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„How research comes to matter. Looking at perceptions of research, research effects, and engagement with research in the case of asexuality."

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Contents

1. Introduction

In the last few decades many sexual and gender identities have emerged, which can be seen in the growing acronym which encompasses these groups – LGBT+ and LGBTQIA being two common variants. Asexuality is one such emerging sexual orientation, that has only recently been recognized as a sexual identity in its own right. Even concerning the afore mentioned acronym there are still diverging opinions on whether the A stands for asexuality or for allies.[1] Asexuality is most often defined as encompassing people who do not (or rarely) experience sexual attraction (The Asexual Visibility & Education Network, 2001-2012a). Related to this exists aromanticism, which is defined respectively as experiencing little or no romantic attraction towards other people. Both orientations exist on separate spectra, which feature several sub-categories. People may for example identify as either asexual, grey-asexual, and/or aromantic, demiromantic, or any of the other subcategories that exist on the ace/aro-spectrum[2].

The emergence of asexuality is inherently linked to the affordances of the Internet and is most often traced back to AVEN (The Asexual Visibility & Education Network, 2001-2012a) - an Internet forum that has allowed for the formation of a community around this recent emergent sexual identity. In the interviews it will be shown that the main reason for this is, that finding other people identifying as asexual in real life is difficult, because there are not many and they are not easily identifiably by their looks or habits. Spaces for marginalized groups, be they united by a sexual orientation (Scherrer, 2008) or an emergent illness (Dumit, 2006), are often found on the Internet. Forums, blogs and message boards are spaces where communities are built and knowledge about them is produced. The Asexuality Visibility and Education Network (AVEN) is the most well-known virtual community for asexuals and offers them the language and the space to define their identity (Scherrer, 2008).

Asexuality, as all sexualities, is rooted in its cultural and historical context. While asexual practices have existed before, 'the asexual' as a kind of person did not exist. Science, asexually identified individuals, and media are equal contributors to what asexuality is today (Przybylo, 2015). Asexuality as a new sexual identity, that can be seen as still emerging and contested, is under constant negotiation (Scherrer, 2008). People identifying as asexual can be described as both 'objects' of scientific knowledge, and as consciously engaging with and challenging scientific research.

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[1] Due to the contested nature of asexuality as a valid sexual orientation, which is an often occurring factor in this thesis, I want to stress that asexuality and aromanticism are existing and valid identities, and treated as such in this research.

[2] Going forward, this thesis will most often use the term 'asexual' to refer to people identifying on the ace-spectrum. Neither my participants nor I were very consistent in our usage of terms, and due to the small sample size no differentiations in the data were looked at. Researching such differences could be an interesting question, but was not feasible in this case. In cases where asexuality subcategories or aromanticism was mentioned specifically in the interviews, it will be indicated as such.

One defining moment in the formation of asexuality was the case of Hypoactive Sexual Desire Disorder (HSDD) in the DSM (Diagnostic and Statistical Manual of Mental Disorders, published by the American Psychological Association). In 2008, when the DSM was undergoing another revision, people identifying as asexual criticized the section HSDD in DSM-IV, which can be read as stating that having no urge to have sex is a mental disorder (Hinderliter, 2009). While homosexuality already had quite a lobby at the time of making changes to the DSM, asexuality still struggled with visibility in society: “A number of us have been itching to challenge the APA on this for quite some time, but felt that we were too small, too little researched, too powerless to do anything” (Jay, 2008). There was not much scientific research on asexuality, a point on which the APA puts much weight when it comes to making changes. Therefore a task force within the asexual community was being established, research (in the form of interviews with people identifying as asexual) was carried out and the final project sent to the workgroup of the APA dealing with revising sexual dysfunctions. These efforts, starting with communicating the dissatisfaction with the DSM within the asexual community, and including the formation of a task force and bringing this issue to the attention of the American Psychological Association, were largely done via the Internet (Jay, 2008), which shows the role the Internet plays in the emergence of this identity. As a result of these actions, a sentence was included in the DSM-5 at the end of the sections on female and male sexual disorders, which reads for the female version (the male being along the same lines): “If a lifelong lack of sexual desire is better explained by one’s self-identification as ‘asexual’, then a diagnosis of female sexual interest/arousal disorder would not be made” (American Psychiatric Association, 2013, p. 434).

Since then a growing interest from both media and academia can be observed and there have been several studies from different academic fields on the subject of asexuality. And even though there have not been any major disagreements between academia and the asexual community since the DSM was successfully changed, there can still be various forms of engagement with academic research on asexuality observed. Most academic work in STS about (patient) groups that studies the relations between scientists and non-scientists concerning the production and dissemination of knowledge, is situated in the biomedical realm – two examples being Epstein’s work on AIDS Activism (1996) and Callon and Rabeharisoa’s studies on AFM, a patient group organizing around muscular dystrophy (2003). Forgoing the complexities of these cases, a simple logic lies behind the engagement of these groups: find the cause, find the cure. In the case of the asexual community – where a firm distancing from pathology can be observed – there is still abundant engagement with academic research via practices such as research participation, reading research, showcasing of calls for research participation, as well as archiving and discussing of scientific studies.

What is the motivation for these engagements with science and academia in the absence of controversy and outside the medical realm?

This question sparked my interest in this case. Investigating this observation I start by taking a closer look at how asexuality has been studied in academia. This leads me to more traditional cases of engagement with research in science and technology studies, namely the afore mentioned patient groups. There have been many studies on how (patient) groups accept, contest, demand, or protest academic research, as well as various studies exploring reasons for research participation. These investigations are however overwhelmingly situated in the (bio)medical field – where the underlying goal is to find the cure (Epstein, 1996; Callon & Rabeharisoa, 2008) or increase willingness for research participation (Brewer et al., 2014). While also resulting from the study of a patient group, the concept of emergent concerned groups (Callon & Rabeharisoa, 2008) offers a way to look at practices of engagement with research and the role they play in the formation of collective identity. Asexuality too can be viewed as still emerging, which offers an interesting opportunity to study an emergent concerned group in its state of emergence. Callon and Rabeharisoa claim that "in order to understand how emergent concerned groups are sometimes capable of constructing stabilized identities, goals, interests, or preferences, it is necessary to examine all the investigations, inquiries, and research studies that these groups undertake to find solutions to the problems they face" (2008, p. 236). Which is what they have set out to do in their study of AFM, during which they have looked at numerous aspects of this group over the span of many years. This case too can be thought of as a science-society encounter - the specific science being academic research about asexuality and the specific society people who identify as asexual. But having slightly less time and manpower to investigate the asexual community and its relations to scientific knowledge, led me to look at a less all-encompassing aspect of this science/society-encounter:

How and when does academic research about asexuality come to matter to people identifying on the ace-spectrum?

The science studies view of public understanding of science argues that it is crucial to look at how publics make sense of and give meaning to science. Therefore the focus of this thesis will not be on observed practices, but rather on how people identifying as asexual make sense of academic research and engagement with it and think of it as relevant for establishing an identity for themselves and in society.

The research question can be divided into three sub-questions, which are informed by my state of the art and theoretical background. They can be seen on a generalized level as how people make sense of research, research impact, and engagement with research. The analysis is structured into three main chapters along the sub-questions, which also contain short sections that are more like a field description in character, in that they are of a more descriptive nature and draw on observations outside the interview data. These chapters help contextualize the rest of the analysis and the themes found therein.

1) How do people who identify on the asexual spectrum make sense of academic research on asexuality?

2) How are the possible effects of academic research and knowledge about asexuality and their realization conceptualized?

3) How are practices of engagement with said research perceived and rationalized?

2. State of the Art

This chapter starts with giving an overview of academic literature about asexuality, from the first interest in asexuality, which originated in the disciplines of psychology and sexology, to studies investigating the link between asexuality and classifications. In a next part, there will be examples of how communities and patient groups have been looked at in the field of science and technology studies. Concluding, there will be a brief discussion about research participation.

2.1. Studying asexuality

In the last decades a rising academic interest in the topic of asexuality can be observed, with most of the earlier research coming from the disciplines of psychology and sexology. In his work on the development of online English language asexual discourse, Hinderliter (2016) devotes a chapter to trace the origins of academic interest in asexuality. He sees the importance of looking at when and where scientific research about asexuality emerged in its entanglement with asexual communities. Before the year 2000 asexuality as a sexual orientation was only one way it was treated in scientific research, the others being as a pathology, as preferential celibacy, or as a throw-away category. To summarize Hinderliter's findings, "while the existence of people who, in current classifications would likely be considered asexual, has been recognized in sexological literature since at least the 19th century, extremely little research had been done" (p. 31) and almost none of it had asexuality as its main focus, but rather used findings concerning this as a byproduct. One such example for this line of enquiry into asexuality would be Kinsey's Group X. In 1948 the Heterosexual-Homosexual Rating Scale, commonly known as Kinsey Scale, was first published. Thousands of people were interviewed about their sexual histories, which showed that assigning people to just three categories – heterosexual, bisexual, homosexual – was not supported by the data. This resulted in the creation of a seven-point scale, which ranges from 0 to 6, and has an additional category X. This category was defined as "no socio-sexual contacts or reactions" (Kinsey Institute, 2018), having been read since as the first mention of asexuality. In cases such as this, asexuality is not the initial focus of the study, but rather an option on a survey that seems to be there for completeness sake - a residual category more so than a valid answer.

Bogaert's paper *Asexuality: prevalence and associated factors in a national probability sample*, which was published in 2004 was only the second academic work which featured asexuality as its main focus and features the finding that in a sample of the British population 1,05% of people claimed to have never felt sexual attraction for anyone at all. In the last 15 years, there has been rising academic interest in the topic of asexuality, with most of the research coming from the disciplines of psychology, gender studies, and social sciences (Hinderliter, 2016). More recently there has also been a rise in academic research that investigates asexuality as an identity. Cowan and LeBlanc (2018) for example look at the various subcategories of asexuality, and how the interplay of descriptions of feelings and the feelings themselves. Hinderliter attributes the rise in academic interest to “a combination of an increase in available research participants, and from increased social interest in asexuality, both resulting from the growth of online asexual communities and some individuals in those communities trying to promote asexual visibility” (p. 35).

Asexuality has also been looked at in connection to medical diagnoses – earlier research in the sense of looking at asexuality as a medical condition, and more recently research from the social science, which builds on the tradition of science and technology studies, showing classifications and standardizations as being simultaneously constructed by and constructing society (Bowker & Star, 1999). In a case study on ‘Female Hypoactive Sexual Desire Disorder’ (FHSDD) Jutel (2010) looks at how layers of social meaning may be concealed in a diagnosis. She does this by investigating the genesis and detection of FHSDD and its screening tools, the role definitions of normal sexuality play, and how different stakeholders, such as the pharmaceutical industry and the asexual community, come to matter. Jutel (2010) states that the diagnosis of FHSDD relies on the assumption that all humans experience sexual urges, in large part due to the theory of evolution, and that therefore their absence has to have a pathological condition at heart. In consequence, the discussion of asexuality is moved into the medical realm, medicine being “simultaneously the explanation and the discipliner” (Jutel, 2010, p. 1085). This is accomplished in part by establishing a diagnosis, but also upheld by epidemiological medical work, which sets its agenda as counting the incidence and prevalence of FHSDD as well as developing screening tools; all establishing FHSDD as a thing to be counted (Jutel, 2010). In case studies such as this, the question of what counts as a medical condition or disorder and how it can be identified mutually structure one another. Thus classifications and standardizations do not mirror the natural order, but are made and therefore deeply political (Bowker & Star, 1999). That classifications are made does not detract from their realness. They relate to the moral and social order of society and in consequence are having an influence on individuals. By assigning a classification, clinicians “trigger a range of actions and consequences […] linked to both therapeutical and social responses” (Jutel, 2011, p.189). Describing symptoms with a diagnosis validates the illness, warrants medical attention and a treatment, and gives the person the right to an identity as ‘being sick’. It puts a condition under medical authority, while at the same time legitimizing being different and defining normality. Going even further it has the power to discipline patients in their behavior, set research agendas and distribute resources (Jutel, 2011).

Stating that classifications do not simply reflect the natural order brings with it the assumption that the validity of a diagnosis can be contested. Such an instance can be found in the critique of the description of a psychological disorder in the Diagnostic Statistical Manual (DSM). People identifying as asexual have criticized the section on Hypoactive Sexual Desire Disorder (HSDD) in DSM-IV, which can be read as stating that having no urge to have sex is a mental disorder (Hinderliter, 2009). Asexuals however, define asexuality as a sexual orientation, encompassing people who do not (or rarely) experience sexual attraction (The Asexual Visibility & Education Network, 2001-2012a). A task force was established and successful in bringing about a change in the fifth edition of the DSM, stating that people who identified as asexual were exempt from being diagnosed as suffering from HSDD.

However, not all new categories and classifications have been imposed upon patients from doctors and practitioners. Many of these diagnoses have been promoted by individuals suffering from the symptoms described in them. Sometimes a classification is therefore not assigned from ‘above’, but “can be a kind of self-labeling that provides a new public identity as an individual having a particular illness or disorder” (Conrad, 2007, p. 46). A diagnosis can legitimate a problem, organize it, get understanding from outside and from the patient and achieve a better chance at treatment (Conrad, 2007). While Conrad does look at the case of homosexuality in a chapter of his book, he describes it as a rare instance of demedicalization and focuses on the efforts to get homosexuality removed from the Diagnostic and Statistical Manual (DSM) and therefore not seen as psychological disorder. As seen above, asexuality too has a history entangled with medical institutions, and being included in the DSM at one point (Scherrer, 2008). But in the same way that medical diagnoses have the power to define “what is ‘normal’, expected, and acceptable in life” (Conrad, 2007, p. 149) - sexual orientations can legitimate and validate a person’s way of life.

Mol and Law (2007) talk about diverging ways of knowing when it comes to the issue of classifications. On the one hand there is a way of knowing the body from the outside, which is objective, public and scientific. On the other hand, there is a way of knowing the body from the inside, which is described as being subjective, private and personal. This opens up the question of how different kinds of knowledges are treated in classificatory work and what expertise is. In the context of asexuality, Przybylo and Cooper (2014) take a slightly different approach and speak of two archives of asexuality, that inform each other, but also limit the understandings of what asexuality is. The ‘truth’ archive is seen to consist of scientific writing, while the ‘vernacular’ archive consists of community spaces and popular publications.

Showing the inherent politicalness and the embeddedness of the genesis of classificatory systems in the sociocultural principles and conventions of their time, we can see that asexuality, as all sexualities, also is rooted in its context - thus being culturally and historically contingent. While asexual practices have existed before, ‘the asexual’ as a kind of person did not exist. “Asexuality has not existed at any other time in Western history, not as ’asexuality’ per se. […] That it is here today is necessarily a crystallization of our specific here and now” (Przybylo, 2012, p. 225). Przybylo goes further into this and investigates in how far scientific writings are a base for such understandings and definitions:

> [A]sexuality, like most sexualities, is in significant and intricate ways carved into existence by science. This is not to say that science alone is inventing asexuality but that science, in collusion with other social forces, is defining what asexuality is and how it functions. (2012, p. 225)

Przybylo (2012) includes both asexually identified individuals and media as equal contributors to what asexuality is today. In her article she investigates the scientific mapping of asexuality and argues that “the scientific study of sex provides opportunities for asexual formation, identification, and action, but also functions to limit and restrict the shape that contemporary asexuality will acquire” (p. 239). Thus she makes a case for scrutinizing scientific research on asexuality. As asexuality is a new sexual identity that still lacks legitimization and can be seen as emerging and contested (Scherrer, 2008), what asexuality is, is under constant negotiation. People identifying as asexual can on the one hand be described as ‘objects’ of scientific knowledge, while another perspective shows the asexual community as consciously engaging with scientific research and challenging its practices.

This sub-chapter has sketched the academic interest in asexuality in the last decades, showing that asexuality is on the move from being seen as a pathology, to being recognized as a sexual orientation and identity by academia. Still, a closer look at how classifications and diagnoses have been looked at in science and technologies studies, has offered a few tentative parallels that show that further investigations into the relationship between academic research about asexuality and asexuality as an emerging sexual orientation, could be fruitful. The next chapter will therefore look more closely at communities and patient groups engaging with science and research.

2.2. Communities, groups, and patient organizations engaging with research

When speaking about lay participation the image conjured is often of a sole individual person. More typically lay participation is carried out by organized social collectives. Only when people grouped together by suffering from the same disease come together and act in concert, can they challenge medical authority effectively (Epstein, 2005). Effective participation, that is participation that has wished-for consequences, gets more likely “when groups build effective organizations, construct new collective identities, and promote groundswells of mobilization and collective action” (Epstein, 2005, p. 173). It can be argued that the formation of a collective and the challenging of or engaging with a scientific authority is happening simultaneously in most cases.

Looking at the history of patient organizations in most Western countries, it can be described by three main claims (Rabeharisoa, 2006). First, people with the same disease find each other, and become aware of their similarities and their shared collective identity. Second, the shared experiences central to this identity constitute a knowledge of their disease which is not found in scientific research, but which is essential to understanding and potentially improving their lives. Third, being afflicted by a disease is seen as giving a patient the legitimacy to engage in decision-making that concerns their situation. The interest in studying patient organizations often lies in the linkage of these claims, from the development of a shared identity and the production and mobilization of knowledge, to political action.

A prominent example is Steven Epstein’s (1996) *Impure Science*, in which he traces the history of how knowledge about AIDS has come to be known as true during major points of the debate. Epstein tells a story in which society (or rather a part of it) takes science to task - it is demanded that scientific knowledge should contribute to solving the societal crisis of AIDS. At first it is an antagonistic relationship, wherein the ongoing biomedical knowledge production and the imposition of categories and labels by an outside authority are criticized, but critique is soon replaced by engagement – opening the doors for a transdisciplinary collaboration, in which both scientists and laypeople are interested in solving this problem and resulting in change within both the social movement and the biomedical community, as well as their relationship. Most such examples about patient groups are clearly situated in the (bio)medical field, where a simple mission can be observed: find the cause, find the cure (see for example Epstein, 1996, p. 31). Additionally such case studies are often concerned with instances of ‘talking back’ to a scientific authority.

In the above chapter we have seen an emphasis on the role a collective cultural position plays in making sense of symptoms and bringing about a classification (see for example Jutel, 2010 and Hacking, 2006). But an important point to remember is that classifications do not emerge out of universal consent: “Each and every classification engages some social perspectives and shuts down others” (Jutel, 2011, p. 202). Classifications give voice to certain perspectives and silence others (Bowker & Star, 1999). These issues of exclusion are the subject of a strand of science and technology literature on the participation of minorities in medical research. One such example investigates ‘informed refusal’ - conceptualized as a corollary to informed consent - by looking at moments of refusal (Benjamin, 2016). These stories are about ‘biodefactors’, people or groups who “attempt to resist technoscientific conscription” (p. 2), and the consequences of opting out or not availing oneself of available biotechnologies. For example, identities diagnosed through genomics are resisted.

Refusal is not just about negating, but also about the potential to create new relationships between researchers, subjects, and the state. “An informed refusal, in other words, is seeded with a vision of what can and should be, and not only a critique of what is” (Benjamin, 2016, p. 4).

Similarly, Callon and Rabeharisoa (2003) open up an interesting point about accepting or refusing knowledge. In their story patients have the ability to opt out of research knowledge gained by genetics and the solidarity to other patients this would imply. It is therefore advisable to look at the act of accepting or refusing knowledge as a conscious one that is connected to perceived consequences and values behind the knowledge.

Going further, Callon and Rabeharisoa (2003) criticize the lack of interest from STS about the relations between scientists and non-scientists concerning the production and dissemination of knowledge. They investigate this ‘research in the wild’ in the case of the French Muscular Dystrophy Association, a patient organization, through a series of articles. Stating that in the AFM case, patients and spokespersons have on the one hand engaged in and promoted research in the wild, while at the same time supporting laboratory research, the aim is then not to put one above another, but to be aware of how both are necessary and contribute to the patients’ well-being. Callon and Rabeharisoa (2003) situate part of the necessity for research in the wild in the fact that the diseases of these patients have not been the focus of much medical and scientific attention, making it the patient’s responsibility to gather information on the diseases and accumulate knowledge. The feeling of being abandoned by scientific research(ers) therefore prompted this patient organization to do their own research – formalizing and publicizing knowledge. “Researchers in the wild are directly concerned with the knowledge they produce because they are both the objects and the subjects of their research” (Callon & Rabeharisoa, 2003, p. 202). A statement that mirrors Przybylo’s (2012) thoughts about asexuality in the forgoing section.

2.3. Motivations for research participation

As we have seen, most studies about communities and groups engaging with research, are situated in the (bio-)medical realm. Inherent in this research is the logic, that people afflicted by a disease are dependent on science for their survival. Being interested in the reasons for a close relationship with scientific research, I take a closer look at a few examples of academic literature on motivation for research participation, thus gaining an understanding of the underlying assumptions and aims for such research, but also at how this is studied and conceptualized.

In a quantitative study Brewer et al. (2014) looked at attitudes concerning participation in health-related research among professional African American women. In their questionnaires they measured the intention and willingness to participate in different hypothetical research studies (participants could for example rate study designs such as giving blood or interviews according to their willingness to participate), as well as asking about such things as the perception of individual risk and benefit of participation and trust in scientists. As an overall conclusion the study established that willingness for research participation was favorable in the group studied.

Research on such participation often deals with the factor of individual research results. Harris et al. (2012) studied how the return of individual research results (IRRs) figured into the perception of parents who had enrolled their children in a genomic repository. Doing focus groups with the parents it was found that the return of IRRs was almost unanimously wished for and connected to a possible individual benefit, while the mere participation was hoped for contributing to scientific knowledge, and therefore a common benefit.

McDonald, Kidney, and Patka (2013) conducted interviews and focus groups with people with intellectual and developmental disabilities, through which they investigated perspectives on participating in research, finding that “research is more likely to be both ethical and successful if researchers pay attention to enhancing autonomy and person-centredness, while at the same time engendering participant trust” (p. 216).

