

Disclosing the Undisclosed? Perceptions of Dutch Higher Education Students on Disclosing their Disabilities

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Abstract

Research has shown that students with disabilities who do use accommodations are more successful in terms of final degree classification compared to those who do not. However, in Dutch universities, access to accommodations must be requested at different levels, meaning that disclosure of ones' disability is inevitable. The official numbers of Dutch students with disabilities registered differ greatly from self-stated numbers (9.4% vs 30%) (Steenkamp, 2015; Van den Broek et al., 2013). This implies that not all students disclose their disabilities at university. Little is known about how and why students choose (not) to disclose their disabilities. This paper describes the results of a qualitative cross-disability study regarding the disclosure strategies of students in higher education by reporting how Dutch university students deal with the disclosure of their disabilities to the university, teachers, and fellow students.

Keywords: university students, disability, disclosure, perceptions

Over the last decade, the number of students with disabilities entering higher education in Western society is increasing (Gil, 2007; Hong, 2015). In the Netherlands, although the numbers are increasing, they are still relatively low. According to official statistics, in 2010 6.5% of full-time students in both higher vocational and university education had a disability, and in 2015 this number had increased to 9.4% (Steenkamp, 2015). The self-stated numbers are higher. In 2015 30% of students in higher education self-stated that they have some form of disability, of whom 10% said they experienced challenges or barriers related to their disabilities that affect their ability to study (Van den Broek, Muskens, & Winkels, 2013).

In order to reduce the potentially negative effects of the barriers, the international community has introduced legislative interventions, including the United Nations Convention on the Rights of Persons with a Disability (UN CRPD, United Nations, 2006). In July 2016, the Netherlands ratified the UN CRPD, meaning that Dutch higher education institutions are expected to take active steps to support inclusive higher education. Up to a certain level, the Dutch government tries to facilitate students with disabilities to study by giving them the possibility of requesting

special funding to compensate for any study delay.

The increased numbers of students with disabilities accessing university have an impact on institutional support services, and support structures. Williams et al. (2017) have reviewed the models of support of disabled students in higher education in the UK. This study shows the trend towards more in-house support, meaning that the support staff is directly employed by the higher education institute, provided through a combination of central support and faculty level services focusing on academic concerns.

Although the institutions' support system seems to be shifting towards a more social model of disability (where it is the society that disables individuals), many current funding systems still emphasise on an individual (medical) model, requiring individual disclosure to secure financial funding (Williams et al., 2017). A recent Dutch national survey shows that support funding is rarely used by students with disabilities in the Netherlands (Inspectie van het Onderwijs, 2018). Indeed, research shows a vast gap between the broad perspective of possibilities created by national legislation and the actual support given by higher education institutions to students with disabilities (Lane, 2017). At the same time, research has shown

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that students with disabilities who do use accommodations are more successful in obtaining their degree than those who do not (Denhart, 2008; Dryer et al., 2016; Getzel & Thoma, 2008; Grimes et al., 2017).

Not only when applying for national funding, but also when applying for in-house support at universities, self-disclosure is requested for accommodations. As in many university systems, in the Netherlands students with disabilities must request access to accommodations at the student office of the university. This demands disclosure of their disabilities, often accompanied by specific levels of proof of the disabilities. This proof can be difficult, costly, and time-consuming to obtain – and sometimes it needs to be done multiple times. Once the students receive accommodations through the university, they often again are required to reveal their disabilities to individual teachers as well.

When looking at the numbers, research shows particular increases in the proportion of individuals with mental health conditions and specific learning difficulties (Centrum Hoger Onderwijs Informatie [CHOI], 2018; Williams et al., 2017). In the Netherlands, 35% of the university students with disabilities report mental health problems, compared to 5% students with physical problems (CHOI, 2018). The extent to which an individual can hide their disabilities plays a pivotal role in the disclosure process. Students with invisible disabilities have to actively decide whether to disclose their disabilities, when, to whom and to which extent (Norstedt, 2019). Having to actively decide about disclosure often brings along multiple dilemmas for the person concerned. Not disclosing one's disabilities and thereby choosing for the strategy of passing as "normal" (Goffman, 1986) can evoke negative emotions and feelings of shame for misrecognizing who one is and can as a result cause feelings of "internal dissonance" (Samuels, 2003, p. 239). Disclosing, on the other hand, can cause barriers such as being granted less opportunities or in general being treated differently (e.g., by students and staff), being stigmatized or discriminated (Åsbring & Närvänen, 2002; Norstedt, 2019).

