Research Article



I'm not a diagnosis: Adolescents' perspectives on user participation and shared decision-making in mental healthcare

Stig Bjønness^{1, 3*}, Trond Grønnestad², Marianne Storm²

¹Centre for Resilience in Healthcare, Faculty of Health Science, University of Stavanger, Norway ²Department of Public Health, Faculty of Health Science, University of Stavanger, Norway ³Department of Psychiatry, Stavanger University Hospital, Norway

*Corresponding author: stig.e.bjonness@uis.no

Abstract

Background: Adolescents have the right to be involved in decisions affecting their healthcare. More knowledge is needed to provide quality healthcare services that is both suitable for adolescents and in line with policy. Shared decision-making has the potential to combine user participation and evidence-based treatment. Research and governmental policies emphasize shared decision-making as key for high quality mental healthcare services.

Objective: To explore adolescents' experiences with user participation and shared decision-making in mental healthcare inpatient units.

Method: We carried out ten in-depth interviews with adolescents (16-18 years old) in this qualitative study. The participants were admitted to four mental healthcare inpatient clinics in Norway. Transcribed interviews were subjected to qualitative content analysis.

Results: Five themes were identified, representing the adolescents' view of gaining trust, getting help, being understood, being diagnosed and labeled, being pushed, and making a customized treatment plan. Psychoeducational information, mutual trust, and a therapeutic relationship between patients and therapists were considered prerequisites for shared decision-making. For adolescents to be labeled with a diagnosis or forced into a treatment regimen that they did not initiate or control tended to elicit strong resistance. User involvement at admission, participation in the treatment plan, individualized treatment, and collaboration among healthcare professionals were emphasized.

Conclusion: Routines for participation and involvement of adolescents prior to inpatient admission is recommended. Shared decision-making has the potential to increase adolescents' engagement and reduce the incidence of involuntary treatment and re-admission to inpatient clinics. In this study, shared decision-making is linked to empowerment and less to standardized decision tools. To be labeled and dominated by healthcare professionals can be a barrier to adolescents' participation in treatment. We suggest placing less emphasis on diagnoses and more on individualized treatment.

Keywords: adolescent; mental health; user participation; shared decision-making; inpatient; qualitative study

Introduction

Most mental disorders emerge in adolescence, and left untreated, mental illness is a serious public health burden (1-3). Inpatient units offer acute mental health services for the most acutely ill adolescents, and there is an increasing need for this type of service (4). However, stigma and a distinct need for autonomy may hinder adolescents from seeking or receiving help (5). Thus, acute inpatient treatment can also result in involuntary treatment (6). The United Nations Convention on the Rights of the Child, national legislation and policies provide the framework for adolescents' right to be involved in decisions that affect their healthcare (7). Still, it is difficult to engage youth in the treatment of their mental disorders (8, 9). More knowledge is needed to establish high-quality healthcare services that are suitable for adolescents, in line with legislation, and to enlist patients as active participants in making choices about their healthcare (10).

In shared decision-making, patients and healthcare professionals work as partners to find the best treatment. Shared decision-making incorporates patient preferences, values, circumstances, and goals, and healthcare professionals provide information on evidence-based treatment options. Finally, the parties arrive at a consensus on preferred treatment (11). A systematic review of the rationale for shared decision-making report that it is a process activating patients to take control in their lives. This process is linked to recovery and person-centered care (12). Both evidence-based medicine and shared decisionmaking are essential to quality healthcare. Shared decision-making translates evidence into practice and improves outcomes. The connection between them provides an opportunity for optimal treatment (13), while addressing ethical concerns (14).

There has been an ongoing shift in the direction of decision-making and person-centered shared treatment in adolescent mental healthcare (10, 15, 16). Shared decision-making is associated with patient engagement and perceived quality and satisfaction with the healthcare services (8, 17, 18). However, most research on shared decision-making have focused on implementation and experiences with decision aids, while little is known about mental health outcomes (18). In addition, there is a lack of conceptual clarity in shared decision-making and a need for clarification of central aspects of shared decision-making in a clinical context (15, 18). There is also a dearth of research in adolescent mental healthcare and adolescents' perspectives (19, 20). Previous qualitative research with adolescents highlights the importance of providing mental health services that incorporate individual expectations, needs, and goals (8, 21, 22). Research should also explore how and if person-centered care contributes to recovery and a reduction in the use of restraints (23).

