Identity, Career Trajectories and Wellbeing Outcomes
A Closer Look at Individuals with Degenerative Eye Conditions

Tali Spiegel
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PhD thesis to obtain the degree of PhD at the University of Groningen on the authority of the Rector Magnificus Prof. E. Sterken and in accordance with the decision by the College of Deans.

This thesis will be defended in public on Thursday 2 June 2016 at 14.30 hours by Tali Spiegel born on 25 March 1986 in Miami, Florida USA
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Chapter 1

Introduction
1.1 Background

Moderate to severe vision impairment and blindness are highly prevalent worldwide. While the definitions of visual impairment and blindness may vary, the strict worldwide estimate is that moderate to severe vision impairment and blindness affect 32 million individuals worldwide (Stevens et al., 2013). This issue is also of high concern in the Netherlands where 1 in every 50 individuals reports being restricted due to vision impairment that cannot be corrected with glasses or lenses (Keunen, Verezen, Imhof, van Rens, Asselbergs, & Limburg, 2011). The focus of this dissertation, however, is on the US context where nine percent of American adults report having a severe visual impairment that cannot be corrected with glasses or lenses (Blackwell, Lucas, & Clarke, 2014).

Being severely visually impaired has been linked to various negative outcomes related to life chances, such as reduced labor market opportunities (e.g., Von Schrader, Malzer, & Bruyere, 2014) and to various aspects of reduced physical, mental and social wellbeing (e.g., Newheiser, et al., 2015; Zhang et al., 2013; Zheng, Christ, Lam, Arheart, Galor, & Lee, 2012). Although the reasons for these negative outcomes seem intuitively obvious, one mechanism is often overlooked, and that is the stigma linked to the identity of visually impaired and blind individuals. Research shows that the majority of the population considers blindness as the most frightening sensory loss they could experience (Dickerson, Smith & Moore, 1997). This fear, in turn, translates into annihilation from those who are visually impaired or blind and enhances the stigma attached to this identity (Allen & Birse, 1990). In his groundbreaking 1963 book, Goffman offers a definition of the concept of stigma:

While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind – in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, a handicap (p. 12).

Labels and stereotypes about visual impairment and blindness, primarily regard the themes of independence and competence. A visually impaired person is presumed to be limited, dependent and generally less “successful” in life. Visually impaired and blind individuals are expected to be impaired in their ability to fend for themselves or function independently.

Such stereotypes are dangerous to the individual and can lead to stern consequences: “By definition, of course, we believe the person with a stigma is not...
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Labels and stereotypes about visual impairment and blindness, primarily regard the themes of independence and competence. A visually impaired person is presumed to be limited, dependent and generally less “successful” in life. Visually impaired and blind individuals are expected to be impaired in their ability to fend for themselves or function independently.

Such stereotypes are dangerous to the individual and can lead to stern consequences: “*By definition, of course, we believe the person with a stigma is not*
Chapter 1 | Introduction

quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often un-thinkingly, reduce his life chances” (Goffman, 1963, p. 16). It follows that an individual who is identified as holding this stigmatized identity will be subject to scrutiny.

Links and Phelan (2001) nuance the process resulting in stigma into three sub-elements. First, labeling of human differences takes place, the aforementioned labels are then linked to cultural beliefs about what are undesirable characteristics and stereotypes, and finally the labeled person is categorized and distinguished as separate to the group. Stereotypes regarding the independence and competence of visually impaired individuals indeed may lead to their exclusion from various layers of societal participation. An important example of this is the labor market. The population of visually impaired and blind individuals is underrepresented in the labor market, are less likely to be employed than people with other disabilities (Erickson, Lee, & Von Schrader, 2010), and when they are employed, they are more likely than other workers to be discriminated against, unrightfully terminated, and under-evaluated (Corrigan & Matthews, 2003). This holds even though individuals, who are visually impaired or blind, can fulfill many jobs on all levels of the labor market (blue and white collar positions) if proper accommodations such as assistive technology are provided. Thus, in light of the consequences associated with a revealed stigmatized identity, individuals with a concealable visual disability face the challenge to manage their identity and identity-related behavior to maximize their outcomes.

This challenge is especially apparent for those who have a degenerative eye condition. Degenerative eye conditions are of special interest as they become more severe over time and often so at an unpredicted rate. So an individual who finds out she has a degenerative eye condition at the age of 20, might expect to slowly lose her eyesight over the course of her lifetime, thus, potentially having functional sight for the great majority of her adult life.

The fear of stigmatization has a major impact on the manner in which individuals manage their identity. Identity management manifests itself through behavioral choices (e.g., concealment, disclosure, passing), which in turn may hold crucial consequences for the individual. Concealment behavior, for instance, may induce the likelihood of labor market participation. However, it may also be physically and psychologically burdening for the individual. Disclosure holds mirrored outcomes to concealment. Disclosure may relate to the alleviation of inhibition and other positive psychological outcomes (such as self-acceptance), but may also result in discrimination in the labor market (Von Schrader et al., 2014).

Having a concealable identity renders the identity “discreditable” (Goffman, 1963). That is, the negative consequences of holding such an identity will only manifest themselves if the “normal” identity of the individual is falsified, and the stigmatized identity is revealed. Thus, a person may postpone preparing for blindness and avoid making use of assistive devices, if she weighs the costs of having her stigma revealed higher than the benefits. The costs and benefits, in turn, change over
time and are dependent on the resources available to the individual (e.g., monetary, social, psychological), and on the degree of visual decline.

The consequences associated with a revealed stigmatized identity are evident in many life domains (such as in personal relationships, in the public sphere, etc.). To date, there is fairly little known about the experiences of those who have concealable conditions in the labor market (Santuzzi, Waltz, Finkelstein, & Rupp, 2014). As suggested above, the role of stigma and concealment might be especially relevant with regards to participation in the labor market, where discrimination levels regarding the population of visually impaired and blind persons are very high (Corrigan & Matthews, 2003). While quite a lot is known about unemployment amongst visually impaired and blind individuals (e.g., Capella-McDonnall, 2005; Erickson, Lee, & Von Schrader, 2010), knowledge about experiences of individuals who do participate in the labor market is remarkably scarce.

This thesis aims to counteract this gap in knowledge, concretely, within the group of those who do participate in the labor market, we focus on those who have degenerative eye conditions, as they illustrate well the struggles and successes individuals are faced with when negotiating their shifting identity (from sighted to blind). Gaining more knowledge about the conditions under which individuals prefer to conceal their identity, and under which they decide to reveal it in the workplace, can help us understand behavioral patterns within the workplace context (e.g. certain concealment behaviors such as driving a car with low vision), career trajectories, and may ultimately provide insights into the physical and psychological outcomes individuals experience within the work context.

An additional reason for focusing on those who participate in the labor market is policy-related. In year 1990, the United States government, headed by president George H. W. Bush, enacted The Americans With Disabilities Act (ADA, Walk, Ahn, Lampkin, Nabizadeh, & Edlich, 1993). The ADA’s role was to protect those with disabilities, and among other things, to assist those with disabilities in obtaining and sustaining work, i.e., protect them against discrimination in the workplace and help them achieve work placement. However, the results thus far leave much to be desired, and the reversed trend with regards to labor market participation, i.e., the substantial decline in labor market participation among people with disabilities (Acemoglu & Angrist, 1998), is a major concern. This outcome is attributed primarily to the higher costs for the employer upon hiring individuals with disabilities under the protection of the act. With this in mind, we consider the groups of those who do participate in the labor market to be of great value for gaining more understanding into their strategies for obtaining and sustaining employment with a disability. While the focus of this thesis is not policy research as such, it can certainly provide insights for policy-making. The interrelation between stigma and identity management (through concealment and passing – behaviors that are meant to disguise or reduce evidence of the stigmatized identity), and the associated career trajectories and wellbeing.
outcomes throughout the life-course among individuals with degenerative eye conditions, are the focus of Chapters 2, 3 and 4 of this thesis.

The final issue tackled in this dissertation concerns peer contact among individuals bearing the same stigmatized identity (Chapter 5). We link participation in networking groups (behavior) to social and psychological wellbeing. While we know from previous literature that contact among individuals with the same stigma may yield positive emotional outcomes for the individual, we still know little about the role of peer contact among individuals with a degenerative eye condition, a stigma which has a dynamic nature (as the identity becomes more established with visual decline). In light of the challenges faced by this group, intergroup acceptance and rejection might act as important mechanisms in explaining outcomes among individuals with a degenerative eye condition. The particular aims and research questions that are tackled in this dissertation are presented in detail in the following section.

### 1.2 Aims and Research Questions

The overarching aims of this work are to identify and disentangle possible pathways between resources and constraints, behaviors, and individual outcomes (wellbeing and career trajectories) among individuals with degenerative eye conditions (see Figure 1.1). In the following, a more detailed explanation about each component is provided.

![Figure 1.1: overarching model](image)

The basic assumption underlying the overall model is that all human beings are motivated to improve their situation, e.g., to improve their wellbeing, for instance
financial security, or to improve important means to wellbeing, such as having a
career. However, individuals do not always have the resources to do so and might face
constraints in their striving, which brings about the urge to find alternative ways to
reach their goals. Individuals with degenerative eye conditions are facing a unique
situation in this respect, because they have the additional constraint of the fear of
stigma. Moreover, they are in a process of changing resources and constraints,
because their disability changes from invisible to visible. The specific – and changing
- circumstances of individuals with degenerative eye conditions affect the choices
they make and are likely to influence the extent to which their choices and behaviors
contribute to the outcomes they aspire to reach.

In this thesis, various behaviors are being considered: concealment, passing and
disclosure (Chapters 2 and 3), mobility choices (Chapter 4), and peer group
participation (Chapters 5). Possible pathways to wellbeing and career trajectories
outcomes are being investigated for each behavior.

This undertaking extends prior research in this field by emphasizing the
interrelations between the various pillars of investigation using an innovative
approach by combining the traditional qualitative manner of studying stigma and
disability (e.g. Brune, 2012; Siebers, 2004, Samuels, 2003; Wilson, 2012) and
enriching it with theory testing.

The research questions addressed in this dissertation are:

• What types of passing, concealment and career trajectories are common
  amongst individuals with degenerative eye conditions? And how do they relate
to wellbeing? (Chapter 2)

• What are the pathways linking the disclosure of a degenerative eye condition
  in the workplace and wellbeing? (Chapter 3)

• How do white-collar workers with degenerative eye conditions experience and
deal with changes in their perceived abilities and available resources in
choosing between car use and alternatives over time? And how do these
individuals motivate the choice to stop or to continue driving? (Chapter 4)

• To what extent does peer network participation relate positively to satisfaction
with participation and to overall subjective wellbeing? And under which
circumstances is peer network participation positive or negative for
satisfaction with participation and for overall subjective wellbeing among
individuals with degenerative eye conditions? (Chapter 5)

1.3 Theoretical Background

A prominent theory used in this field of research is Goffman’s (1963) stigma
theory. The term “stigmatized identity”, as discussed above, refers to an identity to
which the majority group attaches negative meanings. These meanings may lead
the majority group to exclude the person with the stigmatized identity. To avoid adverse
outcomes, individuals with stigmatized identities may choose to conceal their identity if this is possible, or to engage in passing behaviors (or normalizing behaviors). Passing behaviors are behaviors that bring the person with the experienced stigmatized identity (in this case, the visually impaired person) closer to the majority group (sighted persons). The person engaging in these behaviors tries to “mask” her stigmatized identity, while assuming an identity with which the majority group can identify better. Theory on stigma allows us insights into the choices and behaviors behind career pathways taken by individuals with degenerative eye conditions, while also giving us insights into the role of identity and concealment behavior in these trajectories, and how these are predictive of wellbeing. Asserting relationships between fear of stigma, concealment and passing behavior, and the associated outcomes (well-being and career trajectories), is a first step for which stigma theory is very useful.

After establishing the link between constraints (fear of stigma) and disclosure behaviors, we now turn to establishing the theoretical link between disclosure behavior and overall subjective wellbeing. Chaudoir and Fisher (2010), and Beals, Peplau and Gable (2009) suggest alleviation of inhibition and social support as main pathways between disclosure and wellbeing benefits. Alleviation of inhibition suggests that concealing an identity is a taxing and stressful behavior, and that disclosing one’s identity would result in emotional relief. Social support suggests that disclosure can act as a means of accessing social support by others given a positive response from a confidant to the act of disclosure. If others are aware of the identity, they are also able to react in a sympathetic manner. In addition to these two pathways, the use of assistive devices constitutes a third possible physical pathway. The social production function (SPF) theory (Lindenberg, 1996; Ormel, Lindenberg, Steverink, & Verbrugge, 1999) posits that there are basic universal (physical and social) needs, the fulfillment of which contributes to the overall wellbeing of the individual. There are two basic physical needs (comfort and stimulation) and three basic social needs (affection, behavioral confirmation and status) according to the theory. Not using assistive devices, while experiencing visual decline, may interfere with the fulfillment of physical and social needs. For instance, not using assistive devices may lower the work output of individuals, rendering them less productive than others. This, in turn, may influence their ability to fulfill their status need. Thus, from this discussion three possible pathways between workplace disclosure and wellbeing benefits can be distinguished.