While these studies were very group-specific and therefore rather small-scale - measuring hundred participants at most - another part of the literature deals with proposed research in genetic medicine, which is dependent on a large number of participants, while also assumed to be seen as risky and encountered with apprehension. Here the quantitative surveys measure thousands of participants (see for example Kaufmann et al., 2008), putting much weight on controlling the results via confidence intervals and similar measures. These kinds of studies are conducted to specifically show that there is enough support in the general public for a certain kind of research and how to increase the motivation for participation.

The majority of academic literature on research participation seems to deal either with ethical considerations or present a quantitative study on the motivation for participation, most of the time concerning research related to health. In the latter we see a similarity to something discussed above, that the underlying aim of such research is improving willingness to participate by identifying factors that hinder or foster it. Research about motivations, perceived risks, and incentives has most often the goal to increase research participation. The argumentation works because of the underlying assumption that more research efforts lead to improved health. The motivations for research participation and how this participation is conceptualized by the people participating, is however not addressed.

Concerning the case of asexuality, I will therefore look at the relation between research, engagement with research, and a community, and ask:

How and when does academic research about asexuality come to matter to people identifying on the ace-spectrum?

3. Theory

In this chapter I will take a closer look at public understanding of science (PUS) and the concept of emergent concerned groups, to see what they can offer when used as a theoretical background. In a first step I will shortly discuss the concept of emergent concerned groups, which shows some characteristics of my case and how we can think of asexuality in comparison with patient groups. Afterwards, I will give a background on PUS and its specificity in STS, and show how it relates to my case.

3.1. Emergent concerned groups

One of the most prominent works on patient groups in STS is the corpus of studies on AFM, the French Muscular Dystrophy Association, by Michel Callon and Vololona Rabeharisoa. In the following I will sketch the terminus of *emergent concerned group* with which they describe this association (2008) and explain what it might help me to see, if applied to my case.

While Callon and Rabeharisoa acknowledge the work done in sociology on the formation and reproduction of social groups, they offer this critique:

> Generally, they [other theories on group formation] assume that the identity of the group is based on values, projects, practices, interests, or habitus shared by its potential members. This type of approach does not apply to emergent concerned groups, whose identity is an achievement rather than a starting point, a *primum movens*. (2008, p. 232)

AFM has humble beginnings, being founded by a few families with children who were diagnosed with muscular dystrophy - there was little scientific interest in the disease and no cure, research or facts. From this position of too many concerns and questions and no answers, the organization departed to counter this exclusion and indifference. At the center of a concerned group lies the fact that members share the same matter of concerns and express them with common words (Callon & Rabeharisoa, 2008). Here we can see a parallel in Scherrer's (2008) investigation into how asexual identities are negotiated. She argues that while social constructions of sexuality and sexual identity have been theorized in academia, the identities and experiences of people identifying as asexual have not been looked at in detail. Scherrer describes "part of the difficulty in coming to an asexual identity [as] finding the appropriate language" (p. 630). The Internet, and especially AVEN, have helped discover this language. Further, the Internet has allowed for the formation of a community around this recent emergent sexual identity (Scherrer, 2008). Both in the case of muscular dystrophy and asexuality, 'emergent' indicates "that nothing is stabilized: identities are problematic […] Identity and interests are the outcomes, and not the causes, of the action itself" (Callon & Rabeharisoa, 2008, p. 235).

In the AFM case the uncertainties have somewhat lifted in the last few decades. “Expectations, interests, and projects have been formed and then stabilized, constituted, and entrenched in networks and communities where they belong and are recognized” (Callon & Rabeharisoa, 2008, p. 235). While concerns still exist, identities have been shaped, stabilized, and recognized - a first step in the way of forming a path for strategic action. The shaping of this collective identity is tracked by focusing on the engagement in research by patients and their families. In their case, new entities appear through the research, namely the genes that cause the disease. It is this knowledge that allows the construction of a new identity for the patients, and that can also be defended in the public sphere.

The role of patients in this engagement with research can encompass a wide variety, from intermediary to researcher, “depending on the circumstances, the diseases, and their own education, they may become involved in any research-related occupation, from the laboratory bench to the dissemination of information, clinical observation, or the adaptations of therapies or prostheses” (Callon & Rabeharisoa, 2008, p. 238). Examples of engagement and influence in the AFM case are money donations, programs they convince the government to invest in, the popularization of genetic knowledge, funding start-ups in the economic sector, etc. What is essential is, that without their involvement the collectives and the knowledge produced would not look exactly the same – their engagement has an influence. And in turn the construction of the patient’s identity is also influenced by the practices of engagement. Callon and Rabeharisoa (2008) differentiate the cases of concerned emergent groups from laypersons’ engagement in research (which is the probably more well-known STS topic) by saying that only here the construction of a new identity with the goal of being recognized is integral to what is happening. That this happens in part because of research and the entity of genes, differentiates this further from regular social movements.

The case of AFM is a very particular case, especially in its success. Callon and Rabeharisoa link success in the case of the AFM to the group having an “active and influential presence in the scientific, political, economic, and media spheres” (2008, p. 234). But concerned groups can follow different paths and trajectories. Some groups are not recognized and do not become legitimate or gain resources and influence on research or industry. “Many groups concerned are not able to thoroughly and permanently establish their existence; they remain in a state of emergence and sometimes end up disappearing” (Callon & Rabeharisoa, 2008, p. 244).

Asexuality can be argued to be still in a state of emergence – the concept of emergent concerned groups would therefore offer a look at the linkages between engagement in research and construction of individual and collective identity. But what we have seen in this introduction to the concept of emergent concerned groups is, that while there are many parallels that offer valuable insight to my case, many parts of the concept are heavily dependent on the situatedness of AFM in the biomedical sphere. The social identities become rooted in biological characteristics and genes are seen as integral to the formation of an identity (Callon & Rabeharisoa, 2008). A co-construction approach lies at the heart of this concept; thus it builds heavily on the production of entities (genes and prosthetics) through research in which their patient group is involved. They state that the construction of the identity of these groups is “the outcome of real research in which the groups are heavily engaged and that leads to the production of entities […] that participate in shaping their identity” (C&R, 2008, p. 232). In my case there are no technical entities, which is why I will look at public understanding of science to help me focus on the concerns and understandings of the asexual community. Still, emergent concerned groups as a concept helps focus the gaze on what is at stake: identity, or how one is known.

3.2. Public understanding of science

3.2.1. Beginnings of public understanding of science

Public understanding of science (PUS) as a multidisciplinary field looks at the relationship between the ‘public’ and ‘science’. Academic interest in (PUS) came about in the 1980s in the UK. Towards the end of the twentieth and the beginning of the twenty-first century, in a lot of advanced industrial countries, one can witness many conflicts concerning the trust and acceptance the public put in scientific expertise. Examples of issues in which science’s attempts to reassure the public turned out to be rather fruitless, are vaccines and GM food. There was a lot of public skepticism and suspicion towards science and the scientific community faced a lack of interest in science and technology from two directions: the government, which had no interest in science that had no immediate economic value, and the public. Getting no support from those two sides, the scientific community felt it needed to reassert the importance of scientific knowledge and the scientific method. Public understanding of science (PUS) emerged before this background as an endeavor to measure the public’s attitude towards science and the understanding or ignorance of the public towards science (Yearley, 2005). Early PUS builds on the deficit model, which assumes that the public is lacking knowledge and therefore does not trust science. ‘Science’, which holds all the expertise and authority to judge and explain, has to be communicated to ‘the public’.

From early PUS studies, two interesting things can be learned regarding my case. One is, that the attitude towards medical science was overwhelmingly thought of as interesting and scientific: “For one thing, medical research is - in principal at least - clearly aimed at the public good. Medical science without at least a background ideal of healing the sick makes no sense" (Yearley, 2005, p. 117). The other interesting finding is, that "public acceptance of scientific innovations and optimistic attitudes towards science do not automatically relate to people's knowledge of science. […] just encouraging the public to become more knowledgeable about science will not make them more automatically accepting of scientific authority" (Yearley, 2005, p. 118).

There is considerable discussion about the terms central to this topic - while meanings and imaginations of 'the public', as well as explorations of different forms of participation or engagement, have been receiving more attention in recent years, the meanings inherent in 'science' are less often researched. Thought must therefore be also given to how the ways in which publics experience and give meaning to science shape the ways they respond to science.

> Publics may have more nuanced relationships with scientific knowledge than the deficit model assumes. […] Publics have knowledge that intersects with science, they may translate and appropriate scientific knowledge, and they appraise scientific knowledge and its bearers. (Sismondo, 2010, p. 175)

3.2.2. Public understanding of science in STS

Many problematic assumptions are built into the deficit model. The concept of 'the public' is much too simplistic, and the model assumes that more information in science automatically builds trust in science. There are no feedback loops from 'the public' towards science, as information only goes one way. People are not seen as knowledgeable actors, but as in need of education. To conclude, the deficit model does not account for the contextual nature of knowing, missing many ways in which publics' relationship with scientific knowledge is more nuanced than the model assumes (Sismondo, 2010). Which is why, in the 1990s, there was a move from the deficit model of public understanding of science to models of critical engagement with science. This offered more room to investigate why publics should understand science and how they engage with science. The problem is no longer seen as a lack of knowledge, but of inadequate considerations of the public, be it lay expertise or assumptions held about the public or by the public (Sismondo, 2010).

This hinged upon a new understanding of the relationship between science and society, described by Bruno Latour:

> In the traditional model, society was like the flesh of a peach, and science its hard pit. Science was surrounded by a society that remained foreign to the workings of the scientific model:

> Society could reject or accept the results of science; it could be inimical or friendly toward its practical consequences. But there was no direct connection between scientific results and the larger context of society. (…) How different are the connections nowadays between research and society! (…) They are now entangled to the point where they cannot be separated any longer. (Bruno Latour, 1998, p. 208)

We have already encountered some key STS scholar investigating these new aspects of public understanding of science in the state of the art of this thesis (Chapter 2.2), namely Epstein, Callon, and Rabeharisoa. Here I will show another example by Brian Wynne, to showcase the questions and concerns that moved PUS from the deficit model to critical engagement with science model. Wynne (1996) investigated Cumbrian sheep farmers' responses to scientific advice after the Chernobyl radioactive fallout. Sheep farmers were advised on environmental hazards following the Chernobyl accident, and were restricted in their sale of sheep.

Wanting to go further in his analyses of public understanding of science, Wynne (1996) stresses that,

> the best explanatory concepts for understanding public responses to scientific knowledge and advice are not trust and credibility per se, but the social relationships, networks and identities from which these are derived. If we view these social identities as incomplete, and open to continual (re)construction through the negotiation of responses to social interventions such as the scientists represented, we can see trust and credibility more as contingent variables, influencing the uptake of knowledge, but dependent upon the nature of these evolving relationships and identities. (p. 282)

In this case it is shown that trust is not simply explained, but has many factors. For example social factors and 'institutional body language' of science play an important role when it comes to trust or distrust.

The personal and experiential life-world background as well, plays a crucial role in how lay people relate to science and scientific knowledge. If lay expertise, that is cultural and local forms of knowing, are ignored by science, then conflicts are more likely to arise (Wynne, 1996).

"Certain sociologists have suggested that the public may not simply embody values about the world but may also have knowledges of its own to offer: forms of lay understanding or citizen science" (Irwin & Michael, 2003, p. 8). The notion of lay expertise refers to publics having their own knowledges, which may be in accordance with expert conceptions, or challenge them. Moving again into the medical realm, an obvious example is patients having a certain expertise about their own condition and bodies, knowledge of pain for instance. On the basis of their own knowledge and experience, people will assess the credibility of scientist's claims. This lay, or citizen, expertise, can prove a fruitful addition to scientific ventures, for example by adding citizen panels as a review process (Yearley, 2005). In case studies we often see a conflict between lay and scientific understandings. This is due to publics having pre-existing interests in problems and their solution (Sismondo, 2010).

What new insights this science-studies view of public understanding of science then offered is summarized by Yearley (2005) in three points, or 'theorems':

1) Public understanding of science is no longer really concerned with whether people understand scientific knowledge, but about how people evaluate institutions of science.
2) A major factor in how the expertise of scientists and scientific institutions is evaluated, is the trust put in them.
3) The framework of scientific knowledge claims is both technical and social, in that it depends on (often unexamined) assumptions and models about the social world, with which publics can disagree.

In these three theses we see that when publics oppose science, it is not the result of 'misunderstandings'. Rather it is because a study or the solution to a problem is not presented by trustworthy institutions or scientists, lay expertise is not taken into account, or inadequate assumptions are made. In such cases opposition is grounded in concerns about the adequacy of scientific work (Sismondo, 2010).

3.2.3. PUS as theoretical background

The things sought to understand of the public understanding of science, such as trust, and questions like, why should publics understand science and how do they engage with it?, can no longer be measured by a survey, but require different methods (Yearly, 2005).

Traditional STS inquiries into science-society relations start by asking what 'science' and 'society' are, and in what relation they stand - how and where do science and publics encounter each other and how do they communicate?

Wynne (2014) states, that without giving thought to how publics experience and give meaning to science, one cannot make sense of how publics respond to science. On asexuality studies, Scherrer (2008) says that as researchers we often look at academic sources. To open up perspectives on how this knowledge comes to matter, this study proposes to look at the conceptualizations of people who identify as asexual instead.

In STS cases on PUS, such as the GM case, there is an unarguable centrality of science and technology to the public issue. Looking at an example not situated in a technological or medical context, might however offer new views on how understandings of science relate to engaging with research. Additionally, many STS cases feature a controversy and look at ‘talking back’ at science. Looking at a case which might be seen as happening in the absence of controversy (the DSM issue having been solved successfully a few years ago), offers valuable perspectives on how academic research comes to matter. But first one has to look at how academic research, the possible effects of and the engagement with it, are conceptualized. To find answers to my broad main question, a PUS perspective therefore leads me to open up the concepts of ‘science’ and ‘society’ and ask:

1) How do people who identify on the asexual spectrum make sense of academic research on asexuality?

2) How are the possible effects of academic research and knowledge about asexuality and their realization conceptualized?

3) How are practices of engagement with said research perceived and rationalized?

4. Material and methods

In the following chapter I will give a detailed look at the methods chosen to answer my research question, and which aspects it allows me to see.

4.1. Reflections on interviews and gaining access to the field

4.1.1. Semi-constructed interviews

To answer how and when academic research comes to matter, I chose to conduct semi-structured interviews with open-ended questions. Doing semi-structured interviews with open-ended questions allows to get an understanding of the opinions and experiences of the interviewees (Silverman, 2006), therefore the focus of my research lies on the conceptions and perceptions of members of the asexual community. This method allows participants to answer freely based on their personal reflection, knowledge and experience. The interview is collaborative in nature, meaning “interviewer and participant work together to develop a shared understanding of the topic under discussion” (Laurie & Jensen, 2016, p. 173).

> Respondents come to the interview willingly (presumably), interested in the topic – and whatever lures are thrown out – to show up. But their agendas and understandings of what the interview is for, and how it unfolds, depend on the biographical and situated context of their lives – which, in turn, is also historically situated. (Warren, 2012, p. 133)

The interviews relied on a questionnaire, which contained a list of open-ended questions, including follow-ups. The order the questions were asked in did not matter much and varied in the interviews, the only exception being the introductory question. Designing a questionnaire offers structure and flexibility both: leading to important themes of the research, while also remaining flexible (Jensen & Laurie, 2016). After my first interviews, for example, I adapted the interview guideline, because new topics emerged that were of concern to my participants, but which had not occurred to me before.

4.1.2. Field description and gaining access

The field description in this chapter will briefly give an overview of AVEN, the forum at which I posted my call for participants. A more detailed and thorough discussion of the entangled history of asexuality and academia, as well as the role the forum plays in this, can be found at various points throughout my analysis.

Spaces in which marginalized groups build communities, be they united by a sexual orientation (Scherrer, 2008) or an emergent illness (Dumit, 2006), are often found on the Internet. The Asexuality Visibility and Education Network (AVEN) is the most well-known virtual community for asexuals and offers them the language and the space to define their identity (Scherrer, 2008). Looking at the name of this forum, it becomes apparent that one of their goals is listed as education and they describe themselves as also being a "large archive of resources on asexuality" (The Asexual Visibility & Education Network, 2001-2012e). Knowledge found on AVEN facilitates the taking-on of an asexual identity and the building of an asexual community. Asexuals, and most notably AVEN, are producing knowledge themselves and contribute to the making of today's asexuality, while they are at the same time objects of research (Scherrer, 2008; Przybylo, 2012). Besides being able to witness various practices of engagement with academic research on AVEN, the forum is also unique as it is one of the, or even the only, place researchers interested in studying asexuality can and do use for recruiting participants.

On the first page of AVEN (asexuality.org), besides a lot of other information, there are already links leading to calls for participants for scientific studies. This points again at the peculiarity of the relation between the asexual community and research, but also suggested a feasible way for me to recruit interview partners. I chose to use the forum to recruit my participants out of practicality as well as out of interest in the relationship AVEN has with academic research and the role it plays in the asexual community. This meant, however, that my participants were self-recruited. The amount of people who disfavor participating in the research was therefore unsurprisingly non-existent, because answering my recruitment call is already an engagement in academic research.

For the most part the forum is public and members seem to encourage research, but moderators of the forum still function as gatekeepers, deciding which calls for participation to showcase. This is regulated through standard procedures. On the forum, there is a thread called 'Rules for researchers and students' (The Asexual Visibility & Education Network, 2001-2012b) - wherein rules of conduct (for example for recruiting participants) are laid out. According per those rules I sent a description of my study, the consent form for my interview participants, and the participant information sheet that was used in the research call to the Research Approval Board. Very soon afterwards I got an email from a member of the Board, telling me that my information looked complete and asking me if I would like them to also post the research call via other networks, such as Tumblr and Facebook, once the Board had approved my call. I agreed to the latter and about 3 weeks after, my research call was posted on the forum and on various other sites. The only criteria for participants were being over 18 and identifying somewhere on the ace/aro-spectrum. First emails from interested prospective participants arrived very quickly after the call was posted (I received the first 4 messages mere hours after the call was posted). After contacting me via email, I informed them in a bit more detail about the interview and sent them the informed consent. Quite a few people never responded a second time. But if they did agree to the interview, we arranged a date and time for the interview. After having conducted 10 interviews - which exceeded how many interviews I had planned, but still did not reach saturation in some aspects - I declined further prospective participants, as I already had enough material.

The interviewees were predominantly from English-speaking countries, the exception being two persons from German-speaking countries, and one from South America. All of my participants were relatively young, being in their twenties, or early thirties.

The interviews lasted between 1 and 1,5 hours and were conducted via skype (sometimes video, sometimes audio-only) or phone and in English. The only exception to this being one interview that was conducted in person and in German, because the participant also lived in Vienna.

Limitations concerning my recruitment can be seen not only in the lack of people with a disfavourable opinion on research about asexuality, but also in the language, as I was only able to conduct interviews in English and German. Other limitations which were pointed out to me by my interview participants were disability (if someone were deaf), anxiety, and having an Internet connection.

The interviews were recorded and transcribed verbatim, as well as anonymized. In the analysis chapters interviewees will only be identified as P1, P2, etc. Participants will at random be assigned pronouns (she, he, and singular they)[3].

4.1.3. Interview guideline

Following, I want to include my interview guideline, so as to give an idea on how I aim to answer my research questions. I started the interview with more general questions, which are not directly related to my research focus, but are nonetheless important for me to know and are an easy entry-point into the interview situation. The rest of the interview and the order of questions depended on where the conversation went from there. There have been slight changes and adjustments after every interview, but the following are questions I in some form or another tried to get answers to. Not all of the questions will be touched upon in the analysis section, as some did not yield material that helped me answer my research questions.

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[3] Using only singular they was considered and tried, but found as impeding the readability in many ways. This was the case especially because the asexual community often features as a collective identity, and can be easily confused with the individual participant when using singular they.

Since when do you identify as aro/ace and how did you first come to know about asexuality?

How would you define asexuality? In your opinion, is this term fixed or are there still discussions about it?

Would you say you are a member of the AVEN forum? Since when?

What do you participate in on the forum? Has your involvement changed?

What entanglements between AVEN and academia are there?

In what forms and where do you encounter research on asexuality? How about research on other topics (by being a student, researcher, etc.)?

Have you ever read an academic paper on asexuality?

- Where did you get to know about this paper? Which papers do you read and which not? How do you gain access to papers? Do you discuss the papers with people, tell someone about it?

Have you ever participated in a study?

- Which one, why? How did you come to know about it? Did you discuss with/tell someone about it? Have there been research calls you did not answer, why? What do you know about the AVEN Research Approval Board?

Do you feel that there is a general attitude towards research in the community/on AVEN?

Who benefits from research about asexuality and in what ways?

What motivated you to participate in this study? Where do you come across research calls? How do you decide which study to participate in, which not?

What role does the study design play in your decision to participate? Would you be more willing to participate in a questionnaire, an interview, give a blood sample, etc.?

Do you think all research is beneficial/interesting? (Methods, topic, biologizing,…)

Do you think ethics are important? What has to be considered specifically when researching the aro/ace community?

What would you like to be researched about asexuality? Why?

How has your interest in research changed over time and what were the factors?

In your opinion, what qualifies researchers to study asexuality?

From your experience, which disciplines are interested in researching asexuality? Are some more suited than others? Why (not)?

Do you think interests and motivations of scientists and the asexual community differ/have common goals?

Have you noticed that there is a number of researchers who themselves identify as aro/ace? How does that play a role in their research?

What do you think are the motivations of researchers studying asexuality? Do those that identify on the spectrum differ from those that do not?

In how far does the ace community have influence on/in academia and should that be different? In what relation do you think academia and ace community stand to each other? And has that changed over the last years? What is the role of the forum in the relationship between community and science?

Should research results about asexuality be free and accessible? To whom? Understandable as well?

Where does academic research ‘travel’? How is it/should it be spread?

What part does the media play in this? What do academic research vs. interviews with people who identify as aro/ace accomplish as sources in media articles?

In which language have you encountered asexuality and research about it?

In how far is it different to explain asexuality in your native language (if it is not English)?