Our study aims to gain more knowledge about adolescents' participation and shared decision making in mental healthcare. Its objective is to explore adolescents' experiences with user participation and shared decision-making in Child and Adolescents Mental Health Services (CAMHS) inpatient units.

Method

Study design and setting

This is a qualitative exploratory study in a Norwegian public healthcare setting. Two youth co-researchers participated in designing the study, the information sheets, and a semi-structured interview guide. The co-researchers had experience from similar healthcare services and were involved throughout the study (24). The study took place at two public hospitals in western Norway, at four CAMHS units within these hospitals. These CAMHS clinics provide treatment for adolescents 13 to 18 years of age with severe mental health disorders such as psychosis and suicidality. Three of the clinics have acute admissions, but also provide elective treatment. One clinic offers long-term treatment with rehabilitation for adolescents age 16 and older with psychotic disorders.

Recruitment

We used purposive sampling to recruit adolescents admitted to and receiving treatment in the CAMHS inpatient units. The participants had to be 16 to 18 years of age, speak Norwegian, and capable of giving consent. Selection of participants was not limited to specific diagnoses. The chief physician or psychologist made the inclusion assessments, and invitations to participate were handed out by the staff (e.g. nurses). The sample size was estimated at between 10 and 15 participants a priori.

Participants

Ten adolescents (eight females and two males) participated in the study (mean age 16.5). The sample covered both voluntary and involuntary treatment. Some participants had experience from several health services and admissions, and others had just recently made their first contact with mental healthcare services. We did not collect diagnostic data from medical records. However, most participants voluntarily shared details about their mental health problems and background. The diagnoses that they gave, in addition to suicidal intentions and self-harm are provided in Table 1.

Participant ID number	Duration of admission	Total-experience from CAMHS	Self-reported diagnosis	
1	N/A	3 years	Autism spectrum disorder, psychosis	
2	9 days	2 years	Anxiety, depression	
3	12 days	1 year	ADHD, eating disorder	
4	6 months	8 months	N/A	
5	7 days	3 years	Trauma/PTSD	
6	7 days	1 week	Depression, anxiety	
7	22 days	4 years	ADHD, anxiety, depression	
8	21 days	1 year	Depression, ADHD, anxiety	
9	7 days	1 year	Depression, autism spectrum disorder	
10	6 months	1.5 year	Psychosis, anxiety	

Data collection

Data were collected using individual in-depth interviews. The interview guide builds on key principles of person-centered care: valuing people, autonomy, experiences, relationships, and environment (25). To explore participants' experiences with user participation and shared decision-making we asked questions about their expectations of treatment and involvement, the collaboration with therapists and staff, the treatment and opportunities to influence, involvement of family, and the adolescents view on forms and degrees of their participation in the clinic. A panel of five adolescents from a mental healthcare service user organization pilot-tested the interview guide. The questions were modified based on their feedback. All interviews were conducted by the first author (SB) from 1 January 2018 to 19 February 2020. Interviews lasted from 39 to 72 minutes, averaging 47 minutes. The interviews were audiorecorded and verbatim transcribed. After seven interviews, the data was reviewed. All authors read and discussed the transcribed interviews and agreed that they reflected a range of experiences representing the research topic. To ensure the data was sufficiently rich, we carried out three additional interviews (26).

Data analysis

When data collection was completed, interview transcripts were analyzed using qualitative content analysis. We used a six-stage method described by Lindseth and Norberg (27): 1) naive reading to understand the phenomenon; 2) starting a thematic, structural analysis by dividing the text into meaning units; 3) condensing and sorting the meaning units; 4) abstraction of condensed text to sub-themes; 5) establishing themes in a theoretical context, and 6) validating the themes against the original text. The first author transcribed and read all the interview transcripts to become familiar with the data, and then closely making notes of emerging themes. The two other authors (MS and TG) read the transcripts independently, and then all three met to discuss and identify sub-themes. Condensates were organized into these sub-themes. We then discussed the preliminary thematic structure and reached an agreement on themes. Stages 1 to 5 are illustrated in Table 2. In stage 6, the themes were adjusted to make sure they reflected the meaning of lived experience and the essence in the original text (27). The condensates and themes were presented and discussed with the youth co-researcher. By identifying sub-themes independently, involving experienced youth, and arriving at agreement in analysis meetings, we compensated for any possible bias.

