Master Thesis

First experiences of patients with bipolar disorder with recording a film to show their 'euthymic being': a qualitative study

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ABSTRACT

Title: ‘Show Yourself’: First experiences of patients with bipolar disorder with recording a film to show their ‘euthymic being’: a qualitative study.

Background: In practice, it is noticed that the recovery of a patient with bipolar disorder (BD) during hospitalization is differently objectified by professionals working at an admission ward and relatives of the patient. Professionals often indicate that patients’ condition is improving while relatives notice limited improvement. This difference might be caused by a difference in perspective. Hence, a research project was started regarding the development of a film intervention. The recording of a ten-minute film by outpatients to show their ‘euthymic being’ might increase professionals’ awareness of the healthy person.

Aim: The objective of this study is to examine the experiences of outpatients with BD with recording a ten-minute film to show their ‘being’ in a euthymic mood state. These results can contribute to the assessment of the feasibility of the film intervention.

Methods: The design is an explorative, descriptive qualitative research, in the context of a feasibility study. Individual, open interviews were conducted. The Stevick-Colaizzi-Keen method was used to analyse those interviews.

Results: Four themes emerged from the data: ‘Patient in charge’ (involvement of others, setting of the film); ‘Personal expectations’ (different expectations, information provision); ‘Creating a comfort zone’ (preparatory conversation, contact with the ambulatory nurse who supported the patient, ambiance); ‘Reflections on the experiences’ (presenting a genuine image, experience with recording, own reference framework).

Conclusion: All but one participant had positive experiences with the recording process. The development of the film intervention can be continued due to the positive results.

Implication of key findings: For further development, the effect of the film intervention should be investigated by performing a follow-up of patients who recorded a film.

Keywords: Bipolar disorder, film intervention, euthymia, qualitative research

SAMENVATTING

Titel: ‘Show Yourself’: Eerste ervaringen van patiënten met een bipolaire stoornis met het maken van een filmpje om hun ‘zijn’ in een euthyme gemoedstoestand te laten zien: een kwalitatief onderzoek.

Achtergrond: In de praktijk wordt opgemerkt dat het herstel van de patiënt met een bipolaire stoornis (BS) tijdens opname verschillend wordt geobjectiveerd door professionals op de opnameafdeling en naasten van de patiënt. Professionals indiceren vaak dat de situatie van de patiënt aan het verbeteren is terwijl naasten weinig verbetering opmerken. De oorzaak kan een verschillend perspectief zijn. Om deze reden is een onderzoeksproject opgestart voor de ontwikkeling van de filminterventie. Het opnemen van een tien-minuten film door ambulante patiënten om hun ‘zijn’ in euthyme gemoedstoestand te laten zien, kan het bewustzijn van professionals over de gezonde persoon mogelijk vergroten.

Doel: Het doel van deze studie is onderzoeken van de ervaringen van ambulante patiënten met BS met het opnemen van een tien-minuten film om hun ‘zijn’ in euthyme gemoedstoestand te laten zien. De resultaten kunnen bijdragen aan de beoordeling van de feasibility van de filminterventie.

Methode: Het design betreft een exploratief, beschrijvend kwalitatief onderzoek, in de context van een feasibility studie. Individuele, open interviews zijn uitgevoerd. Deze interviews zijn geanalyseerd met de Stevick-Colaizzi-Keen methode.

Resultaten: Vier hoofdthema’s kwamen voort uit de data: ‘Eigen regie’ (betrokkenheid anderen, setting film); ‘Persoonlijke verwachtingen’ (verschillende verwachtingen, informatievoorziening); ‘Creëren van een comfort zone’ (voorbereidend gesprek, contact met ambulante verpleegkundige die de patiënt ondersteunde, sfeer); ‘Reflecties over de ervaringen’ (werkelijk beeld weergeven, ervaringen filmopname, eigen referentiekader).

Conclusie: Meeste participanten hadden positieve ervaringen met de filmopname. Dankzij positieve resultaten kan de filminterventie verder worden ontwikkeld.

