly the treatment procedures, what kind of treatment. Duration […] description of the procedures […]. To get a, well, thorough description basically, of what you are going to go through.”

(Participant 9, female)

3.3 Content

Under this topic it is categorised what information the participants want at the introductory seminar. This means that it is important for the participants to receive information about the different ailments and pain, what was going to happen, what type of treatment is available and how they could get that treatment. And not the least, they wanted to know what they can do themselves and how. This was important with respect to the available treatment options and it will have consequences for further follow up of their treatment. During introductory seminar, participants wanted information about how long they have to wait before they can start their treatment and how much time can they expect to wait? They talked about their experience in relation to the treatment they have received, or will receive.

3.3.1 Mental health

The participants did not spontaneously say that they wanted information about mental health during introductory seminar. When they were asked directly by the interviewer if they wanted information about mental health, most of them answered that it was desirable. When asked why they would want this, some answered that this is a very important topic because it could give them better control over their own ailments with more insights and better understanding of their situations.

> *”Yes, I think it would have been very relevant, maybe one would understand a bit better.”*
>
> *(Participant 2, female)*

Participants pointed that not everybody knows what mental problems involve and therefore, they wanted general information on this topic. A statement from one participant who had experience with treatment, described what she experienced during her own treatment period with regards to how this topic is normally misunderstood by many. Several participants mentioned that those who are referred to a MHC are considered “mad”. Therefore, this makes it difficult for the patients to talk about their problems. They wanted to be taught about this topic to increase their understanding of what mental problems are.

> *”Yes, I think it is very relevant to get information about mental health, we all have mental health and we all have mental ill health. People misunderstand always. So more information about this, yes”.*
>
> *(Participant 8, female)*

3.3.2 Treatment

In this section, the responses from participants on the information required in relation to the course of treatment, available treatment methods and any specific details on these individual methods, is described. Participants needed information depending on whether they have any previous experience from treatment or not. Some of participants were satisfied with information they had received, and some wanted more information during waiting time. Participants expressed their desire of information about available treatments so it can be easy for them to choose among various treatment methods when the treatment starts.

3.3.2.1 Course of treatment

During interviews with participants, who have received treatment previously, different experiences about participants’ treatment emerged. Some participants said that they were satisfied with the information they had received with regards to their treatment. One participant said that for her it was positive to receive brochures to give her an overview of what the treatment course involved just after she was admitted for treatment. While other participants said they could have been given more information, and this has an impact on what information is wanted at the introductory seminar. With regards to the course of the treatment, the participants wanted to know how many stages the treatment will have and what happens when they are admitted for treatment? On being asked directly, one of the participants described her experience like this:

> *"I have been quite lucky and received a lot of papers and things like that from my psychologist, things I can read myself."*
>
> *(Participant 7, female)*

Other participants said that knowledge makes them feel reassured as they become familiar with what will happen during the treatment course. Another participant described that not having knowledge can lead to fear and unease inside, so this information is important.

"Maybe something about how they will proceed. Yes, maybe just a leaflet about how things will happen, for example. So – what they are going to do, and maybe I would have been a bit calmer if I had known … what's going to happen."

(Participant 2, female)

3.3.2.2 Information about available treatment methods

Many participants thought that they get too little information, especially about the treatment choices they have. Some of the participants said they were not aware of the treatments and services that the institution will offer. Another participant had already obtained a lot of knowledge about her own illness and the psychiatric treatments available. She felt that she knows a lot, but she still said that there is a lot of uncertainty surrounding this topic. Therefore, she said that it would be of great help if they received some education on this topic during the seminar, before they are admitted for treatment. She also said that this could help them make choices. This was important with respect to available options and it will have consequences for the further follow-up and cooperation between the participants and the staff. Some participants said it is important because their own efforts are influenced by what they will receive.

The participants also wanted information about the appropriate treatments for their own illness. Therefore, they said that it is necessary to have information about the different available treatment options, so they can make a choice based on the individual situations.

"Yes, sufficient information is important. And the opportunity to ask when you have something on your mind, it is always difficult when you are new and you have a mental illness and you're about to start something. Therefore comprehensive information is important, I think."

(Participant 4, female)

One of the participants who had experienced treatment before said that she did not get information about what type of treatment she was going to receive:

> *"I got a letter to say I was accepted to stay on for further treatment. But I was not told what type of help I was going to get."*
>
> *(Participant 3, female)*

3.3.2.3 Specific details on individual treatment methods

Another topic mentioned during the interviews was that it was important to have information about what the different treatment involve, i.e. what the treatment consists of. The participants were interested in information about what was going to happen and how it would happen. Participants said that feeling secure and looked after are connected to having knowledge about what the method entails. They also said that being educated in what the treatment methods involve will give them a feeling of being able to decide if they want the type of treatment that being offered or not. The experience of one participant who had been treated previously was not positive because of lack of information about what the treatment method involved. She said that she would have declined the treatment if she had known what the treatment involved. The lack of information made her much more passive when she was not satisfied with the applied treatment method. The participants, with and without previous experience, said that they wanted more knowledge about this topic.

> *"To find the best way to help people, there are many treatment methods and they don't all suit everybody, so it is important to have different methods. Yes, you become more positive when there are more choices. You do."*
>
> *(Participant 6, male)*

One participant expressed the importance of having knowledge about prognoses. He talked about being able to know whether the treatment works on those who receive it. A pre-condition for the patient understanding the reason for receiving help with their health and the different treatment methods is that they have received enough information about their prognosis. Therefore, receiving information on prognoses is important to the participants during seminar.