4.2. Analyzing data with grounded theory

Analyzing data from qualitative interviews with grounded theory fits particularly well, as both are “open-ended yet directed, shaped yet emergent, and paced yet unrestricted” (Charmaz, 2006, p. 28). Grounded theory stresses the importance of coding what happens in the lives of the participants and their actions. In my case my questions in the interview situation did not always center directly on real life experiences and past actions, but rather also on the opinion and conceptions of my interviewees about academic research. “As we learn how research participants make sense of their experiences, we begin to make analytic sense of their meanings and actions” (Charmaz, 2006, p. 11).

Charmaz’ approach (2006) differs from grounded theory before, in that she sees theory constructed by the researchers, not apart from them: “My approach explicitly assumes that any theoretical rendering offers an interpretative of the studied world, not an exact picture of it. Research participants’ implicit meanings, experiential views - and researchers’ finished grounded theories - are constructions of reality” (p. 10).

Coding is the most important tool of grounded theory. It means labelling bits of data according to what they indicate. Codes therefore attempt to portray meanings and actions in a story and define what is happening in the data. At least two phases of coding can be distinguished in grounded theory coding: initial and focused. During the initial coding I looked at my data closely and studied it line-by-line, which offers a way for the researcher to stay open to new ideas. It helps the researcher to stay away from their own preconceived notions and hypothesis about their research question, while also keeping them from becoming too immersed in their participants' worldview (Charmaz, 2006). I coded using atlas.ti, as it facilitates the changing of codes and was suited to the amount of data. Initial coding was done on the transcriptions of three interviews, before comparing the codes and starting to form categories and analytical directions.

To get to focused coding, comparing data is key. By looking at the codes gained during initial coding, and choosing the most significant, useful, and frequent ones, I tested them in further coding interviews. The rest of the transcriptions were coded using these preliminary findings. Here coding diverges from line-by-line, and the codes grow more directed and conceptual (Charmaz, 2006).

Grounded theory can be seen as the path between collecting and analyzing my data. The final aim is to construct theories 'grounded' in the data itself, although that is rarely the case for master theses, as there is too little data and too little time. Still, grounded theory is very strict about not relying on concepts too early on during gathering data or analyzing. Charmaz (2006) however allows that researchers will hold prior ideas and skills while coding, but should try to keep an open mind and see where the data takes them. Charmaz uses the notion of sensitizing concepts, after Blumer (1969), which function as initial ideas and guide empirical interests. At the beginning of my research I was guided by the parallels to the cases of patient groups engaging with science, and the controversy over the DSM. This prompted me to ask after the motivation for engaging with research and how effects of research were understood. Specific concepts are developed afterwards, when studying and analyzing the data (Charmaz, 2006, p. 17). In my case public understanding of science emerged as a theoretical background when I was analyzing my data and deciding how to write it up - urging me to look in more depth at the conceptions of science and research participation in my data.

Concerning the writing up of my analysis *codes* and **categories** will be indicated by making them bold or cursive, giving more insight into my analytical process. However, not all codes and categories will be touched upon.

6. Analysis 1: Making sense of (research about) asexuality

How do people who identify on the asexual spectrum make sense of academic research on asexuality?

The chapter starts with looking at how asexuality is defined by my participants and whether this definition is seen as stable or fixed, before going into a more descriptive section that deals with the emergence of asexuality in academia.

This opens up the way to look in more depth at the data, asking a) what kind of research about asexuality my participants are acquainted with and which disciplines they think study asexuality, b) how my participants imagine asexuality researchers and their motivations, and c) how it matters if researchers themselves identify on the asexual spectrum.

The third and last part of this chapter looks at different depictions of asexuality in academia and the media that have come up multiple times in the interviews - Bogaert's 1% and the Kinsey scale, the HSDD case, and a Dr. House episode - and how my participants conceptualize these depictions.

6.1. Making sense of asexuality

6.1.1. Defining asexuality: the acespectrum

When writing up research about asexuality, it is important to define the term asexuality and whom it encompasses. This however puts the researcher in the position to have to decide upon which source they will draw for this definition. My contemplations on this point stemmed on the one hand from how I as a person not belonging to this group felt hesitant to know what was the 'right' definition, and on the other hand already opened up an important question I asked my participants, that I now also had to ask myself, namely who is allowed and has the expertise to define what asexuality is. The choice I made was to draw upon the views of my participants, and look at how they themselves defined asexuality.

Before showing how my participants defined asexuality, and which sources they used for their definition, I want to stress once more that my sample of interview participants was almost exclusively native English-speakers or at least people predominantly situated in English-speaking asexual communities. The conceptions and understandings of asexuality drawn from these interviews are therefore situated in a specific language and culture background, and might differ for other people identifying on the ace-spectrum[4].

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[4] A participant mentioned that in Japan for example the differentiation into asexuality and aromanticism works differently).

> Well, I guess the general definition that doesn't really change is the fact that it's, like, a lack of sexual attraction to, to people. But, (.) the big debate is about what exactly that means for or wh- what it's supposed to mean. Because, I think it's a term that can be applied to many different kinds of people, people who maybe do have sex even though they don't feel sexual attraction or people who are sexual- sex-repulsed or people who- I don't know. That's, that's the term spectrum and also people- that's one definition of the word spectrum in this case. The other is the fact that to be on the asexuality spectrum it's enough to not feel sexual attraction like some of the time or most of the time. (P2)

What we see here (P2) is that the action of having sex has little to do with whether one identifies as asexual or not. And also, that how someone feels does not have to be fixed or static, and therefore the definition also has to be flexible, so that it can encompass these people. In another interview this becomes more explicit: “I know it varies from a lot of people. For me I try to keep the definition broad, so it also applies for other people, but for me it's like just having no sexual interest in other people. Yeah. So, like you wouldn't be attracted to them.” (P9)

In this segment we see that the participant sees her definition of asexuality having an impact on other people. She tries to keep the definition broad, so that it applies to other people with different understandings of asexuality. “So, having that sort of qualifier in front of it allows, I think, anybody to say what their definition is. I don't think any sort of one monolithic source should be the, the ultimate arbiter.” (P9)

There is a “big general definition” (P8), a “core”, which is stated as some variant of not being sexually attracted to other people. But overall we’ve seen that there is an underlying understanding of there being more than one definition, rather many definitions that can be very diverse, as one participant mentions. The idea of the spectrum is used, which means that asexuality as an umbrella term encompasses many different ways to define and experience asexuality.

6.1.2. Fixed definition?

Already during showing how my participants define asexuality, it became apparent that there are many more factors at play than what they themselves experience. An important factor for my participants is that the definition of asexuality is broad and therefore opposes reductionism of people’s experiences.

> I mean the most used definition is, like, people who don't feel sexual attraction and that's sort of the way, that I would define myself. But there are people who, who want to define it by sort of, say people who do feel that attraction, but they don't have any desire to act on it. And I don't

> want to, and I don't think it's right to, if, ‘cause then if we settle on the attraction definition, that excludes those people from the community. And I don't think we really should do that, so I don't think we need to have such a strict definition. (P10)

One participant mentions that she has spoken to a lot of people who like to have fixed definitions for things, herself included, and some of those people are arguing for there to be only one definition. So, there are also a lot of people who think it would be nice to have a set definition, but there doesn’t need to be one.

One of the benefits of identifying on a spectrum is seen as not being expected to identify with the same label for your whole life. If your place on the spectrum changes it’s okay. In comparison to labels such as gay or straight, it is seen as less rigid by my participants. In an interview, a person states “I currently identify asexual to mean (.) not sexually attracted to other people” (P3) - ‘currently’ indicating that what asexuality is, can also change for the person identifying as asexual.

Asexuality as an umbrella term combines underneath it many subgroups, such as grey-asexual or demi-sexual, but also the aromanticism spectrum (see 1. Introduction). One participant mentions that there are still discussions about what falls under this umbrella, but she doesn’t think it matters, as she is sure new things will be “discovered” about the definition of asexuality, and new subgroups will emerge (P7). These definition changes are imagined to emerge out of the community. New subgroups will appear because people find something in common with other people - and when a certain amount of people have something in common it is no longer coincidence or individual preferences, but a characteristic of a new group. As a reason for this belief in changes to come concerning the definition, the interviewee mentions that it took herself 3 or four years to find out she was asexual, and she believes there are still many people that haven’t realized they are asexual yet. This idea of a *Dunkelziffer*[5] *of ace people* comes up often in the interviews, describing that there are a lot of people existing in the world, who do not (yet) know they are asexual.

In this case we have seen that the definition is imagined as being made by the community, especially the part that has developed around AVEN, by talking to many asexual people about their experiences. For a lot of participants, the way they define asexuality is based on their own experiences and the experiences of other asexual people. “I think even if the group, the community definition of asexuality changed from what it is right now, my opinion wouldn't change.” (P3)

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[5] estimated number of unknown cases

6.1.3. Who defines?

There are different opinions on whether and how academic research can contribute to a definition.

Some participants think that input from academic research on the issue of definition would be interesting, that “research could investigate what different people think is the definition and why they think that. And that would be interesting to see and also find the current statistics on who defines it as what.” (P3) But research should “not necessarily be the final word in how we define ourselves.” (P5) The main reason participants state for this is because most people researching asexuality are not asexual themselves, and “it would probably be kind of hard for somebody who experiences sexual attraction to really understand what it would be like to not experience it” (P9). So, to define asexuality, you have to experience it. And therefore it is more for the community to define it (P10).

But still, the time research on asexuality enters the discussion, is seen by one participant mainly as when definitions are discussed.

> Because reshear- research seems to be pretty centered towards finding a, a definition. Which I kind of get, I'm that kind of person. But there isn't really a solid definition. (.) So, you know, when, when people start debating about what the true definition is, then, you know, people sort of bring in, okay, well, there was this study that says the def- the definition is this. But no one really seems to be able to agree. (P10)

Even though it is sometimes viewed as difficult to agree on a common definition within the community, wrong definitions are seen as highly problematic.

> Yeah, there are a lot of people, who don't know much about asexuality and conflate asexuality and aromanticism. They think ace means aro-ace. That's really annoying. It invalidates like two thirds of the community in my opinion. And I wish they'd stop. (P3)

Another example where the issue of definition can go wrong, is when the creator of a webcomic or TV series includes an asexual character, because they want to show their support or be diverse. “And then they don't do research into what they are trying to portray, and it doesn't work, and they end up thinking that asexual also means aromantic, which (.) isn't that great.” (P3)

While a definition for a sexual orientation is viewed as a tool through which you learn who you really are, it cannot be forced upon you by someone else to identify, but the choice should be yours. It wouldn’t work or be beneficial for anybody, says one interview partner (P7), to have a catalogue of criteria defined by science, which you have to fulfill in order to be able to identify as asexual. Identifying is seen as a highly personal and individual thing, that is different from case to case.

In the participants' responses we see that asexual identity and what it is can be different for the individual, the community, and in society. It may be 'fixed' and unchanging for the individual, but contested in public knowledge and debated about within the community.

6.2. Making sense of research about asexuality

This part of the analysis looks in more detail at the question of how people who identify on the ace-spectrum imagine research about asexuality and its researchers. After the first few interviews I realized that my participants had much fewer concrete interactions and ideas about academic research than I had assumed. Many of them were interested in research about asexuality, but had never read any journal papers. This offered a great opportunity to look at how conceptions of research and asexuality research in specific were formed.

6.2.1. Conceptualizing who studies asexuality

In a series of questions, I wanted to get at what kind of research my participants are acquainted with, which disciplines they think study asexuality, and which would be best suited, or they would like to see more from.

The disciplines mentioned most often were: sociology, biology and medicine, and psychology. Two participants also mentioned mathematics, in particular statistics. Following, it will be briefly shown why these disciplines are thought of as interested in or suited to studying asexuality.

A large percentage of scholarly articles on asexuality are seen as originating from the medical field. Examples given are articles relating mental health or hormones to asexuality. The motivation for researchers in this field is seen as studying asexuality as a medical phenomenon, or linked to the disorder of low sex drive. In this light, the fields of biology and medicine, which are viewed interchangeably some of the time, are argued to be able to benefit from studying asexuality. As such, medicine "would be interested in proving that asexuality isn't a medical condition" (P3). For example, differentiating the diagnostic criteria between low sex drive and asexuality, so asexual people are not falsely diagnosed, is seen as being in the interest of the field of medicine.

Sociology in general is also imagined as having an interest in studying asexuality, as sociologists are always interested in new population groups (P2). One participant mentions sociologists might be helpful to asexuality, another is of the opinion that the study of asexuality should definitely include sociology.

Comparing this to how medicine as a researching discipline is viewed, we already see first differences concerning notions such as whom research is beneficial for. One participant describes what difference she sees between the interest in asexuality from health science and from sociology: While studies from health science are focusing on whether asexuality is real - what causes could it have, be they biological or psychological; social scientists investigate how asexual people talk about themselves and asexual communities come into being. The motivations of psychology and medicine/biology seem to align and kind of are about differentiating asexuality from disorders or medical conditions. It is interesting to note that already motivations of disciplines come into play.

But it always depends on the kind of questions that are asked, and asexuality can be studied from many different disciplines. “Really, you can also look at it mathematically and, I don't know, calculate the probability of someone identifying one way or another, I- (.) the possibilities are there, you just have to like be interested in, to look at it from this angle, I guess.” (P2) Although the interviewee concedes that psychology, while not necessarily better suited to studying asexuality, has an easier starting point or asexuality is more accessible, than for mathematics.

> Because, I think, in the field of psychology studying asexuality is an, is an, is like an more obvious topic, the same way that like homosexuality is, is a topic that gets discussed in, in, in psychology, or, or transsexuality or whatever. And (.) I mean, in that way it's just more obvious. That makes it easier of course to, like, find interest in the topic, I think you'd have to, like unless that mathematician is maybe asexual or has some specific reason to be interested in that topic. (P2)

Here we see that *having an interest* is seen as a requirement for researching asexuality. While psychologists are imagined as being interested in asexuality, because there was a debate about whether asexuality is a mental disorder (HSDD case) and because they are interested in other sexual orientations as well, researchers from other fields, such as mathematics would need to have a special reason for studying asexuality or be asexual themselves.

One participant has observed changes in the relation between academia and asexuality, or more specifically about what and who has studied asexuality. In the beginning of academic interest in asexuality it was mostly papers that talk about asexuality in general, from journalists, medicine and psychology. There was also a lot of distrust in asexuality in the beginning - some psychologists seeing asexuality just as addressing difficulties in relationships. Now there are more studies from the social sciences, which try to answer what the actual problems of the asexual community are.

Looking at which disciplines are imagined to be studying asexuality, we can see that ‘interest’ and motivations of these disciplines play a big role. Continuing this inquiry, the next section shows how the motivations of researchers are imagined.

6.2.2. Conceptualizing asexuality researchers and their motivations

Asking about what my participants think the motivations of the researchers for researching asexuality might be, forces them to think about benefits of research, that are not related to being asexual. This was one of the most difficult questions for my interviewees, as many participants stated they had never before thought about why someone who did not identify as asexual would want to study asexuality. While my participants know and think about asexuality research, the researcher doing the research is actually invisible in the interviews until I ask after their motivations.

> I don't know. I haven't really thought about, about that. I mean I guess some of them, like I guess, if, if I was to study asexuality it would just be in the interest of oh, I guess this is interesting, I'll find out a bit more about it, but then I'm coming at it from the perspective of someone who is asexual, so […] it's something that very much affects me. (.) I don't really know like why someone would choose to, except for, like, scientific curiosity, wanting to know more about the world. (P10)

One reason that came up quite often was *scientific curiosity*. My participants imagine researchers intrigued by asexuality, which is a new and unknown concept and which when studied can offer more knowledge about the world. A longer context on academic research on asexuality shows that “the earliest research were: oh we found this on the Internet, Internet, and we, we think it's, it's curious and we're gonna look into them, just to know a little bit more about it” (P6).

> [S]ometimes people have kind of a hard time understanding since they experience sexual orientation [sic!] that people can not experience it and I think that probably strikes curiosity in some of them as to, how can it be that these people don't experience something that's so fundamental to how I see the world. (P5)

These interview segments offer two conundrums to how asexuality researchers are imagined:

1) Not knowing much about asexuality is a motivation for researching it, while not knowing about asexuality is the biggest obstacle to studying asexuality.

2) Identifying as asexual is often seen as the only reason to be interested in researching asexuality, while not understanding a lack of sexual attraction can be a reason for scientific curiosity.

But in general, as a first instance researchers have to be aware about asexuality, to be able to want to find out more about it:

> Well, if they are not asexual I could imagine that maybe they know someone that is asexual and they want to just find out more about it, maybe they've heard about some articles, maybe they have come across AVEN and say they want to look more into it because maybe it seems interesting to them […] maybe they found out about this Group X and wanted to look more into that as well. (.) Maybe. (P1)

Some participants thought the interests and motivations of researchers and participants are kind of similar (P9), while others felt they differed significantly.

> Curiosity, wanting to help, I really like the idea that people would go out and that people […] go out and they want to do things to help other people. So, that's kind of the motivation other than from like for, for personal reasons or otherwise, they would be motivated to do research. (P9)

In the above segment it is not only curiosity that drives researchers, but also *wanting to help*. Another participant also mentions, that while they don't know why anybody would research asexuality, or why I chose this as my thesis topic, "if people really have this idea to work on a niche in psychology or in, yeah, I don't know, in this subject in general, and they want to help people, I, I think really, we really lack research in this matter." (P4)

Another participant does think the motivations of researchers and asexual people differ to some degree. Researchers are seen as being motivated first and foremost by curiosity and wanting to answer a question, and while research can help the asexual community, "I don't think that's necessarily, for the most part, the goal of the research, to help asexual people, like, be identify- be accepted in society or to help them accept the fact that they are asexual and not, like, suffer from it, because they are different or whatever." (P2)

But while the motivations differ, there are some common goals:

> So, probably the easiest found common goal would be, we wanna be understood, they want to understand us. But in terms of things like, if we do it to sort of be validated, they're not necessarily setting out to validate the asexual community, but that may be something that happens as a byproduct of trying to understand us. (P5)

The benefits that could be gained through research are in these cases conceptualized as a byproduct of research.

6.2.3. Conceptualizing asexual researchers

In the previous chapter for many participants the main obstacle in researching asexuality was seen as being aware that asexuality exists. In particular if a researcher does not identify as asexual, they are imagined as not knowing about asexuality, much less studying it.

While looking at research about asexuality, I noticed that some researchers who study asexuality also identify on the asexual spectrum. So, I wondered if my participants were aware of this, and how they thought this might change the motivations of the researchers, or the quality and the impact of the research. By questioning them about how it would matter if a researcher identified as asexual, I wanted to get to know how they conceptualized experience, and objectivity.

Some of my participants were aware of the existence of ace researchers studying asexuality, while some were not. None, however, were surprised by it. “Yeah, I don't know a lot of research, but I would think that most of the people, who know about asexuality are probably asexual (laughing).” (P3) Many instances showed again that *not knowing about asexuality* prevented researchers who did not identify as asexual from researching asexuality. Identifying as asexual is also often viewed as giving you an interest in researching asexuality. One interviewee goes further to explain why they think ace researchers would study asexuality:

> [T]here are very little- very few people that do identify as that and because there has only been so little research I think if, if you are able to do the research on yourself, you would do it, if that makes sense because no one else would be willing to do it, because they don't even know about it. (P1)

While again, it is stressed that other people are less likely to do research, because they don’t even know about asexuality, an implicit meaning in this interview segment is, that research needs to be done. And if “no one else would be willing to do it”, asexual people have to do it themselves, if they are able to (i.e. are a researcher).

Researchers identifying as asexual is generally seen as having either no impact on the results, or as containing both advantages and disadvantages at the same time.

One participant thought if a researcher identified as asexual that could be an advantage, so long as it wouldn’t create a bias. But “I think [?that's a] researcher's job to sort of step away from that. And tr- and be objective about the information.” (P9)

An advantage is that ace researchers better understand the community and the terminology.

> If someone, who wasn't asexual, was researching that wouldn't be a bad thing, I think they would just have to make sure they have input from the asexual community on the kind of stuff they are asking so that they know how to best convey the information, that they are trying to and get what they want out of it. I think it's helpful to know the terminology, so that you can really get the information that you are looking for. (P3)

This is summed up: “So, it, it could be a good thing or it could be a bad thing in terms of objectivity and ability to understand.” (P5)

Another opinion was that research from people identifying on the ace spectrum wouldn’t have ‘mailicious intent’ –

> research won't discredit the asexual identity or community if there, like, i- it doesn't have the intent to discredit everything we feel if the researcher themselves is, are asexual, right? So, you, you won't get like (.) studies that say asexuality is a myth or it's, I don't know, it's a *disease* or something along those lines, which is helpful if there isn't a lot of research anyway, like the sma- the smaller the sample size, the bigger the impact of negative research, I'd say. (P2)

The flip side of the coin however, is that asexual researchers are imagined as not being able to do “really big studies” (P2). They are seen as guided by their interest and their personal stake in the subject, but as not having the same means, nor being as widely acknowledged as a big research institute or a renowned professor - which minimizes the impact in the scientific community and is “obviously a little sad, because that would give more exposure to this topic” (P2). While these views partly maybe draw on the observations of my participants, it can also be argued that how they view asexual researchers is heavily influenced by how they view the asexual community as a whole: as not being widely known and having little influence. The other interesting thing we see in these interview snippets is, that one of the major concerns, besides quality and bias, is the amount of exposure research would garner.

6.3. An Asexuality Canon? Fixed points of academic research in the asexual narrative

After having taken a look at how people identifying define asexuality and conceptualize research about asexuality, I want to take a closer look at a part of the data that shows how talking about depictions of asexuality in academic research or the media, is used to localize and define asexuality.

In the first two interviews I conducted, both participants stated when asked, that they could not recall any specific academic papers or findings that they had read, but said that overall they found new research interesting and read it. However, in answers to different questions, the same academic research was mentioned: HSDD in DSM, Bogaert's 1%, and the Kinsey scale. I was aware of all three of them, the first because the case of hypoactive sexual desire disorder in the DSM was my initial research interest concerning asexuality, Bogaert's 1% because it is the most cited academic paper on asexuality, and the Kinsey scale because I encountered it while looking at how the definition of asexuality is debated on AVEN.