Aanbevelingen: Het effect van de filminterventie behoort onderzocht te worden door het uitvoeren van een follow-up van patiënten die een film hebben opgenomen.

Keywords: Bipolaire stoornis, filminterventie, euthyme gemoedstoestand, kwalitatief onderzoek

INTRODUCTION

In 2010, the overall lifetime prevalence of bipolar disorder (BD) in the Dutch population was 1.3%[1]. BD is ‘’a chronic, complex psychiatric disease characterized by (hypo)manic episodes alternating with depressive mood episodes, mixed episodes, and euthymic mood episodes’’[2]. A manic episode is expressed in an abnormal and elevated mood and activity and increased distractibility[3]. In a hypomanic episode, the symptoms of a manic episode are present but do not cause significant deficits in functioning that admission to a ward is necessary[3,4]. A euthymic mood state means a consistent normal mood; symptoms which indicate a (hypo)manic or depressive episode are absent[2].

According to the Dutch guideline for the treatment of BD[5], the most important aspects of the treatment are pharmacotherapy, psycho-education and promotion of self-management[5]. The treatment is ambulatory. However, when a relapse or recurrence of a manic or depressive episode occurs, hospitalization is often essential. The overall recurrence risk among naturalistic studies is an average of 55.2% of subjects and among Randomized Controlled Trails an average of 39.3% subjects[6].

When the patient in a manic or depressive episode is admitted to the ward, it is noticed in practice that the recovery of a patient with BD is differently objectified by professionals working at the admission ward and relatives of the patient. Professionals often indicate that the patients’ condition is improving while relatives notice limited improvement. This difference might be caused by a difference in perspective. Relatives’ perspective is the patient in a euthymic mood state while professionals’ perspective is the patient during a manic or depressive episode. Consequently, there is a chance that the professional might misjudge the patients’ recovery. For example, discharge can be too early which can lead to extension of the recovery period and/or stress among relatives.

Huber also reported a difference in thinking about health between professionals and patients[7]. It became evident that patients consider health as a broader concept[7]. Huber’s new developed concept of health called ‘positive health’[8-10], assumes that a person is more than his or her illness and the person should be central.

Currently, there is no effective intervention available that might solve the existing difference between professionals and relatives. Hence, a research project is started regarding the development of a film intervention. In this intervention, outpatients, preferably with the aid of a relative, record a ten-minute film. The intention is to show their ‘being’ in a euthymic mood state. Before recording, a preparatory conversation is performed to discuss what the patient want to and will say in the film. During recording, an ambulatory nurse supports the patient. In the film, the outpatient can for example introduce which aspects are

important in a euthymic mood state. On completion, the patient and the nurse watch the film together. The film can be handed over to the professionals at the admission ward. Professionals' awareness of the healthy person might be increased which can lead to a more adequate estimation of whether the occurred recovery fits the patient.

Recently, films were recorded of a number of outpatients. For further development of the film intervention, it is important to gain insight into the first experiences of outpatients with BD with the recording process. These results can contribute to the assessment of the feasibility of the film intervention.

AIM

The objective of this study is to examine the experiences of outpatients with BD with recording a ten-minute film to show their ‘being’ in a euthymic mood state.
The results can contribute to the assessment of the feasibility of the film intervention. With this data, a decision can be made whether the development of the film intervention should be continued.

METHOD

Design

An explorative, descriptive qualitative research, in the context of a feasibility study, was chosen to explore the experiences of patients with BD with recording a film[11] to perform an initial exploration of a small part of the film intervention[11].

Population and domain

The studied population consisted of outpatients with BD, who receive treatment from a psychiatric institution in the Netherlands and recorded a ten-minute film that showed their 'euthymic being'. This study utilized a convenience sample to select participants from five outpatient settings within two psychiatric institutions in the Netherlands. Participants were eligible if they were ≥18 years and in a euthymic mood state. This study assessed the mood state through using two different methods. The first and most significant method determined the mood state of the participants based on their personal estimation. The second method utilizes the self-rating mood scale (VAS) of the 'Life Chart Methodology'(LCM)[12,13](Appendix 1) where a value between 40 and 60 represents a euthymic mood state. Participants were excluded if they were unable to speak and understand the Dutch language.