Meaning unit	Condensation	Sub-theme	Theme
The most important thing for me is to be listened to and taken seriously. I have struggled a lot with that. I am afraid not to be taken seriously or believed. So, then I rather say nothing.	listened to and believed is	Being seen and heard Expectations	To gain trust
They sit and write about me three times a day, but they don't actually know me. They just make their own conclusions.	,	Assessment and diagnosis	To be diagnosed and labeled
I don't like that an adult should decide on my behalf. Then I have nothing to say, it's just how they decide. I think that is very degrading.	0	Treatment decisions Coercion and resistance	Push me, and I don't want to follow

Ethical considerations

All participants gave written informed consent. No sensitive information about the participants was exchanged with the healthcare professionals, and participation had no consequences for the treatment the adolescents received. To make sure the treatment staff were not involved beyond handing out the invitations, the participants returned their consent to participate to a secretary. The participants were also provided with the opportunity to contact the researchers directly by e-mail or mobile phone. The interviews were carried out by the first author, who has experience in conversation and therapy with youth. The researchers had no relationships with the participants, and none of the staff where present during the interviews. The interviews were conducted in the patients' room or an office outside the ward, according to the adolescent's preferences. The involvement of youth co-researchers in the study helped to safeguard the participants' interests and provide an understandable language. The study was approved by the Norwegian ethics committee (reference number 2017/1195) and by the hospitals' internal approval forums.

Results

Five main themes were identified: 1) to gain trust; 2) help me understand; 3) to be diagnosed and labeled; 4) push me, and I don't want to follow; and 5) working together to make a plan that fits. Each theme describes the adolescents' experiences with and perspectives of user participation and shared decision-making.

To gain trust

The participants cited trust as the basic and most crucial element of their treatment. Mutual trust between the therapist and the adolescent was essential for the adolescents to feel secure, recognized, and to speak freely. Thus, trust was described as a prerequisite for shared decisionmaking. The adolescents' trust in the therapists was established when they felt the therapist was present, listening and showed that they "really" cared about them. To be accommodating, to use humor, and to dare to act personally were used as examples. One adolescent advised therapists on how to establish a trusting relationship:

> Don't just talk about what's difficult, and don't just talk about what's easy either. Finding a balance that makes you get to know the person. Show that you actually care about them, not just because you get paid to care. One quickly notices when people don't care for real. (10)

Equally important was the therapists' trust in the adolescents. The experience of being believed, no matter what, was emphasized in several interviews. Otherwise, the therapists drew their conclusions without the adolescents' participation. One participant described the experience of not being believed as so traumatizing that she fled the inpatient unit and jumped from a bridge. It was only after this desperate action, she said, that she was taken seriously. Another youth described the relationship between trust and shared decision-making:

> When I was admitted, everyone who worked there and the therapists, it didn't seem like they believed in me (...) If I had been part of the decision, it would have felt like I had something important to say. But it was those who decided on my behalf (...) I think it

would have helped if the decision had been shared. Then I would rely more on those who worked there. (6)

Those who described good experiences with user participation referred to being included. As a result, the treatment was perceived as appropriate. The trust was linked to some therapists at the clinic. The interviewed participants emphasized that it was important to be part of the decisions regarding the assignment of their treatment team. However, most of the participants said that therapists were randomly assigned without consultation with them. One youth expressed her frustration that she had been stuck with a contact person that she could not stand for almost five months. It was suggested that all clinics should have one designated person who would talk to the patient about the expectations of the therapist, and then figure out who was the best fit.

> Sometimes it seems like they think "he is the therapist, and you are sick, so never mind who the therapist is, just fix." But it is not possible to fix if you do not have a good relationship. (4)

Help me understand

The participants reported a lack of knowledge and information about their treatment. As a result, they experienced admissions to inpatient care as entering the unknown. The admissions and decisions made along the way could appear suddenly. The adolescents were then reduced to passive recipients of treatment. During the interview, the participants were asked to describe the content of their treatment, but most of them found it difficult to explain anything beyond rules and routines at the inpatient clinic. However, several had searched for this information through friends and the internet.

