Factors associated with willingness to participate in scientific research among antidepressant users: a qualitative study

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ABSTRACT

Background: Researchers report challenges to involve antidepressant users in their scientific research.

Aim: To investigate factors associated with willingness to participate in scientific research among users of antidepressants.

Methods: A qualitative study was conducted involving 267 reasons derived from enrollment data of ongoing studies regarding antidepressant usage, interviews with four research assistants, and a focus group discussion with four antidepressant users.

Results: Nine themes were identified: fear, trusting relationship and recognition, taboo/stigma, societal responsibility, practical considerations, the impact of study design, recruiter competence, mental condition, and personal benefit.

Discussion and Conclusion: This study uncovers ambivalence among antidepressant users regarding research participation. Fears include relapse and navigating life without medication, while motivation stems from reducing stigma and fostering open discussions. The willingness to participate is linked to the severity of depressive symptoms, with effective recruitment and trust in healthcare providers enhancing engagement.

INTRODUCTION

The use of antidepressant medication has become increasingly prevalent. In The Netherlands alone, 1.2 million out of circa 17 million individuals rely on antidepressants, which is more than ever [1]. These drugs are mainly prescribed in primary health care for the treatment of symptoms of depression and anxiety. Scientific studies on adequate monitoring and evaluation during treatment are important to increase knowledge on effective guidance of antidepressant users. Equally as important as guidance during treatment, is guidance while discontinuing and tapering off these drugs, and this also requires scientific evaluation. It is important to involve those with experience in the use of antidepressants in scientific research. Unfortunately, a recurrent barrier to studies centered on this subject is the willingness of antidepressant users to participate in such studies.

For example, in an ongoing study (study A[2]) on antidepressant discontinuation, patients' limited willingness to participate is a known problem. This study is a randomized controlled trial aiming to examine methods for antidepressant discontinuation. Recruiting participants for this study has proven to be challenging. Likewise, only 6.1% of approached antidepressant users were willing to participate in a study conducted by Eveleigh et al[3]. Leydon et al. [4] described that willingness to discontinue antidepressants was frequently hindered by two factors: symptoms associated with stopping and uncertain consequences of stopping[4]. Van Leeuwen et al. [5] mentioned an overreliance on antidepressants as an obstacle to discontinuation. This left individuals believing they were unable to cope with daily problems without their medication[5]. Furthermore, confusing and contradictory professional advice, fear of relapse, reliving the past, and disturbing an achieved equilibrium were stated as factors to withhold from antidepressant discontinuation[6-7].

On the other hand, mentioning at the first prescription that antidepressants are ideally used for a limited period tends to augment the willingness to discontinue the medication in the future [6].

Of note, the challenge of recruiting patients in studies on antidepressants is not exclusively encountered in studies regarding discontinuation. Antidepressant monitoring studies face similar difficulties. An example is another ongoing study (study B[8]). Study B aims to explore the duration of recovery from depression after antidepressant initiation and the factors determining the improvement or recovery of individuals. Not willing to participate in these studies might be inherently tied to the nature of the condition of antidepressant users as suggested by Fusar-Poli et al[9] and might overshadow the motivations given by Moran-Sanchez et al. for participating in research which includes altruïsm, the expectation of personal gain, and a desire to help others[10].

The current study aimed to assess the multifaceted factors influencing antidepressant users' willingness to participate in scientific research on antidepressant therapy. Understanding these factors is necessary to increase the participation of antidepressant users in scientific research which in turn is needed to improve effective guidance for these individuals. Ultimately this will contribute to the well-being of those who rely on antidepressants to navigate their daily lives.

METHODS

Design of the study

A qualitative study was conducted. Data was collected from different sources, during three steps in the study.

First, to get familiarized with the reasons for non-participation, data that was collected during the enrollment process of studies A and B was analyzed. These records contained a brief reasoning as to why contacted potential participants refrained from participation.

Second, research assistants of studies A and B who were involved in the enrollment process were interviewed to gain a more in-depth understanding of the previously studied data.

Third, a focus group discussion was held with antidepressant users recruited from a pharmacy in The Netherlands. Individuals fulfilling the inclusion criteria below were identified from the pharmacy's dispensing records.

An overview of the study design is depicted in Figure 1. For each subsequent phase, input was provided by the preceding phase.

Thorne's approach to interpretive description was used to provide a thematic analysis of factors associated with willingness to participate in scientific research[11]. This approach aids in understanding, interpreting, and describing human experiences in their natural context. Every experience exists independently, so it is essential to derive patterns and themes within the subject of interest.

Data collection

As to the first step in the study, potential participants for studies A and B had been contacted telephonically by research assistants to invite them to participate in scientific research. Reasons for non-participation were recorded by research assistants. This data was digitalized. The provided data was analyzed using NVivo (qualitative data analysis software) and rendered the first themes for the subsequent step of interviewing research assistants.

For the second step in the study, research assistants of studies A and B were interviewed following a semi-structured interview guide(Appendix A and B). This guide was developed in light of the identified themes from the data of the enrollment process. The interviews were conducted with pairs of persons: the research assistants affiliated with study B were interviewed via Microsoft Teams, whereas those associated with study A were

interviewed in person. The interviews were recorded and transcribed

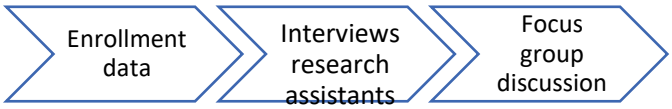

Figure 1 Progression of different phases

word by word. The interviews were also coded using NVivo.