Data collection

Individual, open interviews were conducted since no information was available about the user's perspective. Therefore, it was important that the interviewer had no predetermined questions to remain open-minded for participants' thoughts[11]. Each interview started with the following question: ''Some time ago, you have recorded a film regarding the film intervention project. Can you explain something about the experiences you had with recording this film?''. An aide mémoire supported participants in describing their experiences and provided an exploration of statements from participants[11,14]. The views and assumptions of the researchers concerning the film intervention underpinned the development of the aide mémoire. The aide mémoire was continuously refined since new themes emerged during the interviews which were also important to discuss in the following interviews[14].
The same interviewer (MGL) conducted each interview. These interviews were audio-taped. A log file described for example the ambiance during the interview. Prior to the interviews, there was no professional relationship between the participant and interviewer. Overall, the interviewer had little experience with conducting interviews. However, in her work as a psychiatric nurse, she is accustomed to applying various conversation methods. Besides, the

interviewer performed one pilot interview which was reviewed during a dialogue with PG. The feedback resulting from this conversation increased the quality of interviewing skills.

Procedures

Immediately after recording the film, the ambulatory nurse provided information about this study. Subsequently, the nurse asked the patient whether the interviewer was allowed to contact him/her to provide more information about this study. In the case of approval, the patient signed an informed consent for sharing his or her personal information with the interviewer. Hereafter, the interviewer contacted the patient by telephone to ask whether the interviewer was allowed to send an information letter. An appointment was set by mail or phone when the patient was still interested after one week. The participant chose the interview setting to ensure a secure environment. This is important because participants can feel more at ease when the interview takes place at their home, which can provide richer data[11].

Data analysis

This study performed data analysis by the Stevick-Colaizzi-Keen method[15], tailored to this specific research. Furthermore, an iterative process between the data collection phase and the analysis was performed. The interviewer transcribed each interview verbatim. Prior to the analysis of the results, the researcher conducted bracketing and reread the transcripts to get familiar with the data. The analysis phase included open coding, development of categories, themes, and textural and structural description. The interviewer performed open coding where two random transcripts were, independently from the interviewer, open coded by PG. Subsequently, both parties reached consensus about the derived codes. After five interviews, a code tree was designed and discussed with PG. Hereafter, the second phase of interviews started. Subsequently, codes were compared and grouped into broader categories followed by the development and description of the themes. During each step of the analysis process, a meeting took place between the interviewer and PG to reach consensus. The use of memos and an audit trail improved the transparency of the analytical process. A log file was kept for registration of all research activities, such as bracketing[14]. The interviewer carried out a member check through sending a summary to participants which consisted of preliminary interpretations of the interview[11]. NVivo 11 (QSR International) was used to support the analysis[16].

Ethical issues

According to Dutch legislation, approval from an accredited MREC or CCMO was not necessary[17]. The Scientific Research Committees of two institutions approved this study. Prior to the start of the interviews, all participants signed an informed consent form. The transcripts of the interviews were anonymized.

RESULTS

A total of 14 participants participated in this study. Data saturation was assumed after 12 interviews and established after two additional interviews. Eight interviews were conducted at a location within the organization and six interviews at participants' homes. The average length of the interviews was 41 minutes. Eleven participants responded to the member check. Two of them had a few additions or corrections which have been adjusted.

In Table 1, an overview of participants' characteristics is presented. Eight of the fourteen participants were women. The participants ranged in age: 23 to 62 years. Thirteen participants were euthymic according to themselves. Of these thirteen, three participants scored not between the value of 40-60. Another participant was not completely euthymic according to her personal estimation but able to be interviewed and therefore included in this study.