> I didn't understand much. I had friends in treatment, but I had no idea what it really was. When I was admitted, I didn't know what was going to happen, so I tried to look it up. I think there should have been more information online (...) I still don't know if I'm being examined or treated. (6)

Conversely, a participant who got involved early in the decision-making about admission to inpatient care explained its importance. She was able to postpone an emergency admission. In the meantime, she met the therapist and attended a meeting. She was prepared, aware of the opportunities, and involved from the start. Several interview

linked participants knowledge about the hospitalization and treatment to a feeling of being in control. The participants also argued that they wanted to control healthcare professionals' contact with parents. Although they understood that their parents had to be informed of some urgent matters, they expected to be involved and kept informed. All participants said they had a great need for information about the treatment. Most of them were not told how they could benefit from treatment, possible side effects of medication, and possible treatment alternatives. Thus, it became difficult to participate in decisions about their treatment. One adolescent who had been hospitalized for a long time said she had gradually lost her belief in recovery. She thought it would be easier if she had just known that she could have influenced the choices about her healthcare:

> I don't really know what exists. I've never heard anything about any alternatives. (...) It would have been easier for me if I at least knew there were alternatives. That I could have an alternative. (3)

Treatment meetings with the mental healthcare professionals were referred to as a setting where decisions were made. The young people had different experiences of participating in such meetings. Some wanted to participate, and others did not. However, everyone wanted to be able to influence the agenda of the meetings, and at least know what was being said about them.

To be diagnosed and labeled

The way in which adolescents perceived what others were thinking and saying about them influenced their role and participation. Some participants said they had previously viewed the inpatient mental health clinic as a place for crazy people, as they had seen in movies. Although they said they were tired of life or had problems and needed help, they did not identify with the role of a psychiatric patient. They used terms like "feeling stupid" or "labeled." Those who had been hospitalized or in contact with mental healthcare expressed frustration that previous assessments had left them hanging. The medical record could state "the patient is well known," but they said they had changed or moved on. Some said they were struggling with something else, but they had been stuck with a previous label or diagnosis. Nevertheless, health professionals drew their conclusions based on past reviews.

She dug up things from the past about suicidal thoughts and stuff like that.

But I didn't... I was just tired. Then she had to bring it up again, although it wasn't an issue this time (...) I felt she (the therapist) just read about me. It's kind of different from that time until now. I'm done with it, but then it comes back on. (5)

Disagreement about the problem was often mentioned as a reason for the adolescents' inability to participate. Some compared psychological assessment to taking tests in school. They claimed that it was annoying to answer standard questions because they seemed repetitive and not customized to their needs. They added that it was easy to know how to respond to get one diagnosis or another. The participants rarely perceived themselves as being included in discussions about diagnoses and criticized the diagnoses they had been given.

> They just came and said they think I have that diagnosis. Also, they really push me to take tests. But then I'm more like; I don't need to know, I don't need to get a diagnosis, I just want to get help (...) It almost seems like "Okay, now we have a diagnosis on her, then we know what to do." With that diagnosis, it's easier to fix her in a way. (4)

Integrated care pathways were mentioned, but none of the participants knew much about them. Some said they understood the purpose of diagnosis. It could make it easier for professionals to explain a patient's problem. However, most of the participants clearly stated that they did not support the use of diagnosis because they considered diagnosis as a way of controlling and limiting treatment and user participation. The participants highlighted that everyone is different, and therefore it is vital to listen to the patient's opinion to adapt treatment and services to their individual needs. Many felt incorrectly diagnosed and deprived of opportunities treatment; healthcare influence further to professionals were seen as having reduced them to their diagnosis. For example, one participant said he had struggled with depression, but after being diagnosed with ADHD, the professionals focused on ADHD, not the depression, and considered the "problem as solved." Another participant stated that although the inpatient clinic eventually saw that she was struggling with something else, she did not receive the help that she needed because the diagnosis was misleading. Between admissions, she had experienced rejection at inpatient clinics due to "wrong" diagnosis.

You should have the right to participate in it, not just be fooled into it. And that diagnosis has had a lot of impact, how I've been treated for my problems (...) They've seen the diagnosis, and not who I am and what I need, what I feel, or think. They are fixated on a diagnosis that I do not actually have any more. (1)

Push me, and I don't want to follow

Throughout the interviews, the adolescents expressed resistance to the patient role. Such reactions were related to both voluntary and involuntary treatment. When the mental healthcare professionals had decided something, the adolescents often perceived it as final. Their limited participation led to protests instead of partnerships with mental healthcare professionals. It was particularly evident among those who did not feel involved in their admission.