In subsequent interviews one or more of these cases of academic research were mentioned, as well as an old episode from the TV show Dr. House. From the frequent occurrence of these unprompted mentions it can be surmised, that these instances hold a central point in the narrative and history of asexuality for my participants. These are all depictions of asexuality, that the participants use to locate and define what asexuality is and what it is not for them. The mentions of these instances were coded together under the category of **fixed points in the asexual narrative**. This draws upon the notion that for example while none of my participants were personally involved in changing the definition of HSDD in the DSM, or even were identifying as asexual when that happened, they know about it and remember it, because it is part of a collective experience or memory of the asexual community.

6.3.1. 1% and Kinsey scale

Bogaert's (2004) paper *Asexuality: prevalence and associated factors in a national probability sample* gets cited in much of the following academic literature on asexuality, regardless of the discipline. In it he states the finding that in a sample of the British population 1,05% of people claimed to have never felt sexual attraction for anyone at all.

'Group X' refers to the Kinsey scale, a linear scale describing sexual orientations on a range of 0-6, according to people's sexual histories. Additionally there is a category X, which is used for people reporting "no socio-sexual contacts or reactions" (Kinsey Institute, 2018). The scale was first published in 1948 and often seen as the first mention of asexuality.

One participant recounts that when he first started identifying as asexual, three or four years ago, they looked up research on asexuality and the one paper they clearly remember "was that one study from a while ago by that guy in Britain [that gave us the] 1% number and that is all I'd really heard of." The '1% number' refers to the finding that about 1% of people in a survey claimed to have never felt sexual attraction to anyone. Here his finding is something that is given by the researcher to the community. The interviewee however goes further and says that it would be nice to know how many people actually identify as asexual, because the 1% number is outdated.

One person says that when she first started identifying as asexual, the only research she encountered was “a vague estimate that about 1% of the population might be asexual, but we’re not really sure basically” (P2), but in the time since then she has observed that asexuality has become a more recognized term leading to more research being done about it.

“I think about 1% of the population of the world, which isn't quite a lot but it's still enough that some people will feel out of place if everybody else sees the world like one thing and they don't, don't even know what, what they mean, they feel like an outsider.” (P1) Here we see that the 1% is sometimes described as vague and maybe not accurate, but it is still used in arguments. So ‘given’ is maybe correct, as it can function as a tool.

Another participant mentions the Kinsey scale, saying “asexuality has even appeared on the Kinsey [scale]” and as such might have garnered interest from researchers, who might after hearing about Group X now be interested to look more into asexuality and research it. In this we see, that appearing in an apparently well-known research is seen as offering visibility to researchers and improving the likelihood of asexuality being researched further.

> For some participants Bogaert’s or Kinsey’s work are the only research about asexuality they know. One participant views the Kinsey scale as being accepted in the community as the first mention of asexuality in academic research, even though it was called Group X. Another person says about the Kinsey scale,
>
> Yeah, we, like, we don't really know what to make of it. Cause it wasn't really for ace people, it was like, oh, this is a group of people that are kind of a thing, but I don't really know what to do with them. Let's put them in another category and not deal with it. (P9)

Another person agrees with that statement, and adds,

> Going, going on from that, you can see a clear evolution, right, people have, have a word for that now, it's just not the ones who don't fit in anywhere else. And (.) that's a definite improvement. Now you see, also seen (.) more researchers actively studying asexuality. Like, it isn't just an afterthought anymore and that's great and I hope that over time we will get more research from like bigger institutes with bigger budgets so that the findings will be more widespread in the scientific community […] (P2)

In these mentions, the Kinsey scale works as a category of research that was done in the past, but is not desired anymore.

6.3.2. HSDD case – Establishing asexuality as non-medical

In the state of the art I have briefly discussed the case of hypoactive sexual desire disorder, which will also appear in more depth in later analysis chapters (see Chapter 6.2.1.).

An interviewee explains to me the main difference between hypoactive sexual desire disorder and asexuality without prompting from my part - using it to show what asexuality is not.

> The main difference between that and asexuality is, that people that are asexual are not directly suffering from it. Like, they may feel left out, but in a way they aren't hurting that they don't have those desires instead of people that they wish they could have these, like, they wish they could be in, in that sexual way. (P1)

In two other instances the HSDD case is used to describe the changes asexuality underwent in how it is viewed by psychologists. An interview participant recounts the HSDD case as the only 'fight' he ever heard of between the two.

> I don't think this is as much of a problem now - but there was a problem with psychologists and therapists labeling asexuality as, as a disorder and they were fighting about that for a while, but I'm pretty sure that most therapists these days are a lot more open about ideas of sexual orientation and don't tell you you're crazy. (P3)

In this segment the HSDD case is used as an example for a past, in which to be asexual was to be seen as crazy. The interviewee thinks they changed it because there was a large backlash from the asexual community, which also campaigned about it to the board of psychologists around the same time they were also deciding that transgender is not a mental issue either - "they kind of went with the flow of public opinion" (P3).

6.3.3. Media: House example

While media and the representation of asexual people in it came up in every interview, only one example was mentioned by more than one of my interview participants: an episode of the TV show House. House was a successful TV show which ran for several years; it follows an unconventional diagnostic doctor who solves difficult medical cases. The episode in question is called 'Better Half' and aired in 2012. An interview participant recounts the plot:

> Yeah, so the episode is about this doctor who cures all sorts of strange cases and they had an episode where there were two characters that said they identified as asexual and the doctor set out to cure them and the sort of plot twist of the episode was that neither of them was actually asexual. The man of the married couple had some sort of hormone imbalance that made his

> libido non-existent and the woman thought that he wouldn't like her, if she didn't say she was asexual so she was just pretending to go along with him. So, that kind of (.) really irritated the asexual community, because we kind of felt that the way they were portraying it is that, because the only two people they portrayed as identifying as asexual, one of them had a medical problem and one of them was a liar, that that was sort of implicating that every asexual either has a medical problem or is a liar. (P5)

Here, mentioning this episode is used to define what asexuality is, and what it is not. One solution participants see for bad media representation is that media sources or TV shows who are writing articles or portraying characters that are asexual, would ask actual asexuals or get some input from the asexual community on this. Because if they don't it could end up like this episode of the TV show Dr. House.

6.4. Findings: Analysis 1

How do people who identify on the asexual spectrum make sense of academic research on asexuality?

In this analytical chapter we have seen that my participants view the definition of asexuality as settled at its core. Other ace people however, may define asexuality differently, and it's very important to leave enough room for those other definitions. While the definition for asexuality, especially concerning the subgroups, is imagined as maybe changing in the future, the change is seen as only being able to come from within the community. Research is however sometimes imagined as being able to help with defining asexuality, or is used as a resource when arguing about definitions.

Research about asexuality is perceived as coming mainly from the disciplines of sociology, medicine and biology, and psychology. The interests and motivations of these disciplines play a big role in their conceptualization. Going a level deeper, when asking after the motivations of researchers studying asexuality, we saw that none of the participants had thought about why someone would study asexuality before. Especially if the researcher did not identify as asexual, interviewees were not sure why they would study asexuality - two reasons given were *wanting to help* and *scientific curiosity.* But not identifying as asexual was seen as the biggest obstacle in researching asexuality: because the only reason to know about asexuality is to be asexual. In this we already start to see the importance of awareness of asexuality.

This comes up again when looking at how ace researchers are conceptualized. While experience of asexuality is seen as being possibly both a beneficial expertise and a harmful prejudice, quality of the research was not the only concern voiced by my interview participants. Another concern was the amount of exposure research would get.

In a last section fixed points in the asexual narrative were looked at, meaning specific academic research and a TV show that were mentioned several times by different participants. These show how talking about depictions of asexuality in research or media can be used to define what asexuality is and what it is not.

6. Analysis 2: Unknown, but knowable - Imagining possible effects of academic research and their realization

The first chapter showed how my participants make sense of academic research about asexuality, and who is imagined producing research about asexuality. This chapter will delve into who is imagined to be interacting with said research after it has been created - so, who is the audience. This can be answered by looking at how my participants conceptualize the possible effects of academic knowledge about asexuality and the ways in which these effects could unfold.

How are the possible effects of academic research about asexuality and their realization conceptualized?

The first sub-chapter is of a more descriptive nature and sketches the first encounter between the asexual community and academia - the HSDD case - opening up questions of expertise and different kinds of knowledge about asexuality.

Going into the interview data I will continue by showing how my participants tell of starting to identify as asexual, which shows *moments of alienation* and *feeling different*, and concludes that finding out about asexuality in many cases equaled identifying as asexual - making being aware that asexuality exists a necessary condition for being able to identify as such. While this section deals with asexuality as an unknown entity to oneself, the next one describes it as an unknown entity to others, specifically how explaining asexuality to others as a practice is talked about by my interviewees.

This leads to how research is perceived as scarce and how this is seen simultaneously as cause and consequence of there being little awareness that asexuality exists in academia and the general public. Creating visibility and awareness of asexuality is seen as the central function of research, while finding out more about asexuality is viewed as secondary: There is a distinction between *getting to know asexuality exists* and *getting to know more about asexuality* as possible effects of research. While the first has at its core spreading awareness of asexuality as a consequence of research, the second would imply that new knowledge about asexuality is generated through research. Proceeding from this imagined benefit of academic research, other possible effects are discussed along the lines of who the audience and who the beneficiaries of this research are. In a next step it will be looked at how those imagined effects of academic research are thought to unfold, and who is seen as being able to, or should, do the work to bring these effects to realization.

As most effects are conceptualized as benefits, there will be another section dealing with undesired research, which shows that the biggest concerns are disproving asexuality and a wrong definition of asexuality. Following this, I will look at the conceptions of research that tries to find a biological cause for asexuality, which is wished-for by some participants and seen as problematic by others.

Having now achieved a comprehensive idea of how effects of research and their realization are conceptualized, we come back to the beginning of this chapter and the themes found within the HSDD case, and ask how it matters where knowledge of and about asexuality comes from. One finding is that academia is seen as having an authority that is capable of making asexuality more real to others and also to oneself.

6.1. Academia and the asexual community meet – The HSDD case

The first meeting of academia and the asexual community can be argued to have had an immense influence on the shape both the future academic interest and the community took.

To show this, I want to go back to how my initial interest in this case began, which was during a seminar on medical classifications. One of the papers on the reading list was a case study on 'Female Hypoactive Sexual Desire Disorder' (FHSDD), the diagnosis of which relies on the assumption that all humans experience sexual urges, in large part due to the theory of evolution, and that therefore their absence has to have a pathological condition at heart (Jutel, 2010). The medical classification of FHSDD was introduced in the Diagnostic and Statistical Manual of Mental Disorders (DSM), a handbook by the American Psychiatric Association. People identifying as asexual have criticized the section on Hypoactive Sexual Desire Disorder in DSM-IV, which can be read as stating that having no urge to have sex is a mental disorder (Hinderliter, 2009). During the revision process for the fifth version (DSM-5), the asexual community, despite lacking visibility in society and scientific research about asexuality, wanted to change the definition of this medical classification as it would remove asexuality from being an illness (Jay, 2008). A task force was recruited via AVEN and qualitative interviews with individuals identifying as asexual were conducted, so as to gather facts with which to dispute the phrasing of the diagnosis. The task force was successful and the diagnosis was adapted to exclude people who identified on the ace-spectrum (Hinderliter, 2009; Jay, 2008). This history shaped the relationship between academia and the asexual community and it can be observed that afterwards there was an increasing academic interest in asexuality as a sexual orientation. This chapter of the history of asexuality is told on the blogs of Jay (2008) and Hinderliter (2009), two asexual scholars, and serves as the first instance of engagement with academia which can be observed.

Looking back this shows an encounter reminiscent of other classic STS cases in which groups, usually patient groups, challenge academic knowledge about their condition (for example Epstein, 1996; Rabeharisoa & Callon, 2008). Cases such as these offer opportunities to look at how and when something qualifies as 'real' and who has the authority and expertise to make it so.

I argue that it is also important to study these questions and investigate the views and opinions of members of such groups after such encounters and in the absence of controversy.

6.2. Getting to know about asexuality

One of my first memos while coding was pertaining to thoughts about the divide between *getting to know asexuality exists* and *getting to know more about asexuality* - previously coded together as *getting to know about asexuality.* The question I was asking myself was, what does getting to know asexuality exists mean for my participants and how does this compare to getting to know more about asexuality?

To answer this question I will look at instances in the interviews in which asexuality is an unknown entity, first unknown to my participants, and then unknown to other people.

6.2.1. Asexuality as unknown entity to oneself

The first question I asked in the interviews was how my participants came to know about asexuality and since when they identified as asexual and/or aromantic. This was meant as a more general introductory question, to ease my participants into the interview situation, and in a follow-up question let them explain to me how they define asexuality.

Many times participants when describing how they define asexuality and since when they have identified as asexual, use examples of *feeling different* from everybody else and *instances of alienation* to explain it.

> […] for example as a teenager when my friends said that, okay look at him he's hot or, I don't know, in the gym or in other place, none of this never made sense to me, because I couldn't feel anything. (P4)

Here *feeling different*, is linked to not understanding what 'hot' means - a variant of this is given by a few participants to describe how they realized their feelings and perception differed from their peers. Often a lack of understanding what sexual attraction is, so not knowing what it means if somebody is described as 'hot' is mentioned. Another example given by a participant is thinking romantic subplots in movies are unnecessary.

While my participants noticed these instances of feeling different, one says she didn't notice what the crucial point of feeling different was. Another interviewee saw this as a reason to find out more:

> I think I was about seventeen, when at that point I had a (.) seventeen, I had a boyfriend, I was like, I'm not really interested in sex. He was, and I was like, no. So I broke it off with him. Yeah. And I did some research into it. So, I thought I was like really weird, 'cause […] I didn't understand the meaning of, like, what does hot mean and things like that. So, I st- I did some research into it. (P9)

This specific part of the interview shows how *feeling different* triggers the need to 'research', as the interviewee calls it. She mentions coming across the term asexuality on Tumblr, and after discovering it, "did a lot of reading into it, spent time on AVEN, just lurking mostly" (P9). *Looking up* and *looking into asexuality* play an important part in identifying as asexual or aromantic for my participants. In this particular case we see that the sources mentioned for *looking into*, 'researching', asexuality are not academic, but rather social media platforms directly from ace people.

Other participants report finding out about asexuality, without going looking for it, on the Internet.

> There was a picture explaining different sexualities, some that I didn't even know much about like pansexuality as well, and one of them was asexuality and I looked it up to learn more about it and I started to realize it sounds a lot like what *I* have been experiencing. And the more I looked into it it's (.) yeah it was, yeah it it was a realization for me that that was the term I was looking for to describe what I was feeling, what I was experiencing. (P1)

In these cases asexuality is seen as something to be discovered, a truth, rather than something defined or decided by a group. *Finding out asexuality exists*, explains why my participants are *feeling different*.

In the same vein not knowing about asexuality is viewed as the greatest obstacle to identifying as asexual. One person says that not knowing about asexuality and transgender before going to college was limiting, because "I couldn't identify as something I didn't know existed." (P5)

> I always felt that something is really wrong with me and I was very inconfident, like, I felt that something is physically wrong with me and I was not comfortable in this regard. And also I didn't want to involve any, in any relationship, because I couldn't explain why I don't feel anything. And when I read about this online, I was kind of relieved to know that although there are not many people as other orientations, but there are some people who feel the same as me. And I think knowing that really helped me to identify myself as a normal person. (P4)

Finding out asexuality exists was the reason this interviewee went from *feeling different* to *feeling normal*. Another interviewee also describes finding out asexuality exists as an overwhelmingly good experience,

> it's an eye opener when you realize that you aren't the only one. Like, I've seen stories of people that were ov- over fifty years old and they've only just then come to the realization that they were asexual. And that, that really warms my heart, that they've finally found, I guess an answer to any feeling ever ex- any experience you've, they've ever had has been validated in a way. (P1)

While my interviewees were all in their twenties, or early thirties at best, many mentioned that they thought it was important that also older generations knew more about asexuality, "because there are a lot of older people, who didn't know asexuality existed and therefore didn't realize they were asexual and just thought they were weird" (P3). We see here again, that *feeling different* without having a reason is seen as negative by my participants. Not only in their own experiences, but also to an imagined audience that is not (yet) identifying as asexual.

In all of these recounts we see that finding out about asexuality equals identifying as asexual.

Some tales of coming to identify diverged from this formula. Half of my participants were aware of asexuality for some time before starting to identify on the spectrum. They encountered the term asexuality either on social media sites, such as Tumblr, or because they knew someone who identified as asexual. In a few cases they also reported *feeling different*, but not very often.

> I've known that the term existed for several years, but it was more recent that I sort of thought about it in depth and realized how much it applied to me. And it was only sort of after I identified as ace and started looking on the forums and stuff that I realized that the term aromantic also really applies to me and sort of the way I feel about relationships and people and stuff. (P10)

The last part of this excerpt gives a hint to the crucial distinction of *looking up* and *looking into asexuality*, or in this case aromanticism. While in the section before, *looking up asexuality*, and finding out it exists was crucial, in this tale, *looking into asexuality* gets more weight. We see this more clearly in an example of a participant, that knew about asexuality long before she identified, encountering it during her studies at university. But she states the reason for not identifying as not looking more into asexuality. Once she did that, a few months before the interview happened, she recognized her own experiences and feelings, and started identifying as asexual. For her *looking into asexuality* also didn't mean academic sources, but rather looking for personal stories on Tumblr and reading their experiences. Another participant says,

> I'm this sort of person I didn't want to just sort of hear the term, guess what it might mean and then identify as that. I wanted to know sort of exactly what it meant and sort of how that would fit me before I went- was sure that that was me […] cause when I first heard the term it sounded to me like someone who has no sort of sex drive, no arousal or anything. And I had to do some research to figure out that I could feel those things and still be asexual. (P10)

Even though the terms and definitions for asexuality and aromanticism are perceived as not completely fixed by my participants, in this case it was very important for the person to be sure what asexuality and aromanticism were, before being able to identify as such. *Having knowledge about asexuality* is therefore also important to be able to identify as asexual. For this participant it was important that she found people describing experiences similar to herself, namely not feeling sexual attraction, but experiencing arousal sometimes; those people were still considered to be asexual by other peers on the forum, therefore she felt she could also identify as ace/aro. Besides looking up the definition, reading sections of the AVEN forum in which people describe their experiences is mentioned as an important source for this knowledge about asexuality. Recounts of personal histories and experiences of other people identifying as asexual play a big role for many participants in identifying as asexual too - as they tell it, recognizing the similarities in these experiences makes them realize they too are asexual. Here we see *recognizing oneself in stories and experiences of ace people*.

6.2.2. Asexuality as unknown entity to others – Explaining asexuality

As is the common lot of all master students taking longer than the blink of an eye with their thesis, I got asked about it quite often. A lot of different people are interested in what you are researching: fellow students, friends, parents, work colleagues, strangers you met at a party once. Usually one starts by explaining the interest of the topic and the approach, spending a bit more time on it when people have no background in your field of studies. But when I got asked about my master thesis, I almost always had to explain asexuality first and most of the time got no further than this, because the person I was talking to got hung up on it.

I recognized in my interviews a similar focus on *explaining asexuality*. This happened sometimes in the interview situation when my participants were explaining aspects of asexuality to me, but even more apparent was how they told of their experiences having to explain asexuality to other people. This is viewed as exhausting and repetitive, but also as limiting, as one does not get further than the explanation in talking about it.

> [T]he thing is, for you [asexuality is] an interesting thing to talk about because you're researching it and it's fascinating and whatever, but imagine if that is your life. If every time you, like, basically come out to someone, you have to (.) yeah, y- you have to start that whole spiel again. (P2)

In these retellings explaining asexuality is synonymous with coming out in two ways - first, because they cannot come out to people as asexual without also explaining asexuality, and second, because they cannot talk about asexuality without people asking them why they are interested in it. An exception are people who themselves are ace or aro, and sometimes people in queer communities. But people who are not part of the queer community are imagined as having generally never heard of it.

There's also a feeling of pressure on *explaining asexuality:*

> Especially once you say the wrong thing, you just have to, like, state the wrong thing even once or just like, falter and be insecure and people will, like, doubt you or they will think it's weird or they think, or, like, all kinds of things, they, that they might think, it's because you're such a shy person anyway, it's because you're like frigid, or because you, I don't know, because obviously something must have gone wrong in your childhood or you might still be sick or whatever. They- and once people think like that it's really hard to change their mind, so, it's really, it's such a huge responsibility for s-, for such a small thing, you know. (P2)

Here we see that the participant is afraid of asexuality being wrong-known and not seen as legitimate, if they say the wrong thing.

Explaining asexuality however does not only happen in context with strangers or people one is just starting to get to know. Many participants also recounted experiences of explaining asexuality to friends, families, and partners, after they started identifying on the spectrum. One interviewee for example tells of coming out to her parents, and that they "have been great", and that her mother even checked out a book about asexuality from the library, in order to know more about it. But she immediately adds, that she thinks they would have been more accepting if they had already known asexuality existed.

Another participant has different experiences coming out to her parents and friends,

> according to my own experience, when you talk about asexuality, people just don't understand it. For example, I tried to open up about this to my family, and, and friends, and everyone just says, that yeah, you don't, you haven't felt sexual attraction for- towards anyone because you haven't met the right person yet. Which is absolutely incorrect and they think, like, people confuse it with celibacy or yeah, not meeting the right person. […] So, it kind of, yeah, bothers

> me when coming out or even in my relationships, that people just don't know even what does it mean. And they start to treat you differently sometimes. […] So, I think research and well, educating society would help a lot. (P4)

People not knowing about asexuality is seen as a problem to it being seen as a valid sexual orientation, and research is viewed as the solution that would offer more recognition in society.

In the section before we have seen that recounts of personal experiences are very important for people coming to identify as asexual. Here we start to see that academic research is viewed as important for allosexual[6] people to get to know about asexuality. This will be explored further in the next chapters.