Participants for the focus group discussion (third step of the study) were all registered at the participating pharmacy. The following criteria applied for inclusion: between 18 and 75 years of age, using antidepressants to manage their depression for at least 6 months or those who had used an antidepressant for at least 6 months in the past, willing to provide written informed consent and sufficient command of the Dutch language. Individuals were deemed ineligible to participate if they used lithium, and doses of benzodiazepines equivalent to 10 mg oxazepam or higher alongside antidepressive medication. These psychotropics can potentially provide a distorted perception of the willingness to participate. The ATC code for antidepressants, N06A, was used to identify all antidepressant users in the participating pharmacy. ATC is a standardized coding system used to categorize drugs based on their therapeutic characteristics. Building upon the acquired results from enrollment data and interviews, a discussion guide for the focus group discussion was developed. This structured discussion guide contained four hypothetical study designs (appendix C). The study designs were proposed to the participants to investigate the factors influencing their willingness to participate in scientific research. The discussion guide can be found in Appendix D.

Facilitating and impeding factors of influence on the willingness of antidepressant users to participate in scientific research were determined. This was done by initially coding all identified themes from the three distinct steps separately, followed by an examination of common themes.

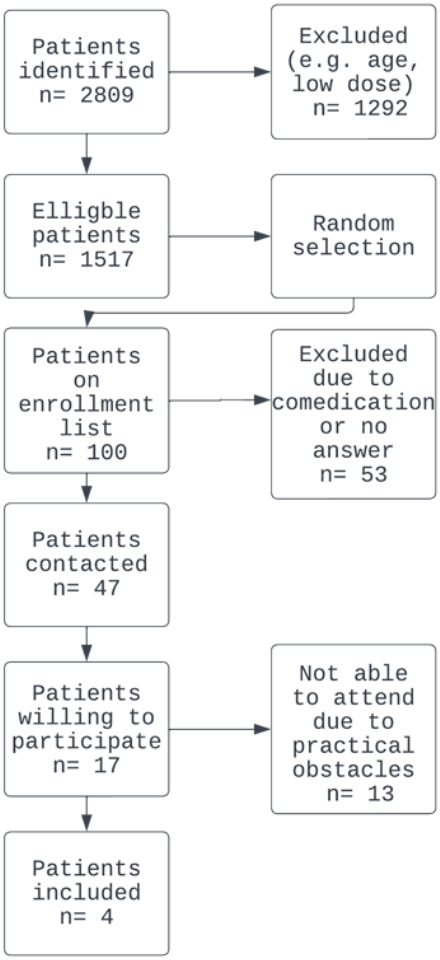

Figure 2. Flowchart of the inclusion process of focus group participants

RESULTS

Execution of study

The enrollment data yielded 267 reasons for (non)-participation provided by antidepressant users. Each

participant shared only one reason. Frequently mentioned reasons for non-participation during initial contact with antidepressant users were: no interest in scientific research (mentioned by 18 individuals), mental condition inhibiting participation (n=28), and practical obstacles such as being too busy (n=22). In the context of study B, anxiety or aversion towards discontinuing antidepressants was expressed 77 times.

The identified facilitating and impeding factors were categorized into 9 themes. The data source for each theme can be found in Appendix E.

Two interviews were conducted, each with two research assistants. All were female. The themes identified through the interviews can be found in Appendix E.

The inclusion process of the focus group discussion is shown in Figure 2. Through the dispensing records of the participating pharmacy, 2809 antidepressant users were identified. 1517 of those met the age range and used a therapeutic antidepressant dose. From this pool, a random sample of 100 individuals was chosen to invite for participation in the focus group. 53 of which were not eligible for participation due to the use of other psychotropic medication or because they did not answer the phone calls. Of the remaining antidepressant users, 17 were willing to participate. Ultimately, four individuals attended the focus group. The other individuals were unable to attend due to personal reasons or logistical obstacles. Among the four participants, three were men and there was one woman. Their ages ranged between 33 and 75 years.

Facilitating and impeding factors

The results are categorized and described in the following themes. Table 1 provides an overview of the identified themes.

Societal responsibility

The innate inclination towards aiding others was mentioned in the focus group when asked why participants chose to participate in the focus group discussion. Participants wanted to contribute to the enhancement of health care and research. Also aiding young researchers and thus supporting science was mentioned as a reason to participate.

"Yes, I think that people, so those who want to reach that stage, should be given the chance to interview people, and what it's about is her education after all. Then we all benefit when she becomes an expert later on, and of course, we're all happy about that." [P2 – Focus group participant)

Personal benefit

Participants expressed their interest in scientific research and stated it gave them a sense of fulfillment to contribute to research. One participant shared he was recovering from severe depressive symptoms. He added that participation in this study represents a form of closure to a challenging period from which he is currently recovering.