> It would be like pushing me to start as soon as I said anything implying that I needed it. I mean, I don't think you can be treated without wanting it yourself, if it makes sense. (9)

The participants described different reactions when they felt pushed to follow decisions made without their involvement. Some of them felt that they had been left with two choices: to disagree with everything or to pretend to agree. Some said they became silent or merely responded "don't know" instead of engaging. One participant felt tricked into treatment without being able to participate in that decision. She said she later rejected everything, because that was the only kind of influence that she had. Other participants said they realized that they needed help and were going to give it a try but became irritated when they felt left out of decisions. It could result in an assumption that the treatment was not working anyway.

> I think I should be allowed to decide for myself because it's easier for me (...) Last time I was here, I was just told to do this and that, and I wondered why and got to know that it's just the way things are. And then it was like I didn't want to follow it. (3)

Those who had experienced involuntary treatment in the past felt that the threshold for using restraints was lower. One participant said she did not get a new chance to cooperate. She sometimes ended up screaming or throwing objects because her opinion was not heard. Another participant gave this example:

> Some people are more like talking to you, and some are talking about you like I'm not there. They talk like we're in different rooms, but I'm there, it's about me, ask me what I need! (...) They could have tried to think what it would have been like for them. Not just think that you are a patient who has freaked out, but rather try to think that there is actually something behind this. (4)

However, examples of positive experiences with user participation and involuntary treatment also emerged. For example, one participant who had been admitted against her own will described experiences with shared decision-making in decisions regarding supervision and being able to leave the ward unescorted. As a result, she expressed satisfaction with the treatment. In general, being part of decisions made inpatient admission seem less negative. It gave a sense of control and made the adolescents receptive to accepting and participating in further treatment.

Working together to make a customized treatment plan

The importance of knowing what would happen during hospitalization and after discharge was emphasized. The adolescents had clear opinions about what a treatment plan should contain, who should be involved in preparing the plan, and what they should be able to decide for themselves. Several participants missed or were not aware of having any plan, and those who had one highlighted the importance of participation in designing it.

> The plan ahead is to find out who I am as a person, find all the red threads that lead to how I am today, which can then help me and tie everything up (...) We have found out what is best and most effective for me. It's the psychologist and me, we have done it together. (2)

Several forms of collaboration affected user participation, not just what happened between the patient and the therapist. Cooperation between the mental healthcare professionals in the inpatient clinic and with other services was necessary to develop a functioning treatment plan. The participants had different experiences with such collaborating and service coordination. As far as most of the adolescents knew, there had been little or no interdisciplinary collaboration between the inpatient the outpatient mental health clinics. and Communication among the clinic, general practitioner, other mental health services, or child welfare was mostly limited to written reports. The adolescents wanted to take part in the treatment planning, but several of them considered this involvement difficult and resulting in poorly coordinated services. Their healthcare professionals seemed to have different agendas and plans for them. One participant described how the inpatient clinic focused on suicide risk assessments to make sure they did not stay any longer than necessary. It gave little opportunity to influence the treatment plan and made the transition between treatment services difficult. A joint plan and establishing relationships with those who were supposed to follow up with them after discharge was suggested to avoid rehave "smooth transitions." admissions and Cooperation with the school was emphasized. Adolescents being involved in this stated that further help was adapted to their needs.

The experience of collaboration within the clinic was also described in various ways. Some participants reported good experiences with being involved and associated it with flexibility and a consensus among the employees. Good interprofessional cooperation made it easier to get involved in and be comfortable with their treatment and decisions. However, several participants perceived disagreement among the staff or a culture that made participation difficult.

> Some are very willing to cooperate, but in my case, the therapists I have are like; I'm right. They don't want to hear what the others have to say. For example, the night shift, we have a good connection and talk very well, write emails to tell things about how I really feel, but he is not willing to listen. (4)

All the participants talked about their own experiences, but they also expressed a desire to contribute to increased user participation at an organizational level. They thought user participation and shared decision-making should be offered through all phases of treatment. Guidelines were proposed, and experienced adolescents should be involved in designing the services. They also believed that conversations with former patients during the treatment would increase engagement, participation, and recovery.