> *"Yes, general information, and say something about what the prognoses are like."*
>
> *(Participant 1, male)*

3.3.3 User involvement

To ensure that the participants were familiar with the term user involvement, they were first asked if they knew the concept. Some of the participants understood the meaning of the concept, while others received an explanation first before they were asked questions. In order for the participants to give accurate information, the interviewers were very careful that the meaning of user involvement was presented very clearly from their side. Therefore, an explanation was given both beforehand and while the interviewers were asking the questions when it was noticed that the participants had not understood it fully.

3.3.3.1 Active involvement

Some of the participants said that user involvement involves the users actually contributing to the design of their own treatment. User involvement can contribute both to the service attaining a higher quality and becoming better suited to the individual's needs and requirements and so that the users feel a great degree of mastery and authority over their own lives, one participant explained. For many participants, it was important that they had a role in their treatment, including wanting more knowledge with regards to user involvement. They experienced that user involvement led to active participation.

Participants said that having knowledge of what treatment involves can lead to improved user involvement because it can motivate them to contribute to their own treatment. Participants emphasized that one manages to contribute more to their treatment by being involved. They also explained that user involvement can lead to the aim of the treatment being clearer and predictable.

> *"It is a very important topic. It is very important to be able to participate as it makes you active, so absolutely."*
>
> *(Participant 10, female)*

3.3.3.2 Own initiative

The participants were clear that information about user involvement is beneficial to them. They would like information regarding user involvement to contain something about own initiative and the purpose should be to facilitate motivation to take the initiative oneself. Participants who had experience with treatment said that their experience with user involvement has been positive. Therefore, they would like to recommend this to new patients who are on the waiting list so that they can benefit from self-help right from the beginning of treatment. The condition is that they can take initiative themselves. They said that, being active themselves, had made a major contribution to their treatment.

”For my part, in order for my treatment to go well, I did a lot myself. I actually think everybody can benefit from all the information they receive, as long as they are interested in it and want it themselves.”

(Participant 7, female)

3.3.3.3 A voice in decision making about treatment

Participants recounted that user involvement also meant that their responsibility became clearer. This is connected to greater consciousness of increased responsibility among them. At the same time, while they are involved, they expressed the importance of being conscious to the fact that they should agree to what will happen with them and they don’t just accept all they get from treatment. Therefore, they thought that this type of information is very important during seminar so that their voice is heard in decisions that affect them. Knowledge about user involvement will give them the strength to be able to accept or reject the treatment decided for them, the participants said.

”This is vital. This is very close to my heart. Without user involvement you are just a brick being moved here and there. You are sitting there and know that you can have an influence; you have a voice yourself and the right to say “yes” or “no”.

(Participant 9, female)

The participants also said that it is important that they should be involved as much as possible in their own treatment, but at the same time, they expressed that this must happen in cooperation with professional or qualified people who work at the MHC. Some participants said they would not be able to manage or get involved without help from the staff. They needed to be “pushed” to get involved. Therefore, they would like this information about whether they can get help from the staff to get involved with self-help.

“But perhaps not at first. You must meet qualified people before you can do something yourself.”

(Participant 5, female)

3.3.4 Patient rights

The necessity of information about patient rights emerged very clearly from the participants in the interviews. All the participants thought it was a relevant topic that should be included in the content of the seminar. One participant answered that this is a relevant because one then know what rights one has: *“It is important to know that too" (Participant 1, male).*

3.3.4.1 The right to choose

Participants said that when they will have the knowledge to influence their own treatment, they have the right to choose, either to undergo treatment or stop treatment. “This also comes in under patient rights,” said one participant.

> ”Patient rights, yes. This means that one can, that it is voluntary whether one wants to have treatment or stop treatment, yes, patient rights are important.”
>
> *(Participant 4, female)*

3.3.4.2 Security

Several participants mentioned that they would like to have the knowledge with regards to the patient rights so that they feel more secure. They said that they will get a feeling of security from knowing what rights they have.

> *”This is because we need information to be secure. If only there had been somebody who could have told me what I could demand and what I was entitled to”.*
>
> *(Participant 8, female)*

3.3.5 User organizations

There were several opinions from participants on whether they wanted information with regards to user organizations and why they wanted it or vice versa.

3.3.5.1 About the organizations

Some of the participants said that it is very important to have information about user organizations during seminar as it is important for patients to know what help is available outside MHC. They would like to know what these organizations are doing, what they offer and what they can help with. It is implied that not everybody understands that the user organizations can help the participants and therefore, it is necessary to present relevant information during seminar. A participant who talked about the user organization said that she herself had experience of getting help from the user organization and therefore, would like that those who are unfamiliar with it should also receive information about it.

> *“Very important. It is very important to make these things clear to many. Perhaps to pinpoint those specially connected to mental health and say that they are available all over the country. Provide information about where they can be found. Most have heard about it, but not everybody understands that they can get help from them”.*
>
> *(Participant 8, female)*

3.3.5.2 Positive experience from user organizations

Some participants wanted to find out about positive experiences and about those who are well again with help from these organizations. One participant mentioned that she would rather not hear from those who have had a negative experience as that could affect the course of her illness and treatment, but the importance of getting teaching on this topic still emerged.

> *”In my view, I think it would have been super. I wanted to hear from patients who got better. I don’t think I wanted to hear about what went wrong.”*
>
> *(Participant 4, female)*

3.3.5.3 Relevant information

Some of the participants mentioned that they want to hear about the offers provided by the user organizations together with information relevant to participants with specific conditions so that it should not take the form of information about everything to everyone.