6.3. Possible effects of research – the good, the bad, and the in-between

When having interview data, one cannot answer what the effects of research are, but one can look at how possible effects of research are perceived. This chapter looks in detail at how academic research about asexuality is conceptualized as having effects, and how these effects are imagined to be realized.

6.3.1. Scarcity of research as a rationale

> I suppose, hypothetically it's possible that there could be a study about asexuality that isn't beneficial, but I don't know what that would be. In my current opinion, I think, currently all research is good. If something bad happens for some reason, I might change my mind, but I don't think I will. More information is better than none. (P3)

My participants were unequivocally in favor of more research. The first and foremost reason for that was not imagined benefits of research, but the fact that there is very little research about asexuality right now. Let's take closer look at the **scarcity of research** and see what rationales are behind that.

While all participants agree that there is not much research on asexuality right now, there is still more than there was before. It is noticed that there has been an increase in research about asexuality in the last few years. When one person first started encountering asexuality, there was no research, only a vague estimate that 1% of the population might be asexual.

> And not much else actual research more li- more along the lines of this is how I feel and this is how people feel that I have encountered. And well, nowadays it's just become a more (.) more recognized term I'd say, so people start wondering about it and doing research about it. (P2)

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[6] allosexual=someone who experiences sexual attraction

One of the reasons for there being more actual research about asexuality seems to be that it is a more recognized term. So more awareness of asexuality leads to more research on it being done. Going back to the first chapter (6.1.2.2.) we have already seen that the biggest requirement for researchers studying asexuality is viewed as them knowing about asexuality in the first place.

The other thing we can see is that **scarcity of research** is a reason for having a good opinion of the few research there is.

> Well, (laughs) I guess I do have to say to some degree everything is interesting, because there is so little out there, still. I mean, (laughs) there's a lot mo-, lot more than there was a few years ago, but it's still not a lot of research. (laughs) […] But I mean, for the start it's just reassuring to have any kind of research at all to show that people are interested and well, that you're worth researching. (P2)

6.3.2. Spreading awareness as a benefit of research

One of the most common codes throughout all my interviews within the category of **effects of research** was *spreading awareness to other people as a benefit of research*. And while this seems a rather long and straightforward code, when I went deeper I realized that it was crucial to look at whom my participants imagined to be the 'people' who should get to know about asexuality.

The main impression the interviews left concerning effects of research was, that it is not so much the specificity, the methods, or the findings that are of importance or have any influence on the impact of research, but that solely the existence of (more) research is already beneficial. On a first level this is because more awareness of asexuality will be 'spread'. Following, one of the interview partners talks about the circumstance that a lot of researchers studying asexuality themselves identify as aro/ace,

> So, of course because most of our researchers are asexual and maybe have not the same means as some big research institute would have, it also means that the impact is smaller in the scientific community. Like, if they are not as widely acknowledged as a big research institute would be or some renowned professor in the field of whatever it is, whatever field they are publishing in. That's obviously a little sad, because that would give more exposure to this topic. (P2)

It is therefore not the results or quality of the research that suffers by not having the means to conduct experiments with for example bigger sample sizes, but the impact that is negatively affected. The next segment illustrates the idea and importance of research 'spreading' even more.

> Well, maybe research isn't the best method to spread it to the whole world […] but you have to start somewhere because there is so little information, so few people know about this. My parents don't even know about it so, well and I don't blame them, nobody talks about it. Especially the media is very sexualized and for 99% of the people it's normal. And when other people feel it's weird for them, they don't fit in, they just- they think that they are the ones that are in the wrong. Instead of that they are accepted, that just everybody is different. (P1)

How far academic research about asexuality travels and whom it reaches is very closely linked to why it is seen as beneficial. The above example shows one explanation for this causal relationship. In the first statement, there is a *moment of alienation* ("they don't fit in") that is the result of there not being much research ("so few people know about this […] nobody talks about it"). Research is seen as one way to spread awareness of asexuality to "the world". People who do not identify as asexual are being made aware of asexuality due to an increase of academic research, and asexuality is normalized as a result. The benefit lies in people who do identify on the spectrum being and feeling 'accepted'.

While the participants were clearly wishing for the spreading of research, the idea of how this could happen and who could make this happen was most of the time left unsaid. The following quote however, offers an example of how and why this spreading could result from more research.

> [E]ventually if there is enough research on it and it's more widely known and accepted in the scientific community, it will eventually be taught like, whether it's in universities or then maybe in schools as part of the sexual education maybe or something […] I think it will be a while before that will actually happen. But I think it's something we can hope for, right. (P2)

This could then, for example, in a distant but desirable and plausible future ("it will be a while before that will actually happen […] but I think it's something we can hope for") lead to asexuality being part of sexual education in schools, which would lead to more people being aware of it and again normalizing it.

Other participants also see *spreading awareness* as a crucial benefit academic research on asexuality could have, but are more critical about the realization of this.

> It would be nice if [research] would sort of, get out there on its own in terms of being visible to the general public, even if they aren't necessarily looking for it, but since a lot of people probably wouldn't read about it unless they had a specific reason to read about it, like somebody they knew said they were asexual, it's probably harder for the papers to get a general audience that way. (P5)

Concerning the question of for whom visibility of asexuality is important, for people still figuring themselves out, or the whole world, or the media, one participant says,

> I mean most importantly, I would say it's important for people who are still trying to figure themselves out. Just to know that it's an option, because for quite a while, I didn't identify a-as ace, because I didn't know that not being attracted to *anyone* was an option. I ju- I kind of thought you had to be attracted to someone at least. (P10)

Breaking it down, she says “to figure yourself out as ace you j- you have to know that it exists and have heard the term” (P10). As for herself, she describes getting to know of asexuality as a coincidence, because she followed general LGBT+ wesbites that mentioned asexuality in a few posts.

Another participant also thinks more research would lead to more people identifying as asexual. Because if there’s more research, more people will look at asexuality, and how my participants imagine this is that the biggest obstacle to identifying as asexual is not knowing asexuality exists. More people identifying on the spectrum is seen as good for those people, as it is discovering a part of yourself and coming to terms with something you struggled with. No participant ever mentions it being good for the community or other people identifying as asexual. While in the case of research there was a clear rationale of more research leading visibility and therefore to even more research, this seems to be absent here, as the case of more people identifying as asexual leading to more visibility and to even more people identifying is never made. They only stress that for the individual who does not yet know they are asexual, it is a very good thing to find out they are.

6.3.3. Finding out more about asexuality as a benefit of research

One of the more seldom mentioned benefits of academic research is *finding out more about asexuality*. This is the only effect where the content of research is important, and not only that it exists and there is more of it.

To find out what aspects this benefit of research touches, we will look at what kind of research my participants wished to see. While my participants had many opinions on the possible effects of academic research on asexuality, and all of them were in general in favor of more research, when asked about what research they would be interested in happening, they found it much more difficult to answer this question.

One participant ties research about asexuality and its benefits very closely to defining sexual or romantic attraction, as this was for her the hardest part in identifying as ace. “it's very hard to figure yourself out and define yourself by the absence of something. So, that was the hardest bit of figuring myself out, I think, was going: okay so if I don't feel sexual attraction, what is sexual attraction?” (P10) For her, the more clearly something is defined, the easier it is for people to figure themselves out. The benefits of finding out more about asexuality were (twice at least) linked closely to people having an easier time figuring out whether they are asexual or not.

Looking at the asexual community and how the community works it also seen as important by a few people. Some participants are interested in the 'make-up' of the community, meaning how many people identify as asexual, what are the different definitions and sub-groups. One participant, for example, thinks it would be interesting to find out what percentage of people actually identify as asexual, as the 1% number (6.1.3.1.) is "quite outdated" (P3).

One participant was not interested in finding out why asexuality exists, but more in research about how people experience it. "And the reason I think that is, because talking about how asexuality exists or how it manifests, the discussion ends right there. You know, it doesn't contribute to what ace people are concerned about when they wake up." (P8) The interviewee continues and states that she isn't interested in research about whether asexuality exists, because she says it exists and therefore it does.

Another person is also is less interested in "sort of generic, asexuals exist" but would be interested in more particular correlations fueled by personal observations in online communities: whether asexuality is more common in siblings or trans-people, and how an overlap might be explained.

Another participant says that currently most studies are from a psychological perspective, but that she herself would be more interested in other research. Such as looking at the language the asexual community has created. But the psychological research are the ones seen talked about. Journalists use those articles as sources, "to look for professional voices that say that asexuality is real. But I am not interested in that […]" (P6).

There are some other examples for wished-for research, from the relation between language and identifying as asexual, to disproving myths of asexuality. Nothing is mentioned twice, but the one thing they have in common, is that when talking about this wished-for research they stress their own personal interest and the benefits this research would have for themselves. While in *spreading awareness* we have seen that the benefit of research is imagined also for other people, in the benefit more *knowledge about asexuality*, it is often only oneself that is imagined as the beneficiary.

6.3.2. Undesired research and harmful effects

Now in the chapters before I have focused on the benefits of academic research my participants perceive. Those by far outweighed any critical standpoints on research. I was however interested in what kind of research would be seen as harmful or not tolerated, and asked my participants about it.

During coding there were many instances where *asexuality as unknown entity* was seen. We've already seen how this is central to the imagined benefits of research, especially awareness. But looking closer at the data there are also instances where *asexuality as wrong-known entity* crops up. This code is used to describe when asexuality is invalidated and seen as not real, not existing, or not normal.

While we have seen that one of the benefits of research is *making asexuality more real,* some participants stressed that researching whether asexuality is real, would be quite harmful.

> [I]f someone wants to research whether asexuality is real, I suppose that would be quite harmful, because we generally do accept that it is real and most people wouldn't really appreciate being questioned in that way. But also trying to settle on, like, too narrow a definition is a bit dangerous. (P10)

But the concerns of my participants went further than research disproving asexuality exists. A good representation of asexuality was seen as important in research. This suggests that there exists a 'correct' or 'true' version of asexuality that has to be depicted by research. Were asexuality represented in the wrong way, one participant is concerned that a) people who were new to the term asexuality would decide that the term didn't fit them because of this one paper, b) "they might decide that they were, but they didn't want to be" (P5).

Another participant mentions that sometimes there are small mistakes in academic research, that can affect how asexual people can benefit or use that research for themselves. One thing where researchers can go wrong is the definition of asexuality - "If for example a researcher gets that wrong, like, what they define as asexuality in their study, then the whole study can be skewed, right?" (P2)

P2 imagines this is an easy mistake to make, but one that ruins the whole study, because then the researcher has not actually studied asexuality and no one will benefit from the study.

> It might even spread misinformation. […] for example, let's say you just stumbled upon the word asexuality and think you might identify with it, and then you do research and you stumble upon that particular paper that gets it all wrong and suddeny -ly well, so many things can, can go wrong for you personally. You might think oh no, I'm not part of it after all, I'm still just a freak. (P2)

A study is remembered, where researchers defined asexuality as a person not “wanting to have sex or something along [?the lines] which is wrong, because, like, many asexual people do have sex for whatever reason.” (P2) Even though the definition of asexuality is still hugely debated, the participant thinks research has to be clear about the terminology, to avoid these harmful effects.

In these examples we see that the idea of what asexuality is, does not hinge upon academic research, but rather has to exist before there is research made and then represented in the correct way in the research. This is one thing where some participants thought research could not help know about asexuality.

Something else that falls into the harmful effect of asexuality as wrong-known, is a lack of diversity. Participants think it would be harmful, if not only asexuality, but the make-up of the asexual community were shown or represented in academia or the media as something other than it is.

Participants think it’s important to get statistical data from all subcategories of asexuality and aromanticism when researching asexuality.

> Because if you try and put human beings into, you know, one of two boxes, either asexual or non-asexual, any time you try and split people up into two boxes, you're gonna have some people that don't fit very well. (P5)

Another person also thinks people not from English-speaking countries, and countries in which LGBT+-issues are not visible, should be included in research, and that there is currently a lack of diversity in research.

6.3.3. Opinions divided: Biologizing research

In my first interviews participants always came to talk about a certain kind of research that aims at biologizing asexuality, research that is seeking causes or reasons for being asexual, be it a hormone imbalance or a genetic factor. My first two interviewees had contradicting views on this kind of research. Shaped through my view that the asexual community was formed in part by distancing itself from being a medical condition, I had assumed this would be a clear-cut case of participants being against it. However, things were not as black and white as I had assumed. Because I wanted to investigate this further, I then decided to include a question specifically to this in my interview when it would not come up on its own. Before I had only asked about what research they were in favor of, and what they would not like to happen. Now I then also at some point asked them about biologizing research, telling them I had heard different views and asking what their opinion was.

In this chapter therefore I will investigate how my participants understand biologizing research and how their opinion of it is linked to what asexuality is and what effect research can have. The existence or nature of such research is not under investigation, and whether it is ‘good’ or ‘bad’ is not the point of this chapter.

The existence of research that looks at the underlying cause is not talked about in specifics, no interviewee mentions a specific paper or publication. But there exists the view that either this research has already been done, is currently being done, or it might hypothetically be done in the future.
One exception is a participant that mentions knowing other ace people who have gotten hormone tests and found that everything is normal. She continues saying that research like that wouldn’t be exciting, “it'd be like: there is nothing wrong with ace people.” (P9) In the interviews the opinions on this were very varied. Some participants were convinced there was no biological cause for asexuality, while others were not sure.

One opinion on this kind of research was, that it should be done, so as to proof that asexuality is not a medical condition. “I guess it would be nice to show asexuality is not a medical condition and that would be nice both for asexuals and for the medical community to know.” (P3) Participants who were sure that there was no cause for asexuality, did not think biologizing research would be harmful in and of itself. “I think researching that question isn't inherently bad, because I don't think they are going to come up with the answer they are looking for.” (P3) She bases the certainty of knowing there is no cause for asexuality on the opinion of her doctor, and on the fact that,

> if asexuality is defined as lacking a sexual attraction to people and it's genetic, then the people with those genes would be less likely to pass on those genes, because they would be less likely to have sex (laughs) […] And it would have died out (laughs). (P3)

Other participants think that there might be a cause for asexuality, but think researching it could be highly problematic. One participant says of research looking for a genetic cause for asexuality,

> in general I like the idea of being able to understand things like that, but (.) I think it, it sort of runs the risk of, like, if, if people, if you find a genetic cause for asexuality, does that mean that people would try and find a cure for it? But it doesn't need to be cured, it's not a problem. But some people view it as one. And yeah, I guess if, if you find the cause for it, that probably means you could find a way of preventing it? And I just don't really think that's ethical. (P10)

Another interviewee is interested in whether asexuality, or any other sexuality, runs in the genes, or has an environmental cause. She continues speaking of asexuality being invalidated the same way homosexuality was at the beginning, and concludes:

> And while I don't *need* a reason why I am the way I am or others are the way they are, maybe it would just, yeah, silence a couple of people that think that we have to be cured, that we have to fit in this one box how the world should work, kind of. (P1)

Another participant also mentions that biologizing research could prove that asexuality is not made up.

In another interview segment we see the ambivalence: Another participant doesn't think that there is a 'chemical reason' for being asexual, but

> if there is anything of the sort that could reassure people that they are not weird or that it's yeah that it's just normal, that it's a normal way of life, that would be fantastic I think. Because people need this kind of academical reassurance I think. […] That was just an easy example, but I don't think it should really, you should try to find a reason why people are asexual. We shouldn't try to find a reason why people are transgender or why they are gay or lesbian, because it's so easy to say that this is the problem then. And we should try to fix that problem once we found out what it is. And I don't want to start on the path. (P2)

6.4. Realizations and pathways of research effects – the example of spreading awareness

Now that we have seen who the imagined audiences of academic research are, and how effects of research are imagined as being realized, I want to look further into this realization and find out who can and has to do the work for awareness of asexuality to be spread. The effect we will look at is *spreading awareness of asexuality*, as it is the most prevalent effect and the one participants used to answer this question with.

Combined to this realization is also the question of who is able to bring this effect about. Early on in my analytical process I wrote a memo: Is explaining asexuality 'work/labor' and to whom does it fall? Here then I want to look at who has the opportunity and obligation to bring about change.

> Well, maybe research isn't the best method to spread it to the whole world, I realize that. But you have to start somewhere because there is so little information, so little peo-, som- few people know about [asexuality]. (P1)

The natural end-product of research was generally seen as a paper in a scientific journal. Going from there, there were different views on what would happen next. So what I wanted to know from my participants was where knowledge about asexuality should go after the research is done and it's published in a journal for example.

One person thinks people reading academic papers about asexuality in journals will only be other people doing research on the same topic. Therefore, it would be important for research about asexuality to be accessible to other people. "The people that the information that the research finds out (.) is going to help is not just future researchers, but also, you know, ace and aro people in my community." (P10) This accessibility is imagined as having different dimensions: first is the issue of having to pay money to read an article in a journal, second is making it visible and readable to people not involved with academia. There is a difference in audience seen between people who are in academia, and people in general. Most people know about research from news articles, magazines or papers, but people "who are kind of in the academic circles" (P6) (studying at university for example) might know research from conferences or seminars. Regarding this, one interviewee says, it would fall on those who do have "the tools to kind of understand the very scientific language" (P10) to be responsible for translating the research into a language that is easier to understand. Another participant agrees that the work to spread research falls on ace people, but that it depends on people's backgrounds, "because I don't know much about psychology, so I kind of had in mind that even if I find a full- [?antex] of the articles I won't be able to understand it. So, I just tried to rely on experience of other people." (P4) Doing summaries of research is one way mentioned to help with understanding research (P9).

Not understanding research was seen as a problem,

> I think research should be more accessible in general, but there's always a risk of people who are not acquainted with the way research works taking it and using it as an absolute and then not understanding what the numbers that come out of it are? (P3)

Here again we see the two dimensions of accessibility. The media is seen as one perpetrator who misquotes studies regularly. In other interviews this was seen as a "marketing problem" (P9) of research. A lot of researchers are not good at publicizing, and often when research gets a lot of public attention, "it's been bastardized so far from what the actual study says" (P9). So being able to properly communicate science is seen as an important step, and "we need a lot of science communicators" (P9).

It's seen as very important where research results are published,

> because a very big majority of research work is communication part, I mean you might have a brilliant result, but if you don't communicate it with other people then it's kind of, yeah, you're

> not adding much to the world, let's say (laughs). So, yeah, it's important to identify the target group or the people who are eager to listen to you, indeed. (P4)

To disseminate ace research a good starting place would be to post summaries of research on AVEN or Tumblr, so that the research becomes accessible to people (in this case the audience is people who identify as ace/aro). In general, participants think the more widely spread research gets the better, because it will increase the access people have to the research. “And also the more widespread your publication, the better the chances that the people who are interested or affected by it will actually see it.” (P2) But one interviewee says they know there are always many restrictions to how a researcher might publish their research. But if possible the goal should always be to publish the research both in the way the researchers “usually officially publish things” in their discipline, like in a journal, but also for the researcher to “just spread it on the Internet via various things, because that's how you really reach people” (P2). This seems to hold true not only for asexuality, but generally for research. In the case of asexuality research, this second route of disseminating knowledge would work, for example

> you could find certain, like, there's obviously AVEN who will spread, spread stuff. Or specific Internet personality people, like specific Twitters or Facebook groups or Tumblrs specifically that will spread things on their- spread it on their own to their huge, to their followers who are actually interested in the topic. Because like otherwise, if you don't know where to publish it on the Internet, you are just shouting into the void, right? […] I think it, it isn't that difficult, if you know (.) where to turn to, right? (P2)

Here the work lies clearly with the researcher, and seems doable, with the biggest obstacle being knowing where to put the research so it gets spread.

While some participants view “ordinary people” (P4) as the audience, others imagine only researchers and people identifying on the spectrum as the audience for research: “I don't think the general population looks up random studies on their free time [or at least most] of them don't.” (P3)

Most agree that knowledge of asexuality shouldn’t only spread to academia, but my participants “think the scientific community is a, is a great first step.” Academic research is also imagined as having a snowball effect. As we’ve already seen in a previous chapter one of the reasons for there being little research about asexuality is that there is little research about asexuality. So research can lead to more research being done, as it spreads awareness that asexuality exists to other researchers in those fields.

One other way to spread awareness, that is imagined as part of a still faraway future, is that asexuality is taught in sexual education in schools.

Looking more in-depth at how the work for *spreading awareness* is imagines, one participant imagines there are two ways people could get to know about asexuality.

> One is them knowing an asexual person, so if more asexual people (.) are open about it all the time, but it's also not the duty of each individual ace to be a spokesperson for the community, so it's really based on them whether or not they wanna come out and be super open about it. I think the other thing mainly is the media, there really aren't any aces in the media, except a few negative portrayals, in which they don't even use the word, so (sighs) I think it's mostly based on the media, honestly. (P3)

So we see that asexual people could do the work for asexuality to be more known, but are not required to. Whereas media could and should do more.

One way ace people are however seen as being obligated in some ways to help with *spreading awareness* is through research participation.

> I think probably some of us are willing to and wanting to participate in research not necessarily for us, but also so that we can point other people who are skeptical about, you know, whether asexuality really exists or whether it is, you know, a legitimate identity, we can point them in the direction of scientific papers or academic papers to not only increase their, you know, understanding of the topic, but also to validate that, you know, hey, it's not just a bunch of weirdos on the Internet who picked up this term. (P5)

6.5. Authority of academic knowledge

Coming back to the beginning of this analytical chapter (6.2.1.) I want to take up the notions of expertise and authority again, and ask how it matters where knowledge about asexuality comes from.

6.5.1. Media as a contrast

In this subchapter I will look at how asexuality in media is viewed by my participants, to see what the parallels and differences are to academic research. Media about asexuality was not the focus of my thesis, but it did come up in many interviews. As we have seen already at the end of the first analysis chapter (6.1.3.3.) one of the fixed points of narrative that was mentioned in the interviews was an example from media - a Dr. House episode. In later interviews I also started asking my participants specifically about media to get an understanding of how important academic research was to them relative to this. Especially after finding out that *spreading awareness* is one of the main imagined benefits, I was curious about how else this was viewed as being achievable, other than through research.