> Your opinion matters, it's your health so you should have something to say for yourself (...) A protocol for it, not a

guide exactly, but guidelines on how to maintain it (shared decision-making) that every therapist should have. Former patients should be involved in making it because they know what it's like. (7)

Discussion

To summarize the findings in our study, a diagnosis was perceived as a label that the adolescents did not identify with. To be labeled or pushed into treatment they did not initiate or control tended to trigger a quite powerful resistance. However, according to the results, to be recognized by the healthcare professionals and included in decisions from treatment onset made the adolescents feel safe to speak up, engage and participate in the treatment. Psychoeducational information, mutual trust, and a therapeutic relation between patients and therapists were considered as prerequisites for shared decisionmaking. Participation in treatment plan throughout the hospital stay and in the transition to other healthcare services was likewise perceived as crucial. The results called for interdisciplinary collaboration within the inpatient unit, but also with outpatient units, municipal services, and schools.

Trust in healthcare providers is essential for adolescents to feel safe and cared for. Trust between patients and therapists has been described in previous studies (18, 28, 29). Routines for adolescents to participate in treatment meetings and selecting their treatment team should, according to our results, be established to facilitate shared decision-making significance (20).The of information is also highlighted in previous research (18, 29). Without information about the treatment and possible options, admission is like entering the unknown. The treatment is perceived as unpredictable, and the adolescents' participation declines. To be informed, trusted, and give someone the power to control decisions regarding their own health and life is a common definition of empowerment (30). Shared decision making has been linked to empowerment in previous studies (17, 18).

Our results report a connection between interprofessional cooperation and user involvement. The results also show a link between shared decisionmaking and workplace culture. Teamwork, positive clinicians, leadership support, and a culture that promotes user participation are key elements in the implementation of shared decision-making (20, 28, 31). Earlier research support an assertion that shared decision-making mobilizes adolescents to engage in therapy thus making it more likely that they will continue with treatment (8, 18). Our results indicate that treatment with a high degree of user participation makes the transition to home or to other health and social services easier and can prevent re-admissions to inpatient mental health units. It requires participation in the formulation of treatment plans. Involving adolescents in decisions affecting them is empowering and results in better, individualized treatment plans (17).

However, a common understanding of the problem and the treatment goal can be challenged by the healthcare services tradition and regulation for using diagnosis. Our results show that the adolescents perceived psychiatric diagnoses as labels. To be labeled and met with authority by healthcare professionals was perceived as a judgment and loss of control that triggers resistance. Our study suggests that labeling is a potential barrier to adolescents' participation in treatment. A systematic review of literature assessing stigma related to mental illness among young people found stigma to be a universal and disabling problem (3). Our findings are in line with the modified labeling theory (32), by showing how a negative behavior description increases stigma and treatment avoidance. Labeling in itself does not create mental illness, but labeling and stigma may cause adverse outcomes and increase vulnerability (3). According to modified labeling theory, stigma and self-stigma are based on conceptions of the patient role and devaluation (32). When someone is diagnosed with a psychiatric disorder, the diagnosis becomes a stigmatizing marker, placing him or her in a cultural category of "mentally ill." The person can then associate negative meanings with their selfidentity. Potential harmful long-term consequences make labeling and stigmatizing a particular concern in adolescent mental healthcare (3). However, in contrast with our findings it should be noted that receiving a diagnosis can be linked to improved access to mental health services and recovery (21).

Spencer (30) presented a concept of empowerment to understand and shape possibilities for young people's health outcomes. Our study reports that the participants perceived themselves as having been labeled by healthcare professionals. According to Spencer (30), adolescents have the potential to act contrary to a dominant perspective, and this resistance can be seen in what they do and do not do. The same phenomenon is explained by Emerson's (33) theory of power relations. Power relies on the patient's dependency on healthcare professionals. If an equal opposing power confronts the power, it can be neutralized. Thus, the patient is, to some degree, in a position to deny or interfere with authority. The power imbalance can also be counteracted by motivational withdrawal (33). The challenge to engage adolescents in treatment and their resistance against diagnosis, as our study results show, can be understood as a defense against stigma and to counteract dependency. It is therefore an

oppositional form of empowerment. However, it entails that adolescents move away from unbalanced relations with healthcare professionals (33). Our results and previous research (17, 18, 28) show that the treatment of mental illness partly relies on developing a trustful relationship with health care professionals. User participation and shared decision-making provide a rationale to rectify the power balance between adolescents and clinicians, empower the adolescents, and reduce involuntary treatment. Shared decision-making can be considered as a procedure to find the most suitable treatment based on a diagnosis. Based on our results, we suggest a broader understanding of shared decision-making considering it as a treatment approach with a high degree of user involvement empowering adolescents in decisions. Shared decision-making without a person-centered care approach may imply a risk of adolescent collectively agreeing on decisions rather than actually taking part in them.