"What I'm saying, yes, I also have a bit of closure if I can do this. If I can show this, if I can share this, if I can tell this, I'm already well on my way." [P3 - Focus group participant]

According to one focus group participant, participating in a study could offer increased surveillance during the discontinuation of antidepressants. For individuals who would like to discontinue their medication but are hesitant, this may be pivotal in their willingness to participate. Being involved in scientific research could foster individual awareness of one's recovery. Engaging in research could

Theme	Facilitating or Impeding factor	Quotes
Societal responsibility	Facilitating factor	*"Yes, I think that people, so those who want to reach that stage, should be given the chance to interview people, and what it's about is her education after all. Then we all benefit when she becomes an expert later on, and of course, we're all happy about that." [P2 – Focus group participant)*
Personal benefit	Facilitating factor	*"What I'm saying, yes, I also have a bit of closure if I can do this. If I can show this, if I can share this, if I can tell this, I'm already well on my way." [P3 - Focus group participant]*
Taboo and stigma	Facilitating and impeding factor	"*You wouldn't say, "Sorry that I have the flu" No, but apparently, you would say, sorry that I'm so down. Sorry that I'm so tired. Sorry that I'm so depressed. That shame and guilt and the associated downward spiral that naturally, naturally self-reinforces with mental health issues, that makes them so incredibly burdensome, that needs to be broken, and that was really the reason to participate in this for me.*" [P3 – Focus group participant) *"But I work for an American software company, they really shouldn't know that I've had mental problems. Then, in the next round of layoffs, I will lose my job." [P3 – Focus group participant]*
Trusting relationship and recognition	Facilitating factor	*"I would choose the pharmacy because they also know exactly which antidepressants you use and, if necessary how to taper off. That is well arranged; they have knowledge of it." [P4 – Focus group participant]*
Recruiters competence	Facilitating factor	*"I think in the beginning, I was a bit more hesitant, I didn't want to do such a sales pitch. But after a while, I did realize that we can genuinely offer something valuable; we provide very good guidance here. So after a while, I did share that it's good to know we approach discontinuation step by step, maintaining close involvement. " [OA4 – research assistant]*
Fear and insecurity	Impeding factor	"*That can also reignite things, and now I don't expect that to happen. I'm feeling very good today as well. So I don't think that's going to happen, but that was something I had in the back of my mind, like, do I want that, or do I dare that, or can I do that?" [P3 – Focus group participant]* *"Because I have quit many times before, and then yes, yes it would be fine for a certain period, but then it would inevitably get worse again, and I'm not going to do that anymore, never again, period. I've suffered too much from it." [P1 – Focus group participant]*
Mental condition	Impeding factor	*"I do know like, at my lowest points, I couldn't even commit to one day" [P3 – Focus group participant]*
Practical considerations	Impeding and	"And potential practical obstacles like time and location. That can certainly be a factor as well. Suppose today I had to be somewhere else

	facilitating factor	in A for work, then unfortunately, I wouldn't have been able to make it, so that's also a reason." *[P1 – Focus group participant]*
Impact of study design	Impeding and facilitating factor	*"Yes, participating, as we mentioned, yields the most valuable information, but it also requires the highest commitment from yourself. You have to go to the hospital every month, and the blood draw is not nothing. That takes some time again. I assume a doctor has to do that. So, it does take some time and effort to participate." [P3 – Focus group participant]* *"That actually triggered quite a bit of emotions, to answer those questionnaires because it was all about, like, do you feel depressed? But I've also heard a few times that it could really bring people back down to a low because it was such a kind of negative questionnaire. That's why I know that some people eventually stopped participating." [OA1 – research assistant]*

Table 1: Identified themes of impeding and facilitating factors influencing the willingness of antidepressants users to participate in scientific research.

provide an opportunity to reflect on past outcomes and compare them with one's current status. Finally, sharing one's narrative and breaking a downward spiral are also aspects that may yield personal gain.

Taboo and stigma

Other reasons for participating were initiating open discussions on mental health, breaking down taboos, and mitigating stigmas.

"*You wouldn't say, "Sorry that I have the flu" No, but apparently, you would say, sorry that I'm so down. Sorry that I'm so tired. Sorry that I'm so depressed. That shame and guilt and the associated downward spiral that naturally, naturally self-reinforces with mental health issues, that makes them so incredibly burdensome, that needs to be broken, and that was really the reason to participate in this for me.*" [P3 – Focus group participant)

The taboo surrounding the use of antidepressants was also mentioned as a reason not to participate. Expression of discomfort surfaced during the inclusion phase of the focus group discussion, wherein individuals were disinclined to discuss antidepressant usage within a group setting. Stepping out of anonymity was also identified during the focus group as a factor contributing to hesitancy. In both instances, individuals feared encountering acquaintances from their social circles.

Trusting relationship and recognition

A key motivator for willingness to participate was trust in the researchers and the research setting. The establishment of this trust was initiated during the enrollment process. Individuals are more willing to participate when they are being invited by a healthcare provider

they are acquainted with. In some cases, inclusion through their general practitioner (GP) is favored. This is mainly because they have a personal connection with their GP, and the GP is aware of one's medical history and personal stories.

"People, I think, have more connection with their general practitioner's office than with their pharmacy. So, at the GP I would often say: "Well you are under the care of your GP, Dr. A, so to speak. Then you already have more of a kind of recognition"" [OA1 – research assistant)

Others prefer to be approached by the pharmacy because they value the pharmaceutical knowledge that the pharmacy possesses or because their family doctor is not highly engaged in their treatment. One participant shared that he finds his GP to be too general in terms of knowledge. When asked who should preferably guide them in a study the next statement was made:

"I would choose the pharmacy, because they also know exactly which antidepressants you use and, if necessary how to taper off. That is well arranged; they have knowledge of it." [P4 – Focus group participant]

It was also suggested that involving an acquainted healthcare provider to asses one's eligibility enhanced the willingness to participate. Presumably, this would contribute to increased trust in the research.

The flip side of the coin is mentioned in the interviews with the research assistants. Within these discussions, they conveyed that in cases of a strained relationship with the healthcare provider on whose behalf they are contacting the individuals, there is a notable reluctance to participate. Moreover, some expressed opposition to sharing their information with researchers, perceiving it as a compromise to their privacy.