Most of the participants haven’t seen much ace-representation in television, and if they have it’s usually not felt to be a good representation. “In general, in like media like in, in film and stuff, it's portrayed in a way that's, like, pretty damaging I guess. Because, most characters, who are either openly or sort of implied asexual are sort of very cold and unfeeling. Or it's a problem that gets fixed.” (P10) In the Dr. House episode for example it is portrayed as something that isn’t real and can be fixed. Here again we see, that my participants see this as *asexuality as wrong-known* - media is representing a view of asexuality that is not correct. However, one participant mentions vis-a-vis the ‘cold’ stereotype:

> I know lot of people are like trying to get away from the the, the ace stereotyping, like cold and scientific, but that's, that's basically me, so I-I like seeing those types of characters, but I know like a lot of people wouldn't. (P9)

This is an important aspect for many of my participants, that they felt it was important to be able to relate to asexual characters portrayed in media. One participant mentions knowing a few ace characters on television, such as Todd from Bojack Horseman, “but I didn't really like, it didn't really like resonate with me? So I didn't really look into the shows.” (P9)

Here then we see that there is difference between more awareness of asexuality and representation. While with awareness it is important that other people see it, with representation the participant themselves are the only audience.

Other participants stress the fact that in almost every movie or TV show there is a sex scene, or at least a kissing scene.

> If you're not in a relationship in a movie you're considered as a loser or, yeah, a sad one and the one who is left out of the group of friends and stuff. And, yeah, so it really gives you this perception that happiness equals being in a relationship and especially being in a physical relationship. Therefore I think, yeah, media is really important in this. So, we have no place in media, let's say. […] As I said, all of the excitements are in relationships, let's say, it doesn't matter if it's in, yeah, a printed version or TV. There's just no attention to us. (P5)

The interviewees all felt “very, very underrepresented” (P10) in the media. And if there is an article on asexuality, for example, then “the gist of it tends to be, oh look this is a thing. And I kind of feel that maybe we should have moved past that?” (P10) While on the one hand we have seen that exposure and visibility of asexuality are very important to my participants, some do mention a wish that media and research move past the question of whether asexuality exists and onto more interesting or urgent things.

But another participant counts some of those articles as good asexuality representations. It is getting more common, they say, that online news sources, at least those that focus on LGBT-specific stuff or have a feminist perspective,

> publish a reasonably well-done article on, this is what asexuality is. Which is good to see. It's also interesting to see that usually every time after one of those comes back you can see a little bit of a spike in the number of people who are visiting and joining AVEN, [which] is cool to see. (P5)

So more awareness through media can also lead to more people identifying as asexual.

Another question I asked was actually about media and which sources to use: asexual people's experiences or academic research. This built on the one hand on my observations and the kind of articles I saw and that there are those two or some that combine them. When asked most participants agree that media articles about asexuality should use both academic research, as well as personal stories as sources for knowledge about asexuality.

> Well, I think it, it probably would accomplish most sort of, like, with a combination of the two. Like, for some people, some people put a lot of value on there being research in order for them to kind of accept something as real. But, like, if you, if you are only looking at scientific research, it becomes very impersonal and sort of far removed. Like, oh yes, these people exist. But you don't think about them as like, oh, that could be someone you know. So, you should be more sensitive about it, I guess. (P10)

Even if people are aware of asexuality, they might not be convinced of its reality, which is where the authority of academic research comes in.

> I think [media] probably plays a bigger role than the academic papers in terms of exposure, because a lot more people are going to read a tabloid article or some sort of, you know, online news source than they are likely to go to look in a psychological journal for a paper on asexuality. But the media is also more likely to be a mixed bag in terms of, how accurately or how negatively or positively they portray asexuality. (P5)

Academia is then in contrast seen as less of a 'mixed bag', meaning that portrayals of asexuality are seen as more accurate. While we have seen that quality is seldom imagined to be an issue regarding academia, in media concerns about the portrayal of asexuality come up quite often.

One participant, for example, thinks that media on asexuality can be done well, but can also be done badly. But science in contrast is imagined as making an effort to portray asexuality well (P7). This is felt to be in part because research follows certain criteria, such as sample sizes and reproducibility of studies. Concluding, the interviewee mentions simply trusting science more (P7).

6.5.2. Authority of academic knowledge?

One effect of academic research on asexuality that cropped up in all my interviews, is that having academic knowledge gives a sort of authority. As we will see this authority works to the outside, towards other people and society as a whole.

In the following part more light is shed on how benefits of research are also linked to academic knowledge having some kind of authority.

> I think well anyone, everyone could profit from [research] to some degree because it's just more information about people who live in our world on the simplest level. Then of course, asexuals would immediately benefit from having that information and maybe profiting in feeling reassured or by having actual numbers to point out if someone's doubting them. And that's the other thing, if you have actual research to point to it's much easier to like reassure- or parents that are worried that their child is sick because they are not interested in sex, or people who doubt that asexuality is real. The more research there is, the easier it is to disproof that. (P2)

Here then, the persons to whom research has to spread are people identifying on the aro/ace-spectrum. On the one side this offers them “reassurance” by again, normalizing asexuality. On the other hand they profit by “having actual numbers to point out if someone’s doubting them”. In the last part of the segment the participant says that academic research can help disproof anyone claiming asexuality is not real. For the effect **academic research as authority** the research was important to be made and exist, but it did not have to travel and go anywhere or do anything. Often it was talked about like *pointing towards research*, so research in this way is something that can be utilized by people identifying as asexual to proof to other people that their sexual orientation is not made up, but real.

> It probably helped a little bit in confidence at the beginning of being able to tell people: I am asexual. Not just, I found these people on the Internet, they sound like me, but also you know, I found these, you know, academic papers and they've also helped me come to the conclusion that, you know, this sounds like me and this is a real thing. And sometimes that can be helpful, when you point to somebody who's skeptical towards them, you're like: See? Asexuality does exist. Though of course with some people it doesn't matter how many papers you show them, they are still gonna believe, no we didn't have that label in our day, it doesn't exist. (P5)

Academic research is therefore seen as being able to make asexuality more real to society as a whole, and can be used as a tool when explaining asexuality to someone who doubts it exists.

But on what hinges this authority of science as proof? One participant thinks it simply comes down to "more research trying to understand [asexual] people, presumably they wouldn't be trying to understand us if we didn't exist." (P5)

The specificity and authority of *academic* knowledge and how it is linked to making asexuality real is what I want to explore next. As seen in the following statement, academic research can provide legitimacy – to oppose doubts from outside the community.

> I feel like a lot of the feeling that sort of the lesser known, like sexualities and things, is that people sort of dismiss them. [?Oh] this is just this new thing that people are inventing. And that by having sort of research on that, I guess it gives it some sort of legitimacy? Like you can say to people, no this is not just a thing that I'm making up. This is real, look there's, there's research and everything. And that's sort of, sort of one of the, the main things that people hear, like, when they come out as ace, is, oh that's not real. […] So, I think research really helps with sort of, no it's not, it's a phase, I- it's not just like, I'll find the right person eventually. It is a real sexuality. (P10)

But what is behind this legitimacy and how can academic research prove that asexuality is real? Another participant says research can spread facts really easily,

> I'm a person I like to read facts and research, so that's what I really like to rely on more than I'd say, personal, like personal stories have their p- have their time and place, they can foster empathy and what not. But (.) like actual numbers also, you also need the numbers to back it up. (P2)

Another participant does not think academic knowledge is more legitimate than anecdotes and accounts of personal experiences,

> but there are people that would be like, no it has to be recognized by academia for it to be important. […] a lot of people are like, oh it's not real and whatnot. So I think, so a lot of people they do- they would be- have to agree with like a scientific study. So it lends credibility to, to, like, the orientation. (P9)

One participant (P8) says whether research comes from outside the asexual community does not make a difference to ace people reading and learning about asexuality. But,

> I think it would make a difference to the general public to know that, okay some actually qualified people made a study on asexuality because they're not asexual themselves, they have more credentials or, or precedent to have an authority on what is important in our lives and what isn't. That would be a resp- that would be a public response, definitely. (P8)

Others too (P5) see the authority of academic knowledge located in the lack of bias.

> I think the idea of having somebody who is not supposed to be biased, somebody who doesn't have a sort of reason for deciding that this is a disorder or not a disorder, that these people are, you know, mentally stable or unstable or these people are, are just making things up or not making things up. I think having this come from somebody who doesn't have a reason for deciding one way or another, makes other people more likely to accept their decision or the ideas they have too. (P5)

To the outside, people who do not identify as asexual, academic research can prove asexuality exists. It can be used as a tool and a resource in case asexuality is doubted. In all cases we will see that it is actually not knowledge about asexuality that is sought, but recognition of asexuality.

But does academic knowledge also have an influence people on the inside, people identifying as asexual? One participant (P7) says both academic research and accounts from asexual people have their advantages. With direct interviews, you see experiences in which you can recognize yourself (and your own experiences). Academic research on the other hand offers more general knowledge. It is imagined as easier to argument with academic research when explaining, which shows how research and the credibility it offers can be a tool and a resource. And it also shows that explaining goes hand-in-hand with arguing (for it to be real).

In another interview it is stressed, that while research is important,

> for me the most important thing always is our own voices. And our own narratives. And that we, we can [?talk] directly to people from in papers and in articles or in, or in blogs or in talks. That our voice is, is more important and that research can help, but we, we- our voices are the most relevant in this, in this conversation. (P6)

An important part on how academic knowledge can affect people identifying as asexual is the definition of asexuality. We've already seen before that research is not beneficial if it does not get the definition of asexuality right. When asked how reading research that uses a 'wrong' definition of asexuality affects her, the participant offered the following answer,

> It doesn't anymore, because nowadays I'm sure enough in my identity, at least for the moment […] like I'm in a sure enough place at the moment, that that doesn't really affect my identity. Anymore. (P2)

Here we see that while academic research can offer legitimacy when faced with doubts by people who do not identify as aro/ace, the definition of what counts as asexuality is untouchable by academia. Researchers can generate more knowledge about asexuality, they can help normalize it by spreading awareness, they can search for reasons why people are asexual, but they cannot change what asexuality *is*. Even though participants said that there are still debates as to how asexuality is defined and what subcategories it encompasses, those debates are situated within the community.

And while research that uses ‘correct’ definitions was also seen as being able to help get to know oneself better and feel validated, there are limits as to what it can do,

> […] If you are part of the community you'll have other things to worry about and figure out about yourself, like, that just research can't help you with to some degree. Like accepting yourself and what not. Research can help of course, because it can give you facts, it can give you statistics, it can give you clear numbers. But a big part of that just has to come from within yourself and from the people around you and well. (P2)

Here again the benefit of academic knowledge lies in being able to “give you facts”, but there are other components it “can’t help you with”. There is a part inherent in the asexual identity that can come only from the person themselves.

6.6. Findings: Analysis 2

How are the possible effects of academic research and knowledge about asexuality and their realization conceptualized?

The second analysis chapter tackled the question of how the possible effects of academic research and their realization are conceptualized by my interviewees. Linked to this is a very crucial aspect to ask to the data, that is heavily influenced by public understanding of science as a theory, namely who the imagined audience for research about asexuality is.

Going back to the beginning of this chapter, which recounted the HSDD case and how the asexual community and academia met, I have shown that years after this encounter it still matters to members of the asexual community how asexuality is known of.

Questions asked in this chapter were: For whom is it important to have knowledge of asexuality, and for whom knowledge about asexuality? Who can and should do the work to realize visibility? One finding is that getting to know asexuality exists differs significantly from getting to know more about asexuality.

The title of the chapter, ‘Unknown, but knowable’, speaks on a first level of asexuality, and how it is not known by many people or in academia, but it could be known. ‘Knowable’ describes that the existence of asexuality and people who identify on the ace-spectrum is not contingent upon whether it is known. Asexuality, and especially the definition of asexuality, is seen as a truth. Research has the power to show this truth (i.e. depict asexuality correctly) by spreading awareness that asexuality exists, or it can be used as a tool or resource to prove asexuality is real. As such academic research is seen as functioning as one way of knowledge transfer into society. But research cannot change what asexuality is. Only the community could change how asexuality is defined.

The benefits of research are talked about only in terms of potential. Impact of research is not perceived as having already happened in some form, but as something that will or might happen. Very seldom research is seen foremost as directly beneficial to people who already identify on the ace-spectrum. Research does not play a direct role in the lives of my participants, but the effects of academic research are rather seen as spreading awareness of asexuality to people not (yet) identifying as asexual or aromantic. This spreading awareness of asexuality is seen as the central benefit of research.

The audience for whom this matters is imagined as a broader, allosexual, public, which also contains people who are asexual, but do not know it yet.

7. Analysis 3: Motivations and rationales of engagement with research in the absence of controversy

How are practices of engagement with research about asexuality perceived and rationalized?

In the previous chapter it was shown that research for the most part is not seen as having a direct impact on my participants, but the major effect of research is rather seen as spreading awareness to people not (yet) identifying as asexual. And yet, many instances of engagement with academic knowledge can be observed also in the absence of controversy, from reading research to participating in this interview situation. The third analysis chapter therefore seeks to answers how practices of engagement with academic research about asexuality are perceived and rationalized by the participants of my study.

In a first descriptive sub-chapter I will reflect on instances of engagement between academia and the asexual community I have observed before I started doing my interviews.

Next, I will show what different instances of engagement with research my participants mention taking part in, and their motives and reasons for doing so - the practices and rationales of engagement with academic research. Examples include reading research papers, discussing research with other people, archiving research, and participating in research studies (especially this specific interview situation).

In the following I will look at how engaging with research comes to matter to my participants. For example, by taking a closer look at *looking up research,* a pattern can be observed: while people who were new to identifying as asexual reported that looking up and reading research had an effect on them personally, people who felt steadier in their identity told of their interest in research changing over time and that they no longer looked up research as much as they used to in the beginning.

The last sub-chapter deals with how the asexual community and its relationship to academia is conceptualized, including what role the forum, AVEN, plays in this.

One finding of this chapter is that while all my participants are interested in participating in research, not many are interested in reading research. This shows that wanting research to exist and wanting to know about research are two different things. And only participating in research is seen as having the potential to affect change.

7.1. Observations about engagement after controversy

To set the scene for this chapter I want to go back to my initial interest in this research topic. During a seminar on standards and classifications in medicine, I had read a paper about the HSDD case in the DSM (see chapter 6.2.1.). While looking for information and accounts of how the change in the DSM came about years earlier, I was surprised to find that the asexual community was still occupied with academic knowledge about asexuality. Having an addition in the DSM that put asexuality outside of the realm of medicine, and made it clear that it was not considered a psychological disorder, seemed like a success that required no follow-up entanglements between the asexual community and academia. But while researching I encountered academic papers about asexuality, calls for research participation, discussions about scientific articles, and many other instances that showed the continued interest of both academia and the asexual community towards each other. This ‘engagement in the absence of controversy’ is what drew me first to the topic of my thesis, and the rationales of which I set out to discover.

In a first step to gain a closer understanding of what these engagements entail, where they are located and who is participating, I will look at where entanglements between academia and the asexual community can be observed. This will not be a complete list, as some interactions cannot be observed[6], but rather it should serve the purpose of giving an overview of what engagements I have observed and have thus informed me in my research.

7.1.1. Engagements in and around AVEN

During the course of my research I came to notice several instances of engagement with academic research, most of which were gathered around AVEN. One unique aspect of the forum is that it is one of the, or even the only, place researchers interested in asexuality use for recruiting participants and sometimes the forum itself is subject of research (as seen in Hinderliter, 2016). An interview participant mentions:

> AVEN is usually the first place that people find out about asexual when they type a question on Google or they see an article and they link to that website. So, it's kind of the collective point of all asexuals, or most at least. So, I guess it's the main entry point for people that want to research asexual people, asexuality. It's the best point to reach out to people, because there are so many collected there. (P1)

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[6] It is not necessary to gain access to all of the spaces in which engagement with research might happen, such as different social media networks or groups which meet in real life. What is important is to remember that other spaces in which the asexual community operates exist and that my research is influenced by what I did and could observe

During my own process of recruiting people for interviews, I noticed a few peculiarities: While most of the forum is public and visible to non-members and research seems to be encouraged, the moderators of the forum still function as gatekeepers regarding calls for participants. On the forum, there is a thread called 'Rules for researchers and students' (timewarp, 2017) - wherein rules of conduct (for example for recruiting participants) are laid out. It was updated early in 2017 and begins with the following paragraph:

> The asexual community is very interested in promoting research on asexuality, and we want to do what we can to help researchers in their work. To help ensure the well-being of members of AVEN and to promote communication with members of the asexual community throughout the research project, we ask researchers to follow a few rules. (timewarp, 2017)

To be allowed to post a call, one has to submit a description of their study, the consent form, and the participant information sheet to the Research Approval Board. But beyond such expected formalities for ensuring the seriousness of the research proposed, there were other interesting instances to be found in the rules. Researchers are asked to read an 'Open Letter to Researchers' which was penned back in 2009. Already in the beginning we can see the importance put on both scientific research as well as the Internet:

> We believe that researchers have an invaluable role to play in promoting understanding of asexuality, and that a better understanding of asexuality will promote a richer understanding of human sexuality more generally. Prior to the creation of online asexual communities in the early 2000s, the study of asexuality was largely limited to isolated case reports with no means of doing more systematic research. Thanks to the growth of online communities—and increasingly offline communities as well—the possibilities for researching asexuality have grown enormously, and an increasing number of people in a variety of disciplines are studying it. As members and allies of the asexual community, we are committed to promoting research on asexuality and working with researchers in a variety of fields. Based on our experience in the asexual community, we have a number of observations and recommendations. (Lord Happy Toast, 2011)

The recommendations include for example giving the option of feedback in a survey or interview situation, which shows the interest of the asexual community in talking back to science and the investment in the findings. Researchers are further encouraged to join a mailing list for studies about asexuality (Asexualitystudies Archives, 2010), which started in May 2010. Requests to post calls for participants which are granted by the Research Approval Board are posted in a subforum which shows the relationship between academia and the forum (The Asexual Visibility & Education Network, 2001-

2012b): in the last year more than 25 calls for participation have been posted, mostly for surveys and occasionally interviews.

These insights into the entanglements of the forum with research, which go back many years, but are also very recent, were on the one hand formed by the history of asexuality with academia (most notably by the case of HSDD in the DSM), but also inform how the asexual community and its members position themselves towards research and the findings produced. The asexual community sees itself as "[committed] to promoting research".

Another entanglement found on the forum is a bi-monthly newsletter published by AVEN called AVENues, which had 'Asexuality & Research' as a topic of an issue in 2016 (The Asexual Visibility & Education Network, 2016). In this newsletter, several studies about asexuality are summarized and a researcher is interviewed. Furthermore, members are asked as to why they think that research about asexuality is important – the answers to which (such as that it is important for being publicly understood and accepted) have influenced me in my expectations of the reasonings of my own interview participants to which I posed a similar question. How did that work out? Did I get similar/different answers?

7.1.2. Bibliographies

What I also stumbled upon very early in my research in this topic were bibliographies which collect academic studies about asexuality (Sennkestra, 2017; CosineTheCat, 2016), where motivations for participating and reading research can be observed. As such it is stated that this specific bibliography has as its aim to help asexual community members gain a better understanding of asexuality and follow the current research.

7.1.3. Asexuality conference

Many asexuality conferences have been held, starting with the first International Asexual Conference, which was held at the 2012 World Pride in London.

The announcement for the conference in 2018, which was held in London, states in an invitation text:

The conference is open to anyone interested in asexuality, whether you are a member of the community, the media, a researcher, a health professional, an LGBTQ+ activist, or simply someone who wishes to learn more." (The Asexual Visibility & Education Network, 2001-2012d)

7.2. Rationales, practices, and motivations for engagement with academic research about asexuality

The chapter before showed examples of engagements with research that I had observed before I began to interview my participants. Those observations informed me in my methods choices, because I then decided that I wanted to understand how participation in and engagement with research came to matter to people who did not have a medical condition. In this chapter therefore, I take a closer look at what instances of engagement with research my participants mention taking part in, and their motives and reasons for doing so.

7.2.1. Reading research

Having looked in the previous chapter (Chapter 6.2.) at where academic research is thought to travels to and who is imagined as the audience for it, in this chapter the focus will be on how my participants talk about reading research.

Many of my participants were very much in favor of more research, but could not recall any specific studies they had read or heard about and had only a vague idea of what they would find particularly interesting or worthwhile for researchers to look into. Some of my participants were unsure when answering whether they had ever read an academic paper about asexuality, saying for example "I have probably read about [asexuality research], I, I don't know what it was though, I don't really remember" (P1) or "I don't think I have read any, like, in full. But, I, I think I looked at one that was on that post on AVEN about like whether animals can be asexuals […]" (P10). This could be in part because they felt I was expecting them to have read papers on asexuality, or it shows that the content of the paper is not memorable and not as important as the act of reading it.

Another participant states that they have read some articles, but mostly read about people's experiences, so personal stories and anecdotes. When asked if there was a specific article they remember:

> Not that I can clearly remember of, but, well, I don't remember the name of the article or the writer but there were some researchers about relation between happiness and single-being a- and also the proportion people who are single and asexual. And, yeah, that's something that occurs to me at the moment. (P4)

Which again could point in the direction that after reading not much happens with an article and the act of reading as engagement is more important than the content of the articles.

In another interview reading research is imagined, however, to have an effect on oneself,

> I think when you read research about asexuality it kind of validates your identity? Like, yes, people are taking this seriously and people believe me, when I tell them this. It's, it's kind of validating. (P3)

One participant (P7) tells that she looked into academic research on asexuality briefly a few weeks ago. During an afternoon she skimmed a few papers, but states that there wasn't anything where she thought she had to look closer. "And for myself, for the ‚Hausgebrauch', tumblr is sufficient. To understand myself, and be able to assess myself and such things." (P7, translated) Here a distinction is made between different uses for knowledge about asexuality: For their own 'household use' (Hausgebrauch) Tumblr is sufficient, but because the interviewee is studying to become a biology teacher, they are also interested in reading more scientific texts, to be able to argue the case of asexuality better. For this purpose searching on AVEN for scientific knowledge about asexuality seems better researched and more trustworthy than Tumblr, and the sources of arguments are easier to trace.