> *“Certainly if they have an offer, which is useful to hear about. All kinds of information are important in this way – but it must be something that concerns you.”*
>
> *(Participant 1, male)*

3.3.5.4 Recognition

Some participants mentioned that it is difficult for them to speak about their condition and distress with others. The reason they wanted to hear about user organizations is that it will help them with their self-confidence and sense of security. A female participant described it as follows:

> *“That they have gone through the same as you and not … that you know that they are safe as they have gone through the same as you”.*
>
> *(Participant 9, female)*

It was mentioned that the information on others who have been through similar ailments/illness will be able to influence ones opinion and treatment in another way. Several participants mentioned that they have a good experience with the user organizations and therefore, want to hear about this topic during seminar.

> *”I have a lot of experience on this. Perhaps after a while it is positive. Yes. I think it can be. Then maybe you don’t think it is just yourself. Even if you know that it is not just you, you feel it. Experiences are useful.”*
>
> *(Participant 5, female)*

3.3.5.5 Relating to several people

Some participants had a different view on receiving information about the user organizations during seminar. They said that this topic is not a top priority for them and that it can be too much information for them. Also, they did not want to contact too many people since this can easily lead to too much focus on the illness. It can also become difficult to come out of sickness-related situations that will be presented. For this reason, they felt they could wait a while before hearing about this topic.

> *”I feel in any case that one should not go around too many different people. As then it becomes, I don’t know, you know, if you have to talk to somebody new all the time, then that can be a bit unpleasant”.*
>
> *(Participant 7, female)*

4. Discussion

4.1 Discussion of methods

Qualitative research is suitable for studies of themes into which little or no research has previously been done, as is the case in this study[83]. It allows for the meaning of the questions and the answers provided to be explored with the participants. The researcher as an interviewer had "the power" in the interview so that the central theme is focused throughout in the interviews. This requires focus and a level of awareness from the researcher. This flexibility can be considered as strength of this study. It is only natural that the participants branch off into other themes during interviews while at the same time bringing up relevant topics and interesting material that I had not considered beforehand. This led to new relevant information from the participants and this can strengthen the reliability of the study. According to Postholm[84], the research will be influenced by the researcher's own theoretical point of view and experience. Interviewers experienced that participants talked about themes that were not included in the interview guide. This gave a new perspective on things that could be included in the seminar. Thus, the strengths of qualitative research are participant interviews that gave room for flexibility and opportunity to ask follow-up questions in order to clarify any misunderstandings.

The strength of this study is also that it has come up with good arguments for what patients need as information during waiting time. There is no previous research within the same theme and this study contributes with knowledge about the possible content of an introductory seminar that can help patients with treatment while facilitating user interaction. The purpose of this study is to explore more deeply what participants want and what are their expectations from such an introductory seminar through qualitative research methods. Based on the research question, it was appropriate to have a strategic sample of participants. Therefore, two rounds of interview were conducted to make sure that sufficient participants and reasonable saturation of data is there. The second round provided an opportunity to go deeper in the topics where more information was required and this can also be considered as strength for this study. There were problems getting hold of some of the participants. They were contacted by email after agreeing to participate in the study. Some of them did not show up at the agreed times. Some of them were not in the city and it was not possible, therefore, to meet them. In total, 10 participants were interviewed and this seems sufficient enough to simultaneously keep track of all the data and analyze it in depth so that adequate time is available to extract important statements from the participants. Malterud says that in qualitative studies a large number of participants can make the material difficult to follow and the analysis shallow[74]. However, it is not ruled out that a larger sample size would have given a more varied picture of the phenomenon. It should be noted that if the participant's size is increased, it may result in a larger study than a master's thesis.

As mentioned earlier in the methodology section, the data that has been collected for this study is part of a larger main research project. Being part of the original research project has its advantages and disadvantages. One of the advantages is that you can bring a new perspective to the interviews, the analysis and the result. A disadvantage could be that the author of this master's study did not take part in the first interviews and thus may have missed information that could be difficult to interpret from the transcriptions. One example is that she did not have the opportunity to observe the participants and understand the non-verbal communication. Body language and facial expressions can contribute to the content of the interview and reveal feelings, irony and opinions[73, 74]. However, this was not found as a significant problem as both the interviewers and the participants verbally expressed themselves quite well and in a way that was easy to understand. Also, second round of interviews were done by the author herself.

It was found that the participants expressed themselves sincerely and were enthusiastic about the theme. The participants' concentration, attention, motivation and form on the interview days may have affected the answers to a certain extent. However, it was not noticed that this effected interviews or the topics participants talked about, in any way. This validation was created through dialogue during interviews. It was found that these types of validation helped to go deeper into the themes and the proof of this is also available in the transcriptions. Following feedback from the participants, general impression was that they were given plenty of space, the dialogue flowed well and, overall, the data material gives a comprehensive picture of having information for the introductory seminar. The validity of the data material is strengthened in that it was asked suitable questions that enabled the participants to provide full and comprehensive statements and thus, this strengthens the study[85].

Credibility or reliability is about how reliable the study is and is primarily associated with the interview, transcription and analysis, where the researcher accuracy in the process is emphasized. This particularly applies in relation to the interview guide and the formulation of questions when conducting interviews for this type of study. This has been related to the connection between reliability and validity and high reliability is a prerequisite for data having high validity[86]. In this qualitative research study as in other methodologies, the researcher is has influence on the process. This means that the reliability of this study will depend on the researcher's preparations, performance and follow-up work. Strength regarding the reliability of the tasks is that interviewers asked good first as well as follow-up questions and the answers were given to the questions that were asked. To make sure that the questions were not misunderstood, the interviewer directly asked participants if they have understood the question correctly. A semi-structured interview guide was used that ensures that the participants provided data about the same themes. It was experienced that some interviews provided more comprehensive information than others.