The social exclusion theory (Festinger 1954) allows us to understand the considerations and motivations behind risk behavior among individuals with a degenerative eye condition. The core premise of the social exclusion approach is that certain groups are restricted in access to physical places, which in turn influences their access to goods (e.g. restricted access to work leads to restricted access to goods and commodities), leading to social exclusion. Specifically, due to the characteristics of this group, we look at transportation exclusion (Lucas, 2012) and on driving behavior
in particular. Social exclusion is not a dichotomous state. A person could have restricted access or may have to make more of an effort than others to gain access. For instance, at least in the US, driving is the most efficient mode to access certain commodities. An individual who cannot drive may instead receive a ride or use public transportation, usually connected with additional effort. Exclusion also depends on resources, and hence may change over time. A person may have been able to drive when she had more vision but is now restricted in her ability to drive.

We can anticipate driving behavior and the use of alternatives by looking at common practical and normative motivations for driving. From a practical point of view, driving is often efficient. From a normative point of view, driving is also the most preferable commute mode as it relates to normative expectations. Driving in western societies, and perhaps mostly so in the US, symbolizes maturity, citizenship and masculinity (Carrabine & Longhurst, 2002; Sheller, 2004; Urry, 2007). Consequently, driving is an important means for societal integration and inclusion, especially in the labor market.

Finally, we introduced two additional theoretical frameworks to link participation in peer networks for people with visual impairment, with social wellbeing (satisfaction with contact) and with overall subjective wellbeing: homophily, as a sociological approach to peer contact (e.g. McPherson, Smith-Lovin, & Cook, 2001) and social comparison theory as a social-psychological approach to peer contact (Festinger, 1954). Homophily suggests that similarity on various dimensions can render the individual more satisfied with a relationship and can induce higher wellbeing. In the present work on individuals with a degenerative eye condition, we consider both experiential elements (those related to the life-transition, such as the severity of the disease) and structural elements (similarity on additional demographic characteristics outside of the life-transition, such as age) (Suitor, Keeton, & Pillemer, 1995).

Social comparison theory suggests that the value of similarity initially depends on identification (Buunk & Ybema, 1997). Social comparison theory posits that individuals strive to assess their value in the most accurate way, by comparing themselves to similar others. The manner in which an individual will compare herself to others depends on whether or not she identifies with the subject of comparison. This, in turn, will influence the type of social comparison processes, which will take place. A lack of identification may induce downward comparison processes, which serve ego-enhancing motives and are often not well experienced by the individual. Identification, in turn, may lead to upward comparison processes taking place, which serve goal-enhancing purposes and are often positively experienced by the individual. Comparing these two frameworks allows for better insights into the mechanisms behind peer relationships and the role of identity therein.
Chapter 1 | Introduction

1.4 Multi-method Approach

In collaboration with a US-based foundation promoting medical research to cure blindness, I have collected both interview and survey data between October 2013 and August 2014. Both studies have been reviewed and approved by the ethical committee of the Department of Sociology, University of Groningen.

Initially, qualitative semi-structured interview data were collected, to take a closer look at both the challenges and the successes that shaped the work trajectories of the participants. I collected their life stories using an inductive grounded theory approach (Hennink, Hutter, & Bailey, 2010). Forty individuals were interviewed. Participants were asked to tell their life story, while focusing on their challenges and triumphs in the workplace. Criteria for participation in the study were as follows: participants were required to be at least 40 years old, had to have a degenerative eye condition for at least 10 years, and to have faced challenges related to their eyesight during their career. The majority of the interviews (24) took place in person, at a location chosen by the participant, usually their home or a café.

The main themes identified in the interview data acted as the guidelines for the survey questionnaire. The survey data included questions on the following themes: identity, demographic information, physical and overall subjective wellbeing, eye condition, workplace, social networking with peers and additional information regarding device and assistance use. Data were collected using an online platform (surveymonkey) known for its compatibility with web accessibility technology. The target population consisted of individuals who have a degenerative eye condition, lived in the US and were older than 18. One hundred and forty two individuals completed the survey.

1.5 Analytical Strategy

Two researchers (Vera de Bel and myself) inductively, separately, and independently coded the qualitative interviews. After all interviews were coded, a joint “family codebook”, based on the code themes identified by the two coders was made. The main analytical strategy used was the “Bigger Picture” approach (Hennink, et al., 2010), where the analysis takes a circular approach between the individual narratives and the family codebook to identify patterns and variation from the patterns in the data (Chapter 2 and 4).

Two studies make use of a mixed methods approach (Chapter 3 and 5). In Chapter 3 the proposed theoretical pathways through: 1) the alleviation of inhibition, 2) workplace social support, and 3) the use of assistive devices, were tested using both the qualitative and the quantitative data to complement each other. These pathways were tested as mediators in pathway models in STATA. We then tested whether these same pathways were visible in the qualitative data thus making use of the bigger
picture approach. As we were testing our hypotheses, we conducted our pattern search between individual narratives and overarching patterns while looking at codes that related to the themes identified from the theory.

In Chapter 5, two separate theoretical frameworks were examined: homophily and social comparison. The hypotheses based on the homophily principle were tested using the survey data and by computing regression models within STATA’s structural equation modeling environment. The hypotheses based on social comparison theory were tested using the interview data. The bigger picture approach was used in a similar fashion as in Chapter 3.

1.6 Overview of the Four Studies

Chapter 2: Keeping up appearances: The role of identity concealment in the workplace among adults with degenerative eye conditions and its relationship with well-being and career outcomes

Having a stigmatized identity can induce prejudice and discrimination from the individual’s social surrounding (Goffman, 1963). Individuals with a visible stigmatized identity often encounter discrimination in the work context. For this reason, individuals with concealable disabilities, such as those with degenerative eye conditions, often tend to prefer concealing their identity. When the disability becomes more visible, individuals may choose to engage in passing behaviors, which allows them to assimilate to the majority group (e.g. maintaining eye contact while having a conversation). The decision to conceal or reveal one’s identity depends to a great extent on the chosen career path, the position an individual has in the labor market, and on the degree to which her eyesight has deteriorated (or is expected to deteriorate). For instance, an individual who started her career working as a film editor, a highly visual field, and is anticipating losing her eyesight at a slow pace, may choose to conceal her identity. This study had the aim to describe the interplay between work trajectories and passing patterns among individuals with degenerative eye conditions. We explored the variation in patterns with relation to disease progression and career phases and sought to ascertain whether wellbeing patterns emerge, which relate to the different patterns of career and identity management (disclosure vs. concealment) trajectories.

Chapter 3: What are the pathways linking the disclosure of a degenerative eye condition in the workplace and wellbeing? A mixed methods approach

Similar to the notions of Chapter 2, we assume that stigma can cause the individual participating in the labor market to fear discrimination, prejudice and being under-evaluated. For this reason, individuals with concealable conditions often choose
to conceal their identity in the workplace. However, according to previous literature on disclosure of stigmatized identities (Beals, Peplau, & Gable, 2009; Chaudoir & Fisher, 2010), disclosure may be beneficial through the pathway of the alleviation of inhibition and through the pathway of social support. Since the focus of this chapter is on a subgroup of individuals with a changing condition, which has not been investigated in the past, it is important to consider that there may be additional physical pathways to individual benefits. Disclosing a degenerative eye condition in the workplace allows the individual to make use of visible devices, such as assistive technology or mobility devices. These may help her in her workplace performance. Social production function theory suggests that assistive devices can act as resources for the fulfillment of physical and social needs once previous resources (the individual’s vision) are depleting. We thus expected to find three pathways between disclosure and wellbeing benefits: 1) the alleviation of inhibition, 2) social support (in the workplace) and 3) the use of assistive devices.

Chapter 4: Having both hands on the steering wheel: Car driving behavior among white-collar workers with degenerative eye conditions

Due to high car reliance in the United States, individuals with restricted driving abilities face severe accessibility constraints in the labor market. Previous literature shows that individuals have a preference for car driving as it enhances labor market opportunities, even when driving is not needed for completion of work tasks or work commute (Baum, 2009). Thus, even if an individual has driving restrictions, due to vision impairment, she may choose to engage in driving behavior to avoid exclusion from the labor market. In this chapter, we took a qualitative approach to gain insights into how white-collar workers with degenerative eye conditions experience and deal with changes in their perceived abilities and available resources in choosing between car use and alternatives over time. Moreover, we aim to gain insights into the motivations behind car driving behavior.

Recent transportation-related interpretations of the social exclusion theoretical framework suggest that exclusion is not a dichotomous state (Schwanen et al., 2015). A person is not included or excluded, but rather can be placed somewhere on the gradient in-between these two concepts. Hence, our general expectation is that there will be “between individual” variation in the degree of exclusion alongside “within individual” differences in exclusion over time. We place the motivations for car-driving behavior within two branches of social exclusion dimensions: practical aspects and normative aspects of social exclusion. The first refers to mobility constraints associated with not driving, while the latter refers to social constraints and societal views of driving as a cultural asset. Both are expected to play a role in driving and commute behavior patterns.
Chapter 5: We’re all in the same boat: Individual outcomes associated with participation in networking groups among individuals with degenerative eye conditions

In this chapter we investigate what role peer similarity plays with respect to satisfaction with participation in peer networking groups (social wellbeing) and in overall subjective wellbeing among individuals with degenerative eye conditions. Previous studies reported mixed findings with regards to the benefits achieved from participation in support or networking groups. To establish whether and when peer contact leads to social wellbeing (satisfaction with contact) and overall subjective wellbeing, we employed two theoretical frameworks: homophily (McPherson, Smith-Lovin, & Cook, 2001) and social comparison theory (Festinger, 1954). Experiential similarity and structural similarity (Suitor, Keeton, & Pillemer, 1995) are expected to relate to the two outcomes. After testing the role of homophily in individual outcomes, the role of social comparison is examined. We expected that identification on experiential and structural dimensions would affect which social comparison processes the individual engages in (i.e. upward or downward comparison). The type of social comparison individuals engage in depends, among other things, on identification with others as peers (Buunk & Ybema, 1997) as it determines whether an individual engages in social comparison (which is associated more with upward comparison) or contrasting processes (which are associated more with downward comparison processes). In the absence of identification, contact is expected to lead to downward comparison processes, resulting, in turn, in dissatisfaction with contact and reduced wellbeing or fewer benefits from contact. Identification, however, is expected to lead to upward comparison processes, resulting, in turn, in satisfaction with contact and enhanced subjective wellbeing from contact.

1.7 Reading Guide

In Chapters 2 through 5 the various studies of this dissertation are presented. Chapters 2 through 4 focus directly and indirectly on the manner in which individuals with degenerative eye conditions deal with the challenges they are faced with in the workplace regarding their identity management. Chapter 5 focuses on peer contact and its relationship with identity. In the final chapter of this dissertation, Chapter 6, overall conclusions are presented and discussed.
Chapter 2

Keeping up appearances: The role of identity concealment in the workplace among adults with degenerative eye conditions and its relationship with well-being and career outcomes*

Abstract

This study aims to describe the interplay between the work trajectories and the passing patterns of individuals with degenerative eye conditions in different phases of their career, as well as the disease progression and the career and well-being outcomes associated with different work and passing trajectories. Qualitative interviews on the topic of work trajectories were conducted with 36 working or retired individuals with degenerative eye conditions. The “bigger picture” method was used to explore passing and concealment behavioral patterns, and their associations with various work trajectories. Five patterns of passing and concealment behavior in the workplace were identified and were linked with various work trajectories among visually impaired study participants: 1) no career adjustments, concealed condition throughout career; 2) revealed condition after adjusting career plans; 3) increasingly open about their condition over the course of their career; 4) engaged in career planning, always open about their condition; and 5) Engaged in limited career planning, always open about their condition. Patterns characterized by less planning and more identity concealment were associated with more stress and lower levels of self-acceptance, while patterns characterized by more planning for vision deterioration and less passing behavior were associated with higher levels self-acceptance and fewer obstacles over the course of an individual’s career. The study’s findings can serve as a guide for health professionals.

* This chapter is co-authored with Vera de Bel and Nardi Steverink. This Chapter has been published as: Spiegel, T., De Bel, V., & Steverink, N. (2016). Keeping up appearances: the role of identity concealment in the workplace among adults with degenerative eye conditions and its relationship with wellbeing and career outcomes. Disability and Rehabilitation, 38(7), 627-636.
2.1 Introduction

There is little dispute that individuals with disabilities suffer from disadvantages in the labor market (Vornholt, Uitdewilligen, & Nijhuis, 2013). They are less likely to be employed (Vornholt et al., 2013), and when they are employed, they are more likely than other workers to be discriminated against, unrightfully terminated, and under-evaluated (Corrigan & Matthews, 2003). That explains why many people with “invisible disabilities” (i.e. disabilities that are not immediately apparent in interactions with others) choose not to reveal their condition in the workplace. Individuals may keep their disability concealed by engaging in what is referred to in the literature as “passing behaviors” (for illustration: Brune, 2012; Samuels, 2003; Siebers, 2004; Wilson, 2012). Passing behaviors (or normalizing behaviors), according to Goffman (1963), are behaviors that bring the person with the experienced stigmatized identity (in this case, the person experiencing a disability) closer to the majority group (non-disabled persons in this case). The person engaged in these behaviors tries to “mask” his or her stigmatized identity, while assuming an identity with which the majority group can better identify. The term “stigmatized identity” refers to an identity to which the majority group attaches negative meanings. These meanings may lead the majority group to exclude the person with the stigmatized identity.