As obstacles to reading research, three things are mentioned:

Some of my participants (P3) state that they would read research about asexuality, if they knew it existed or would know how to find it.

Reading research is "a really huge time commitment for someone who, who does not have a scientific interest in the thesis itself, just like, a personal interest, or whatever, it's a huge time commitment and you also need to, like, get through a lot of very scientific phrasing that might not be natural or you to read, right?" (P2)

A lot of academic papers on asexuality are behind a pay-wall and not accessible, which is seen as the biggest obstacle to reading research.

Most participants agree that academic research in general should be more accessible and that it shouldn't be paywalled for people without an institutional affiliation. Some participants mention that they have, or used to have, access to most papers because they were studying at university. Research is seen as developed for humans to know about themselves, and therefore hopefully a system can be achieved that makes research more accessible. One participant (P6) says that they know it's not the researcher's choice whether it is accessible, because the institutions or whatever make them publish in those journals.

> It would be great if, you know, people could access whatever scientific or academic papers they wanted, whenever they wanted, but I also understand that the journals who publish them have

> to put so much, you know, time and effort into making sure that they get the best papers and that they get, you know, edited properly, that I understand why they have to, you know, charge people money to view them. (P5)

Previous to my interviews I had expected that people would be of the opinion that specifically research about asexuality should be accessible to people identifying as asexual, in part because by participating in studies they contributed to it being made. But in the interviews none of my participants mentioned any sort of proprietary feelings about asexuality research or that they could demand something like access to research papers from academia. Only that they had to participate, so research could do *them* a favor.

One way that is mentioned to subvert the problem of accessibility is doing bibliographies, that is archiving research.

While we have seen a few instances of how engaging with research comes to matter in experiencing identity, now we will look at how experiencing identity comes to matter in engaging with research. At first I was baffled by the contradictory answers of my participants about whether research matters to them personally and how they experience their identity. However, a pattern emerged: people who mentioned being new to identifying on the ace-spectrum differed in their opinion regarding this, to people who had identified for a longer time. I then tried in following interviews to more specifically ask my participants if their interest in research had changed over time and found many persons for whom it had and only one for whom it hadn't.

> It's been awhile since I've gone looking for particular papers. I looked a lot when I first found asexuality [?there was] this kind of looking for validation of: yes we exist and not just, you know this random group of mostly teenagers online, but, you know, we exist in a way that even some, you know, academic communities acknowledge that, you know, we exist. (P5)

In this interview excerpt we see many themes from the second analysis chapter again - namely that research is seen as providing validation through acknowledgement of asexuality by the academic community. What is interesting is however the first part of the quote, in which the participant tells that "it's been awhile since [they have] gone looking" for research, but that they "looked a lot when [they] first found asexuality". During coding my data I came across a lot of instances of *looking up research* in my interviews. But delving deeper in the mentions my participants made I was at first curious about *how* they looked up research, but quickly realized that it was the *when* that was interesting: Except for one person all my interviewees who introduced themselves as not being new to identifying as asexual (usually longer than half a year, a year), told me that they *used to look up research more* than they did now. Those participants recount being more interested in research about asexuality “in the beginning”, when they first started identifying. At that point, they mention wanting to know more about and understand asexuality, its definitions and community. Research is used as a resource to find out more about asexuality, and make them feel validated.

A participant mentions that reading research doesn’t alter how they experience their identity anymore, “because nowadays I'm, like, sure enough in my identity, at least for the moment.” But in the beginning, when she was still trying to figure out where on the ace-spectrum she falls,

> it could be really weird if you read something that's, that contradicts a fact that you thought was widely established. Especially if the pool of research you, you have is that small to begin with, right? If you read five papers and one of them states something different than the others. It's much more condemning than if you read, like, fifty papers and one states something different. And yeah, so in the beginning, I guess, it was really hard and I think for some people it might still be, who are just stumbling upon this now. (P2)

Again we see the importance of when you engage with research and how steady you are in your identity. Another interview partner recounts that when they started identifying as asexual they were “sort of looking into the research in order to find out more about asexuality. And now it's more like I wanna participate in it for the sake of visibility. Because I'm, I'm pretty much sure of myself.” (P10) Here we see that *looking up research* and *participating in research* have different rationales.

> But I think a lot of people don't know about and so having this research done would help other people. Like, I think this would have been helpful from the before, when I was learning about myself. (P9)

Here we see that research is imagined having an effect and helping people who are not sure about their (a)sexuality, but also people in general who want to know more about asexuality. Participating is therefore seen as helping people who do not (yet) identify as asexual.

7.2.2. Archiving research

Archiving research describes that someone within the community reads the research, summarizes it and distributes it on various sites, or that someone within the community collects academic papers on one site for example (having read them is here not necessary). With the first one (the summarizing) a part of the question is also who has to do the work (for understanding) for whom (see also Chapter 6.2.4.).

In the following interview segment it can be seen that archiving research is a way to subvert the problem of accessibility.

> Well, I do th- I do think there was at, at one point, years ago, there was a paper I wanted to read about asexuality and I would have had to pay a sub- suscri- subscription fee to unlock the whole paper and, and stuff like that. I, I, I vividly remember that because at that point there was very little research at all, so (.) hitting a barrier like that wa- was, made me really mad at that point (laughs). But since then I, I don't think I have encountered that problem again. Mostly because if I can't find the, the actual research paper, if it's on the topic of asexuality, often there will be people who summarize whatever the paper said and post it somewhere online, because well the community is aware that it's interesting for most people to- like, for people inside the community to read even if they, even if it's not possible for them to pay, so they will summarize it and note any interesting finds. (P2)

Archiving research did not come up in many interviews, being only mentioned by three participants. But one person I interviewed has been working on a bibliography for some years by now. She does not actually read all the papers, because her interest is not in the content, but stems from the fact that she is a library and information scholar and has the skills to do a bibliography. She personally isn’t that much interested in specific academic research, but she does it “to help people find information”.

7.2.3. Disseminating research: Discussing research and the Asexuality Conference

As we’ve already seen in the previous analysis chapter, spreading awareness is seen as an important possible benefit of academic research (Chapter 6.2.). One of the points that interested me was what happened to academic papers about asexuality. By whom were they read? And if they were read, would that be the extent they traveled or would they be talked about with someone else?

Only one or two participants briefly mention talking about academic research with other people. Others give reasons of why they do not discuss research.

One obstacle mentioned to discussing research on asexuality is that some of my participants (P4) are not really out. One person for example notes that while she is interested in research about asexuality and would like to discuss it, she imagines that in a real-life situation people would then immediately ask her why she is so passionate about this topic - inherent in her statement is that only people who identify as ace or aro are interested in asexuality - so discussing research about asexuality would equal coming out as asexual, a situation which she does not want to happen or is not ready for. If it were an option to post anonymously in a group about this, she definitely would do that.

Another interviewee mentions being shy at the time when they read academic papers on asexuality as the reason for not discussing them, but they would read what other people had to say about the papers online. Of that they say:

> So, some of it was interesting, when people would sort of pull apart different parts of the paper and really look at, you know, whether they think the way this person went around, you know, researching asexuality, whether they thought this was, you know, likely to be a good representation of the community or discussing, sort of, particular parts of the paper. The people who were more likely to pick out, like, one sentence that they didn't feel comfortable with and then go on a long rant about, they weren't quite as interesting. (P5)

This goes again to the question what does discussing articles do.

For another interviewee the reason for not discussing research is that their friends are not interested in research or statistics. But,

> If something comes out related to asexuality though, we usually talk about it in our [asexual club at university]. And that's always fun, because there's usually not any ace news (laughs), so whenever there is some, we all get excited. (P3)

One participant mentioned the Asexuality Conference to me, saying she was interested in going, but couldn’t due to work.

> Okay, my first intention would have been that I have never met another asexual person in my life (laughs), so I think it's a place that I also read that other asexuals were going to participate there, so I really wanted to meet people in person rather than just reading and or texting them on Facebook or other social media. So, that was my first intention, and secondly I also wanted to talk to resear- researchers and maybe, yeah, just tell these things that now I'm telling you, that they could help us or society, with what they do. And also hear about the new [research] in this regard. (P4)

For this person attending the Asexuality Conference would fulfill a lot of other reasons besides disseminating research.

7.2.3. Participating in research

Having shown various forms of engagement with science, which consisted of people interacting with research in a one-way way, this section looks at a specific form of engagement: participation in research.

Due to the self-recruiting format of my study, all of my participants could be described as being in favor of participating in research, as they had answered my research call. Therefore I can only look at the motivations of my participants for participating in research. To look at how people thought of participation in research, I asked after their experiences with previous research studies, and looked at how they reflected on the specific interview situation they were in with me and how they enacted themselves as research participants.

While many of my research participants had not participated in research before doing the interview with me, a few had previously participated in surveys. For most of my participants it was the first interview situation they had participated in. It was noted as positive that qualitative research offers the possibility to get in-depth information about asexuality (P9, P2).

> Which I, which I really like, because (.) often when you kn- these studies, study requests, things you find online, they are very superficial in the end. And the questions that, that are being asked. And that's always sad, because if you only ask superficial questions […] your results won't be as meaningful as if you focus on specific things and go more in-depth. (P2)

The interviewee observed that research was being done via questionnaires most of the time, because it's easier. Taking part in the census by AVEN in comparison, involves ticking boxes, and is seen as offering less depth than a qualitative interview.

While the choice of method drew the interest of some participants, the topic of my research was of little consequence to most of them. Only one person mentioned that they were particularly interested in the topic of my research, the others stated that they also would have participated if the topic were different, so long as it had to do with asexuality.

The motivation of one interview partner (P6) to participate in my study stems from that they feel it is important for them to talk about the perspectives of someone who is not in the English-speaking community. The participant states that most of the research right now is in English and therefore they felt it important to participate, because they wanted me as the researcher also to know about what has been done in the Spanish speaking context. Here we see that one of the reasons for participating in research, is the desire for asexuality to be depicted correctly (here: diverse) in this research (parallels to Chapter 6.2.).

One of the main reasons for people participating (P1) in my research goes back to the previous analytical chapter and the discussion of a particular imagined possible effect of research - *spreading awareness* (Chapter 6.2.). This effect is contingent in most cases on the scarcity of research, which can be seen in the interview excerpt below:

> I have seen s- that some people have definitely researched asexuality, but (.) you don't really see too much of that, because so many people don't even really know that asexuality exists still. So, that's kind of the main reason that I thought it was important to contact you, because I want to spread awareness that [asexuality] exists. (P1)

In the above segment one can see how the motivation for research participation ("I want to spread awareness that this exists") is clearly informed by the scarcity of research ("you don't really see too much") and one reason participants gave for the lack of research is that almost no one knows about asexuality ("so many people don't even know that asexuality exists"). Incidentally the main possible benefit of research that interviewees mentioned, is that asexuality will be more widely known. Asexuality is here then not only linked to not being widely known in society, but also to the scarcity of research.

> I think my motivation comes from (.) I think, you know, it'd be a good idea for there to be more research out there for people to find on asexuality and one of the best ways that I have to make sure that happens is, if somebody comes by asking if there are asexuals, or asexuals that meet certain criteria, that want to participate in a research study, that I'll volunteer. (P5)

Participating in research is here seen as *being able to enact change*.

When asked after her motivation for filling out surveys or participating in this interview, an interviewee answers:

> Well, when I was sort of figuring myself out, I felt that there wasn't, there's not a lot of visibility or knowledge about asexuality. And I feel like, because I'm in a position where it's safe for me to be out and to talk about it and everything, that I want to do that. And I want to sort of help with visibility and things. Because I, I'm in a position where I can. (P10)

In this excerpt we can also see that visibility and knowledge about asexuality are categorized as different things, that share in their scarcity. And not everybody can do the work necessary to bring about a change in the knowledge of and about asexuality. The participant however feels she can, and therefore she should.

> Well, there are a lot of people that come new to this theme of asexuality and think, okay fine I'm asexual but it doesn't impact me that much and I don't really need or want to speak about it. Just

> kind of holds back from it. But the majority of people in the community want more visibility, especially in the media. That people realize that we're here, we do exist and I think most are willing to, more than willing to partake in these studies. Just that more people can find out about this. (P1)

Participating in research is seen as a condition for spreading awareness, almost a price to pay, and something that needs to be done by people who are able to do that. Someone has to participate in research to further the goals of the community. Another interviewee mentions, that "[…]I'm not sure [research] would help me significantly. But I would like to help others, by contributing to this study." (P9, p. 5) Here again we have *helping others* as motivation for participating in the study. The case can be made that there is an imagination of **being a good member** of the asexual community, and that means answering research calls when one is able to.

In some of the interviews, participants explained their motives with *embodied reasons for participating,* meaning that the reason they answered my research call was dependent on the kind of person they are, or the things they like.

> I'm the kind of person if I stumble across a research request for people who are asexual or aromantic, and it's something, like, it's within my power to participate or to at least apply. […] because I know that there aren't that many people active in the community or, like, active enough to at least to get those research requests (laughs). So, so, I at least apply to, because we, because to get this kind of research we *need* participants. […] So, yeah that's, that's why I applied, just because I think, I, I kind of see myself as, as having a bit of a responsibility to at least try to help if I can, if I want to see any research on this topic (laughs). Like, if, right? H-how can you expect change if you don't, if you are not willing to do anything for it, right? (laughs) (P2)

The above quote is the answer of one of the interview partners on why they answered my research call and chose to participate in this study. She starts of by stating that "[she's] the kind of person" that answers research calls, giving an insight into the linkage of identity and attitude towards research. While here she says people in the community are not "active enough", in questions about the general attitude towards research, she stated that the community looks favorably on research, saying "generally I think people welcome new research and if possible are happy to respond to those requests." (P2) The motivation for participation is linked to the imagined benefits of research. We see this clearly in the segment "I […] apply because to get this kind of research we need participants". In the next sentence, it becomes apparent that there is also a feeling of responsibility in the sense that if one is able to, one should "try to help". By helping (I.e. participating in research) she wants to effect "change", telling that the current situation is not desirable. One aspect of the situation that she want to change is that there is little research about asexuality being done, and little awareness of asexuality. While in this segment of the data, the interviewee equals being able to help, to fitting the research call (i.e. falling in the right category) in other interviews more aspects of being able to help were mentioned. Examples are being comfortable talking about one's sexual orientation, having a private place to talk, having an Internet connection, not being shy, and being able to hear. The participants who mentioned these requirements for being able to participate in research never questioned the willingness to 'help', only the opportunity. Another example for an embodied reason for participating, is an interview partner that says, „I'm like a really science-oriented person, so I love to be able to contribute to, like, to academic knowledge about this." (P9) When using embodied reasons for participating, it seems as though there is no effort or choice involved in the research participation.

Overall we can see that participating in research is imagined as having an effect on other people, way more so than other forms of engagement. While reading research is seen as being able to have an effect on yourself, by participating in research my participants feel they can affect change. "[W]e do need to have of course some volunteers otherwise we don't, we're not going to get anywhere." (P1)

7.3. Community and its relationship with academia

After conducting the first interviews and starting initial coding, I realized that the use of the term 'community' had gone unreflected by both me and my interview participants. When I first started to research asexuality, I found most information on the AVEN forum. I had assumed that if not all people identifying as asexual, then at least all of my participants, would be members of AVEN, because my research call was posted on AVEN. As only a small interview sample was possible in the scope of this thesis, this did not matter much methodologically, besides including a few questions on the role the forum plays for how my participants engage with research. However, already the second person I interviewed, stated that she is no longer a member of the forum and encountered my research call via Tumblr (as AVEN disseminates research calls to other social media platforms). In the following interviews, I tried to look closer at how my interview participants conceptualized the asexual community, and what role this community plays in how they engage with and relate to research. To gain a better understanding of the term 'asexual community', I will turn my eye to the Internet, and show how the affordances of the Internet are commonly agreed as what allowed for the formation of a community around asexuality. The forum and its relation to community is investigated, with a special focus on the role the forum plays in providing and regulating access to research participants.

7.3.1. The forum and its role for community

The Internet plays a big role in the formation of communities and identities. There are various studies looking at how the Internet facilitates group formation - be it of patients or of members of the same sexual orientation (see for example Dumit, 2006). Hinderliter (2016) too observes that “technological, social, and economic changes in recent decades have led to new possibilities for communication and for forming communities that are not tied to a specific geographical location” (p. ii) and states that although mentions of asexuality in newspapers and academic works can be found earlier, there is no evidence of asexual organizing prior to the 1990s, adding that,

> a number of lines of evidence suggest that widespread use of the Internet has been necessary for the development of asexual discourse. First, after considerable searching, I have been unable to find any pre-Internet asexual organizations with any sort of continuity with online asexual communities. (p. 7)

Scherrer (2008) also talks about the importance of a virtual space in which a common language can be found for the forming of an asexual community. It can therefore be argued that the formation of an asexual community is closely linked to the Internet, which is also mentioned by some of my interviewees:

“There isn't much outside of the Internet as I've seen about asexuality really. So, without the Internet I probably would never have found out [that I was asexual].” (P1)

And while there might be earlier instances of groups forming around asexuality around forums, blogs, or message boards, the emergence of an asexual community is most often traced back to AVEN (The Asexual Visibility & Education Network, 2001-2012a) - an Internet forum that was founded in 2001. This is also mentioned by interview participants:

“I think AVEN was the beginning of everything and I still think the largest ace presence on the Internet is in AVEN.” (P3)

In the interviews, it also becomes evident that AVEN functions as a source of knowledge about asexuality. This can be seen by participants mentioning how they searched for more information on asexuality on the Internet and stumbled upon the forum. In the following interview segment *looking up asexuality* and the *finding of a community* are closely linked:

> Well I looked it up, I just typed asexuality in google and I came to aven.org - Asexuality and Awareness Network […] and it's nice to see that there are other people who feel the same way, those things, experience things similar to me. Because in real life I don't know any other asexual people and most of my life I thought that I was the only one experiencing things differently. (P1)

While this participant mentions that in real life they don't know any other people who identify as asexual and the asexual community for them is therefore limited to whatever is happening online, other participants talked about being part of a group of asexual people who met regularly in real life (most often these groups were founded in the context of university and life as a student, and all depended on the Internet to be able to meet up in real life). These different accounts serve as an example for how difficult it is to generalize what the asexual community is, whom it encompasses, and where it exists, while also reminding us that not all spaces in which entanglements between asexuality and research might exist are observable for me as a researcher.

While in the beginning I thought most of the activities of the asexual community would be limited to AVEN, I quickly found out during my interviews that there are communities on other social network sites, such as Tumblr or Facebook as well. In one interview a participant was asked after the yearly AVEN census – a survey organized by AVEN in which questions regarding nationality, age, and sexual identification, are asked. In the interview, they mentioned that, "they started on AVEN and then all the other asexual communities of the Internet – because everything is linked to AVEN – it'll start spreading there too and it ends up spreading all over Tumblr and Facebook." (P3)

While AVEN does enjoy a particular status among all of the places around which people identifying as asexual or aromantic group together, and is for example seen as "the hub for the asexual community online" (P5), it is important to remember it is not the only space in which the community exists. It is debatable in how much the status of AVEN has to do with how AVEN is built and organized or simply because it was the first such platform. When asked about how places like AVEN play a role in the relationship between academia and the asexual community, one participant noted,

> I think AVEN is the place that has the most relationship with academia because they are taken seriously, other places are too unorganized to really have a relationship with academia. […] it can talk kind of as a spokesperson for the ace community, because a lot of asexuals are on there and it's pretty much comprised mostly of asexuals. […] I think AVEN is organized and there's a clear- it's clear there's someone managing it. […] In other corners of the Internet, the ace community is one little pocket of a bigger site, and so, there's not as much, there's not as much I guess validity from them. (P3)

Even though earlier the same participant talked about how the asexual community encompasses a wide variety of social media networks surpassing the singularity of AVEN, here then we see that AVEN is still the one with the most relationship to academia, due to the way it is organized.

However, not all of my participants, and not all people identifying on the asexual spectrum, are members of this forum, even though they still feel as part of the asexual community and sometimes are active on other platforms. And even though groups that meet in real life are scarce, not everybody has access to the Internet and some people who identify on the asexual spectrum are therefore not able to participate in online communities and are routinely excluded from being able to participate in research about asexuality. Another point concerning the composition of the forum is that not all 96000 members of AVEN identify on the ace-spectrum, as one section of the forum also functions as a space for allies, friends and partners, who are looking for more information or to share experiences.

One participant defines community as,

> the asexual community which is not necessarily just asexual people, but asexual people who are acting actively, sort of communicating with other aces and it mostly is online, because that's sort of the easiest place where we find each other. (P10)

7.4.2. Activities on the forum

Many of my participants mention the *asexual community being small* at different instances, meaning it has few members. One of the consequences of this is seen in the interviews as that much of community happens online.

> So, a lot of it happens online, because we're such a small percentage of the community that can be hard to find each other in person, so a lot of it does happen online. Though I have met more asexuals in person then I would've guessed. I went to a really small college, we had about 350 people living on campus and I met five other asexuals there during my four years there, which really surprised me. (P5)

Finding other ace people is an important aspect of how the asexual community comes to be, and because the community is small, it is easier to find other ace/aro people online and that’s why community primarily happens online.

Another interview partner mentions that there are Facebook groups for aces at their university and that it is in part easier to meetup online than to meet in real life, mainly because “because there don't seem to be all that many of us […] not very easy to just find aces.” (P10) This statement connotates an uncertainty about the actual sum of people identifying as ace - there don’t *seem* to be all that many of them. It is unknown how many people, what percentage, identify as ace. This goes further:

> I think like aces in particular, it's difficult to be like visibly ace unless you go around wearing the ace flag all over the place. Like say for, for gay people to be visible, if they are in a homosexual relationship that's pretty visible. But aces can be any kind of romantic orientation, it's not immediately obvious that someone is ace from the outside. So, it's sort of harder to tell, like, in person. […] Online just tends to be a really good place to find other aces. (P10)

Concerns for visibility therefore also translate in real life, finding it hard to be seen and recognized by other people identifying on the ace-spectrum.