It should be noted that the results from this study must be interpreted with caution because they express opinions and experiences of a small number of participants.

4.2 Discussion of results

In this chapter it will be discussed the key factors that emerged in regarding what patients' wants from an introductory seminar before the start of their treatment at a MHC. This section is divided in three main parts similar to the results section in order to answer the following questions:

1. Why do participants want information during waiting time?
2. How should the seminar be organized?
3. What should be the content of the introductory seminar?

As noted in the introductions section, there is very limited literature available on this topic and, therefore, it has been tried to discuss the results from this study to other similar studies even across other health areas outside psychiatry.

4.2.1 Information during waiting time

Since waiting time for treatment may have negative implications[87-89], our intention was that the pre-therapy educational intervention could offer the out-patients some activities during the waiting time. It has been found that information before treatment may help patients cope with the waiting time[90] and consistent with two similar pre-therapy preparation studies[57, 91], this study indicates that pre-therapy interventions may create a more positive and purposeful waiting time, as an improvement in the patients' well-being and mental health conditions.

From the results it is quite evident that participants want information that can help them cope with the waiting period. Participants have given different expressions of what is the reason for requesting relevant information. The participants were asked questions about how their experience has been during the waiting time, do they want any information, or do they feel that the information is missing before the treatment starts? Participants said that they feel left out while they are on the waiting list and do not have much information as to who can they expect to get help from during that time. According to the participants, it is quite difficult to wait and they are anxious as they do not know what will happen next, how long it will take and who they will face when they enter for treatment. Data collected from the interviews points that participants are not satisfied with the information they normally get before the start of their treatment. Most of the participants said that they had too little or no information while they were on the waiting list and that resulted in restlessness and insecurity among them. This corresponds well to the other similar studies available in literature. Hantonen et al[47] stated that problems related to patient education described by patients through interviews were lack of information and a lack of pre-requisite knowledge related to their mental health problems. Helbig et al[90] reported that seeking information about the personal mental health problem was highly prevalent among participants on a waiting list at a MHC. According to Coulter et al[36], providing relevant information to patients is fundamental to their engagement and if the individuals do not have the capacity to obtain, process and understand information, it will be difficult for them to make appropriate health decisions. Hill et al[69], also reported that patients with mental disorders eagerly await information about their own care and a role in decision making regarding their treatment and care.

4.2.2 Organization

From the analysis of the results, it became clear as to how participants wanted the information to be communicated at the introductory seminar. They wanted the information presented and exhibited in a way that they can make optimum use of the seminar day. Here are the key highlights from the interviews on the organization of the introductory seminar based on the responses from the participants:

(a) The selected group should not be larger than 10 persons
(b) Oral information is more preferable than written information
(c) Information provided should be straight forward and to the point information
(d) Seminar should contain specific information that directly relates to participants
(e) Information related to MHC such as staff, treatment procedures, facilities and rules and regulations should be provided

According to literature, verbal information can be easily individualized in relation to the patient's needs and is designed to create closeness and confidence, while making it easy to get useful information[92]. On the other hand, written material can give the patient an overview and be used as a basis for further information and instruction if the patient wants or needs it[93]. Written information is something patients can take out, read and review when it suits them and when they need it[94]. Coulter et al[40] reported that written information is only effective when combined with verbal/oral interactions between patients and health professionals. Hatonen et al[47] study also stated that a majority of patients at a MHC wanted information through discussion with staff that is verbal information.

With regards to the specific information that should be related to those attending the seminar, literature also shows that clear, steady speech is appropriate when explaining something. Precise, direct language should, therefore, be used while avoiding ambiguous and unintelligible words. Language that is easy to understand without technical terms is preferred. Information should be adapted for each individual[95, 96]. All these factors can result in security and mutual understanding between participants and organizers[97].

4.2.3 Contents

This is the most important section of this study and includes the discussion on the contents of the introductory seminar as analyzed from the results obtained from interviews of the participants.

4.2.3.1 Mental health

Good mental health according to the World Health Organization (WHO) can be defined as "a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community"[98]. A mental illness is a health problem that significantly affects how a person thinks, behaves and interacts with other people. It is diagnosed according to standardized criteria. A mental health problem also affects how a person thinks, feels, and behaves[99]. Mental health disorders make up 21% of illnesses worldwide and from a global perspective are ranked in third place[100]. In Norway, mental health disorders are the second highest cause of people on disability pension and the highest cause of lost working years[101].

The participants only had a general understanding of what the term *mental health disorder* meant. Some had a lot of knowledge about their own mental health, while others only knew a little about their disorders. Some participants felt that it made it easier for them to gain a better understanding of their symptoms and their past medical history. The results showed that almost all participants were interested in having information about mental health disorders. This is a relevant theme that should be included in the introductory seminar and that all participants should be informed of. The main objective of education on mental health is to enable the participants to tackle their life situation. This involves achieving better health, experiencing meaning and maintaining their state of health. The literature says that good information about the disease or disorder is important so that participants are aware of their rights. The participant can, for example, make a different decision if that person is aware of the treatment that is on offer in relation to their disorder or illness[102].

The majority of the participants were also looking for information about causes of mental health problems during interviews. This involves understanding why one is sick or suffering from these disorders. According to Ruyter et al[103], information should be made up of information about the patient's complaints, information about possible treatment and explanations, any risks and side effects of treatment as well as information about prognosis[103]. One of the participants pointed out the importance of having information about diagnosis as well. To gain an insight into the state of health and the health service provided, the patients should be given the requisite information. This is not just limited to treatment but also includes diagnosis and prognosis[104]. Previous similar studies also showed this is an interesting theme among patients. Hatonen et al[47] reported that 90% of the patients who were interviewed at a MHC wanted information about diagnosis. Brataas mentioned that good information can have positive short-term and long-term effects with regards to both reducing mental stress and the life course of health-related significance for a diagnosis[95]. This also provides support for the participants' resources and functions.