[Table 1]

Findings

Four major themes emerged from the data. 'Patient in charge' is the first theme, characterising the way participants choose a particular setting of the film and involved others in the film. The second theme, 'Personal expectations', characterized what they expected regarding the recording process and the information provision. The third theme, 'Creating a comfort zone', whereby the preparatory conversation, the ambiance and the contact with the ambulatory nurse who supported the participant seemed important, influencing factors. The last theme, 'Reflections on the experiences', described how participants look back at their experiences, wanted to show a genuine image of themselves and described their thoughts about future use of the film.

Patient in charge

The data showed that the patient was in charge during the recording process.

Different perspectives emerged regarding the involvement of relatives or others in the film. Three participants, who involved others in the film, said it was pleasant that this person was visible or said something about them. On the other hand, seven participants indicated that an involvement of relatives was not desired. A frequently stated reason by participants was the film is about their personal perspective regarding their euthymic mood state and not about the perspective of their relative.

The setting of the film seemed an important, influencing aspect for participants. Eleven participants recorded the film at home and mentioned this was pleasant. The main reason was they feel (more) at ease in their own environment. A familiar environment was important according to participants.

> *''I have filmed in the garden, it was in the sun, my two dogs around me. That was just very confidential.''(P1)*

On the other hand, three participants recorded the film in a room at the organization. They wanted to keep their private situation and 'being patient' separate.

A few participants decided to show personal things in the film. Other participants did not feel the need to show personal things. They mentioned it had no added value.

Personal expectations

Half of the participants stated they barely had expectations and were open minded before the recording process. Nonetheless, six participants stated they expected fear of being on camera, were afraid they would show a wrong image of themselves, would hesitate or say the wrong things.

> *''I have a bit camera fear and I'm not at the front when taking pictures, so I felt tense.''(P6)*

Half of the participants mentioned the information was clear before the recording process. A minority of participants stated they had difficulty forming an image of what they could expect. A few said it should be clearer how they can prepare themselves.

Creating a comfort zone

The preparatory conversation, the ambulatory nurse who supported the participant and the ambiance seemed to be helpful for making participants feel (more) comfortable.
Participants said the conversation was helpful in for example formulating the themes which would be talked about in the film.

> *''I had no performance anxiety and that was also because of the preparatory conversation.''(P2)*

The data showed that the first contact with the nurse was different for each participant. Different perspectives appeared when participants were asked about the (un)familiarity with the nurse. Participants who knew the nurse, stated it was not a problem, it was even an advantage or they felt more comfortable. Three participants, who did not knew the nurse, said it was not a problem or even pleasant. However, two participants were not positive about the unfamiliarity before recording. Overall, none of the participants were negative about the nurse.

''The behaviour of […(nurse)] did not distract me.''(P14)

''I felt comfortable with her.''(P5)

Some participants mentioned that the questions asked by the nurse during recording was a pleasant aspect. They said that the questions guided them or served as a reminder. Positive confirmation by the nurse was also referred as a pleasant aspect by some participants.

''During recording she repeatedly raised her thumb, which also gave me support.''(P2)

Most participants mentioned it was a relaxed or cosy atmosphere. Some said this was very important or helpful in the whole process.

''Also had a lot of fun,…,because of that you're relaxed.''(P3)

One participant said if she was depressive, she would have more performance anxiety. Another participant stated she was a little depressive during recording. This made her more nervous and therefore it was harder for her.

Reflections on the experiences

All but one participant experienced the recording process as positive. The participant who wasn't really positive said this related to camera fear. Most participants reported they were satisfied with the result and showed a genuine image of their 'euthymic being'.

''When I see the film, I think, yes that's me.''(P5)

''I think it shows well how I feel and behave and which interests I have.''(P11)

Some participants said they showed the film to relatives or therapists, they confirmed to have seen a genuine image of the patient's 'euthymic being'. Two participants mentioned they have not shown a complete image of their 'euthymic being'. One stated it is not a complete picture of functioning in different situations. The other mentioned that she was a bit tense.