By looking briefly at what those participants, who are members of the forum, mention as doing on the forum, we can see what role it plays for them.

Many participants report that the section on AVEN, in which other ace people talk about their experiences and definitions was very helpful for them to figure out how to identify (see Chapter 6.2.). An important aspect is reading about other people with similar experiences. For some people just looking at stuff on AVEN is enough, while other people post occasionally.

> I tend to hang out in the welcome lounge a bit and welcome people, 'cause I remember how good it felt the first time I created an account and said hello, and there were all these people that were saying hello to me too. (P5)

Encountering people with similar experiences, be it by interacting with them or reading about them, is one major benefit of the forum my participants mention. Most don’t know any other asexual people in real life.

Other participants (P3, P5) mention hanging out at sections that don’t necessarily have anything to do with asexuality, for example a poll section. “[S]ometimes it's nice to just kind of wander around the other pages and talk to other people who are asexual about things, that are not necessarily about asexuality and just kind of hang out.” (P5)

Another participant (P7) tells me they don’t care about the community, and don’t need one.

The opinions on whether AVEN is a good site to keep up to date on and get to know academic research differ. While some (P4) are of the opinion that it serves this purpose very well, others (P5) think that beyond the research participation request page, there is not much from the academic side on the forum.

7.4.3. Community opinion about research

Because I chose qualitative interviews as my method, in my data I can only look at how my participants view academic research. And as these participants are self-selected, the chance that one of my interviewees was critical towards research was slim. I did however ask my interview partners how they thought the asexual community thought about research, which gives an interesting start to look at how they conceptualize the relation between the community and research.

Some participants mention only noticing that the asexual community in general has a favorable opinion about research. “[M]ostly I think because we have a lack of awareness of asexuality, anything that takes notice of us, we get excited about.” (P3) And people in the ace community are interested in seeing more research and participating in research. “[G]enerally, I think people, people welcome new research and if possible are happy to, to respond to those requests.” (P2)

In other interviews this pro-research attitude of the community is slightly mitigated (P5, P7), with interviewees being of the opinion that a

> particular sort of section of AVEN is definitely pro-research, but as for the community as a whole, I think a lot of people there go just to hang out with other people like them and aren't necessarily interested in participating in interviews and surveys. (P5)

Overall none of my interview participants can remember any incidents where the asexual community was criticizing research (except for the HSDD case).

One participant (P6) however, does mention that she thinks people in the asexual community need to be more critical towards research. In her opinion a lot of asexual people think about research for validation more than research for knowledge. The reason why the community looks to research for validation is seen as rooted in the beginning of the asexual community, in the 90s and 2000s, when the whole view of asexuality came from the few researchers talking about asexuality. And while this is seen as understandable, to still look at research for validation is viewed as problematic by this participant, but she doesn’t know how to go about changing the views of the community.

7.4.4. The role of the forum in the relationship with academia

Many participants think the forum plays a central role in connecting academia and people who identify as asexual, because AVEN is usually the first place that people find out about asexuality.

> I'd say that like AVEN is sort of the largest sort of body that sort of represents the asexual community and stuff. So, it sort of ends up acting as a link between the community and, like,

> academia or just, also just like the wider community. If people wanna know stuff about asexuality, AVEN tends to be where they go. (P10)

So, researchers looking for information about asexuality or wanting to recruit participants, often land at AVEN. The reason for this is seen that AVEN is simply the first thing you find when you google asexuality. The forum however plays not only a role in linking researchers to the asexual community, but also linking the community to research. One participant for example mentions that on the forum sometimes people ask if there has been any research on a specific topic and then people link to research papers and other resources (P10).

Another participant thinks the forum plays a part "in sort of connecting people who want to do research and people who are willing to participate" (P5).

> So, I think a lot of people in the asexual community would be less likely to find these surveys and research opportunities if the forum wasn't there, because if they don't get posted there, people would probably need to go search for opportunities to be a research participant, which I think probably most of the community is not motivated enough to do research to actively go and look for it, but if it kind of, if it comes to them they're much more likely to participate, I think. (P5)
>
> I think AVEN is the, is the p- place, that has the most relationship with academia, because they are taken seriously. Other places are too unorganized to really have a relationship with academia. […] I think that AVEN is kind of the most situated to have a relationship with academia, because it can talk kind of as a spokesperson for the ace community, because a lot of asexuals are on there and it's pretty much comprised mostly of asexuals. (P3)

The management and organization of the forum is seen as one of the main reasons for researchers choosing to communicate with the asexual community via AVEN.

> So, if you, for example, if you put, if you are trying to contact the ace community of Tumblr, it would be extremely hard to contact them, because there is no one person you can send it too and know that most of them will see it. There's not like one forum, it's just an interconnected web of people who know each other. […] With AVEN they are all in one place, I think that helps a lot. (P3)

This then gives AVEN the necessary requirements to be the spokesperson for the asexual community in regard to matters of research. The forum is also seen as doing the work necessary for this responsibility (P7).

I was also interested if my participants had observed any interactions between the asexual community and researchers, after a study has been finished. And whether they thought there should be a way to give feedback on research, as this was mentioned in the ‘Open Letter to Researchers’. A participant mentions she (P5) doesn’t think there is much communication between researchers and participants or the community after the study is done, although it would probably be a good idea.

> Probably the most we get is, sometimes at the end of the survey it'll be like, is there anything else you want to add or is there any way we could have improved this study, but other than that there is not a lot. (P5)

An opportunity to give feedback on research, is seen as something “we get”, so as something that researchers have to provide.

> I would assume it might be advantageous for the researchers to have a way to kind of get feedback on whether people think that the way they've conducted this research is, you know, was a good way to do it, were they missing some topic that they probably should've been asking about 'cause it's related or anything along those lines. (P5)

If the research is problematic on some level, for example not being a good representation of asexuality, then the community usually doesn’t realize it until it’s published. Which is seen as too late.

Another interviewee thinks the relation between academia and the asexual community is characterized by the small size of the asexual community and the fact that you need to have a special interest in the area to study asexuality - this is seen as leading to a lot more influence than in other cases, because it is imagined that usually the community is monitored to some degree to gage reactions and facilitate participant recruitment.

> So, you will usually like get some degree of backlash if you mess up. (.) And because you usually have a special interest, you don't- I don't think people write about asexuality just for the heck of it or because it's an easy topic or they can make easy money off it or something, then they will be more inclined to fix any mistakes they've made if the community points it out. (P2)

Even though in this interview we see more opportunity for communication between the asexual community and academia, the participant wouldn’t call this a dialogue per se, but says “for the most part it's more the community shouting at the person who, who messed up and them maybe reacting (laughs).” (P2) This ‘shouting’ works on platforms such as Facebook or Tumblr, or someone will share an email-address that people can write to and tell the researcher they messed up. P2 remembers one instance that was reported on AVEN, in which the researcher amended their research, but doesn’t remember the specifics.

7.4.6. Gatekeeper needed?

For the most part the forum seems to encourage research, displaying links to research requests on the first site already. But moderators of the forum still decide which calls for participation are allowed to be posted, functioning as gatekeepers. This is regulated through standard procedures, which is outlined in the ‘Rules for researchers and students’ (The Asexual Visibility & Education Network, 2001-2012b). According to those rules, I sent a short description of my study, including the consent form and the research call, to the Research Approval Board.

During this process of gaining field access I was wondering in how far these inner workings and decisions about what research calls get posted, are invisible to users of the forum, and which parts they are aware of. Therefore, I added a question regarding this to my section on the activities in the forum and asked my interview partners if they knew how these procedures worked. I wondered if my participants were aware of these gatekeepers, what their opinion of them was, and whether ethics should play an important role when studying asexuality.

The Research Approval Board is described in one interview as a filter for the forum. Most of my interviewees were aware of the Research Approval Board, although none were quite sure on how they formed their decisions. Especially because they also don’t see the research requests that aren’t allowed - although they think most of them are allowed. There are different opinions on whether it is good or bad to have this filter.

> I think it is important that we (.) well, that we know that it's official. Because we, if- even if you don't really see it but asexuals can get attacked, just made fun of and it's, well, I, I personally would feel more comfortable to know it's, it's official, the research instead it's some amateur that just kinds of- kind of wants to make fun of us, to invalidate us, or anyway, so. (P1)

The Approval Board is seen as an intermediary that checks whether the researchers wanting to talk to the community are legitimate researchers. When research requests are permitted to get posted, the members of the forum know, “hey this person's actually a scientist and who they say they are.” (P5) This is not necessarily seen as having to do with the asexual community being seen as a marginalized group, but in one instance juts as an issue of “just sort of general online safety, you know, don't give your contact information out to, you know, random strangers on the Internet […]” (P5).

> I think it's nice to have them there in case for some reason someone was being super offensive. But overall (.) I don't know, I think it's good to have them there and I don't see them having much negative impact, because they do let most things through. I don't know how much time it takes for them to let something through though, if it takes too much time then that would be a detriment to a study. (P3)

In the above quote it becomes apparent that while generally it is thought good to have a gatekeeper just in case, it can very easily become harmful, that is when it hinders research being done. The first and foremost concern of the participant therefore is that research faces no obstacles.

Another interviewee doesn't think it's good that there is a gatekeeper.

> I mean if a researcher is coming from university or from a vetted research institute, there is no reason for being checked again, let's say. Because people should be free to agree or disagree with anything that they read or know about, but there should be, there shouldn't be any limitation on the content I would say. (P4)

In this discussion of gatekeepers any possible negative effects of research do not really come up, as they also have not really come up in the previous analysis chapter.

7.5. Findings: Analysis 3

How are practices of engagement with said research perceived and rationalized?

I began by showing how my participants talk about practices of engagement, and focused specifically on how the interview participation of this thesis is reflected on. Going further the relation of academic research and participation in academic research on one's individual identity, as well as how steadiness of identity matters to how one uses research as a resource, is looked at. The end of this chapter then shows how engagement of the community with research is thought about, with a special focus on the role the forum plays in the relationship between community and academia.

The main insight of this chapter is that reading research does not equal participating in research. Wanting research to exist and wanting to know about research are two different things. That's why research participation and reading research are not coupled most of the time. I had assumed the two fall together in engagement, but in the recounts of my participants there was a marked difference between the two practices of engagement.

Research participation is a requirement for research to exist (at least that someone participates). And as we have seen in many interviews, this is very important for my participants (’being a good member’). Participation is however not a requirement for wanting to know about research. This makes apparent that there is a distinction between research for validation and research for knowledge, in that the existence of research is very much important for the imagined benefits, but the content is of no consequence.

8. Discussion

How and when does academic research about asexuality come to matter to people identifying on the ace-spectrum?

Like a well-worn suitcase I have carried this thesis with me for a very long time. Through different phases of my life – both personal and academical – I have travelled and put my assumptions, thoughts, findings and conclusions about this case into the thesis. But I have also taken some things out, when they no longer fit, so that the carrying would not become too cumbersome. Consequently this thesis as it is now has been formed and informed by many thoughts and sources that have become invisible in this final iteration. One of those things I want to make visible again, to help me bind together my findings.

I first encountered asexuality in a seminar on classifications and standardizations in medicine, which shaped my vision and led me to ask as a very early research question, how asexuality as a new identity was negotiated by academia and the asexual community. Asking and answering this question was not possible or advisable for many reasons. In an attempt to move to another research focus, landing myself at looking at perceptions of science and engagement in research, I deliberately threw many parts of this initial research idea out. One such thing I deliberately kept out was thoughts and theories on identity. But as often is the case with such decisions, they tend to sort themselves out while the researcher is looking the other way. In my case identity steadily crept back in, more and more with each draft and analytical cycle. It still feature mainly in the background of my thesis, and thus I want to take a brief moment to make it apparent once more in the discussion, as it is a crucial aspect in drawing together my findings.

Going back to the state of the art, we have seen that classifications and standardizations are in the tradition of science and technology studies looked at as both constructed and constructing. Engagement with science too is shown as playing a role in the formation of collectives. It can be argued that in the case of asexuality and HSDD in the DSM, we see the formation of a collective and the challenging of a psychological authority as happening simultaneously (based on Hinderliter, 2009; Jay, 2008). Concerning the creation of an identity, Hacking (2006) states, "I have long been interested in classifications of people, in how they affect the people classified, and how the effects on the people in turn change the classifications" (Hacking, 2006, p. 2). Thus Hacking is interested in how scientific classifications bring a new kind of person into being. Specifically he looks at the "[d]ynamics of the relation between people who are known about, the knowledge about them, and the knowers" (Hacking, 1998, p. 6). He argues that by assigning a classification to people, which are here part object of scientific inquiry and part subject, a new way to conceive of and experience being a person is created. He calls this ‘making up people’. Parallel to the example of homosexuality given in the state of the art and mirroring what Przybylo (2012) pointed to - even though asexuality was likely practiced before, asexual was not a way to be. Applying a classification and diagnosis on an individual has consequences, and the person is not as it was before (a ‘moving target’). Culminating in a ‘looping effect’ the effects on the persons in turn have an influence on the way the classification is perceived, creating a circular roundabout (Hacking, 2006). We see this mirrored in Przybylo’s (2012) concerns, about how academic research can limit what asexuality is. This co-constructivist perspective can also be found in Callon and Rabeharisoa’s concept of emergent concerned groups (2008).

In the analysis we can clearly see asexuality as emerging, in that its identity is an achievement, which is imagined as in part being realized by academic research. Academic research offers the tool to argue for the existence of asexuality in the public sphere. The figure of ‘the scientist’ does not appear often in the visions of my participants. But academic research does hold a special place. While academia and science is not the only institution that is seen as being able to produce legitimate knowledge, it is the only one that is imagined to be seen as legitimate by ‘society’, that is people not identifying as asexual. The greatest concern is that the depiction that is shown through science to the outside, is also ‘true’. To the outside, people who do not identify as asexual, academic research can thus prove asexuality exists. In this case research is a tool that can be used in case asexuality is doubted. Throughout the analysis we see, that it is not knowledge about asexuality that is sought, but recognition of asexuality.

In the rationale of *spreading awareness*, we see that my participants employ a deficit model: society as a whole has too little knowledge/awareness about asexuality and a transfer from science or media to the broad public might help with that and negate any negative effects the lack of knowledge has (both for my participants, and for the people not yet identifying as asexual). What is interesting is that the audience for this knowledge, for my participants, was most often comprised of people (not yet) identifying as asexual. Many of the STS studies on communities and (patient) groups tend to look predominantly at the relation between those groups and ‘traditional’ experts, such as scientists, policy makers, or medical practitioners. In my case, ‘traditional’ experts do not feature dominantly. Most often the concerns of my participants of who should have knowledge of and about asexuality, are centred on ‘society’. Academic research and researchers are thus seen as a stepping stone towards bigger goals, as a resource or tool.

The scarcity of research and little awareness of asexuality is mentioned negatively by all of my participants. While most interviewees stressed that almost all research is beneficial and important, as there is so little of it, two participants voiced that they wanted to move beyond research proving asexuality exists and is real. Critique about research was practically non-existent in my interviews. While due to the self-recruiting format of my study, I had already assumed that most participants would probably be in favor of research, there was very little research that was imagined as potentially not being beneficial. The question begs whether research about asexuality is seen as functioning like a Maslow Pyramid: only after the basic needs have been fulfilled (there is awareness of asexuality and it is seen as real), can research be done that generates more knowledge about asexuality. The question in this case being who would be able to initiate this move – academia or the asexual community?

In studies on communities engaging with science, 'talking back' to science is seen as crucial moment fraught with many tensions. Talking about the possibility of an 'informed refusal', Benjamin notes,

> It should be noted, that the capacity to refuse rests upon a prior condition of possibility - that one has been offered something in the first place. Such offering, in turn, implicitly sets one apart from those who have been altogether neglected and excluded, so as not even to have the chance to refuse. (2018, p. 5)

It can be argued, that so long as the prevalent feeling in the asexual community is that they are excluded and neglected by academia and society, they feel there is no choice to talk back, refuse, or critique research. In the analysis we have seen that right now, most of my participants did not feel they could afford to be critical about research, because in their opinion they have great need of it and it is scarce.

When looking at engagement with research it becomes apparent, that research is not only seen as a tool, but also as being able to affect change. In this case as well, what is at stake is identity, namely how asexual people and asexuality is known. As mentioned above, the 'truth' of asexuality is important to my participants. Through research participation it is seen that the depiction and the shown reality of what asexuality is or how asexuality is known or seen, can be influenced. Research participation is the only practice of engagement with research that is conceptualized as an act of agency capable of co-creating what asexuality is known as. Almost always participants stressed that it was important that someone participates in research. That it was specifically themselves participating was only seen as important in one or two cases, in which interviewees reported they wanted to participate in my research to make sure a certain perspective (Spanish-speaking for example) was represented. In these cases also a certain depiction of asexuality is sought, that represents the 'truth' of the specific experiences of my participants.

Answering the question of how and when research about asexuality comes to matter to people identifying on the ace-spectrum, we have put the focus on what is at stake in this case: how asexuality is known. Looking at the relations between research, identity and community, we have seen that research has different meanings in different contexts. It is seen both as a resource or a tool in getting more awareness of asexuality, and recognition in society. It is also imagined as being able to bring change, in how asexuality is known. Participating in research is the only practice of engagement seen as being able to enact agency in this process of change.

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Annex

Abstract

Asexuality is both an emerging sexual identity category as well as an object of scientific research, with many efforts to locate and legitimize it. Science is not alone in the endeavor of forming asexuality, as research on asexuality is not only carried out by academics, but also by individuals identifying as asexual – most prominently those organizing around AVEN (an Internet forum that has allowed for the formation of a community around this recent emergent sexual identity). People identifying as asexual can therefore on the one hand be described as 'objects' of scientific knowledge, while another perspective shows the asexual community not only as consumers but as (co-)producers of scientific knowledge.

Most academic work about (patient) groups that studies the relations between scientists and non-scientists concerning the production and dissemination of knowledge is situated in the (bio-)medical realm (most notably Epstein's work on AIDS Activism, and Callon & Rabeharisoa's studies on AMF). Forgoing the complexities of these cases, a simple logic lies behind the engagement of these groups: find the cause, find the cure. In the case of the asexual community – where a firm distancing from pathology can be observed (see for example the case of HSDD in the DSM) – there is still abundant engagement with academic research via practices such as research participation, census-making, and archiving and discussing of scientific studies. Through analyzing qualitative interviews with people identifying as asexual, this thesis investigates how and when research about asexuality comes to matter to people identifying as asexual. Using the concept of emergent concerned groups and public understanding of science as a theoretical background, it will be investigated how research, research effects, and research participation are conceptualized by the interview participants.

Looking at the relations between research, identity and community, we have seen that research has different meanings in different contexts. It is seen both as a resource or a tool in getting more awareness of asexuality, and recognition in society. It is also imagined as being able to bring change, in how asexuality is known. Participating in research is the only practice of engagement seen as being able to enact agency in this process of change.

Deutscher Abstract

Asexualität ist sowohl eine neue sexuelle Identität als auch Gegenstand wissenschaftlicher Forschung, mit vielen Bemühungen, sie zu lokalisieren und zu legitimieren. Die Wissenschaft ist nicht allein im Bestreben, Asexualität zu beschreiben, da die Erforschung der Asexualität nicht nur von Wissenschaftler*innen betrieben wird, sondern auch von Individuen, die asexuell sind - am prominentesten ist hier die Organisation um AVEN (ein Internetforum, das die Bildung einer Gemeinschaft um diese erst kürzlich entstandene sexuelle Identität ermöglicht hat). Personen, die als asexuell identifizieren, können daher zum einen als „Objekte" wissenschaftlichen Wissens bezeichnet werden, während eine andere Perspektive die asexuelle Gemeinschaft nicht nur als Konsumenten, sondern als (Mit-) Produzenten wissenschaftlicher Erkenntnisse zeigt.

Die meisten wissenschaftlichen Arbeiten über (Patienten-) Gruppen, die die Beziehungen zwischen Wissenschaftler*innen und Nicht-Wissenschaftler*innen hinsichtlich der Erzeugung und Verbreitung von Wissen untersuchen, befinden sich im (bio-) medizinischen Bereich (insbesondere Epsteins Arbeit zum AIDS-Aktivismus und Callon & Rabeharisoas Studien zu AMF). Wenn man auf die Komplexität dieser Fälle verzichtet, liegt eine einfache Logik hinter dem Engagement dieser Gruppen: Ursache finden, Heilung finden. Im Fall der asexuellen Gemeinschaft, in der eine deutliche Entfernung von der Pathologie beobachtet werden kann (siehe beispielsweise den Fall von HSDD im DSM), besteht nach wie vor eine reiche Auseinandersetzung mit der akademischen Forschung durch Praktiken wie Forschungsbeteiligung, Zensusbildung und Archivierung und Diskussion wissenschaftlicher Studien. Anhand von qualitativen Interviews mit asexuellen Personen, wird in dieser Arbeit untersucht, wie und wann die Forschung über Asexualität für Menschen relevant ist, die als asexuell identifizieren. Anhand des Konzepts ‚emergent concerned groups' und ‚public understanding of science' als theoretischem Hintergrund wird untersucht, wie Forschung, Forschungseffekte und Forschungsbeteiligung von den Interviewteilnehmer*innen konzeptualisiert werden.

Betrachtet man die Beziehungen zwischen Forschung, Identität und Gemeinschaft, so findet sich, dass Forschung in verschiedenen Zusammenhängen unterschiedliche Bedeutungen hat. Es wird sowohl als Ressource als auch als Instrument gesehen, um mehr Bewusstsein für Asexualität und Anerkennung in der Gesellschaft zu schaffen. Es wird auch gedacht, in der Lage zu sein, die Asexualität bekannter zu machen. Die Teilnahme an der Forschung ist die einzige Praxis, von der gedacht wird, dass sie in diesem Prozess der Veränderung eine Handlungskraft hat.