<u>Recruiters competence</u>

During the interviews with the research assistants, the significance of adequate recruiters became apparent. This encompasses the caller's expertise and competence and his/her role in dispelling doubts. Additionally, the recruiter's skill in attentive listening and comforting the patient is crucial. These elements collectively contribute to increasing willingness. Moreover, the manner in which the recruiter conveys information is pivotal. The recruiter should adeptly tailor the amount of information to suit his/her audience, not transforming the conversation into a promotional pitch aimed at maximizing participant inclusion. When further inquiries were made about the amount of information provided by the assistants, the following response was given.

"I think in the beginning, I was a bit more hesitant, I didn't want to do such a sales pitch. But after a while, I did realize that we can genuinely offer something valuable; we provide very good guidance here. So after a while, I did share that it's good to know we approach discontinuation step by step, maintaining close involvement. " [OA4 – research assistant]

Following this statement, the interviewed assistants shared that they adjusted to the conversational tone and tailored the provision of information accordingly. One of the research assistants shared it is important to consider the intrusion into someone's day when posing a profound question.

<u>Fear and insecurity</u>

The fear and uncertainty associated with discussing antidepressants and depressive symptoms and the potential of actual discontinuation of antidepressants represent a substantial impediment. Discussing mental health in depth in a research setting may jeopardize one's mental state.

"*That can also reignite things, and now I don't expect that to happen. I'm feeling very good today as well. So I don't think that's going to happen, but that was something I had in the back of my mind, like, do I want that, or do I*

dare that, or can I do that?" [P3 – Focus group participant]

Furthermore, openness on mental health presents an obstacle due to existing taboos and stigmas. The fear of stepping out of anonymity and revealing the use of antidepressants is not always straightforward. It depends upon various factors like the environment in which some were brought up or the corporate culture of one's job whether or not someone feels comfortable to share this.

Insecurity in one's abilities and eligibility can also deter participation. During the patient inclusion process, one individual expressed reluctance to participate, citing she believed that others could likely perform better than she could.

Fear of discontinuing antidepressants is a significant deterrent to people's willingness to participate. This is primarily due to prior negative experiences with discontinuing antidepressants. In addition to that, certain individuals find therapeutic value in their medication and fear the potential consequences that discontinuation may yield.

"Because I have quit many times before, and then yes, yes it would be fine for a certain period, but then it would inevitably get worse again, and I'm not going to do that anymore, never again, period. I've suffered too much from it." [P1 – Focus group participant]

Mental condition

Willingness to participate is strongly related with the severity of depressive symptoms. Whenever someone is suffering from symptoms like persistent sadness, anxiety, fatigue, loss of energy, or difficulty concentrating, participation poses a significant burden. The reluctance to participate in research is inherently linked to the nature of the symptoms. Poor mental well-being has frequently been noted during the inclusion of patients for studies A, B, and the focus group. Embarking on a long-term commitment proves to be quite challenging when depressive symptoms are too burdensome. This was also mentioned in the focus group.

"I do know like, at my lowest points, I couldn't even commit to one day" [P3 – Focus group participant]

Furthermore, individuals also harbor concerns about the potential impact of the study on their mental well-being. In the interview with the research assistants of study B, it was mentioned that some people refrained from participating because they were apprehensive that the questionnaires might evoke too many emotional responses.

Practical considerations

In some patients, the hesitation to participate is not a matter of unwillingness but rather a practical impossibility. Potential participants express being too occupied with work, children, or other responsibilities, hindering their ability to participate. Not everyone can leave work easily for instance. Within the focus group, there was an expressed willingness to allocate 2 to 4 hours monthly for research. Respondents further suggested that the perceived importance of the research correlated with the willingness to devote additional time. Additionally, logistical challenges were acknowledged, such as the impracticality of monthly retrieval of study medication.

Moreover, the focus group participants underscored the necessity of adapting communication channels based on individual preferences; some prefer online engagement, while others favor in-person gatherings.

Impact of study design

Additionally, this research revealed that the willingness to participate in research is significantly correlated with the design of the study. During the analysis of the enrollment lists, various reasons were identified showing this correlation, including apprehension regarding discontinuing medication, the presence of an open study phase, and obstacles related to the distance from the medication

retrieval site. Within the context of a focus group, engaging in discussion with like-minded people was regarded as a facilitating factor for participation. Additionally, fear of relapse when the narrative of others was brought up was mentioned.

Regarding a personal interview, an internal dilemma was brought to light in the focus group discussion. While afforded the privacy to articulate personal experiences in a one-on-one interview, concerns arose regarding the potential for the researcher to delve too deeply into one's mental condition. The latter was not universally regarded as favorable.

Observational studies were perceived as having the lowest threshold for participation due to the possibility of online questionnaires; however, the prolonged commitment associated with them was deemed challenging. This challenge was particularly pronounced in cases where there was no compensatory provision, such as a stipend. Undertaking a commitment spanning 24 months, for instance, was notably burdensome, especially when depressive symptoms were at their peak.

In a randomized controlled trial (RCT) on tapering, the foremost reason for declining participation was the fear associated with discontinuing antidepressant medication. This often stemmed from previous unsuccessful attempts. Some individuals were reluctant to cease their antidepressants because it was effective for them. Moreover, the uncertainty of being allocated to a particular study arm acted as a deterrent. Collectively, these reasons resulted in the lowest inclination to participate compared to the other study designs. Despite this, focus group participants acknowledged that such studies provide robust evidence, somewhat enhancing willingness.