Recently, some studies have looked into the reasons for students to choose (non-)disclosure to the higher education institute (Cole & Cawthon, 2018; Grimes et al., 2018). Although these insights are relevant, it remains unclear how and why students choose to disclose to specific individuals, such as teachers or fellow students. In addition, most former studies focused on specific groups of students, such as students with mental health problems or learning disabilities (Cole & Cawthon, 2018; Lightner et al., 2012; Martin, 2010; Roth et al., 2018), whereas in this study

a cross-disability perspective is used. An overview of disclosure strategies of students in higher education is, to our knowledge, still lacking. Therefore, the aim of this article is to give insight into how and why Dutch university students deal with the disclosure of their disabilities to university, teachers, and fellow students. Better understanding of the reasons for students to either disclose or not disclose their disabilities to different parties has the potential to improve support mechanisms for students with disabilities.

Methods

Design

The general aim of the study was to investigate experiences of students with disabilities during their studies at the VU University Amsterdam, in which disclosure was one subject. A qualitative research design was chosen (Guba & Lincoln, 1989). As a qualitative research instrument, semi-structured interviews were chosen, as these are preferred for gaining an understanding of personal experiences (Lincoln et al., 1985). Content analysis was used to explore the data (Elo & Kyngäs, 2008; Kvale, 1996).

Data Collection

Purposive sampling was used to capture diversity in respondent characteristics. Characteristics such as gender, field of study, academic year, and type of disability were taken into account during the recruitment process. A call for respondents was spread through leaflets provided to different departments and via an online student platform. In addition, snowball sampling was used after each interview, by asking respondents if they knew any other students who could be approached.

During the interviews with students at VU University Amsterdam, a topic guide was used. This guide was developed based on relevant literature about barriers experienced by Dutch higher education students with disabilities (e.g., Steenkamp, 2017; Van den Broek et al., 2015). Afterwards, topics were discussed with experts from www.ervaringswijzer.nl, a platform where people with disabilities exchange experiences of living with their disabilities. The guide contained topics that covered themes about how nondisclosure played a role in students' study experiences, any problems they encountered, how the university, the teaching staff such as lecturers, mentors and teachers, and fellow students handled these problems, and their expectations concerning support of these three groups. In consultation with the respondents, interviews took place at the university. All interviews were held face-to-face and were carried out

by students of the VU University Amsterdam. Prior to data collection the students followed a training on how to conduct qualitative interviews.

After respondents' permission, interviews were audio-recorded and transcribed verbatim. The interviews were conducted between November 2014 and April 2015, and lasted 45 minutes on average. All respondents took part voluntarily. Confidentiality was maintained through restricted access to the data, destruction of the audio files following transcription, and decoupling the transcripts from identifying information.

Respondents

Sixteen students, nine females and seven males, ranging from 19 to 26 years of age agreed to participate in the study. Respondents were studying in different faculties (i.e., Faculty of Science, Medical Faculty, Faculty of Law, Faculty of Behavioural and Movement Sciences, Faculty of Social Sciences, and Faculty of Economics and Business Administration). Students were diagnosed prior to their enrollment at VU University Amsterdam with physical, mental health problems and/or learning disabilities. Diagnoses varied widely, and included Multiple Sclerosis, Crohn's disease, Delayed Sleep-Phase Syndrome, dyslexia, depression, and obsessive-compulsive disorder (Table 1). Following the UN CRPD, a cross-disability approach was chosen deliberately, meaning that respondents were not grouped based on diagnosis, but on shared experiences. This decreases the risk of stigmatisation (as it does not focus on specific illness characteristics) and increases insights into the common elements of different diseases or disorders (Hoppe et al., 2011). Most respondents had experienced disability-related symptoms during the period when the interview was conducted. Several respondents were behind in their studies, while others were still on schedule. It should be noted that all respondents had non-visible disabilities, meaning that they to actively choose to either disclose or not. Their considerations will be discussed in the results.