The degree of concealment tends to vary depending on the disabled person’s ability to keep the disability a secret, and also on his or her evaluation of the need for concealment at different stages of employment (Lingsom, 2008). According to Goffman (1963), an individual with a concealable stigmatized identity will put great effort into concealing his or her identity in various social settings, and in the workplace in particular, to avoid undesirable consequences such as discrimination or termination. While some individuals might keep the disability a secret until they establish a job placement (e.g., until they sign an employment contract), others may choose to conceal their identity until they have “proven” themselves as contributing employees (Clair, Beatty, & MacLean, 2005; Olney & Brockelman, 2003). Some disabled individuals conceal their identity for the majority or the full trajectory of their employment, and thus experience considerable emotional and physical strain (Pachankis, 2007), while other disabled people are always open about their condition. When concealment is no longer fully possible (because, for example, the costs of concealment become too high) individuals often engage in normalizing behaviors (Brune, 2012; Wilson, 2012): i.e., although their identity as a disabled person is no longer a secret, they still engage in behaviors intended to make them appear “normal”.

Issues related to the visibility and concealment of disability are especially salient among individuals with degenerative eye conditions, as these conditions become more severe over time, but can be hidden for a significant portion of a person’s career.
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Issues related to the visibility and concealment of disability are especially salient among individuals with degenerative eye conditions, as these conditions become more severe over time, but can be hidden for a significant portion of a person’s career
important component of the adjustment process. The decision by a visually impaired
Finkelstein, & Faden, 2010), and found that taking on the disability identity was an
revealing the identity, or the role of concealment in individual career trajectories.

Previous research has not fully explored the different states between concealing and
stereotypes about the functional and visual capacities of visually impaired people
(Dickerson, Smith, & Moore, 1997) is another reason why these individuals may try
to conceal their disability (Goffman, 1963; Jangra, Ganesh, & Thackray, 2007).

Having an invisible disability in the workplace, and especially having a
degenerative eye condition, presents the disabled person with a dilemma. On one
hand, the person may perceive that passing as non-disabled may increase his or her
chances of obtaining and sustaining employment and advancing in the workplace. On
the other hand, as noted above, the effort involved in concealment may threaten the
individual’s mental and physical health. The physical strain associated with trying to
pass (e.g., avoiding cane use and consequently walking into obstacles) is an additional
challenge. Moreover, the person may find it difficult to decide when to reveal his or
her identity. A study on a population similar to the group being examined in the
current study modeled the adjustment to progressive vision loss (Hayeems, Geller,
Finkelstein, & Faden, 2010), and found that taking on the disability identity was an
important component of the adjustment process. The decision by a visually impaired
individual to accept the disability identity and to reveal it to others is a process, which
typically entails making cost-benefit calculations (Hayeems et al., 2010). However,
previous research has not fully explored the different states between concealing and
revealing the identity, or the role of concealment in individual career trajectories.

The first aim of this study is to describe the interplay between the work
trajectories and the passing patterns of individuals with degenerative eye conditions in
different phases of their career and disease progression. This is especially important
as the existing studies, which explored the topics of passing and concealment
behavior among individuals with visual impairments and with other disabilities
mainly focused on single-case narratives (e.g., Brune, 2012; Samuels, 2003; Siebers,
2004; Wilson, 2012). While some of these studies offered a thorough description of
the processes associated with passing, our goal is to present a more generalizable
description of the processes individuals with degenerative eye conditions experience,
and how these processes interact. The second aim of this study is to describe the
career and well-being outcomes associated with different work trajectories, and with
various concealment and passing pathways. We used a qualitative approach (with a
sample of 36 individuals), which allowed us to gain insights into the experiences of
individuals, while providing us with the opportunity to identify patterns of behavior.
2.2 Method

2.2.1 Ethical Statement

Ethical standards have been ensured using guidelines in line with the Declaration of Helsinki (Hennink, Hutter, & Bailey, 2010). Various ethical principles have been taken into account, including anonymity and confidentiality, minimization of harm, and consent. Anonymity was achieved by removing identifying information from the written transcripts (e.g., names and locations), and this information has also been removed from the publication. All data linked to this study are safely stored on the network of the University of Groningen, and only the primary investigators have access to the data. Emotionally taxing circumstances for participants were kept to a minimum. Finally, all the participants have given their verbal and written consent to participate. The ethical committee of the sociology department of the University of Groningen, the Netherlands, has confirmed that the study followed ethical procedures.

2.2.2 Sample

Participants were approached through a US-based foundation, which supports medical research on eye diseases. Criteria for participation in the study were as follows: participants were required to be at least 40 years old, to have been living with a degenerative eye condition (participants had either Retinitis Pigmentosa or Stargardts) for at least 10 years, and to have faced challenges related to their eyesight during their career.

The sample size was reached through information saturation (Hennink et al., 2010). First, an invitation letter was sent to 40 individuals who matched the criteria for participation; 36 agreed to participate, but four cases needed to be excluded. Two cases with hearing and vision decline were excluded due to emotional difficulties, which arose in the interview process. One case was excluded due to a lack of symptoms, and one case was excluded due to language barriers.

Second, after interviews had been carried out with the remaining 32 individuals, the author recruited additional participants through a snowballing procedure. This led to the subsequent inclusion of four additional individuals. At that point, the first author, who had conducted all of the interviews, noted that no new insights were provided in this second round, and thus decided to stop looking for additional participants. In total, this study includes the data of 36 individuals.
2.2.3 Data Collection

The majority of the interviews (24) took place in person at a location chosen by the participant; usually their home or a café. The remaining 12 interviews were conducted by phone because of difficulties in arranging a suitable location for a meeting. Both types of interviews took on average 50 minutes. Table 2.1 provides descriptive information about the 36 participants included in the analyses.

Because we wanted to investigate both the challenges and the successes, which shaped the work trajectories of the participants, we collected their life stories using a grounded theory approach (Hennink et al., 2010; Strauss & Corbin, 1994). The setup of the interviews (as well as coding and analysis) was, therefore, primarily inductive. However, a list of specific topics based on existing insights on work-related issues in individuals with impaired vision was used as an additional guideline (Table 2.2). Participants were asked to tell their life story, and to focus on the role their eye condition played in their work trajectory. While participants were not directed in their storytelling, they were asked to provide additional information if they did not cover the additional topics in their narratives.

Table 2.1: Descriptive information on the 36 participants

<table>
<thead>
<tr>
<th>Name and pattern</th>
<th>Age</th>
<th>Eye condition</th>
<th>Diagnosis</th>
<th>Eye-sight</th>
<th>Marital status and children</th>
<th>Education</th>
<th>Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Susan</td>
<td>66</td>
<td>RP</td>
<td>37</td>
<td>10 degrees of central vision</td>
<td>Second marriage</td>
<td>College</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Eleanor</td>
<td>59</td>
<td>RP</td>
<td>19</td>
<td>10 degrees central vision. Uses cane</td>
<td>Married with two children</td>
<td>College</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Emily</td>
<td>59</td>
<td>RP</td>
<td>20’s</td>
<td>Central vision remaining</td>
<td>Second marriage. Two children</td>
<td>College</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Michael</td>
<td>60</td>
<td>RP</td>
<td>43</td>
<td>Central vision remaining</td>
<td>Married. One child</td>
<td>College</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Greg</td>
<td>59</td>
<td>RP</td>
<td>25</td>
<td>Restricted central vision. Uses cane</td>
<td>Married. Two children</td>
<td>College</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Kim</td>
<td>55</td>
<td>RP</td>
<td>41</td>
<td>8 degrees. Uses cane</td>
<td>Divorced. In a relationship. One child</td>
<td>College</td>
<td>Phone, snowball</td>
</tr>
<tr>
<td>Josh</td>
<td>53</td>
<td>RP</td>
<td>15</td>
<td>5 degrees central vision. Uses cane</td>
<td>Married. Five children</td>
<td>College</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Rick</td>
<td>54</td>
<td>RP</td>
<td>27</td>
<td>5 degrees vision.</td>
<td>Married second time.</td>
<td>College</td>
<td>In person, original pool</td>
</tr>
</tbody>
</table>
2.2.3 Data Collection
descriptive information about the 36 participants included in the analyses. Both types of interviews took on average 50 minutes. Table 2.1 provides the participant; usually their home or a cafe

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Eye Condition</th>
<th>Diagnosis</th>
<th>Uses cane</th>
<th>Other Vision</th>
<th>Family Status</th>
<th>Relationship</th>
<th>Interviews</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 Oliver</td>
<td>54</td>
<td>RP</td>
<td>18</td>
<td>Negligible central vision. Uses cane</td>
<td>Married. 2 children</td>
<td>College</td>
<td>Phone, original pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Joey</td>
<td>42</td>
<td>RP</td>
<td>19</td>
<td>Functionally blind. Uses cane</td>
<td>Married. One child</td>
<td>College</td>
<td>Phone, original pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Noah</td>
<td>82</td>
<td>RP</td>
<td>26</td>
<td>Functionally Blind. Uses cane</td>
<td>Married. Two children</td>
<td>College</td>
<td>Phone, original pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Lauren</td>
<td>73</td>
<td>Stargardt</td>
<td>40</td>
<td>Good peripheral vision</td>
<td>Married second time. Two children</td>
<td>Masters</td>
<td>In person, original pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Patrick</td>
<td>68</td>
<td>RP</td>
<td>18</td>
<td>Functionally Blind</td>
<td>Married. Two children</td>
<td>College</td>
<td>Phone, original pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Dylan</td>
<td>53</td>
<td>RP</td>
<td>37</td>
<td>Functionally Blind</td>
<td>Divorced. Three children</td>
<td>College</td>
<td>Phone, original pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Debra</td>
<td>55</td>
<td>Stargardts</td>
<td>33</td>
<td>Some peripheral vision</td>
<td>Never married in a relationship</td>
<td>Incomplete</td>
<td>In person, original pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Dan</td>
<td>50</td>
<td>RP</td>
<td>13</td>
<td>Some usable peripheral vision</td>
<td>Married. Two children</td>
<td>Incomplete</td>
<td>In person, original pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Henry</td>
<td>67</td>
<td>RP</td>
<td>22</td>
<td>Functionally Blind. Uses cane</td>
<td>Married. One child</td>
<td>College</td>
<td>In person, original pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Nick</td>
<td>59</td>
<td>RP</td>
<td>18</td>
<td>Functionally Blind. Uses cane</td>
<td>Married. One child</td>
<td>College</td>
<td>In person, original pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Phil</td>
<td>82</td>
<td>Stargardts</td>
<td>17</td>
<td>Functionally blind. Uses cane</td>
<td>Married second time. Three step children</td>
<td>College</td>
<td>In person, original pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Dick</td>
<td>42</td>
<td>RP</td>
<td>27</td>
<td>Restricted central vision</td>
<td>Divorced in a relationship</td>
<td>Masters</td>
<td>In person, original pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Roger</td>
<td>52</td>
<td>Rods Cons degeneration</td>
<td>42</td>
<td>Functionally Blind. Uses cane</td>
<td>Married. Two children</td>
<td>Medical doctor</td>
<td>Phone, snowball</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Ron</td>
<td>60</td>
<td>Form of RP</td>
<td>17</td>
<td>Some ‘foggy’ functional vision</td>
<td>Married third time. Five children</td>
<td>College</td>
<td>In person, original pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Adam</td>
<td>73</td>
<td>RP</td>
<td>39</td>
<td>Restricted central vision. Uses cane</td>
<td>Married. Two children</td>
<td>College</td>
<td>In person, original pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Benjamin</td>
<td>52</td>
<td>Stargardts</td>
<td>5</td>
<td>Some peripheral vision</td>
<td>Divorced. One child</td>
<td>Masters</td>
<td>In person, original pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 James</td>
<td>70</td>
<td>Stargardts</td>
<td>5</td>
<td>Functionally Blind. Uses cane</td>
<td>Married. One child</td>
<td>PhD</td>
<td>Phone, snowball</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 2.2: Pre-established discussion topics that have been covered during interviews

<table>
<thead>
<tr>
<th>Themes</th>
<th>General description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Background</strong></td>
<td>Growing up experience, growing up experience with eye condition</td>
</tr>
<tr>
<td><strong>Eye condition</strong></td>
<td>Type, degree of vision loss, coping, behavioral strategies in different settings</td>
</tr>
<tr>
<td><strong>Work life choices</strong></td>
<td>Career description, interplay between eye condition and career choices, dealing with work environment.</td>
</tr>
<tr>
<td><strong>Identity</strong></td>
<td>Self-acceptance, identity as visually impaired</td>
</tr>
<tr>
<td><strong>Social surrounding</strong></td>
<td>The role of others (outside of the workplace) in the well-being and coping with eye condition, general content with social surrounding, contact with other visually impaired individuals.</td>
</tr>
<tr>
<td><strong>Demographic information</strong></td>
<td>Short questionnaire about educational background, household composition, socio-economic status, religious affiliation, volunteering behavior (available upon request)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4 Rachel</th>
<th>52</th>
<th>RP</th>
<th>31</th>
<th>Functionally Blind. Uses guide dog</th>
<th>Married</th>
<th>College</th>
<th>Phone, snowball</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 Justin</td>
<td>67</td>
<td>Stargardts</td>
<td>20's</td>
<td>Some peripheral vision</td>
<td>Married</td>
<td>College</td>
<td>Phone, original pool</td>
</tr>
<tr>
<td>4 Norah</td>
<td>53</td>
<td>RP</td>
<td>21</td>
<td>10 degrees of central vision</td>
<td>Divorced twice. Three children</td>
<td>PhD</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>5 Gabrielle</td>
<td>45</td>
<td>RP</td>
<td>26</td>
<td>Good central vision</td>
<td>Married. Two children</td>
<td>Arts academy</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>5 Michelle</td>
<td>51</td>
<td>RP</td>
<td>38</td>
<td>Good central vision. Uses cane</td>
<td>Cohabiting</td>
<td>College</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>5 Carol</td>
<td>50</td>
<td>RP</td>
<td>30</td>
<td>Functionally Blind. Uses cane</td>
<td>Married second time. One child</td>
<td>College incomplete</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>5 Gwen</td>
<td>63</td>
<td>RP</td>
<td>40's</td>
<td>Good central vision. Uses cane</td>
<td>Married. Two children</td>
<td>No complete college.</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>5 Sarah</td>
<td>58</td>
<td>RP</td>
<td>37</td>
<td>Some central vision</td>
<td>Divorced. Three children</td>
<td>College</td>
<td>Phone, original pool</td>
</tr>
<tr>
<td>5 Katy</td>
<td>56</td>
<td>RP</td>
<td>23</td>
<td>Good central vision. Uses cane</td>
<td>Divorced and remarried. Three children</td>
<td>College</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>5 Jill</td>
<td>70</td>
<td>RP</td>
<td>17</td>
<td>Some central vision. Uses guide dog</td>
<td>Married. Two children</td>
<td>College</td>
<td>Phone, original pool</td>
</tr>
<tr>
<td>5 Monica</td>
<td>77</td>
<td>Stargardts</td>
<td>18</td>
<td>Some peripheral vision</td>
<td>Married. Three children</td>
<td>No completed college.</td>
<td>In person, original pool</td>
</tr>
</tbody>
</table>
2.2.4 Reflexivity

The authors of this paper acknowledge that reflexivity issues may affect this study (Altheide & Johnson, 2011), as the first author is visually impaired. She may, therefore, have a biased view on the issues concerning the study population. To address this potential bias, another fully sighted researcher has been asked to code the data as well. Including both an “insider’s” (first author) and an “outsider’s” (second author) view allowed for better data analysis. More information on reflexivity issues can be found in the discussion section.