In conclusion, the challenge of engaging adolescents to participate in their treatment is related to their need for autonomy and their perception of unbalanced power relationships and stigma in healthcare services. A reluctance to be labeled calls for a flexible approach adapted to an individual's needs and less emphasis on diagnosis. Shared decision-making has the potential to increase adolescents' engagement, strengthen cooperation between healthcare professionals and patients, and reduce the use of involuntary treatment and readmissions to inpatient clinics. Emphasis on information and the patient-therapist relation is necessary for the success of treatment. Involvement of adolescents before admission and routines for the patient's participation in the treatment plan are recommended. Further research on specific personwill strengthen centered interventions the understanding and evidence for shared decisionmaking in CAMHS.

Limitations

The sample size in this study is small and may not be representative of all adolescents in CAMHS. However, saturation in qualitative research is related to the adequacy of the sample and depth of data, not to the sample size itself (26, 34). The data collection period is long as the study population was rather delimited and vulnerable. Recruitment through the clinic could have made the population harder to reach and constitute a possible bias. We are aware of the potential bias when the sample is selected by the participants' therapists and responses may be affected by the quality of their relationship. To counter such bias, the therapists had no role other than conducting an assessment of the adolescent' competence to give consent.

Acknowledgment

We thank the adolescents who gave their time and shared their stories, and the institutions that assisted us in the recruitment. We also express our gratitude to the youth co-researchers Martine Olivia Johansen and Celina Hetlelid for their valuable contribution and to the Change Factory for testing and commenting on the interview guide.

Disclosures

The authors declare no conflict of interest. The University of Stavanger funded the project. The authors alone are responsible for the writing and content of this article.

References

- Jones PB. Adult mental health disorders and their age at onset. Br J Psychiatry 2013;202(s54):s5-s10.
- Kessler RC, Amminger GP, Aguilar-Gaxiola S, Alonso J, Lee S, Ustün TB. Age of onset of mental disorders: a review of recent literature. Curr Opin Psychiatry 2007;20(4):359-64.
- Kaushik A, Kostaki E, Kyriakopoulos M. The stigma of mental illness in children and adolescents: A systematic review. Psychiatry Res 2016;243:469-94.
- Skokauskas N, Fung D, Flaherty LT, von Klitzing K, Pūras D, Servili C, et al. Shaping the future of child and adolescent psychiatry. Child Adolesc Psychiatry Ment Health 2019;13:19.
- Tharaldsen KB, Stallard P, Cuijpers P, Bru E, Bjaastad JF. It'sa bit taboo': a qualitative study of Norwegian adolescents' perceptions of mental healthcare services. Emot Behav Difficult 2017;22(2):111-26.
- Jendreyschak J, Illes F, Hoffmann K, Holtmann M, Haas C-R, Burchard F, et al. Voluntary versus involuntary hospital admission in child and adolescent psychiatry: a German sample. Eur Child Adolesc Psychiatry 2014;23(3):151-61.
- Lansdown G. Every child's right to be heard. A resource guide on the UN Committee on the Rights of The Child general comment no. 12. Save the Children UK on behalf of Save the Children and UNICEF; 2011.
- Kapp C, Perlini T, Jeanneret T, Stephan P, Rojas-Urrego A, Macias M, et al. Identifying the determinants of perceived quality in outpatient child and adolescent mental health services from the perspectives of parents and patients. Eur Child Adolesc Psychiatry 2017;26(10):1269-77.
- Radez J, Reardon T, Creswell C, Lawrence PJ, Evdoka-Burton G, Waite P. Why do children and adolescents (not) seek and access professional help for their mental health problems? A systematic review of quantitative and qualitative studies. Eur Child Adolesc Psychiatry [2020 Jan 21] doi: 10.1007/s00787-019-01469-4.
- Wolpert M, Vostanis P, Martin K, Munk S, Norman R, Fonagy P, et al. High integrity mental health services for children: focusing on the person, not the problem. BMJ 2017; 357:j1500.
- Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean?(or it takes at least two to tango). Soc Sci Med 1997;44(5):681-92
- James K, Quirk A. The rationale for shared decision making in mental health care: a systematic review of academic discourse. Ment Health Rev J 2017;22(3):152-65.