Data Management and Analysis

During an initial process of inductive open coding of the wide-ranging interviews, in which the first and second author went through the data in detail to identify all the themes that could characterize what is being said. We looked for in vivo categories used by participants themselves to describe the world. In this first open coding different themes were identified. These were for example themes regarding choices of going to university, expectations students had towards themselves and the university and experienced

societal expectations. Also the theme of disclosure was identified as an important theme, as this played a role in many aspects of the respondents' experiences. Based on this first open coding, the decision was made to focus the further analysis on the theme of disclosure. Following the thematic coding process (Green & Thorogood, 2018), all interviews were then again thoroughly read. Afterwards, interviews were coded, resulting in a coding scheme with themes and sub-themes. In this phase, deliberation about codes by the first two authors took place to improve confirmability of the findings (Frambach, Van der Vleuten, Durning, 2013). In the last coding phase, codes and themes were organized and structured. After finishing the coding process, corresponding quotes were compared, and the most suitable were selected for the final report.

Results

In this section, an overview of the findings is given. First is described how students with disabilities consider disclosure to fellow students, then to teachers, and finally considerations regarding disclosure to the university are given.

In general, the analysis showed that students considered disclosure at different moments showing that disclosure is no static or singular event, but rather something that has to be handled on a daily basis (Samuels, 2003). Overall, two moments can be distinguished; the first is during enrollment, when the university asks new students to fill out forms that include questions about special needs or disabilities. This specifically involves disclosure to the university. Disclosure to individuals (teachers of specific courses and fellow students) finds place during the academic year. This shows that disclosure to the university happens at a different time and in a different manner than to individuals. The respondents made different considerations regarding their disclosure which will be discussed hereafter, but for all it was something they explicitly thought about: "I think sometimes it is hard to disclose. It took me half a year before I even mentioned it [the disability] at all" (Respondent 1, multiple sclerosis).

Disclosure to the University

In general, most disclosing students informed the university about their disabilities right at the start of their education, by filling in a general university form that is sent to all students and includes questions related to special needs. The main reason for respondents to disclose to the university was a desire for information and advice, but they also saw it as a precaution in case something went wrong

during their study due to their disabilities.

At the start of my study I told the study advisor about my disability. Not because I was suffering at that time, but just in case if something should happen, they are already aware and they are able to help as good as possible. (Respondent 4, complex regional pain syndrome, imbalance problem, hyperacusis)

Respondents hoped that the university would take their disabilities into account and help them with adjustments if needed. Some students hoped the university would take initiative upon their disclosure of their disabilities. They pointed out that expecting them to request support themselves creates a high threshold. They also did not expect having to discuss their disabilities time and time again.

I think that the student advisor should contact the students that have given notice of their disability. Then it also seems he or she is interested, and I think that will be better than the other way around...If you don't like to talk about it, I think you wouldn't easily send an e-mail or make an appointment. (Respondent 13, eating disorder)

A couple of respondents decided not to disclose their disabilities at all upon enrollment. They felt that nobody would take their needs into account, and therefore disclosure would not be beneficial. The fact that the university is a large institute where people are not known individually also seems to play a part in the decisions of some respondents not to disclose.

I already had in mind that the chance [of doing an exam verbally] is zero [laughing]. So, with this idea I thought "whatever," I am going to do it just like I always did, which means I have to study more than two hours every day. That is how I dealt with it. . . . The dean is not interested in individual students anyway. (Respondent 10, dyslexia)

Disclosure to Fellow Students

The context of the university, and especially the way in which classes are organised, had an impact on the disclosure strategy of respondents. In Dutch universities, students often change classes and classmates per course, meaning that they do not work with the same group of students over a longer period. This creates a higher barrier for students as they consider disclosing their disabilities, as they know they will have to do so again in every new course. Due to the changing composition of the classes, students seemed

to feel less part of a group, and they expected other students to not have too much interest in them either: "Because I am always with different people, I do not know them very well. That is why I do not tell them I have autism. It is no use to them anyway" (Respondent 12, autism).

Some respondents chose not to be open about their situation, even when they needed to explain their absence. This seemed to be more often the case for respondents with non-physical barriers. The barrier to being open about their situation was experienced as higher by students with mental health and learning disabilities.