2.2.5 Data Analysis

The interviews were fully transcribed and anonymized by the first author. The first two authors then coded all the interviews in ATLAS.ti. The guidelines for coding and analyzing these data using the grounded theory method were taken from Hennink et al. (2010). The two authors first worked separately, and discussed the main codes, which emerged in the data after each additional four transcripts were coded. The two coders identified similar coding themes. A joint “code family book” was then created by the two coders, which was used in the subsequent analysis. The family codes used in this paper can be found in Table 2.3.
### Table 2.3: Main code families used in the analysis (alongside demographic information)

<table>
<thead>
<tr>
<th>Code family name</th>
<th>Typology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adaptation and adjustments to vision loss</td>
<td>Adapting and adjusting behavior and emotion to vision loss</td>
</tr>
<tr>
<td>Career planning and adjustment</td>
<td>Work and career adjustments and planning (or lack thereof) in relation to vision loss</td>
</tr>
<tr>
<td>Challenges in education</td>
<td>Challenges in education related to vision loss</td>
</tr>
<tr>
<td>Emotional challenges</td>
<td>Emotional challenges relating to vision loss</td>
</tr>
<tr>
<td>Supportive workplace</td>
<td>Support and accommodations at work</td>
</tr>
<tr>
<td>Work challenges</td>
<td>Work challenges regarding obtaining and sustaining employment</td>
</tr>
<tr>
<td>Work discrimination</td>
<td>Discrimination in the workplace</td>
</tr>
<tr>
<td>Work and wellbeing</td>
<td>Reports on wellbeing being affected by work related concerns</td>
</tr>
<tr>
<td>Workplace strategies</td>
<td>Strategies individuals obtain and sustain employment</td>
</tr>
<tr>
<td>Concealment as workplace strategy</td>
<td>Concealment acting as a strategy for obtaining and sustaining employment</td>
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<tr>
<td>Passing behavior strategies</td>
<td>Passing and concealment behavior</td>
</tr>
<tr>
<td>Concealment motivations</td>
<td>Motivation to conceal identity</td>
</tr>
<tr>
<td>Concealment implications</td>
<td>Reported positive and negative implications (both physical and mental) of revealing identity in the workplace</td>
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<tr>
<td>Revealing motivations</td>
<td>Motivations for revealing or being open about identity</td>
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<tr>
<td>Revealing implications</td>
<td>Reported positive and negative implications (both physical and mental) of revealing identity in the workplace</td>
</tr>
<tr>
<td>Strategies to revealing identity</td>
<td>Strategies for how participants revealed their identity</td>
</tr>
<tr>
<td>Identity conflict</td>
<td>Participants reports on identity conflicts between being visually impaired and sighted</td>
</tr>
<tr>
<td>Challenges related to visibility</td>
<td>Challenges participants perceive related to being visible to others as visually impaired.</td>
</tr>
<tr>
<td>Cane</td>
<td>Use of a cane or a guide dog and the meanings attached to it</td>
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<tr>
<td>Guide dog</td>
<td>Use of a cane or a guide dog and the meanings attached to it</td>
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<tr>
<td>Professional rehabilitation</td>
<td>Use of a professional rehabilitation programs and the meanings attached to it</td>
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<tr>
<td>Assistive technology</td>
<td>Use of assistive and the meanings attached to it</td>
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</table>
Applying the “bigger picture” method (Hennink et al., 2010), the first author consulted the main code families which influenced the work trajectories of participants, and examined the narratives in an effort to discern behavioral patterns. After the first author had identified patterns in the data, the second author examined the narratives to determine whether she detected the same patterns. The second author confirmed the general conclusions of the first author, assigning the same patterns to 34 of the 36 participants. However, the authors disagreed about the degree of planning involved in the work trajectories of two of the participants. The authors made a joint decision to consider the participants’ work trajectory planning related to vision loss from the moment the participants were aware of the condition, and not beforehand (e.g. if the disease onset was at the age of 40, that was the point of reference). After this condition was applied, agreement on the participants’ placement within the patterns was achieved.

As an additional test, the authors had follow-up conversations with two of the participants (one in person and one by phone) in which they were asked for their views on the results and their personal placement within them. Both participants expressed their approval of the findings.

### 2.3 Results

Five different work trajectory and passing behavior patterns emerged in the participants’ life stories. These patterns will be described in this section. We should, however, preface our presentation of these stories with some general remarks. First, while some of the participants exhibited variation in their behavior over the course of their work trajectory, we will focus on their main behavioral strategy. Thus, although there may be some overlap in the behaviors of participants who were identified as having different patterns, the primary pattern of behavior of each participant was distinct from the other patterns. Second, some aspects of the patterns were on a continuum. For example, at one extreme were the participants who concealed their disability throughout their career, while on the other were the participants who were mostly open about their identity for the majority of their career. Other aspects of the patterns, such as the career trajectories themselves, were not on a continuum. Finally, it should be noted that the patterns are not intended to illuminate normative views, but rather to give insights into the various outcomes associated with different behavioral patterns.

In the following, we provide a general description of each pattern accompanied by illustrative quotes. We then discuss the implications of the behavioral pattern for the well-being and career outcomes of the individuals who display that pattern (see Table 1 for participant placement).
Pattern 1: No Career Adjustments, Concealed Condition Throughout Career

The common baseline of the six individuals who displayed this pattern is that they have decided (consciously or not) to pursue what they consider to be a “normal” work trajectory. They did not make their career-related decisions based on their anticipated vision loss. While five of these participants took early retirement, the remaining participant, a video editor named Greg, was struggling to find work. Greg discovered his condition during an early phase of his career. Like most other individuals who display this pattern, Greg, reported weighing the pros and cons of pursuing a career, especially one that is visual in nature:

I continued on my career [at the age of 25], trying to figure out what I should do. Whether I should go back to school, become a psychologist, or some other field where visual stuff was not that important. But I decided not to, I decided that I was gonna stick with my film career and the guy [doctor] said I had 30 years, so I figured out the math and I said alright I’ve got 30 years, so I’ll be 55. So I said 30 years is good enough. I’ll worry about it at 55.

Individuals in this pattern perceived that making such a choice was worthwhile even though they also seemed to think that doing so was incompatible with their anticipated visual decline.

As they assumed that their chosen career paths would not accommodate visual decline, the participants said they believed they would benefit from concealing their condition in the workplace. Among the reasons participants cited for their decision to conceal their condition were fear of discrimination, fear of termination, and anxiety about being treated as less capable in the workplace. For instance, Susan, a retired manager in a brokerage house, said she believes that revealing her condition would have led to termination or demotion in the workplace. When asked whether she considered being open about her condition, she replied:

Well, I was already being judged as being a poor performer even though I had been excellent up until that point. As the RP [Retinitis Pigmentosa] got worse the performance went down and so it was difficult - no. I probably would have been fired . . . It was a situation where, if you don’t perform at the top of your game, you’re not any use to the company. Therefore you serve at the pleasure of your employer.

Eventually, she retired on disability benefits as it became more difficult for her to do her job while still concealing her identity. These individuals expressed the view that there was no room for physical limitations in the labor market in which they were
competing. They asserted that if their condition had been revealed they would have encountered discrimination or an unwillingness to accommodate their disability. They also said that they assumed that as the condition progressed they would be increasingly unable to meet work demands. Most of the individuals decided to stop working and were not terminated. For example, both Michael, a retired consultant, and Kim, a retired corporate law attorney, reported that they were underperforming in the later stages of their career, and made the choice to leave without being asked or encouraged to do so.

Participants reported that not being open about their condition was a source of strain. For example, Greg recalled the difficulties he experienced:

*So that [concealment] went on for years until one day it was becoming harder and harder for me to hide it, you know. I was literally walking into walls and I would not go out with anybody after work to the bars. I would not socialize with anybody . . . So, here I am getting heavier cause I’ve been working 60 hours a week and gaining weight. Very stressed out that they’re gonna discover me any day now.*

All the participants who displayed this pattern reported having higher levels of wellbeing and experiencing relief after retirement.

**Pattern 2: Revealed Condition After Adjusting Career Plans**

Six of the participants displayed this pattern. All six reported that they became aware of their eye condition before the age of 30, but that the condition did not play an important role in their early career choices. They gave two main reasons why their initial career decisions were not determined by their impairment. First, they noted that their educational training took place before they knew of their condition. Second, like the individuals who displayed the previous pattern, these participants said they made a decision that the condition would not influence their future career choices. All six of these individuals started on their career path while concealing their condition.

Eventually, as concealment gradually became too difficult to sustain, they shifted to a different line of work in which they believed they could be open about their condition. Like the participants who displayed the first pattern, these participants said they believe that being open about their condition would have led to discrimination in the workplace. Rick, for instance, who worked in fashion retail in the first part of his career, was certain that revealing his condition would have led to his termination. He reported having been fired in the past due to his disability. For this reason, he engaged in concealment behaviors:
I was so frightened of being uncovered, that I would work in my office until I knew all my bosses had left and then I’d leave. And if they were working late, I would stay later cause I didn’t want anyone to confront me outside as we were walking out and I couldn’t see.

This behavior was taxing and eventually proved to be unsustainable, leading him to abandon this career path and start his own business.

As their condition progressed and concealing it was no longer a feasible tactic, the participants often shifted to engaging in normalizing behaviors; i.e. behaviors that would allow them to appear as assimilated as possible with the majority group. Even after they had disclosed their condition in the workplace and had made adjustments to their careers, some participants reported that they still engaged in normalizing behaviors. For example, Noah, a fully blind business owner, said he continued to minimize his disability:

I felt it was important to keep my disability or my lack of eyesight out of the equation, to the extent I can. So a [guide] dog would put it right in front of them, in the middle of anything, any relationship . . . I have felt (. . .) that if I were in a business meeting or going to a business meeting with people I didn’t know, I hadn’t gained that trust afterwards. It would change how they thought about me in ways that would limit the relationship.

This example shows that even when participants had revealed their condition and made career adjustments, they often remained conflicted about their identity. Each participant’s definition of “normal” depended on the degree of his or her visual functionality. If, for example, a participant could be mobile without using a white cane, then she or he might consider using a cane as being too visible. If another participant needed a white cane, then she or he might consider using a guide dog as being too visible.

Some participants acknowledged that there were positive aspects associated with their visual impairment. For example, Joey reported:

People are more comfortable sharing information with me quicker than they may if I didn’t have this disability...I’ve become a better listener by not being able to see well. I’ve become a better problem-solver. I’ve become more, let’s say, empathetic. And there’s probably a laundry list of other things.

Participants who displayed this pattern reported developing greater self-acceptance over time.
Pattern 3: Increasingly Open About their Condition Over the Course of their Career

Nine participants displayed this pattern. In contrast to the participants who displayed the previous two patterns, these participants did not shift their career focus later in life. Instead, they revealed their identity gradually over the course of their planned career trajectory. They all reported that they had concealed their identity in the workplace at the start of their career, even though most said they believe their employer would have accommodated their visual limitations. These participants also all reported that they eventually revealed their condition, although their reasons for doing so varied.