4.2.3.2 Treatment

The participants emphasized the importance of being informed about treatment at the introductory seminar. The majority of participants wanted information regarding this theme. Even participants, who already had experience of treatment, wanted this to be covered in the seminar. The reasons provided by the participants for receiving information on this topic include: (a) this will help them make choices about treatment methods; (b) this can result in improved user involvement and interaction between users and staff. This correlated well to the literature where it is noted that the participants can feel safer in the situation, and the situation is more understandable to them if they have adequate information about the illness and treatment[105].

The patient's right to information is central and is based on patient autonomy[104]. However, one of the participants reported that she received no information whatsoever about her treatment; she mentioned this several times during the interview. Adequate information about what and when things will happen should help the participants to better understand the situation[95]. Hatonen et al[47] also reported that the patients in their study were seeking information about the treatment.

Information about the various treatments offered or the treatment alternatives that are found at the institution were a top priority for the participants. Nine out of ten participants would like information about this theme at the introductory seminar. The participants also mentioned that they get a lot of information about treatment alternatives on the internet. There are lots of websites providing good information, but at the same time, the literature also states that information obtained from the internet is not always quality assured[36]. The participants, therefore, need advice about information that is useful for them[102]. The participants clearly stated that they would like information about what the various treatment methods entail, what they are about and what the result might be, i.e., specific details about individual treatment methods. This is supported by the Hatonen et al[47] study that showed the importance of information about treatment alternatives as 98 % of the participants in that study said they wanted education within this theme. Hill et al[69] reported that patient friendly information and decision aids need to be developed within psychiatry so that patients can chose among various available treatment methods. Terrell et al[68] also pointed that it will be very useful for MHC patients to know and understand available alternative treatments while waiting or at very early stages of the treatment. Therefore, it would be desirable to have this topic included at the introductory seminar.

4.2.3.3 User involvement

To avoid a misunderstanding of the term *user involvement*, an explanation of what it means and what it entails was given to all the participants, as suggested by Joseph-William et al[24]. Almost all participants think that user involvement is important, and thus it is necessary to have training on user involvement and how to be an active participant at the seminar. Meanwhile there were 3 in 10 participants who did not feel that this was their top priority for the seminar.

In official Norwegian reports (the Norwegian Ministry of Health and Care Services 1992:8) «The Norwegian Patients' Rights Act» was integrated as the background to Proposition No. 12 to the Odelsting 1998-99, pt. 5.1.1. In the draft for §4-1 dealing with sound healthcare standards «Healthcare shall be given in such a way that the patient as far as possible is involved in and uses the patient's own resources». Thus the purpose of user involvement is that the participants can demand good healthcare, and this is difficult to get without significant patient involvement. According to Brataas, good information and explanations are a prerequisite to enable the participants to acquire adequate basic information to understand the situation and thus be able to get involved and cooperate[95]. Participant involvement is often crucial for a good result. Also, as mentioned in the introduction section, SDM and PP are the key models for the modern day health care and should be an important part of the introductory seminar.

One of the principles of user involvement is that the patient should have control of important parts of his life while also receiving help on his own terms[106]. The essence of the matter is that user involvement should be adapted to the individual's ability to give and receive information[107]. A study by Tomkins et al[97], showed that the patients want more information and explanations, and a lack of these made decision-making more difficult. More information and explanations would reduce anxiety and provide them with a better starting point and this is the main goal for organizing an introductory seminar.

The participants clearly stated that it was important to be involved and give their opinions as and when required. Several participants also mentioned that good multidisciplinary cooperation with the service provider is important i.e. user involvement is most practical when qualified people are involved. This is backed up by Syse[108] who stated that the patient should become a partner with the healthcare staff. For user involvement to be meaningful, more than half, i.e., 6 out of 10 participants would like to cooperate with professional staff. However, this can have both negative and positive consequences. The participants can quickly become dependent on doing exactly what the service provider wants and the participant's opinion is thus not taken into account. On the other hand, it can be good for the participants to be pushed into actively participating in their treatment. Some of the participants wanted to take self-help measures or have already done so as part of user involvement initiative and therefore, they were looking for motivational or relevant information that they can apply themselves relating to their disorders and possible treatment. According to Coulter et al[40], SDM and self management or help are mutually supportive approaches that should be given equal importance and implemented consistently. Results from Helbig et al[90] study also showed that the vast majority of patients (around 95%) instigated at least one form of coping or self-help activity related to their mental health problem, as reported through a patient survey.

Coulter et al[36] reported that the evidence suggests that true SDM is not widely practised. Service providers often fail to explore patients' values and preferences and risk management is often poorly expressed by service providers and not well understood by patients. Therefore, relevant information pertaining to SDM and PP should be a main focus of the introductory seminar in order to make participants aware of the underlying concepts and benefits. There is one more theme related to user involvement that has not been included in the results section as it was not evident from the responses of the participants and this theme includes the supply of information to the kin or family members of the participants. Granum[92, 93] pointed out that many patients/service users would like their kin or close relatives to be informed about their disorder/problem or treatment. This can be important to the patients as kin often act as a resource for them. In order for the kin to act as a resource for the patients, it is important that they are well informed. Therefore this theme is highlighted here that the next of kin can be part of this and receive information subject to participant consent during the introductory seminar.