DISCUSSION

Summary

This study has uncovered a sense of ambivalence concerning the willingness to participate in scientific research. Users of antidepressants carefully weigh their fears and insecurities against the potential benefits that the research may bring to themselves, society, and health care. These fears encompass fear of relapse, fear of navigating life without their medication, and fear of openly acknowledging their use of antidepressants. The drive to mitigate the existing stigma regarding antidepressant usage and to facilitate open discussions about the use of antidepressants without shame is a motivation to participate in scientific research. Furthermore, the willingness and ability to participate are inherently linked to the nature of the depressive symptoms. When one is substantially burdened, there is no mental capacity to engage in research. Awareness of the potential impact that participation can have on one's mental well-being, may give rise to hesitation. This hesitation stems from the fear of reopening old wounds or being negatively affected by the stories of other participants. The competence of recruiters and the established trust relationship with healthcare providers involved in the research enhance the willingness to participate. In some instances, the reluctance to participate is not a matter of unwillingness but rather a practical impossibility. Finally, it was found that the willingness to participate is also associated with the study design, as it can either promote or hinder willingness.

Comparison with existing literature

These findings are in line with other studies, as others have reported [4,6,7] uncertain consequences of stopping, fear of relapse, and reliving the past are impeding factors related to the willingness to discontinue antidepressants. The unwillingness to participate due to the nature of the depressive symptoms was also mentioned in the literature[9]. Yet, these findings are supplemented by the observation that the potential impact on mental well-being from

participation can be a reason for reluctance to engage in scientific research. As in a previous study[10], facilitators of willingness to participate in scientific research are found to be a personal benefit, and the desire to help others. This study has resulted in new insights concerning the influence of study design on the willingness of antidepressant users to participate in scientific research. Furthermore, is has highlighted the role that the taboo surrounding antidepressant use plays in the considerations of AD users. In addition to the patient perspective, the viewpoint of research assistants has also been incorporated into this study.

Strengths and limitations

Little previous research has been conducted to explore the willingness of antidepressant users to participate in scientific research. This study has illuminated both patient perspectives and experiences of research assistants, thereby facilitating the exploration of factors from different sources. This study provides novel insights into this relatively unexplored area. As a limitation, not all research assistants of studies A and B have diligently documented the rationales for (non)-participation, resulting in an incomplete data set. The sample of focus group participants was limited to one local pharmacy and only one focus group was held with four participants, making the sample size small. As a result, the findings might not accurately represent the perspectives of the full range of antidepressant users (selection bias). Furthermore, individuals who choose not to participate cannot be questioned. Attempts have been made to address this by including enrollment data and conducting interviews with research assistants. Focus group participants may be inclined to provide socially desirable answers as opposed to what they truly feel. To minimize this interrogation bias only open-ended questions were posed and efforts have been made to establish a trusting relationship with the participants.

Implications for practice

The findings of this study can assist other researchers in recruiting participants for research involving antidepressant users. A primary consideration lies in the awareness of the fears that may be present among antidepressant users regarding their involvement in scientific research. By appointing competent recruiters who empathize with the challenges faced by antidepressant users, these fears can be addressed promptly. Additionally, it is advisable to recruit participants through healthcare providers with whom they have a trustful relationship, creating a secure environment for potential participants. Cold calling poses the risk of approaching individuals who, due to their mental condition, may not be able to participate; the right timing of the approach proves essential for willingness to participate. It is also recommended to find people where they are, meaning that the communication medium – whether through phone or face-to-face interaction- during the research should depend on the participant's preference. Lastly, offering a safety net during the study and indicating this beforehand is beneficial. Providing access to a professional contact person when the participant experiences difficulties with their mental health during the study, can foster a secure environment. In future studies, an expansion of the focus groups may be considered to encompass a broader range of opinions. Additionally, exploring factors associated with participant adherence during antidepressant-related studies could provide valuable insights to further enhance studies involving antidepressant users.

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SUPPLEMENTARY APPENDIX

Appendix A: Semi-Structured Interview Guide Study A

Sectie 1: Onderzoeker

Vraag 1: Is study A het eerste onderzoek waar je voor belt?

Vraag 2: Hoelang bel je al voor study A?

Vraag 3: Heb je eerdere ervaringen met het includeren van patiënten voor onderzoek?

zo ja: wat zijn die ervaringen

Achtergrond / training

Sectie 2: huisarts vs apotheker

Vraag 6: Hoe ziet de werving eruit?

Vraag 7:Wat is het verschil tussen individuen die door de apotheek zijn aangedragen en individuen die via hun huisarts zijn aangedragen.

Screening fase

Sectie 3: factoren voor

Vraag 8: Welke argumenten om deel te nemen worden genoemd?

- Afhankelijk van het antwoord kun je doorvragen en om meer informatie vragen.

Sectie 4: factoren tegen

Vraag 9: Welke argumenten om niet deel te nemen worden genoemd?

- Afhankelijk van het antwoord kun je doorvragen en om meer informatie vragen.

Vraag 10:In het logboek wordt gesproken over psychisch niet stabiel als reden om niet deel te nemen, wat wordt hiermee bedoeld?

- Wie stelt vast dat potentiële deelnemer niet psychisch stabiel is.

Vraag 11: Wat vertellen mensen over eerdere stoppogingen?

Vraag 12: Welke angsten worden uitgesproken?