Henry, an attorney, said he chose to conceal his condition when he started his work trajectory because at that time there were no protective laws in place, such as the Americans for Disability Act (ADA). After the ADA went into effect, he decided to inform his employer of his condition to ensure that he was given technical accommodations. He did, however, report dissatisfaction with the responses he had received:

*I have indicated I have trouble seeing in court, it was too dark. The reward for that is one morning I found on my desk a flashlight and a magnifying glass.*

Patrick, a business owner, and Phil, a retired restaurant owner, said their initial rationale for concealing their disability was the fear that clients would perceive them as being incompetent. This, however, proved not to be the case for Patrick, as he noted that he was able to build a large clientele even after he could no longer avoid being open about his condition. While Patrick is functionally blind and is, therefore, unable to conceal his impairment, he admitted that he still engages in various normalizing behaviors:

*I refuse [to] admit it, not to me and not to the world [that I am blind]. Even though I know and they know. Psychologically I will not take a dog and will not take a cane. I have enough money that there’s always a young man or a young woman, or a friend or whatever, that I basically hold them.*

According to Patrick, having a young person serve as a guide allows him to appear more “normal”, and is, therefore, a more desirable solution than using a cane or a guide dog. He claimed that engaging in such behaviors gives him a greater feeling of control.
Chapter 2 | Keeping up appearances

Dick, Nick, Dylan, Phil, and Dan reported their increasing visual limitations forced them to tell their employer about their condition. Dick admitted, however, that he has not fully revealed his limitations in his workplace, because his remaining vision is still sufficient to allow him to pass as fully sighted. He reported that conflicts often arise when others misunderstand his physical limitations:

*I said to [coworker] ‘hey can you get me to the bathroom?’ And I don’t know if she thought I meant take me to the bathroom and go inside the room, I don’t know what she thought but she screams out ‘Oh my god, for Christ sake, Ron, he needs to take a leak,’ across the table with like 15 credited CEO’s . . . I was mortified. I didn’t recover from that kind of experience.*

These setbacks led Dick to experience more negative moods and doubts about his future career. But all the other participants who displayed this pattern reported that revealing their condition helped them reach a more desirable position in the workplace. Once they had proven themselves and/or had achieved a relatively high status in the workplace, they were more comfortable revealing their condition. As Debra, a marketing director, put it:

*I wanted to [tell him about my vision problem] the first day I went to work with him in his office . . . Then I thought, when I was getting closer, I came to my senses and said, if I say that’s gonna be all he sees. He doesn’t even know me . . . I’m helping him reach his goals. I have to prove myself . . . I have to help him realize his agenda before I can start throwing out my thing.*

She observed that it was important to her that her professional abilities were judged on the basis of her skills and not on her visual limitations.

All the individuals who displayed this pattern reported that they experienced a great deal of stress associated with passing behaviors, and that revealing their condition yielded both positive and negative outcomes. While Patrick, Debra, Roger, Henry, and Phil reported that they experienced relief and that their career was unaffected, the remaining participants reported mixed outcomes. Being open about their impairment produced emotional relief, but it also frequently created more challenges in the workplace.

**Pattern 4: Engaged in Career Planning, Always Open about their Condition**

While only three of the seven participants who displayed this pattern knew about
their condition at a fairly young age (before they underwent training or obtained higher education), they all exhibited a similar behavioral pattern: namely, they were always open about their visual limitations in the workplace. While some of these participants, such as Benjamin, Adam, and Ron, could have easily relied on passing behaviors, they chose to be open.

Ron, a company owner, discovered his condition as a teenager. He said he decided that being his own boss would make it easier for him to create an environment that is physically accommodating of his needs (e.g., having assistants and a driver). Thus, revealing his condition has always been functional for Ron. When asked whether he had considered engaging in concealment behavior, he responded:

*No, only because I started my own company and everything was on my back and so I did not have to rely on anyone else telling me what to do.*

Both Benjamin, a legal aide, and James, a college professor, received financial support for their educational training through associations for individuals with visual impairments. Their willingness to align themselves with or to request assistance from such associations indicates that they had a certain level of acceptance of their condition.

While the majority of the participants who demonstrated this pattern (five out of seven) said they are usually open about their condition when looking for a new job, two of the participants, Norah and Justin, reported taking a different approach. Both Norah and Justin said they typically conceal their eye condition when searching for a job, and wait until they are given a formal offer before revealing it. Norah observed that in her experience, disclosing her condition on the application, and thus before she had been identified as a worthy candidate, tends to result in fewer job opportunities:

*My first set of applications I sent out, I disclosed about my visual impairment and I didn’t get called for any job interviews. Then I thought ok. I’m gonna get smarter. I’m not gonna talk about that anymore. Left it out. And I got called back on almost every application I submitted, I got called for an interview.*

Both participants described this strategy as physically and mentally stressful. Once they received a job offer, they proceeded to revealing their condition. They both also indicated that in certain work settings their condition was even considered an advantage (e.g. when the work involved conducting research on the topic of disability). In those cases, they were more upfront about their condition.

In general, the participants who displayed this pattern expressed the least distress associated with workplace and identity management. As they were also less preoccupied with passing, they exhibited greater self-acceptance than participants in the previous patterns. Even though they were mostly open about their limitations,
these participants experienced career success. The fact that they found out about their condition rather early may have been an advantage, as this may have given them more time to process this knowledge emotionally, and to plan for their future.

**Pattern 5: Engaged in Limited Career Planning, Always Open about their Condition**

The eight participants who displayed this last pattern were all women. Motherhood and housekeeping seemed to influence the employment choices of these participants more than those of the other women in this study. These participants reported that when they were in the labor market they felt little pressure to advance professionally. Thus, they did not describe the implications of being “caught” as being particularly costly. These participants stated that advancement in the labor market was not very important to them. It is, therefore, possible that their lack of participation in the labor market, or their lack of professional advancement when they were working, is largely attributable to their identification with traditional gender roles.

As both Monica and Jill work in administration in their partner’s business, the costs of revealing their condition to their ‘employer’ are not currently an issue for them. However, apart from Monica and Jill, the majority of the women who displayed this pattern reported experiencing ongoing difficulties with employment. While Michelle and Carol reported trying to use associations for the visually impaired to help them get training and employment, they noted that their efforts produced no long-term employment opportunities. Carol described her experience with employment as follows: *I didn’t know what [I’m] capable to do with the sight. I would think oh my god, I don’t know what to do with my life.*

While all the women who displayed this pattern had discovered their condition rather early (while in their early thirties at the latest), they reported having been less concerned about long-term employment arrangements in the early stages of their career than the individuals who displayed the other patterns. Sarah, who is no longer caring for children and has recently divorced, admitted that her lack of proper employment training has begun to present challenges for her:

*Just doing what I have to do and trying to figure out how I’m gonna continue to survive and have enough income. That’s been difficult, cause I don’t have college, so I had no great profession to fall back on ... Supposedly if you go to the commission for school, you have to go full-time and I can’t do that because I need to work to survive and then of course, if you do go and you fail, they’re not gonna pay for it of course. I don’t have enough money to survive without working.*
This suggests that the failure to plan for a career early in life makes it challenging to integrate into the labor market at a later point in time, especially as a visually impaired person. Thus, while these women, like the individuals who displayed the fourth pattern, appear to be very accepting of their identity as a visually impaired person, they seem to have encountered employment challenges. These challenges may be of a similar nature to those of fully sighted women who are caregivers and who try to integrate into the labor market at a later life stage.

A summary of these patterns, along with their associated career and well-being outcomes, can be found in Table 2.4.

Table 2.4: Pattern summary

<table>
<thead>
<tr>
<th>Pattern</th>
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</thead>
<tbody>
<tr>
<td><strong>1. No career adjustments, concealed condition throughout career</strong></td>
</tr>
<tr>
<td>Make career training and career path choices without consideration of eye condition.</td>
</tr>
<tr>
<td>Reveal their condition at the end of career trajectory.</td>
</tr>
<tr>
<td>Retire early.</td>
</tr>
<tr>
<td>High stress during career trajectory, increased wellbeing and self-acceptance after retirement.</td>
</tr>
<tr>
<td><strong>2. Revealed condition after adjusting career plans</strong></td>
</tr>
<tr>
<td>Make career training and career path choices not considering eye condition.</td>
</tr>
<tr>
<td>Experience increased difficulty and stress. Decide to reveal their condition and make adaptations in their career planning to accommodate vision restrictions.</td>
</tr>
<tr>
<td>Report high content with their later career choices, self-acceptance and general wellbeing.</td>
</tr>
<tr>
<td><strong>3. Increasingly open about their condition over the course of their career</strong></td>
</tr>
<tr>
<td>Career training and career path choices are reported as compatible with vision restrictions.</td>
</tr>
<tr>
<td>Participants conceal their condition for a part of their career for various reasons (such as pride, fear of injustice).</td>
</tr>
<tr>
<td>Participants reveal their condition due to increased difficulties in task completion or fear of underperformance.</td>
</tr>
<tr>
<td>Most participants experience relief and stress reduction.</td>
</tr>
<tr>
<td><strong>4. Engaged in career planning, always open about their condition</strong></td>
</tr>
<tr>
<td>Participants make career training and career path choices that they experience as accommodating to their condition.</td>
</tr>
<tr>
<td>These individuals report being open about their condition during their careers and report low levels of passing behaviors (aside for two participants who disclosed after receiving a job offer).</td>
</tr>
<tr>
<td>Participants report high wellbeing levels in the workplace and high self-acceptance in and out of the workplace context.</td>
</tr>
<tr>
<td><strong>5. Engaged in limited career planning, always open about their condition</strong></td>
</tr>
<tr>
<td>This pattern consists only of women. Their main occupation was caretaking for family members or housekeeping.</td>
</tr>
<tr>
<td>These women were always open about the condition in the workplace (when working).</td>
</tr>
<tr>
<td>They reported difficulties integrating into the labor market. Possibly related to being a caretaker and not only to vision loss. The majority of women reported high self-acceptance.</td>
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2.4 Discussion

Our primary goal in undertaking this study was to contribute to the literature by describing the interplay between work trajectories and the passing and concealment patterns of individuals with degenerative eye conditions in different phases of their career and disease progression. We also set out to describe the wellbeing outcomes which are associated with different work trajectories, and the concealment and passing pathways individuals with visual impairments use. We detected five distinct behavior patterns among the study participants (Table 2.4). Some of the most noteworthy results will be discussed in the following.

First, previous research on the process of deciding when to reveal a stigmatized identity has indicated that individuals engage in cost-benefit processes (Hayeems et al., 2005; Martz, 2003). These studies have suggested that when the costs of concealing the identity become too high (e.g., because concealment has become too physically or emotionally taxing), the person will choose to reveal the identity. The current study takes this research further by showing that while cost–benefit processes are indeed evident in the narratives of the participants, understanding the nuances in these motivations is important when seeking to explain the link between concealment behavior and well-being outcomes. For instance, an employee who conceals his or her condition because she or he is worried about being discriminated against will experience a different emotional burden than an employee who conceals his or her identity because she or he wishes to be evaluated based on his or her professional skills (and the visually impaired identity).

Second, in this study, we have shown that even individuals who are open about their identity in the workplace might still engage in normalizing behaviors, which may in turn work to their advantage in gaining and sustaining employment. This finding may be regarded as a key contribution of this study. It points to the importance of understanding revealed identities in the workplace among this group as existing on a continuum, and not as representing a dichotomous outcome. While a client or an employer might be aware of an employee’s visual limitations, the individual in question may still be concealing the degree of functional limitations she or he is experiencing by, for instance, avoiding using a cane. It remains unclear whether engaging in “normalizing” behaviors (e.g., choosing a cane over a guide dog) is really useful in creating rapport with colleagues and clients, or whether this acts as a “placebo effect”. The latter explanation suggests that individuals who have a greater feeling of control over their visibility tend to be more successful in the workplace.

Third, while the decision to conceal their identity until they were established professionally seems to have been associated with positive career outcomes for participants (like in pattern 3), it was also found to have been stressful and taxing, both physically and mentally. This finding is in line with research which modeled the
taxing outcomes associated with concealing stigmatized identities (Pachankis, 2007).

Finally, in light of research in the field of disclosure of stigmatized identities, the evidence on the question of whether individuals with a stigmatized identity should conceal their identity has been mixed. Some studies on invisible and visible disabilities have suggested that for positive employment outcomes it is preferable to have a concealable disability (e.g., Southall, Jennings, Gagne, 2011), while other studies have pointed to the benefits of revealing one’s identity (e.g., Martz, 2003). Our results suggest that there is no clear answer to the question of whether disclosure is advantageous or disadvantageous for an individual’s career outcomes and general well-being. While revealing the identity may reduce the stress associated with trying to pass and can enhance self-acceptance (Hayeems et al., 2005), being open may also have negative effects on the person’s career outcomes. This is especially true for individuals who discovered their condition at a later stage of their career, and who thus lack the tools (e.g., the ability to compensate with assistive devices) they would need to adjust their career path (as was the case with some of the individuals from pattern 1).

While this study adds to our knowledge, a few limitations need to be addressed. First, the data collection was done partly in person and partly by telephone. The latter method may have limited the kinds of information received by the interviewer (such as information through body language), and may have made it more difficult to establish the level of rapport which is often achieved when meeting in person. However, it should be emphasized that the interviewer noted no reservations about speaking freely on the part of the participants who were interviewed by phone. This is also indicated by the length of the phone interviews, which on average did not differ from the length of the interviews conducted in person.

A second possible limitation is that one of the data coders is visually impaired, which raises the issue of reflexivity (Altheide & Johnson, 2011). On one hand, the fact that she is visually impaired has helped her in gaining the trust of the participants and in obtaining more in-depth information from them. On the other hand, her relationship to the target group may have affected her analysis of the data. The additional coder acts as a buffer to this potential bias, but it cannot be ruled out completely.

A final limitation might be that the study population was relatively uniform. The majority of participants were highly educated and from a secure economic background. Furthermore, there was little ethnic and or racial diversity in this sample. Therefore, our findings cannot be generalized to the entire population of people with degenerative eye conditions.