4.2.3.4 Patients' rights

According to Hummervoll[109], service providers should ensure that the participants are given the information they need in line with legal requirements so that this is both accessible to and reassuring for them. Information is necessary according to §3-2. Patients' and service users' rights to information: *"Service users should have information that they require for an adequate insight into the service offered and to protect their rights*". §1-1. *Purpose* The Norwegian Act on Patient and User Rights (The Norwegian Patients' and Users' Rights Act) states the following: *"The purpose of the act is to help ensure that the public is given equal access to good-quality services by giving patients and service users rights to health and social services. The provisions of the act should help promote a relationship of trust between patients/service users and health and social services, promote social security and maintain respect for the individual patient or service user's life, integrity and human worth"*. The act sets out rules about the relationship between the patient and the health service/healthcare staff and focuses on the patient and the patient's needs. It is, therefore, necessary that patients or the participants are well informed about the services offered so that participants can protect their rights.

Participants also felt that patient rights should be a central theme. It is necessary to know where a particular type of service can be found, how to get it and if there is any assistance that can be received in this regards. This is supported by the results from Hatonen et al[47] study, where 92% of the participants said that they need information about general patient rights during interviews, and only 4% said that it is not relevant information. According to the literature[102], some patients find this type of information difficult to understand on their own and this can lead to anxiety, therefore, the information about patient rights is essential. Also, around half of the participants stated that information about patient rights is essential for their own security. Hummervol[109] stated that when participants' rights are emphasized and protected, the alliance between service providers and patients can be strengthened whereby the participants' experiences and situations are better understood. In a secure environment the participants can attain a better feeling of control of their treatment and associated rights.

The section on the information on patients' rights should also include something about the right to make a complaint if the patients or the participants are not satisfied with the service provider, as requested by some of the participants. Hatonen et al[47] also reported the importance of educating patients about their right to make a complaint. Hummervoll[109] stated that the service providers have a duty and a responsibility to inform patients about their right to make a complaint. Coulter et al[36] reported that patients want greater openness and honesty from health care professions, including full disclosure of medical errors and adverse events that have affected them. Information about the right to make a complaint can give the participants a feeling that they are being taken seriously and respected, which can then prevent anxiety and uninhibited behavior.

4.2.3.5 User organizations

Whether or not the participants wanted information about user organizations varied somewhat in relation to what they understood by the concept or priorities in relation to other themes. Four of the participants said that this is a relevant theme that should definitely be included during the seminar, while one was unsure, one did not know what it meant, two said they do not need this information as they did not want to deal with so many people and two did not respond to this questions about this theme. Out of the four participants who said that this information is important, two would like this theme included in the seminar as this gives them better self-confidence and security and they feel that they are not alone in such situations because many people had gone through the same experience as them. They regarded meeting other people as positive because of the possibility to get external help while waiting for their treatment at MHC. Having information about user organizations can give the participants an opportunity to meet others who are in the same situation and compare personal experience and look at similarities and differences in relation to the experience of others. According to Andreassen, this can lead to the opportunity to find a variation in needs and wishes and distinguish between random and unfortunate individual experiences[110]. Hatonen et al[47] study also showed that 67% of the participants were interested in having more information within the user organizations' theme, and 18% said this is not relevant information. Therefore, this category has been prioritized, because, based on the literature, it can be argued that this theme can be useful for participants.

5. Conclusions

This qualitative study is based on the research questions that will investigate what information patients' need while on the waiting list and what topics an introductory seminar may contain. This study tries to find what information is necessary for patients to cope with their problems while waiting for the actual treatment to start. This can lower the risk of patients dropping out from the treatment and can be a platform for increased contact between patients and service providers during the waiting time. By way of the seminar, large numbers of patients will be reached at a time and will offer additional help to all of these patients.

Participants clearly pointed that the relevant information is needed so that they can handle the waiting time better and become less anxious. Results also showed how information should be presented during the seminar. They preferred oral information than written and the information should be presented and exhibited in such a way that they can make optimal use of the seminar. This correlated well with the literature where it is noted that participants can feel safer in the situation, and the situation is more understandable for them if they have adequate information.

The main findings in this study corresponded largely with previous research and literature. The results showed that almost all participants are interested in having general information about mental health and related problems so that they have a better control over their own ailments with more insights and better understanding of their situations. Participants also expressed their desire for information on course of treatment and treatment methods offered by MHC. Information about treatment can be necessary because it can make the treatment choice easier when they are called in for treatment and will also help them understand the benefits and side-effects of various available treatment methods.

Most of the participants think that user involvement is important, and thus it is necessary to have training on user involvement and how to be an active participant. Meanwhile there were 3 in 10 participants who did not feel that this was their top priority for the seminar. For many participants, it was important that they had a role in their treatment, including wanting more knowledge with regards to user involvement. However, some of participants wanted to follow up with their health personnel, before they took the initiatives for participation. Also, the necessity of information about patient rights emerged very clearly from the participants in the interviews.

Most participants wanted to get information about various user organizations that can help them cope with their problems. Some wanted to receive information on the positive experiences of other patients, some thought that information on the offers and types of help available will be useful and some felt a sense of security and boost in self-confidence to know that there are help sources other than MHC. There were also some participants who did not want or it was not their main priority to get information on these organizations as they did not want to share their problems with too many persons outside of MHC. Also, whether or not the participants wanted information about user organizations varied somewhat in relation to what they understood by the concept or priorities in relation to other themes.

Implications for practice and further research

Following related studies can be part of future research:

1. A study should be conducted to confirm the results obtained from this present study preferably with more participants and they may come from random MHCs across Norway
2. Quantitative study to check the effect of the introductory seminar delivered patients during their waiting time at a MHC on the mental health, treatment, prognosis and user involvement outcomes

Information obtained in this study can become an important quality indicator for the services provided at a MHC, which may possibly be improved, so that patients can have better advantage of the time they are waiting for the treatment.