- Hoffmann TC, Montori VM, Del Mar C. The connection between evidence-based medicine and shared decision making. JAMA 2014;312(13):1295-6.
- Drake RE, Deegan PE. Shared decision making is an ethical imperative. Psychiatr Serv 2009;60(8):1007.
- Munthe C, Sandman L, Cutas D. Person centred care and shared decision making: Implications for Ethics, public health and research. Health Care Anal 2012;20(3):231-49.
- Kongerslev M, Storebø OJ. Towards preference-based and personcentered child and adolescent psychiatric service provision. Scand J Child Adolesc Psychiatry Psychology 2017;5(3):89-91.
- Hayes D, Edbrooke-Childs J, Town R, Wolpert M, Midgley N. Barriers and facilitators to shared decision-making in child and youth mental health: Exploring young person and parent perspectives using the Theoretical Domains Framework. Counsel Psychother Res 2019;20(1):56-67.
- Cheng H, Hayes D, Edbrooke-Childs J, Martin K, Chapman L, Wolpert M. What approaches for promoting shared decisionmaking are used in child mental health? A scoping review. Clin Psychol Psychother 2017;24(6):O1495-O1511.
- Langer DA, Jensen-Doss A. Shared decision-making in youth mental health care: Using the evidence to plan treatments collaboratively. J Clin Child Adolesc Psychol 2018;47(5):821-831.
- Bjønness S, Viksveen P, Johannessen JO, Storm M. User participation and shared decision-making in adolescent mental healthcare: a qualitative study of healthcare professionals' perspectives. Child Adolesc Psychiatry Ment Health 2020;14(2).
- Law H, Gee B, Dehmahdi N, Carney R, Jackson C, Wheeler R, et al. What does recovery mean to young people with mental health difficulties? –"It's not this magical unspoken thing, it's just recovery". J Ment Health 2020;29(4):464-72.
- Persson S, Hagquist C, Michelson D. Young voices in mental health care: Exploring children's and adolescents' service experiences and preferences. Clin Child Psychol Psychiatry 2017;22(1):140-51.
- Gabrielsson S, Sävenstedt S, Zingmark K. Person-centred care: clarifying the concept in the context of inpatient psychiatry. Scand J Caring Sci 2015;29(3):555-62.
- Mawn L, Welsh P, Kirkpatrick L, Webster LAD, Stain HJ. Getting it right! Enhancing youth involvement in mental health research. Health Expect 2016;19(4):908-19.
- Harding E, Wait S, Scrutton J. The state of play in person-centred care. London: The Health Policy Partnership Ltd.; 2015.
- Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. Qual Health Res 2016;26(13):1753-60.
- Lindseth A, Norberg A. A phenomenological hermeneutical method for researching lived experience. Scand J Caring Sci 2004;18(2):145-53.
- Abrines-Jaume N, Midgley N, Hopkins K, Hoffman J, Martin K, Law D, et al. A qualitative analysis of implementing shared decision making in Child and Adolescent Mental Health Services in the United Kingdom: Stages and facilitators. Clin Child Psychol Psychiatry 2016;21(1):19-31.
- Hayes D, Edbrooke-Childs J, Town R, Wolpert M, Midgley N. Barriers and facilitators to shared decision making in child and youth mental health: clinician perspectives using the Theoretical Domains Framework. Eur Child Adolesc Psychiatry 2019;28(5):655-66.
- Spencer G. Young people and health: Towards a new conceptual framework for understanding empowerment. Health (London) 2014;18(1):3-22.

- Scholl I, LaRussa A, Hahlweg P, Kobrin S, Elwyn G. Organizational-and system-level characteristics that influence implementation of shared decision-making and strategies to address them—a scoping review. Implement Sci 2018;13(1):40.
- Link BG, Cullen FT, Struening E, Shrout PE. A modified labeling theory approach to mental disorders: an empirical assessment. Am Sociol Rev 1989;54(3):400-23.
- Emerson RM. Power-dependence relations. Am Sociol Rev 1962;27(1):31-41.
- O'Reilly M, Parker N. 'Unsatisfactory Saturation': a critical exploration of the notion of saturated sample sizes in qualitative research. Qual Res 2013;13(2):190-7