Future studies should expand the study population, targeting other segments of the population with degenerative eye conditions, or applying a quantitative approach which would make it possible to study passing behaviors and work trajectories using a much larger sample with people from various backgrounds. Future research could also consider additional factors which could influence concealment behavior in the
workplace and related career outcomes, such as the role of mentors and protectors in the workplace.

Despite the limitations of this study, we believe that our findings provide new insights into the experiences of an important subgroup of people with degenerative eye conditions. By taking into account the insights on passing and work trajectory patterns provided by this study, health professionals may be better able to help individuals who are considering disclosing their identity prepare for the challenges they are likely to face.
Chapter 3

What are the Pathways Linking the Disclosure of a Degenerative Eye Condition in the Workplace and Wellbeing? A Mixed Methods Approach*

Abstract
Using a mixed methods approach, we investigated the pathways linking the disclosure of a degenerative eye condition in the workplace and wellbeing. Two pathways were identified in the literature on the disclosure of stigmatized identities: the alleviation of inhibition and social support. In light of the unique characteristics of this group, we have consulted the Social Production Function Theory, which suggests an additional physical pathway through the use of assistive devices. Our survey and interview data support the assumption that the alleviation of inhibition represents another pathway to wellbeing. The interview data partially supports the presence of the other pathways.

* This chapter is co-authored with Rafael Wittek and Nardi Steverink and has been submitted to a scientific journal and is invited for publication upon minor revisions.
3.1 Introduction

A stigma is a personal characteristic or behavior— or a reputed characteristic or behavior— that can lead an individual to be categorized and stereotyped by others in a particular context and in a disagreeable manner. The stigma is usually related to a person's character, a group she belongs to, or a physical attribute (Goffman, 1963). A stigmatized identity can be visible (such as racial background) or invisible (such as certain types of chronic diseases). Disclosing an invisible stigmatized identity can have both negative and positive consequences for the individual.

Research thus far suggests that disclosing a stigmatized identity in the workplace may result in discrimination, prejudice, and the devaluation of the individual with the stigmatized identity (Badgett, 1996; Dovidio, Major, & Gramzow, 1999; Gouvier et al., 1991; Herek, 2007; Herek, 2009; Miller, & Major, 2000). This in turn may have adverse consequences for the stigmatized person's identity formation, wellbeing, health, cognition, and behavior (Dovidio, Major, & Crocker, 2000; Miller & Major, 2000; Pascoe, & Smart Richman, 2009). The adverse consequences associated with the stigmatizing of certain identities in the workplace may be especially severe for individuals with degenerative eye conditions. Individuals with vision impairment suffer from high unemployment rates: in the United States, the rate is above 60% (Erickson, Lee, & von Schrader, 2010). As these rates are even higher than those of many other disability and minority groups (Bell & Mino, 2013), the issue of the disclosure of visual impairments in the workplace is critical.

It has also been shown, however, that disclosing a stigmatized identity can be beneficial for the individual. When a person stops trying to hide her identity, she may, for example, have higher self-esteem, more energy, and lower stress levels (Corrigan & Matthews, 2003; Clair et al., 2005; Derlega, Metts, Petronio, & Margulis, 1993; Jourard, 1971). Yet the existing studies on the benefits of disclosure have not focused specifically on the benefits in the workplace. This makes it difficult to draw conclusions about which disclosure pathways are associated with positive outcomes in this specific context. Moreover, most studies on the topic of disclosure focus on the antecedents that lead individuals to disclose their stigmatized identity (Clair, Beatty, & Maclean, 2005; Greene, Derlega, & Mathews, 2006; Ragins, 2008). The few studies on the consequences of disclosure for positive wellbeing have focused mainly on the effects of the confidant's reaction (i.e., a positive response is beneficial for reducing stress, while a neutral or negative response is not), and on esteem-related emotions (Clair et al., 2005; Corrigan & Matthews, 2003; Derlega et al., 1993; Jourard, 1971). Thus, little is known about the conditions under which disclosure in the workplace is beneficial for wellbeing, especially for the unique group of individuals with degenerative eye conditions (Hayeems, Geller, Finkelstein, & Faden, 2005).

An additional reason to focus on the group with degenerative eye conditions is
3.1 Introduction

A stigma is a personal characteristic or behavior—or a reputed characteristic or behavior—that can lead an individual to be categorized and stereotyped by others in a particular context and in a disagreeable manner. The stigma is usually related to a person’s character, a group she belongs to, or a physical attribute (Goffman, 1963). A stigmatized identity can be visible (such as racial background) or invisible (such as certain types of chronic diseases). Disclosing an invisible stigmatized identity can have both negative and positive consequences for the individual.

Research thus far suggests that disclosing a stigmatized identity in the workplace may result in discrimination, prejudice, and the devaluation of the individual with the stigmatized identity (Badgett, 1996; Dovidio, Major, & Gramzow, 1999; Gouvier et al., 1991; Herek, 2007; Herek, 2009; Miller, & Major, 2000). This in turn may have adverse consequences for the stigmatized person’s identity formation, wellbeing, health, cognition, and behavior (Dovidio, Major, & Crocker, 2000; Miller & Major, 2000; Pascoe, & Smart Richman, 2009). The adverse consequences associated with the stigmatizing of certain identities in the workplace may be especially severe for individuals with degenerative eye conditions. Individuals with vision impairment suffer from high unemployment rates: in the United States, the rate is above 60% (Erickson, Lee, & von Schrader, 2010). As these rates are even higher than those of many other disability and minority groups (Bell & Mino, 2013), the issue of the disclosure of visual impairments in the workplace is critical.

It has also been shown, however, that disclosing a stigmatized identity can be beneficial for the individual. When a person stops trying to hide her identity, she may, for example, have higher self-esteem, more energy, and lower stress levels (Corrigan & Matthews, 2003; Clair et al., 2005; Derlega, Metts, Petronio, & Margulis, 1993; Jourard, 1971). Yet the existing studies on the benefits of disclosure have not focused specifically on the benefits in the workplace. This makes it difficult to draw conclusions about which disclosure pathways are associated with positive outcomes in this specific context. Moreover, most studies on the topic of disclosure focus on the antecedents that lead individuals to disclose their stigmatized identity (Clair, Beatty, & Maclean, 2005; Greene, Derlega, & Mathews, 2006; Ragins, 2008). The few studies on the consequences of disclosure for positive wellbeing have focused mainly on the effects of the confidant’s reaction (i.e., a positive response is beneficial for reducing stress, while a neutral or negative response is not), and on esteem-related emotions (Clair et al., 2005; Corrigan & Matthews, 2003; Derlega et al., 1993; Jourard, 1971). Thus, little is known about the conditions under which disclosure in the workplace is beneficial for wellbeing, especially for the unique group of individuals with degenerative eye conditions (Hayeems, Geller, Finkelstein, & Faden, 2005).

An additional reason to focus on the group with degenerative eye conditions is
that because sight loss is a gradual process, it can be difficult for people who are losing their sight to decide when the right time is to disclose that they have this feared and often misunderstood condition (Dickerson, Smith, & Moore, 1997). Concealing the condition may reduce the likelihood that an individual will face discrimination and prejudice. However, waiting too long before making the disclosure can result in physical and mental strain, as keeping up appearances with worsening eyesight can be dangerous (Hayeems et al., 2005; Spiegel, de Bel, & Steverink, 2016). It is important to establish when the disclosure of a degenerative eye condition in the workplace is beneficial for the wellbeing of the individual. Examining the effects of disclosure in the workplace among this group is the main contribution of this study.

### 3.2 Theoretical Framework

While fairly little is known about the benefits of disclosure in the workplace for individuals with degenerative eye conditions, there are some theoretical guidelines we can use from previous literature to make some assumptions. The literature points to two main pathways linking the disclosure of a stigmatized identity and wellbeing.

The first pathway, “alleviation of inhibition,” suggests that disclosure can reduce or diminish the stress associated with concealment. Once the stigmatized identity is revealed, the individual has the ability to express inhibited emotions and traits, which can in turn influence her overall sense of wellbeing (Chaudoir & Fisher, 2010). This pathway has also been referred to as emotional processing (Beals, Peplau, & Gable, 2009). Since a physical disability can be difficult to conceal not just emotionally, but also physically, we expect to find that this pathway is highly evident among those with degenerative eye conditions (Beals, Peplau, & Gable, 2009; Chaudoir & Fisher, 2010).

The second main pathway is through “social support.” It has been suggested that the degree of instrumental and emotional support received from the individual’s confidants in relation to the act of disclosure is an important determinant of wellbeing (Beals, Peplau, & Gable, 2009; Chaudoir & Fisher, 2010). It also seems very likely that for individuals with a degenerative eye condition, receiving instrumental and emotional social support after they disclose their condition in the workplace contributes to their wellbeing. Thus, we expect to find that social support in the workplace context operates as a second pathway to benefits from disclosure.

So far we have noted that the individual’s emotional processes and the reactions of the individual’s social contacts are important pathways linking disclosure and wellbeing. However, we can also expect to find that, because of the particular characteristics of people with visual impairments and the challenges they face, an additional, physical, pathway linking disclosure to wellbeing may emerge. Because concealing a degenerative eye condition in the workplace will limit the ability of these individuals to gain access to physical accommodations (i.e., assistive technology or
mobility aids), they may find it increasingly difficult to meet their work responsibilities. The failure to perform well at work may in turn take a toll on their overall wellbeing. We have therefore decided to introduce an additional pathway based on the Social Production Function (SPF) theory. The SPF theory (Lindenberg, 1996; Ormel, Lindenberg, Steverink, & Verbrugge, 1999) suggests that there are basic universal (physical and social) needs, the fulfillment of which contributes to the overall wellbeing of the individual. When these basic needs are not met, the individual is at risk of experiencing stress and deficits in effective functioning and wellbeing, which may in turn negatively influence the individual’s wellbeing (cf. Ryan & Deci, 2000).

There are two basic physical needs: the need for comfort and the need for stimulation. The need for comfort refers to basic somatic needs, such as hunger or thirst. The need for stimulation refers to the need for physical and cognitive challenges. There are three basic social needs: affection, behavioral confirmation, and status (Lindenberg, 1996; Steverink & Lindenberg, 2006). Affection refers to the need of an individual to love and to give and receive affection, both through physical proximity (e.g., a hug) and through emotional closeness (e.g., having the feeling of being listened to). Behavioral confirmation refers to an individual’s need to receive validation for her behavior from people whose opinion she values. Finally, status refers to the need of an individual to be respected, independent, and seen as a person with unique skills and accomplishments. In seeking to fulfill these social needs, an individual makes use of her resources (e.g., friends, family, job positioning) and sets goals for herself that aligned with meeting these needs (e.g., making a friend or getting a high status job).

Although the SPF theory posits that the fulfillment of the two physical needs and the three social needs is essential for a basic level of wellbeing, it also suggests that if the individual lacks the resources to meet all of these needs, the fulfillment of some of these needs can, to a certain extent, compensate for the inability to fulfill the others (see Steverink & Lindenberg, 2006).

Thus, keeping a stigmatized identity secret may be seen as a strategy that helps an individual fulfill her social needs. A person’s professional network may be expected to fulfill her behavioral confirmation and status needs. These two needs are met when coworkers, employers, subordinates, and/or clients validate the performance of the individual. As we know from empirical studies (Badgett, 1996; Herek 2009; Dovidio, Major, & Crocker, 2000; Heatherton, Kleck, Hebl, & Hull, 2000) and from theories on stigma (Goffman, 1963), in professional settings individuals with stigmatized identities tend to be undervalued based on prejudices and preconceptions related to the stigmatized identity. Because revealing her identity can have negative implications for the fulfillment of her needs, an individual may choose to conceal her identity.

On the other hand, keeping a stigmatized identity a secret may interfere with the individual’s ability to fulfill her physical needs. For instance, over time commuting
may become a challenge for an individual with a degenerative eye condition, and may be expected to become increasingly difficult if she avoids using a white cane or a guide dog in order to conceal her identity. After the individual has disclosed her disability identity, she will be better able to manage her physical restrictions by making use of assistive devices, and will thus find it easier to fulfill her physical needs.

The use of assistive devices can help people with disabilities meet both their social and physical needs. When an individual avoids using assistive devices, she runs the risk of performing worse than her able-bodied peers, which may hinder the fulfillment of her status and behavioral confirmation needs. While social support (the second pathway) can be seen as related to the fulfillment of the need for affection, the use of assistive devices in the workplace can act as a means of fulfilling the additional social needs of behavioral confirmation and status. Whether these two needs are met depends on whether the individual’s workplace contacts positively evaluate her behavior. Thus, the individual’s needs go beyond the needs that can be met through emotional and instrumental support.

This theoretical framework would suggest thus that the benefits the individual derives from disclosure will depend greatly on the extent to which her needs are fulfilled, and the interplay between the fulfillment of these various needs (i.e., fulfilling one need may come at the cost of fulfilling another). Thus, we may expect to find that the physical pathway, through the use of assistive devices, will be beneficial for both the physical and social aspects of wellbeing through the fulfillment of both physical and social needs.

In the current study, we use a mixed methods approach to investigate when the disclosure of a degenerative eye condition relates positively to wellbeing. Using survey data, we will first test the direct association between disclosure and wellbeing, and examine whether the three pathways—i.e., the alleviation of inhibition, workplace social support, and the use of assistive devices—are mediators of this association. Using qualitative life stories interview data, we investigate how the participants experience disclosure in the workplace, and how it relates to their wellbeing. We then explore the participants’ experiences of the three pathways in the life stories.