6. References

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7. Attachments

Attachment 1 – Interview guide for both rounds of interviews

Utdrag fra protokoll: Prosjektets hovedmålsettinger:
Hensikten med studien er å undersøke hva pasienter / brukerrepresentanter ønsker i et introduksjonsseminar til nyhenviste voksne pasienter som står på venteliste i et distriktspsykiatris senter. Et introduksjonsseminar tar sikte på å utdanne pasienter, slik som å gjøre dem i stand til å velge blant tilgjengelig behandlingstilbud. Dette blir sett på som en måte å hjelpe pasienten få en større medvirkning i egen behandling og derved redusere risikoen for å falle ut fra behandling. Dernest er målet å hjelpe pasientene til å mestre sine problemer mens de venter på behandling, gi informasjon som kan bidra til å øke selvhjelp og gi informasjon om primærhelsetjenesten og brukerorganisasjoner som kan kontaktes i løpet av ventetiden.

Disposisjon

Start med innledning og så spør om personalia (alder, utdanning, yrkeserfaring, sivil status). Start med helt åpent spørsmål, pas ”setter dagsorden” – følg opp ut fra det.
Hei hvor gammel er du?
Hva er du utdannet som?
Hva jobber du/ har jobbet som?
Er du gift, Bor alene?

Jeg spør noen åpne spørsmål, og du svarer på dem. Det er ikke noen riktige eller gale svar. Er det noe som er uklart, spør du, ok?

Innledning

Start med: Takk for at du deltar. Intervjuet tas opp på lydbånd, som slettes når prosjektet er ferdig (Sett på kassettspiller). Kort om prosjektet (Poenget er å få vite hvilke type informasjon er viktig for pasienter som står på venteliste for behandling i DPS) og meg. Informer om rett til å trekke seg både under intervjuet og senere – da slettes alle data. Alle opplysninger behandles fortrolig. Frivillig å svare på spørsmål.
Har du spørsmål før vi starter?

START: Hva slags type info ønsker du (EVT at pasienter skal) å få før du starter behandlingen?

- Hva slags **type informasjon** ønsker du før behandling starter?
- Hva slags informasjon trenger du for å kunne **velge** behandling?
- Hva slag informasjon trenger pasientene for å **håndtere ventetiden** før behandling?
- Hvilke informasjon er nødvendig for deg for å **få mest ut av din behandling** og **for å kunne medvirke aktiv** i den?
- Andre pasienter har nevnt følgende tema, hva tenker du om disse og hvorfor /hvorfor ikke synes du de bør være med (stilles etter at pasienten ikke har mer å si)
    - Pasientrettigheter
    - Behandlingstilbud som finnes ved DPSet
    - Psykisk helse
    - Brukermedvirkning
    - brukerorganisasjoner

(Eksempel på spørsmål som kan brukes for å få fram kulepunktene over:

- Hvor relevant er det å ha informasjon om pasientrettigheter på introduksjons seminaret? Hvorfor syns du er viktig/ nødvendig med informasjon om pasientrettigheter?
- Tror du det er relevant med informasjon om psykisk helse? Hvordan er dette tema relevant? Hvorfor ønsker du informasjon om det?
- Er det interessant å informasjon om brukerorganisasjoner? Vet du hva det er? Kan det være et aktuelt tema å ta opp på introduksjonsdagen? Hvorfor syns du det er relevant?)

HUSK PÅ
Spør om hvorfor de ønsker / sier det de sier – få mest mulig dybde
Få bekreftet tolkningen (validering).
Hva var konteksten for opplevelsen?
”Hva mener dere er viktig med slike seminar?”, ”Hva ønsket dere ut av seminaret”? "dine forventninger”? Viktige temaer?
Spør om hvorfor en valgte ut tema hvilke tema? ”kan du fortelle hvordan du valgte ut temaene til kurset?”. Få bekreftet tolkningen (validering)
Tror dere at seminaret vil hjelpe dere i det daglige liv? hvordan?
Hva synes om rammene?
Forslag til andre tema som burde vært tatt opp? Hvilken informasjon etterspørres? Hvorfor ?

Avslutning: Er det noe mer du har lyst til å fortelle om? Har du noen spørsmål?
Kan ta kontakt senere hvis spørsmål.

Attachment 2 – Supplement to interview guide

Forslag til intervjuguide pasienter i venteliste før seminaret

Utdrag fra protokoll: Prosjektets hovedmålsettinger:
Hensikten med studien er å utvikle og evaluere effekten av et introduksjonsseminar til nyhenviste voksne pasienter som står på venteliste i et distriktspsykiatrisk senter. En kvalitativ studie skal pasientens intervjues for å utvikle innholdet i et introduksjonsseminar
Nytteverdi: Et introduksjonsseminar må ta utgangspunkt i pasientens behov. Denne delen vil gi data som skal brukes til å utvikle innholdet i introduksjonsseminaret. Gjennom å studere pasientens behov, får man kunnskap som kan danne grunnlag for å arbeide med forbedringer i klinikken, noe som også kan overføres til andre DPSer.

Studie spørsmål
- Hva slags type informasjon ønsker pasientene før behandling starter?
- Hva slags informasjon trenger pasientene for å kunne velge behandling?
- Hva slag informasjon trenger pasientene for å håndtere ventetiden før behandling?
- hvilke informasjon er nødvendig for deg for å få mest ut av din behandling og for å kunne medvirke aktiv i den?