When my situation became worse and I was absent, I always said that I was just ill and then I did my share [of the assignment] just another time. I do not think my fellow students really need to know what disorders or diseases I have. (Respondent 13, eating disorder)

On the other hand, there were also respondents who explained that they chose to be open about their situation. Sometimes they did not give a lot of detail about their condition, but they decided to provide enough information so that fellow students understood the situation and could act upon it. This was especially the case for respondents who needed help from fellow students because of their disabilities. In these situations, it is considered that non-disclosure can create risks if an emergency situation occurs and bystanders are unaware of the practical or medical measures that must be taken. Disclosing necessary information to avoid risks is a common strategy in these situations (Charmaz, 2010; Norstedt, 2019).

I did not inform them [students] about CRPS [Complex Regional Pain Syndrome]. However, I did tell them about the hyperacusis and the imbalance problem. I briefly explained what it is and that it is possible that I get ill unexpectedly. And because we also have practical courses, also in a research lab, I told my study partner and teacher just what to do or what not to do in case of an attack. So everybody is a bit prepared of what can happen. (Respondent 4, complex regional pain syndrome, imbalance problem, hyperacusis)

In general, the respondents who disclosed to fellow students chose to be open about their disabilities to only a small group of students, often those with whom they worked on assignments. One of the respondents explained that by being open about her situation, she hoped to get some support from fellow

students during assignments, and also to deal with the possibility that her health could get worse.

I let them [students she works with on an assignment] know that I hope they will take this [the disability] into account. And explain to them that when I'm in the hospital, that I appreciate them to come visit me or something. (Respondent 5, cystic fibrosis)

One respondent seemed to have a more idealistic reason for her disclosure. She hoped that by being open about her disability, it would create more understanding, and taboos might be broken. This respondent chose to be open about her disability and explain aspects of the disability to fellow students. She felt this could lead to more acceptance and respect. "Above all I would say, talk about it! It is not something weird and it only helps if you talk about it" (Respondent 16, obsessive-compulsive disorder).

Overall, the respondents showed to be hesitant in disclosing their disabilities to fellow students, mainly due to the regularly changing class composition.

Disclosure to Teachers

The results show that the respondents have different reasons to disclose their disabilities to mentors and teachers, compared to fellow students. The main reason to voluntarily disclose their disabilities was because they hope to receive some understanding of their situation. "I told my mentor in advance, like okay, I have Asperger's. Merely so he can keep this in mind for evaluations or gradings" (Respondent 9, Asperger syndrome).

I also always inform the teacher, because we have obligatory meetings and the chances are high that I'll miss one, and I do not think it would be fair if they would decline further participation in the course because of that. (Respondent 5, cystic fibrosis)

Until recently, it was necessary for students to report their disabilities to every course coordinator, as the system did not automatically inform the coordinators about the special needs of the students. This was experienced as very frustrating by the respondents, because it also meant that they sometimes were obliged to disclose their disabilities in front of fellow students.

I indicated my anxiety disorder at enrollment, so I do not understand at all why I have to explain it again and again in each course, and that they are not able to connect this to my student number. In

this way anyone would be able to see that I have this when they check my number. (Respondent 14, anxiety disorder)

However, for a variety of reasons, most respondents chose not to inform their teachers about their disabilities. First, they felt that telling about their disabilities would probably lead to people treating them differently, either by feeling sorry for them or by stigmatizing them.

Yes, indeed that is weird, I just do not want to give in and I do not want to be treated differently. That is also the reason why I have not chosen to make exams in separate rooms. Because, you know, you just want to be normal. (Respondent 3, attention deficit hyperactivity disorder)

On the one hand, you explain to people that you have a quite serious disease, and that it also has many implications for what you can and cannot do and that you often are in the hospital and things like that. But on the other hand, I have never wanted to be treated as the "sick girl." (Respondent 5, cystic fibrosis)

Second, respondents seemed to use their time at university as a foretaste of their later work life, and in a way compared their relationship with their teachers with that of an employer. Students with different kind of disabilities said they did not expect their future employer to take their needs into account. They follow the same strategy as many employed people with invisible disabilities (Norstedt, 2019) and try to pass as "normal" (Goffman, 1986). They felt that others see their disabilities as something negative, which they therefore try to hide. "The thing is that you don't want people, in the future in the work field, to know this of you because it is a weakness. Yes, yes it's a weakness" (Respondent 10, dyslexia).