Almost half of the participants stated they are glad that the film exists in case it is necessary. Some participants said they could tell everything they wanted in the film and the recording process went quickly.

Showing the difference between character and BD was an important feature of the film according to most participants. Participants wanted to show a different side of them which is their 'euthymic being'. Almost half of the participants mentioned it was important that for example their eyes and smile were visible. A few said this is more important than the content.

''Because when you are talking, you already show who you are.''(P5)

Each participant responded differently to seeing themselves in the film. Five participants commented this was or can be confrontational. Watching the film has been postponed by a few patients.

''I think it is confrontational because I see myself and then I find myself stupid.''(P4)

Participants' thoughts and recommendations about future use was an aspect that frequently occurred in the interviews. Most participants said they hope the film will help them during future admissions and think it is a good tool for professionals.

''I think they get a better picture of how they should interact with someone and how they can better approach the person.''(P8)

A few participants expressed their curiosity, doubts and/or asked questions regarding the application and storage of the film. Besides, some participants mentioned the film is a snap shot and a few reported the film should be changeable.

''You should just record a film every three years. Just as well as you need to adjust your relapse prevention plan every time.''(P8)

Five participants stated the film can be used as own reference framework. According to these participants, the film can be watched during admission or in a hypomanic mood state. They mentioned it can help them to make a comparison and see they need help or they are not euthymic yet.

> *''Professionals should put me in a room with a beamer and then I see myself talk for ten minutes. I think of course I'm here for a reason. This is me instead of my current mood state.''(P9)*

DISCUSSION

This present study demonstrates that all but one patient had positive experiences with recording a film to show their 'euthymic being'. The patient who wasn't really positive stated this related to camera fear. Influencing factors which contribute to the positive experiences were the setting of the film chosen by the patient, the preparatory conversation, the ambulatory nurse who supported the patient and the ambiance.

Most participants represent a genuine image of their 'euthymic being'. Participants hope that professionals can make the comparison between their character and BD and see the person behind the patient. This is supported by a study which gives insight in what outpatients with BD consider ''good care''[18]. ''Good care'' means acknowledging and being responsive to the uniqueness of the person. BD is one aspect of their life and they ask for awareness for using their strengths in the personalised treatment[18]. This is in line with Huber's concept 'positive health' in which persons feels accustomed to their strength. Despite a disease, a person can feel healthy for a big part of their life[10]. In the present study, participants hope that professionals take notice of their 'euthymic being' with the film and use this knowledge in the treatment.

The influencing factors which makes the participant feel (more) comfortable often relates to the relationship with the nurse. It is not an unexpected and remarkable outcome for relationships to have an important role in forming experiences of patients. This is in line with a study which demonstrates that relationships with staff is a core theme within service users' experiences[19]. Communication is a central theme in which talking, listening and understanding are the associated activities[18]. In the present study, participants stated they could tell everything they wanted in the film and the nurse listened to their story and took the time. In the future, the importance of the relationship with the ambulatory nurse must not be undervalued. For example, the nurse can have an important role with intervening in patients' camera fear.

The themes 'personal expectations' and 'creating a comfort zone' appeared to connect with each other. Half of the participants were stressed before recording (due to performance anxiety). It is expected that patients can earlier reach a more comfortable state when the expectations of patients are better analysed prior to the start of the recording process. These expectations should be managed appropriately by the nurse by signalling the existence of stress, searching for the source, providing clear information about the recording process and motivating and encouraging the patient[20,21].

Also, despite the fact that most participants stated the information in advance was clear, many participants mentioned they barely had expectations and were open minded before the recording process. This proves they did not exactly know what they could expect. In addition, most participants said the preparatory conversation helped in getting a clear understanding of what they would say in the film. In response to what is stated above, possibly more information needs to be provided to the patient in the future.