3.3 Method Survey Data

3.3.1 Ethical Statement

The survey (survey content and consent form) and the interview study have received approval from the ethical committee of the sociology department of the University of Groningen. Consent was obtained from all of the participants, as they agreed to the consent statement on the first page of the online survey.
3.3.2 Survey Data Description

An online survey was administered among individuals with degenerative eye conditions who were over age 18 and were living in the United States. The participants were approached through a nonprofit organization for medical research on vision loss based in the U.S. The survey was also advertised through the National Federation for the Blind (NFB), through various social network groups (support groups for individuals with low vision on Facebook), and through email lists for individuals with low vision. Given the various methods of outreach, we do not know what the exact response rate was. The survey was completed by 143 individuals of whom 108 indicated that they were either currently employed or retired.

3.3.3 Measures

Wellbeing was measured using three concepts that are often mentioned in the literature in conjunction with each other as measures of subjective wellbeing (Pavot & Diener, 1993): life satisfaction, positive affect, and negative affect. Life satisfaction was measured using the Satisfaction With Life Scale (SWLS, Diener, Emmons, Larsen, & Griffin, 1985). This five-item scale consists of items such as: “In most ways my life is close to my ideal.” The answer categories range from one (strongly disagree) to seven (strongly agree). This is a highly reliable scale (alpha=.92). Positive and negative affect were measured using the short (five items per concept) PANAS scales (Thompson, 2007). Participants were asked to indicate the degree to which they had experienced certain feelings in the last two weeks on a scale ranging from one (very slightly to not at all) to five (extremely). Among the items that represent positive affect are “alert” and “determined” (Cronbach’s alpha=.84), while among the items that represent negative affect are “afraid” and “nervous” (Cronbach’s alpha=.84).

Disclosure in the workplace was measured with the following item: “To what degree are you open about your condition at your current workplace (or if not working – your last workplace) from 1 (conceal it entirely) to 5 (completely open about it)?” It is important that we see disclosure as a fluid rather than as a dichotomous concept, as individuals can choose to make a partial disclosure of their identity by, for example, concealing the severity of their disease, or disclosing their condition to certain work contacts only.

Anxiety was measured using a seven-item scale (GAD-7, Spitzer, Kroenke, Williams, & Löwe, 2006), in which participants were asked: “Over the last 2 weeks, how often have you been bothered by the following problems?” An example of an item is: “feeling nervous, anxious or on edge.” The answer categories ranged from zero (not at all) to three (nearly every day). The scale has been reversed to measure reduced anxiety (Cronbach’s alpha=.90).
For social support of work related contacts, we used the coworker support and supervisor support scale (Schwartz, Pieper, & Karasek 1988). Examples of items are: “How often do you get help and support from your coworkers?” and “How often do you get help and support from your immediate supervisor/s?” The possible responses for both work-related social support items ranged from zero (all the time) to five (never). As in the previous case, the scale has been reversed to measure high work social support (Cronbach’s alpha=.78).

Use of assistive devices was measured by looking at three sub-factors. To measure the factors using assistive technology at work and using a cane at work, the respondents were asked whether they used assistive technology at work (yes/no) or used a cane at work (yes/no). The third factor, using a guide dog was measured by asking the respondents whether they made use of a guide dog (yes/no). We constructed a dichotomous variable indicating whether individuals made use of either one of these three assistive devices, with zero indicating that they did not use any assistive devices, and one indicating that they used at least one assistive device (Analyses were conducted with the three concepts separately, and similar results were found. Results are available from the first author upon request).

We also controlled for additional factors that might play a role in the wellbeing of individuals with degenerative eye conditions. We considered age (in years). We also looked at how long ago the participants started experiencing difficulties due to their vision (measured in years). Using the 10-item difficulty with activities subscale from the Visual Functioning Questionnaire (VFQ-25, Coleman 2002) we measured the degree of difficulty the participants were experiencing with daily activities (Cronbach’s alpha=.83). Finally, we controlled for whether the participants were currently employed or retired (employed=1, retired=0). For descriptive statistics see Table 3.1.

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Min</th>
<th>Max</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life satisfaction</td>
<td>4.77</td>
<td>1.55</td>
<td>1</td>
<td>7</td>
<td>107</td>
</tr>
<tr>
<td>Positive affect</td>
<td>3.32</td>
<td>.86</td>
<td>1</td>
<td>5</td>
<td>106</td>
</tr>
<tr>
<td>Negative affect</td>
<td>1.70</td>
<td>.71</td>
<td>1</td>
<td>5</td>
<td>105</td>
</tr>
<tr>
<td>Disclosure</td>
<td>3.98</td>
<td>1.17</td>
<td>1</td>
<td>5</td>
<td>101</td>
</tr>
<tr>
<td>Reduced anxiety</td>
<td>3.31</td>
<td>.67</td>
<td>1</td>
<td>4</td>
<td>106</td>
</tr>
<tr>
<td>Work support</td>
<td>3.42</td>
<td>.84</td>
<td>1</td>
<td>5</td>
<td>98</td>
</tr>
<tr>
<td>Use of devices</td>
<td>.75</td>
<td>-</td>
<td>0</td>
<td>1</td>
<td>101</td>
</tr>
<tr>
<td>Age</td>
<td>49.34</td>
<td>15.16</td>
<td>23</td>
<td>88</td>
<td>108</td>
</tr>
<tr>
<td>Difficulty with activities</td>
<td>2.86</td>
<td>.78</td>
<td>1.1</td>
<td>5</td>
<td>107</td>
</tr>
<tr>
<td>Eyesight deterioration</td>
<td>24.45</td>
<td>18.99</td>
<td>0</td>
<td>76</td>
<td>104</td>
</tr>
<tr>
<td>Working</td>
<td>.76</td>
<td>-</td>
<td>0</td>
<td>1</td>
<td>108</td>
</tr>
</tbody>
</table>
3.3.4 Analysis

Using Stata 13, we conducted pathway analyses with the SEM command to estimate the association between disclosure and life satisfaction, positive affect and negative affect, and the mediation effects of reduced anxiety and workplace social support. Missing values can cause skewed results, as we do not know whether the missing values are structural or random. To deal with missing data, we used Maximum Likelihood for Missing Values (MLMV; Bodner, 2008). The pathway model test in this software is, however, unable to perform MLMV for logistic outcomes. Because of the restrictions on the use of dichotomous mediators using the SEM modeling in STATA, we tested the pathways related to device use using OLS regression models. To deal with the missing data in this portion of the analysis we applied chained multiple imputation techniques (White, Royston, & Wood, 2011).

3.4 Survey Data Results

3.4.1 Bivariate Analysis

When we look at the correlation table (Table 3.2) we can see that negative affect and positive affect are correlated with life satisfaction. As these measures are used to measure the concept of subjective wellbeing, this is an expected outcome. The only relationship of concern in this context is when the correlation between the scales that measure (reduced) anxiety and negative affect is higher than .6. The two aforementioned scales have been developed to measure these two unique concepts, and hence will be used in their original form. However, we acknowledge the drawbacks of analyzing highly correlated concepts together, and will use caution when interpreting the results of the models that implement the two concepts together.

Given that a simple correlation test is not the most appropriate means of assessing the relationship between a dichotomous and continuous variable, we have also performed a chi-square test to test whether there are concerns with modeling the use of devices together with the three dependent variables. The results were insignificant.
3.4.2 Direct Associations and Mediation Analyses Results

The first step in this analysis was to test whether disclosure is associated with the three wellbeing outcomes. As we can see in Table 3.3, the results are in the expected direction: disclosure is positively associated with life satisfaction ($\beta = .25, p = .003$) and positive affect ($\beta = .19, p = .023$), and negatively associated with negative affect ($\beta = -.23, p = .007$).

The next step was to test whether the three factors—i.e., reduced anxiety, workplace social support, and the use of devices—mediated the association between disclosure and wellbeing. We found a significant indirect association between disclosure and life satisfaction ($\beta = .07, p = .025$), and between disclosure and negative affect ($\beta = -.15, p = .014$), through reduced anxiety (see Table 3.4). This result supports the notion that reduced anxiety may act as a mediator of the relationship between disclosure and wellbeing. The pathway model of reduced anxiety and life satisfaction had an $R^2$ square of .17, while the pathway model of reduced anxiety and negative affect had an $R^2$ square of .14.

While disclosure was positively associated with both workplace support (see Table 3.4, $\beta = .72, p = .024$) and the use of devices (see Table 3.5, $\beta = .29, p = .001$), we found no support for an association between these two factors and the three subjective wellbeing outcomes, and, by implication, no support for a mediation pathway.
Table 3.2: Correlation table

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life satisfaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive affect</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Negative affect</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

P-values in parentheses

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Table 3.3: Direct association between disclosure and wellbeing

<table>
<thead>
<tr>
<th></th>
<th>Life satisfaction</th>
<th>Positive affect</th>
<th>Negative affect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disclosure</td>
<td>.25 (.003)</td>
<td>.19 (.023)</td>
<td>-.23 (.007)</td>
</tr>
<tr>
<td>Age</td>
<td>.09 (.215)</td>
<td>.25 (.016)</td>
<td>-.13 (.140)</td>
</tr>
<tr>
<td>Difficulties</td>
<td>-.25 (.004)</td>
<td>-.15 (.059)</td>
<td>.08 (.185)</td>
</tr>
<tr>
<td>Deterioration</td>
<td>-.10 (.171)</td>
<td>.05 (.313)</td>
<td>-.04 (.354)</td>
</tr>
<tr>
<td>Working</td>
<td>.05 (.330)</td>
<td>.24 (.017)</td>
<td>.05 (.314)</td>
</tr>
</tbody>
</table>

$N=108$, one-tailed results in line with theoretical expectations.

Standardized coefficients are presented with p-values in parentheses.
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Table 3.4: Mediation of reduced anxiety and work support on the three wellbeing outcomes

<table>
<thead>
<tr>
<th>Path specification</th>
<th>Anxiety</th>
<th>Path specification</th>
<th>Work support</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Life-satisfaction</strong></td>
<td></td>
<td><strong>Life-satisfaction</strong></td>
<td></td>
</tr>
<tr>
<td>Total $R^2$</td>
<td>.17</td>
<td>Direct effect, outcome: work</td>
<td>.27</td>
</tr>
<tr>
<td>Direct effect, outcome: anxiety</td>
<td></td>
<td>support</td>
<td></td>
</tr>
<tr>
<td>Disclose</td>
<td>.21 (.015)</td>
<td>Direct effect, outcome: life</td>
<td>.29 (.001)</td>
</tr>
<tr>
<td>Direct effect, outcome: life satisfaction</td>
<td></td>
<td>satisfaction</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>.37 (.000)</td>
<td>Work support</td>
<td>.06 (.262)</td>
</tr>
<tr>
<td>Disclose</td>
<td>.17 (.026)</td>
<td>Direct effect, outcome: life</td>
<td>.23 (.009)</td>
</tr>
<tr>
<td>Indirect effect, outcome: life satisfaction</td>
<td></td>
<td>satisfaction</td>
<td></td>
</tr>
<tr>
<td>Disclose</td>
<td>.07 (.025)</td>
<td>Direct effect, outcome: life</td>
<td>.01 (.267)</td>
</tr>
<tr>
<td>Total effect, outcome: life satisfaction</td>
<td></td>
<td>satisfaction</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>.37 (.000)</td>
<td>Work support</td>
<td>.06 (.262)</td>
</tr>
<tr>
<td>Disclose</td>
<td>.25 (.003)</td>
<td>Direct effect, outcome: life</td>
<td>.25 (.003)</td>
</tr>
<tr>
<td><strong>Positive affect</strong></td>
<td></td>
<td><strong>Positive affect</strong></td>
<td></td>
</tr>
<tr>
<td>Total $R^2$</td>
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<td>Direct effect, outcome: work</td>
<td>.25</td>
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<tr>
<td>Direct effect, outcome: anxiety</td>
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<td>support</td>
<td></td>
</tr>
<tr>
<td>Disclose</td>
<td>.21 (.014)</td>
<td>Direct effect, outcome: positive</td>
<td>.29 (.001)</td>
</tr>
<tr>
<td>Direct effect, outcome: positive affect</td>
<td></td>
<td>affect</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>.21 (.013)</td>
<td>Work support</td>
<td>-.02 (.442)</td>
</tr>
<tr>
<td>Disclose</td>
<td>.14 (.069)</td>
<td>Direct effect, outcome: positive</td>
<td>.19 (.027)</td>
</tr>
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<td></td>
</tr>
<tr>
<td>Disclose</td>
<td>.04 (.057)</td>
<td>Direct effect, outcome: positive</td>
<td>-.006 (.422)</td>
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<td>Anxiety</td>
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<td>Disclose</td>
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<td>Direct effect, outcome: work</td>
<td>.18 (.025)</td>
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<td><strong>Negative affect</strong></td>
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<td><strong>Negative affect</strong></td>
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<tr>
<td>Total $R^2$</td>
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<td>.25</td>
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<tr>
<td>Direct effect, outcome: anxiety</td>
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<td>support</td>
<td></td>
</tr>
<tr>
<td>Disclose</td>
<td>.22 (.012)</td>
<td>Direct effect, outcome: negative</td>
<td>.29 (.001)</td>
</tr>
<tr>
<td>Direct effect, outcome: negative affect</td>
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<td>affect</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>- .69 (-.000)</td>
<td>Work support</td>
<td>-.06 (.276)</td>
</tr>
<tr>
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<td>- .07 (.137)</td>
<td>Direct effect, outcome: negative affect</td>
<td>-.21 (.018)</td>
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<td></td>
</tr>
<tr>
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<td>.01 (.279)</td>
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<td></td>
</tr>
<tr>
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<td>- .69 (.000)</td>
<td>Work support</td>
<td>-.06 (.276)</td>
</tr>
<tr>
<td>Disclose</td>
<td>- .23 (.009)</td>
<td></td>
<td>-.23 (.008)</td>
</tr>
</tbody>
</table>