Tema som skal med i intervjuguiden: Bakgrunn, hvilke type informasjon, kommunikasjon, tidsramme, forventninger, mål og brm og event forventede resultat av pasientopplæringen

Disposisjon

Start med innledning og så spør om personalia (alder, utdanning, yrkeserfaring, sivil status). Start med helt åpent spørsmål, pas "setter dagsorden" – følg opp ut fra det.

HUSK PÅ

Spør om hvordan følte seg / opplevelsen "hvordan følte du deg da?"
Få bekreftet tolkningen (validering). Hva var konteksten for opplevelsen? "Hva mener dere er viktig med slike seminar?", "Hva ønsket dere ut av seminaret"? dine forventninger"? Viktige temaer? Spør om hvorfor en valgte ut tema hvilke tema? "kan du fortelle hvordan du valgte ut temaene til kurset?". Få bekreftet tolkningen (validering)

Sjekkliste

_____Personalia: Gjengi opplysninger evt har samlet eller spør om: alder, sivilstand, utda., yrkeserfaring

Andre spørsmål

_____forventninger til et slikt seminar. Temaer?
_____ Tror dere at seminaret vil hjelpe dere i det daglige liv? hvordan?
_____Hva synes om rammene?
_____ Forslag til andre tema som burde vært tatt opp? Hvilken informasjon etterspørres?

Innledning

____Takk for at du deltar. Intervjuet tas opp på lydbånd, som slettes når prosjektet er ferdig
____(Sett på digital-spiller). Kort om prosjektet og meg. Informer om rett til å trekke seg både under intervjuet og senere – da slettes alle data. Alle opplysninger behandles fortrolig. Frivillig å svare på spørsmål.
____ Samtykkeerklæring
_____Har du spørsmål før vi starter?

Innledende spørsmål START : Da poenget er å få vite hvilke type informasjon er viktig for pasienter i venteliste, så lurer jeg på **Hva slags type info ønsker du å få før du starter behandlingen? (La pas fortelle om så mange ting som mulig)**

Videre Hva slags type informasjon ønsker du før behandling starter? Hvorfor? Hva slags informasjon trenger du får å kunne velge behandling? Utfordringer? Ønsker? Narrativer? Hva slag informasjon trenger du får å håndtere ventetiden før behandling? Hvilke informasjon er nødvendig for deg for å få mest ut av din behandling og for å kunne medvirke aktiv i den?.
Når ikke flere svar, be pas vurdere om følgende er relevant og hva som evt er relevant under disse: Psykisk helse? Behandlingsmuligheter? rettigheter? Selvhjelp? Erfaring fra brukerrepresentanter? Brukermedvirkning?

Avslutning: Er det noe mer du har lyst til å fortelle om? Har du noen spørsmål?
Gjenta at kan trekke seg. Kan ta kontakt senere hvis spørsmål.

Attachment 3 – Information provided to patients before interviews and the consent form

(Til pasienter)

Invitasjon til å delta i forskningsstudie: Informasjonsseminar om brukermedvirkning og behandlingsmuligheter for pasienter på venteliste i psykisk helsevern

For å gi beskjed om du ønsker å delta må du kontakte masterstudent Sucheta Krishan på telefon 93818918 eller e-post: such_1983@yahoo.no

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Bakgrunn og hensikt

Brukermedvirkning og pasientopplæring er en lovpålagt oppgave i psykisk helsevern i Norge. Likevel fins det lite forskning på hvordan pasientopplæring og brukermedvirkning fungerer i psykiatrien. Vi ønsker med denne studien å utvikle og evaluere et informasjonsseminar til nyhenviste pasienter, pasienter som er under behandling og de som har avsluttet med behandling.

I denne undersøkelsen hvor det gjennomføres individuell intervjuer ønsker vi å få kunnskap om hvilke informasjon du tror er nyttig å få i et slik seminar.

Prosjektet er godkjent av Regional komité for medisinsk og helsefaglig forskningsetikk, Midt Norge (REK 4.2009.77), og Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste.

Denne studien gjennomføres av sykepleier og masterstudent Sucheta Krishan og er en del av en masteroppgave i Klinisk Helsevitenskap ved NTNU (Universitetet i Trondheim). Veileder er professor Aslak Steinsbekk, institutt for Samfunnsmedisin, NTNU

Hva innebærer studien?

Du blir bedt om å stille opp på et intervju. Intervjuet vil være en samtale mellom deg og masterstudenten. I intervjuene vil du bli spurt om ditt syn på hvilke behov for informasjon pasientene har før de får behandling, slik at de kan ha mest mulig utbytte. Intervjuene vil vare rundt en time og bli gjennomført der det er mest hensiktsmessig for deg. Intervjuet vil bli tatt opp på lydbånd.

Hva skjer med informasjonen om deg?

Prosjektmedarbeiderne har taushetsplikt i henhold til Forvaltningslovens § 13 og Helsepersonelloven § 21. Alle persondata behandles konfidensielt og lagres i en database slik at deltakerne kun er registrert med et løpenummer. Undersøkelsesresultater samt navneliste, hvor slike eksisterer, oppbevares forskriftsmessige. Anonymisert grunnlagsdata vil bli oppbevart til 2017.

Frivillig deltakelse

Det er frivillig å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få deg konsekvenser for deg.

Spørsmål
Dersom du har spørsmål til studien, kan du kontakte masterstudent Sucheta Krishan på telefon 93818918.

Vennlig hilsen,

Sucheta Krishan
Avdelingssjef Masterstudent

Svarslipp – leveres til masterstudent når dere møtes

Jeg er villig til å delta i studien

(Sted, dato, signatur)

(Sted, dato, signatur av masterstudent)