Something surprisingly and unexpected was that some participants mentioned the film can be used as own reference framework. This statement can be connected to the advancement of self-management skills. Adequate self-management includes the ability to monitor their own health condition[22]. If patients use the film as own reference framework, they are able to make a comparison and estimation of their condition.

Strengths and limitations of this study

A limitation of this study was the small sample size, however the sample was large enough to reach data saturation. A strength of this study is the varied population. The patients are of all ages and the distribution in gender is almost equal. Another strength is the fact that most patients confirmed the member check which increased the validity of the data[14]. Also, a strength is the independent coding by MGL and PG of two transcripts. Other activities which enhanced the methodological quality were the audit trail by using a log file and audio recording which consists of the exact words of the participant[11,14].

One aspect in this study needs further consideration. The fact that three participants scored not between 40-60 according to the VAS and one participant was not completely euthymic during the interview might have influenced the interviews and their reflection on the experiences. Consequently, the results can possibly be influenced. The mood state of the participants was based mainly on their personal estimation because this can be more important than a number. This is in line with other research which stated that patients with BD perceived that scoring a specific mood state is inconvenient. It is not 'custom made'[23]. Besides, not every patient uses the VAS of the LCM in their personal treatment and patients stated guidance in using the LCM is necessary[23].

Implications for clinical practice and future research

With this study, a first step is realized towards the further development of the film intervention. Due to the positive results of users' perspective, it can be determined that the film intervention is a promising intervention and feasible for the patient. The development of the film intervention can be continued. However, the film intervention has not yet been

applied in practice and the effect of the film intervention is unknown. Therefore, a follow-up should be performed to follow patients who recorded a film to assess whether the film will be used by patients when they are admitted and subsequently to examine the effect of the film intervention in the care for those patients[24]. During this follow-up, it is important to pay attention to the practical applicability of the film. For example, how the film will be embedded in the patient's file.

This research focused in particular on a few outcomes of the acceptability, demand and practicability of the film intervention. Other outcomes which should be assessed before the implementation of the film intervention are for example the integration within existing programs and a cost analysis[24]. Besides outcome evaluations, it is important to perform process evaluations to understand why the film intervention works, fails or how it can be improved[25].

Conclusion

All but one patient had positive experiences with the recording process. This research demonstrates that the film intervention is feasible for the patient. The development of the film intervention can be continued due to the positive results. For further development, the effect of the film intervention in the care for patients with BD should be investigated by performing a follow-up of patients who recorded a film.

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TABLES

Table 1

Demographic and clinical characteristics (N = 14)

Characteristic	
Women, *n (%)*	8 (57.1%)
Age (years), *range ; mean (SD)*	23 – 62 ; 41.71 (10.31)
Living situation, *n (%)*	
Single	4 (28.6%)
Married	4 (28.6%)
Living together, not married	5 (35.7%)
Partner, not living together	1 (7.1%)
Diagnoses, *n (%)*	
Bipolar I	14 (100%)
Date established diagnosis (years ago) *range ; mean (SD)*	3 – 23 ; 10.5 (7.4)
Mood state during interview [a]	
VAS score ≤40 (depressed)	2 (14.3%)
VAS score 40-60 (euthymic)	10 (71.4%)
VAS score ≥60 ((hypo)manic)	2 (14.3%)
Length period current euthymic mood state (months), *range ; mean (SD)*	0.75 – 48 ; 15.06 (12.06)
Number of manic episodes last year, *range ; mean (SD)*	0 – 2 ; 0.21 (0.56)
Number of depressive episodes last year, *range ; mean (SD)*	0 – 3 ; 0.29 (0.8)
Number of hospitalizations during life due to manic episodes, *range ; mean (SD)*	1-9 ; 3.36 (2.5)
Number of hospitalizations during life due to depressive episodes, *range ; mean (SD)*	0-5 ; 1.14 (1.77)

Note.

[a] All but one patient stated they were euthymic according to themselves. One patient stated she was not completely euthymic, but able to be interviewed and therefore included.

Appendix 1 Self-rating mood scale (VAS) of the 'Life Chart Methodology'