Then I decided for myself, well okay, I could go to people and ask for help, but I cannot do that forever and so I will have to manage things myself. So in fact that is what I am going to do. (Respondent 9, Asperger syndrome)

Discussion

This paper has given insight into how university students deal with the disclosure of their disabilities to the university, teachers, and fellow students. Findings from this study suggest that, although it is not

always a choice to keep one's disabilities a secret, most respondents seemed reluctant about being open about their disabilities. If they choose to be open, they seemed to carefully weigh to whom, when and to what extent they wanted or needed to disclose. An overview of how and why students do not disclose is given in figure 1. The aspects taken into account when deciding about disclosure are similar between students that disclose and students that do not disclose. The same downsides and benefits are mentioned by both groups; however, individuals weigh the benefits differently, resulting in different outcomes.

The results show that disclosure is experienced as a difficult process, where costs (e.g., stigmatization) and benefits (e.g., getting the needed accommodations) are constantly balanced. Accommodations offered by the university after disclosure should lead to inclusion of students with disabilities, but effects of stigma and labelling can work against this (Roe et al., 2010). The use of labels for disabled people is very much linked with the debate surrounding power. Due to what Foucault (1985) called biopower, individuals desire to live up to the norms of normality. This power exists "everywhere" and is constantly exercised by the state through the systemic application of law, policy, and administration (Ostiguy, 2018). The fact that the Dutch universities require students seeking accommodation due to their disabilities to engage prescribed policies and procedures for their request, is one such example. In a more subtle way, this power leads to restricted choices of the students with disabilities (Harvey, 2018), for example where students feel that some courses (e.g., ones with multiple written exams) are not the right choice for them (e.g., for students with dyslexia).

Apart from these power-structures on a societal level, the effects of stigma and labelling also play a role on a micro level, namely in the interaction between individuals. Looking at the interactions between students with disabilities and their fellow students or teachers, can give insight into how stigmatized identities are created (Åsbring & Näräven, 2002). It relates to the meaning of having a disability, which is a symbolic meaning, that is constantly modified through experience (Blumer, 1969). The fact that students in our study express their disabilities as "a weakness" is a result of interactions with people. The meaning of disclosure therefore not only depends on hierarchical arrangements and specific policies, but also on the social values and norms that are experienced in individual interactions with others (Charmaz, 2010).

As discussed above, disclosing ones' disability inevitably means getting a label. Although labels have impact on people's identities, they should not

be seen as essentialist entities. They can be handled in very different ways. Our results show that nondisclosure is an active process, which gives insights into the active role that students with disabilities can play when dealing with their label. They can be very open (even taking an activist role) or they can hide their label. What choices are made can differ over time or in different contexts (Åsbring & Näräven, 2002). This implies that there is as certain fluidity of identity, instead of essentialist ideas about what it means to have a label (Braidotti, 1994). One should be very careful not to treat people with a label as victims of their label, as this reinforces stigmatization.

Strengths and Weaknesses

All interviews were conducted by relatively inexperienced interviewers. This may have affected the quality of the interviews. In order to increase the quality of the interviews, the topic lists were thoroughly viewed by senior researchers.

All of the respondents were students at VU University Amsterdam. The diversity of degree programmes and diagnoses among the respondents was high, but research at another university might uncover different characteristics and results. For example, for someone with agoraphobia, the choice to study at the Open University, which provides education through online distance learning, implies a different starting-point and situation than the choice of studying at a traditional campus-based university like VU University Amsterdam. There could be something specific to the Dutch education system, students' expectations of a top science university, or to the reputation or actual practices of the VU University Amsterdam regarding disability support or accommodations, that could skew respondents' choices, but did not show up in this study.

Recommendations

The fact that access to services in Dutch universities is gained through the use of labels, creates a dualism between ability and disability (Harpur, 2012), between disabled students and their non-disabled peers (Harvey, 2018). Harvey (2018) suggested that "perhaps it would be better to reconceptualise higher education as a space where 'the student' is classified as the heterogeneous entity" (p. 108). By following this suggestion, labels such as "disabled student" or "student with special needs" would become unnecessary.