Sectie 5 : Informatievoorziening

Vraag 13: Hoeveel informatie geef je en wanneer besluit je meer informatie te

Appendix B: Semi-Structured Interview Guide Study B

Sectie 1: Onderzoeker

Vraag 1: Is study B het eerste onderzoek waar u voor belt?

Vraag 2: Hoelang belt u al voor study B?

Vraag 3: Hebt u eerdere ervaringen met het includeren van patiënten voor onderzoek?

zo ja: wat zijn die ervaringen

Sectie 2: Verschil huisarts en apotheker

Vraag 4: Hoe ziet de werving eruit?

Vraag 5: Merkt u verschil tussen individuen die door de apotheek zijn aangedragen en individuen die via hun huisarts zijn aangedragen.

Sectie 3: redenen voor

Vraag 6: Welke argumenten om deel te nemen worden genoemd?

Afhankelijk van het antwoord kun je doorvragen en om meer informatie vragen.

Sectie 4: redenen tegen

Vraag 7: Welke argumenten om niet deel te nemen worden genoemd?

Afhankelijk van het antwoord kun je doorvragen en om meer informatie vragen.

Vraag 10: Wat vertellen potentiële deelnemers over hun huidige mentale gezondheid?

Sectie 5 : Informatievoorziening

Vraag 11: Hoeveel informatie geef je en wanneer besluit je meer informatie te geven?

Vraag 12: Hoe denk je dat de informatie overkomt op potentiële deelnemers?

Vraag 13: Heb je in het verleden wijzigingen aangebracht in de inclusieprocedure op basis van feedback van deelnemers? Zo ja welke wijzigingen en wat was het resultaat.

Appendix C:

Casus 1:

Focusgroep: Eenmalig 1-2 uur praten met een groep mensen over een bepaald onderwerp

Casus 2:

Interview met antidepressiva gebruiker van 1 uur
Wat zijn perspectieven, overtuigingen, behoeften en wensen van patiënten ten aanzien van afbouwen?

Casus 3:

Monitor onderzoek
Hoelang duurt het voor iemand herstelt van een depressie?
Om de maand een online vragenlijst (10-30 min)
Eventueel telefonisch interview van ca. 15 min
Maximaal 24 maanden monitoren

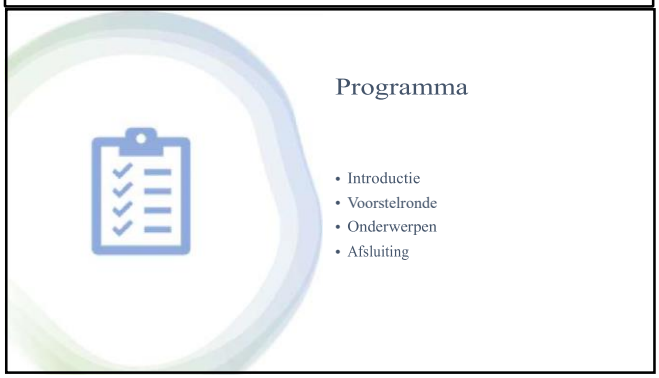
Casus 4:

Experiment naar afbouwen
Heeft de wijze van afbouwen invloed op het lange termijn beloop van depressie?
Willekeurige plaatsing in een van de twee onderzoeksgroepen
Groep 1 bouwt snel af
Groep 2 bouwt langzaam af
1x keer in de maand medicatie ophalen in een ziekenhuis
vragenlijsten + metingen bloedafname

Appendix D:


Radboudumc
Universiteit Utrecht
Focusgroep
Bereidheid deelname onderzoek


Welkom
Ervaringsdeskundigen!


Programma
Introductie
Voorstelronde
Onderwerpen
Afsluiting


Doel
Uw mening horen en nieuwe inzichten verkrijgen aangaande deelname aan wetenschappelijk onderzoek

Praktische gang van zaken

- Geïnformeerde toestemming
-

Voorstelronde

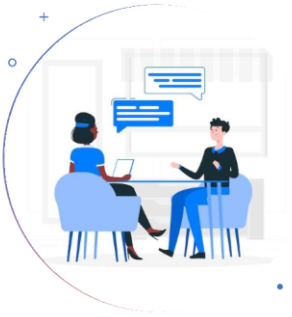
- Naam
- Motivatie deelname?
- Twijfels gehad over deelname?
- Wat zou je graag willen bereiken met deze deelname

Casussen

- 4 soorten onderzoek
- Zou u willen meedoen?
  - Waarom wel?
  - Waarom niet?

Casus 1

- Focusgroep
- Eenmalig 1-2 uur praten met een groep mensen over een bepaald onderwerp



Casus 2

- Interview met antidepressiva gebruiker van 1 uur
- Wat zijn perspectieven, overtuigingen, behoeften en wensen van patiënten ten aanzien van afbouwen.

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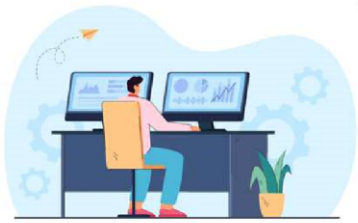
Casus 3

- Monitor onderzoek
- Hoelang duurt het voor iemand herstelt van een depressie?
- Om de maand een online vragenlijst (10-30 min)
- Eventueel telefonisch interview van ca. 15 min
- Maximaal 24 maanden monitoren



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Casus 4

- Experiment naar afbouwen
- Heeft de wijze van afbouwen invloed op het lange termijn beloop van depressie?
- Willekeurige plaatsing in een van de twee onderzoeksgroepen
  - Groep 1 bouwt snel af
  - Groep 2 bouwt langzaam af
- 1x keer in de maand medicatie ophalen in een ziekenhuis
  vragenlijsten + metingen bloedafname

Praktische overwegingen

- Hoeveel tijd bent u bereid te besteden aan een wetenschappelijk onderzoek
- Hoe ver bent u bereid te reizen voor een wetenschappelijk onderzoek?
- Geeft u de voorkeur aan fysieke contactmomenten of online bijeenkomsten?