This principle of seeing society and more specifically students in a heterogeneous manner, is much in line with the principles of the Universal Design of Learning (UDL; Rose & Meyer, 2006). UDL stands

at the forefront of contemporary efforts to create universal access to educational curricula for all students, including those with disabilities. Flexible schedules, full (online) accessibility to study materials (multiple means of representation), providing information in different types of meetings (multiple means of engagement), different types of examinations (multiple means of expressing knowledge) are just some simple examples (Rose et al., 2006). Although the philosophy of UDL is upcoming in the Netherlands, inclusive universities do not yet exist (CHOI, 2018). At this point the VU University Amsterdam scores second to last of all Dutch universities if it comes to supporting students with a disability. This made this university especially interesting for this study. However, research on a broader group of students, from different universities is recommended. This could give insight, not only in why and how students disclose, but also in aspects that were helpful in this process.

In this study, only the perspectives of students were taken into account. Future research could also focus on the perspective of service providers, teachers and fellow students, in order to gain a broader view.

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As a guest researcher, Florence van Mierlo is related to Disability Studies in Nederland. She received her BA degree in educational sciences which she completed at the VU University Amsterdam. Her research interests lies in human behavior in challenging situations.

Geert Van Hove, professor in Disability Studies at Ghent University in Belgium, organizes her research projects as close as possible to those who have lived experiences about the topic studied.

Alice Schippers, Ph.D., worked for twenty years in policy, management, research and higher education in the disabilities field. She holds a coordinating senior research position at the Disability Studies unit of the Medical Humanities department of the Amsterdam UMC. Her interests are on (family) quality of life, inclusion, and collaborative research.

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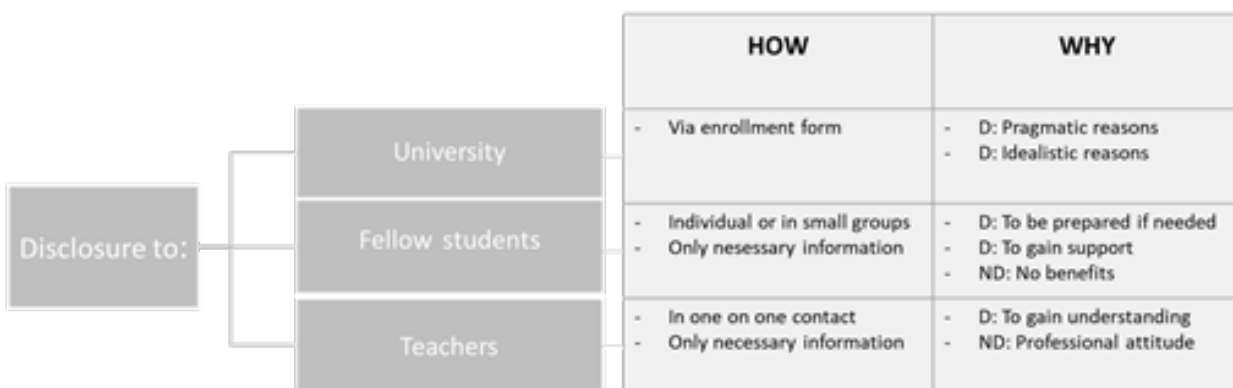
Table 1

Respondent Characteristics

Respondent	Gender	Study	Disability
1	Female	Psychology	Multiple sclerosis
2	Male	Psychology	Fibromyalgia
3	Female	Cultural Management and Organization	Attention deficit hyperactivity disorder
4	Female	Biomolecular Sciences	Complex regional pain syndrome, imbalance problem, hyperacusis
5	Female	Psychology, Law	Cystic fibrosis
6	Male	Criminology	Crohn's disease
7	Female	Medical sciences	Delayed sleep-phase syndrome
8	Male	Biomedical sciences	Crohn's disease
9	Male	Biology	Asperger syndrome
10	Male	Psychology	Dyslexia
11	Male	Computer Science	Attention deficit hyperactivity disorder
12	Male	Physics, Astronomy	Autism
13	Female	Business Economics	Eating disorder
14	Female	Anthropology	Anxiety disorder
15	Female	Earth science	Depression, anxiety disorder
16	Female	Medical sciences	Obsessive-compulsive disorder

Figure 1

Overview of Results



Note. D stands for disclosure and ND for non-disclosure.