Zorgverleners

Door wie zou u begeleid willen worden tijdens een onderzoek?

Hoe zou u benaderd willen worc voor een onderzoek?

15

Zijn er nog andere dingen die meespelen in uw keuze?

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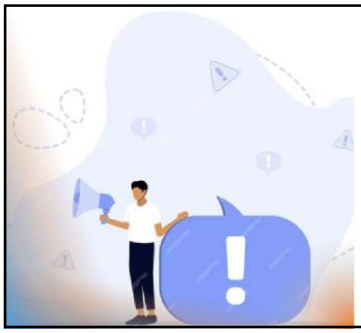

Wat was voor u het belangrijkste punt?

17

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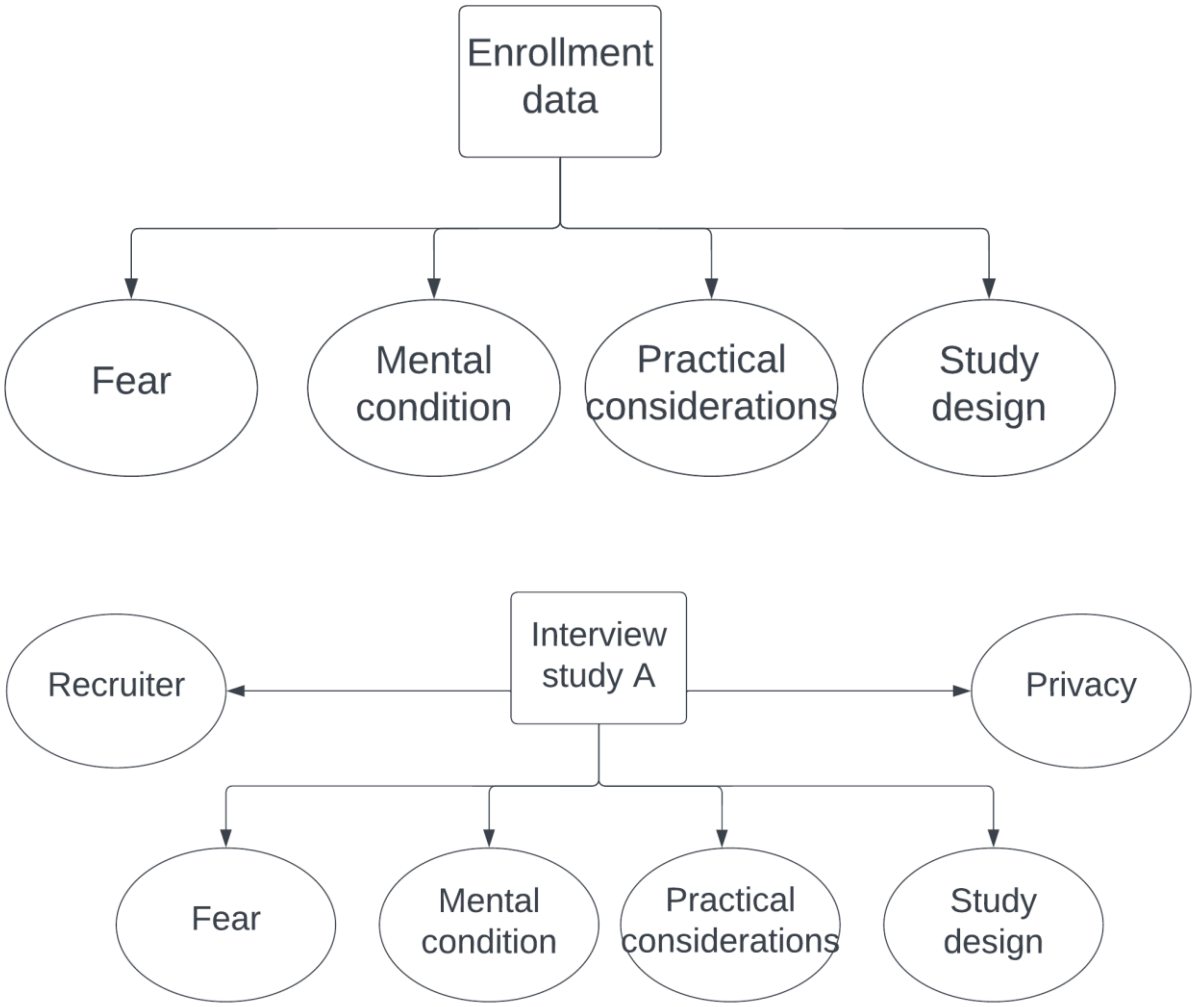
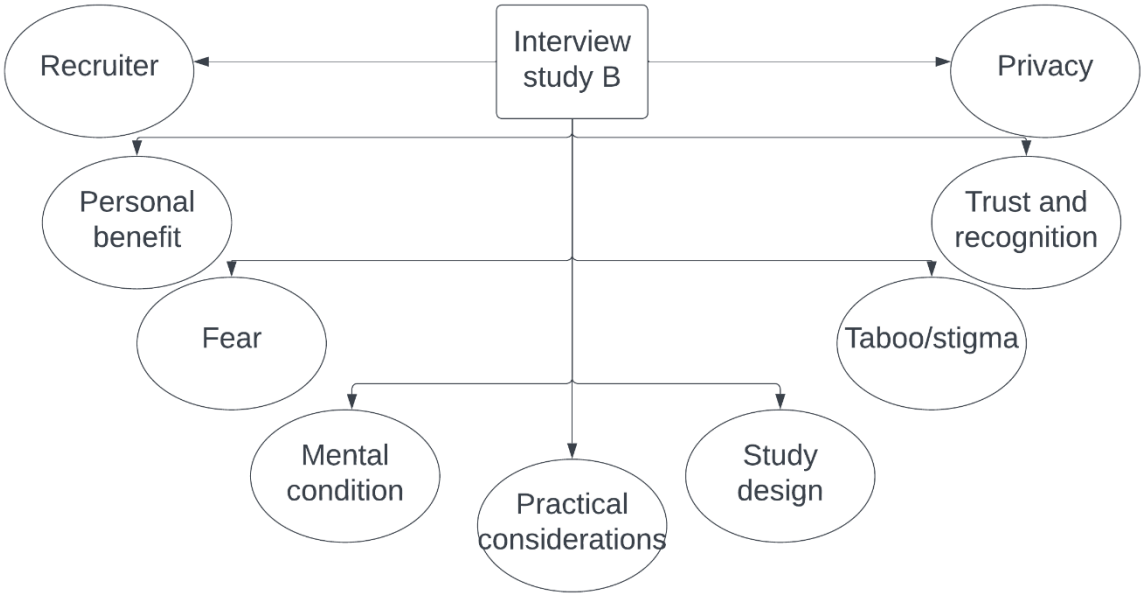
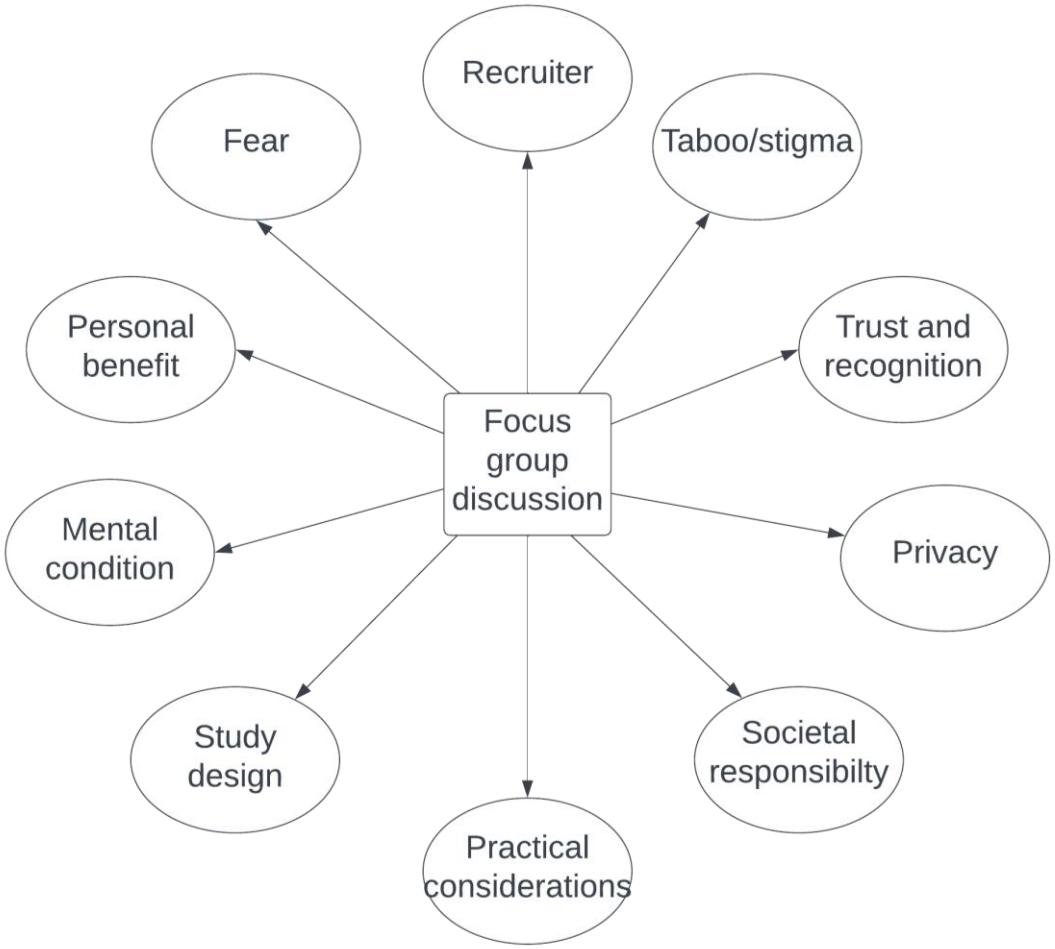
Appendix E: Data source for each theme




Interview study B
Recruiter
Privacy
Personal benefit
Trust and recognition
Fear
Taboo/stigma
Mental condition
Practical considerations
Study design


Focus group discussion
Recruiter
Fear
Taboo/stigma
Personal benefit
Trust and recognition
Mental condition
Privacy
Study design
Societal responsibilty
Practical considerations