$N=108$, one-tailed results in line with theoretical expectations. Standardized coefficients are presented with $p$-values in parentheses. For the purpose of convenience control variables are excluded from the tables but the full tables are available upon request.
Table 3.5: Mediation of use of devices on the three wellbeing outcomes

<table>
<thead>
<tr>
<th>Dependent variable</th>
<th>Devices</th>
<th>Life-satisfaction</th>
<th>Life-satisfaction</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>R square</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Devices</td>
<td>.33</td>
<td>.13</td>
<td>.14 (.109)</td>
</tr>
<tr>
<td>Disclosure</td>
<td>.72 (.024)</td>
<td>.26 (.004)</td>
<td>.23 (.012)</td>
</tr>
<tr>
<td>Pseudo R square</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Devices</td>
<td>.10</td>
<td>.10</td>
<td>-.00 (.496)</td>
</tr>
<tr>
<td>Disclosure</td>
<td>.18 (.031)</td>
<td>.18 (.036)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Negative affect</th>
<th>Positive affect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pseudo R square</td>
<td>.09</td>
<td>.10</td>
</tr>
<tr>
<td>Devices</td>
<td>-.23 (.010)</td>
<td>-.13 (.128)</td>
</tr>
<tr>
<td>Disclosure</td>
<td>-.23 (.026)</td>
<td>-.20 (.026)</td>
</tr>
</tbody>
</table>

N=108, one-tailed results in line with theoretical expectations. Standardized coefficients are presented with p-values in parentheses. For the purpose of convenience control variables are excluded from the tables but the full tables are available upon request. Pseudo R square is reported for the dichotomous outcome: devices.

3.5 Method Interview Data

3.5.1 Sample

The participants were approached through the same organization used for the survey portion of the study. The individuals who fit the study criteria were sent a participation letter. The criteria for participation were that the individual was over the age of 40, had been experiencing a degenerative eye condition for at least 10 years, and had been employed at the onset or during the progression of the disease.

The number of participants (n=36) was reached through information saturation (Hennink, Hutter, & Bailey, 2010). Four out of the 36 interviews from the original sample were removed from this study for several different reasons: in two cases interviews with respondents who had experienced dual sensory loss were cut short due to their emotional state; in one case the respondent did not have any serious symptoms; and in one case there were communication difficulties due to language barriers. Through a snowballing procedure four more participants were reached. The first author, who conducted all of the interviews, stopped looking for additional participants when no new insights were provided.

Of the final group of participants, 28 had a form of Retinitis Pigmentosa and eight had Stargardts. While all of the participants had held white-collar positions at some point in their life, three of the 36 had not completed college. When asked about their current employment status, 24 of the respondents indicated that they were participating in the labor market, one reported being between jobs, four said they were unemployed, and seven said they were retired. The youngest participant was age 42 at the time of the interview, and the oldest participant was age 82. The average age of the participants was 59. For more descriptive data on the participants, see Table 3.6.
# Chapter 3 | Linking disclosure and wellbeing

## Table 3.6: Participants summary on the three various mediators

<table>
<thead>
<tr>
<th>Pseudo name</th>
<th>Age</th>
<th>Diagnosis age</th>
<th>Disclosure timing</th>
<th>Experience disclosure</th>
<th>Allegation</th>
<th>Support</th>
<th>Devices</th>
</tr>
</thead>
<tbody>
<tr>
<td>Susan</td>
<td>66</td>
<td>37</td>
<td>Before retiring</td>
<td>Positive</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Eleanor</td>
<td>59</td>
<td>19</td>
<td>Before retiring</td>
<td>Positive</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Emily</td>
<td>59</td>
<td>20’s</td>
<td>Before retiring</td>
<td>Positive</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Michael</td>
<td>60</td>
<td>43</td>
<td>Before retiring</td>
<td>Positive</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Greg</td>
<td>59</td>
<td>25</td>
<td>During career</td>
<td>Positive and negative</td>
<td>Yes partial</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Kim</td>
<td>55</td>
<td>41</td>
<td>Before retiring</td>
<td>Positive</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Josh</td>
<td>53</td>
<td>15</td>
<td>During career</td>
<td>Positive</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Rick</td>
<td>54</td>
<td>27</td>
<td>During career</td>
<td>Positive and negative</td>
<td>Yes partial</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Oliver</td>
<td>54</td>
<td>18</td>
<td>During career</td>
<td>Positive</td>
<td>Yes</td>
<td>Yes paid support</td>
<td>Yes at time of disclose</td>
</tr>
<tr>
<td>Joey</td>
<td>42</td>
<td>19</td>
<td>During career</td>
<td>Positive</td>
<td>Yes</td>
<td>Yes paid support</td>
<td>Yes at time of disclose</td>
</tr>
<tr>
<td>Noah</td>
<td>82</td>
<td>26</td>
<td>During career</td>
<td>Positive</td>
<td>Not reported</td>
<td>Yes paid support</td>
<td>S</td>
</tr>
<tr>
<td>Lauren</td>
<td>73</td>
<td>40</td>
<td>During career</td>
<td>Positive and negative</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Patrick</td>
<td>68</td>
<td>18</td>
<td>During career</td>
<td>Positive</td>
<td>Yes</td>
<td>Yes paid support</td>
<td>Yes partial</td>
</tr>
<tr>
<td>Dylan</td>
<td>53</td>
<td>37</td>
<td>During career</td>
<td>Positive and negative</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Debra</td>
<td>55</td>
<td>33</td>
<td>During career</td>
<td>Positive</td>
<td>Yes</td>
<td>Not reported</td>
<td>No</td>
</tr>
<tr>
<td>Dan</td>
<td>50</td>
<td>13</td>
<td>During career</td>
<td>Positive and negative</td>
<td>Yes</td>
<td>Yes partial</td>
<td>No</td>
</tr>
<tr>
<td>Henry</td>
<td>67</td>
<td>22</td>
<td>During career</td>
<td>Positive and negative</td>
<td>Yes</td>
<td>Yes partial</td>
<td>Yes</td>
</tr>
<tr>
<td>Nick</td>
<td>59</td>
<td>18</td>
<td>During career</td>
<td>Positive</td>
<td>Yes</td>
<td>Yes partial</td>
<td>Use of devices acted as a disclosing factor</td>
</tr>
<tr>
<td>Phil</td>
<td>82</td>
<td>17</td>
<td>During career</td>
<td>Positive</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Dick</td>
<td>42</td>
<td>27</td>
<td>During career</td>
<td>Positive and negative</td>
<td>No</td>
<td>Yes partial</td>
<td>No</td>
</tr>
<tr>
<td>Roger</td>
<td>52</td>
<td>42</td>
<td>Disclose immediately</td>
<td>Positive</td>
<td>Yes</td>
<td>Always received support</td>
<td>Disclosures and use were simultaneous</td>
</tr>
<tr>
<td>Ron</td>
<td>60</td>
<td>18</td>
<td>Disclose immediately</td>
<td>Positive</td>
<td>Always disclosed</td>
<td>Yes paid support</td>
<td>No</td>
</tr>
<tr>
<td>Adam</td>
<td>73</td>
<td>39</td>
<td>Disclose immediately</td>
<td>Positive</td>
<td>Always disclosed</td>
<td>Always received support</td>
<td>No</td>
</tr>
<tr>
<td>Benjamin</td>
<td>52</td>
<td>5</td>
<td>Disclose immediately</td>
<td>Positive</td>
<td>Always disclosed</td>
<td>No</td>
<td>Disclosures and use were</td>
</tr>
</tbody>
</table>

*Note: S = 58*
### Table 3.6: Participants summary on the three various mediators

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Diagnosis</th>
<th>Disclose immediately</th>
<th>Positive</th>
<th>Always disclosed</th>
<th>No</th>
<th>Disclosure and use were simultaneous</th>
</tr>
</thead>
<tbody>
<tr>
<td>James</td>
<td>70</td>
<td>5</td>
<td>Disclose immediately</td>
<td>Positive</td>
<td>Always disclosed</td>
<td>No</td>
<td>Disclose and use were simultaneous</td>
</tr>
<tr>
<td>Rachel</td>
<td>52</td>
<td>31</td>
<td>Disclose immediately</td>
<td>Positive</td>
<td>Always disclosed</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Justin</td>
<td>67</td>
<td>20’s</td>
<td>Disclose upon hiring</td>
<td>Positive and negative</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Norah</td>
<td>53</td>
<td>21</td>
<td>Disclose upon hiring</td>
<td>Positive and negative</td>
<td>Yes</td>
<td>No</td>
<td>No but uses devices</td>
</tr>
<tr>
<td>Gabrielle</td>
<td>45</td>
<td>26</td>
<td>Not disclosed in current workplace</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Michelle</td>
<td>51</td>
<td>38</td>
<td>Disclose immediately</td>
<td>Positive and negative</td>
<td>Always disclosed</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Carol</td>
<td>50</td>
<td>30</td>
<td>Disclose immediately</td>
<td>Positive and negative</td>
<td>Always disclosed</td>
<td>No</td>
<td>No but uses devices</td>
</tr>
<tr>
<td>Gwen</td>
<td>63</td>
<td>40’s</td>
<td>Disclose immediately</td>
<td>Positive</td>
<td>Always disclosed</td>
<td>Yes</td>
<td>Yes partial</td>
</tr>
<tr>
<td>Sarah</td>
<td>58</td>
<td>37</td>
<td>Disclose immediately</td>
<td>Positive</td>
<td>Always disclosed</td>
<td>Yes</td>
<td>No but uses devices</td>
</tr>
<tr>
<td>Katy</td>
<td>56</td>
<td>23</td>
<td>Disclose immediately</td>
<td>Positive</td>
<td>Always disclosed</td>
<td>Not reported</td>
<td>No but uses devices</td>
</tr>
<tr>
<td>Jill</td>
<td>70</td>
<td>17</td>
<td>Disclose immediately</td>
<td>Positive</td>
<td>Always disclosed</td>
<td>Yes, family business</td>
<td>No but uses devices</td>
</tr>
<tr>
<td>Monica</td>
<td>77</td>
<td>18</td>
<td>Disclose immediately</td>
<td>Positive</td>
<td>Always disclosed</td>
<td>Yes, family business</td>
<td>No</td>
</tr>
</tbody>
</table>

#### 3.5.2 Data Collection

Because the aim of the study was to work inductively to gain insights into a relatively unexamined subgroup, we chose to use a grounded theory approach (Hennink et al., 2010; Strauss & Corbin, 1990). This approach enabled us to work inductively on this subgroup.

We collected the life stories of participants, with an emphasis on the role their vision loss played in their work trajectory. While the participants were encouraged to recount their story freely, a set of themes (based on previous literature, see Table 3.7) was used as a guideline. If the participants were having difficulties reporting their life story, the themes were consulted to help them complete the task.

The majority of the interviews (24) were done face-to-face, and the rest were done by phone (12). On average, each interview lasted 50 minutes.
Table 3.7: Pre-established discussion topics that have been covered during interviews

<table>
<thead>
<tr>
<th>Themes</th>
<th>General description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background</td>
<td>Growing up experience, growing up experience with eye condition</td>
</tr>
<tr>
<td>Eye condition</td>
<td>Type, degree of vision loss, coping, behavioral strategies in different settings</td>
</tr>
<tr>
<td>Work life choices</td>
<td>Career description, interplay between eye condition and career choices, dealing with work environment</td>
</tr>
<tr>
<td>Identity</td>
<td>Self-acceptance, identity as visually impaired</td>
</tr>
<tr>
<td>Social surrounding</td>
<td>The role of others (outside of the workplace) in the well-being and coping with eye condition, general content with social surrounding, contact with other visually impaired individuals</td>
</tr>
<tr>
<td>Demographic information</td>
<td>Short questionnaire about educational background, household composition, socio-economic status, religious affiliation, volunteering behavior</td>
</tr>
</tbody>
</table>

3.5.3 Data Analysis

The interviews were transcribed fully and coded inductively by the first author and an additional coder in ATLAS.ti. The coding was done independently, and after each additional four interviews were coded, the two coders reported on the main emerging codes. A “joint family code” (see Table 3.8) was then created and used in further analyses (Hennink et al., 2010).

To answer our research questions, we used a “bigger picture approach” (Hennink et al., 2010). The main family codes were related to the benefits of disclosure and the respondents’ work-related challenges and achievements. The three factors were then reconciled with the bigger picture; i.e., with the individual narratives. A scheme that reflects the general experiences of participants with disclosure, and the role the three factors play in the narratives of each participant (if applicable), was then created.
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<table>
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<th>General description</th>
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</thead>
<tbody>
<tr>
<td>Background</td>
<td>Growing up experience, growing up experience with eye condition</td>
</tr>
<tr>
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</tr>
<tr>
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</tr>
<tr>
<td>Identity</td>
<td>Self-acceptance, identity as visually impaired</td>
</tr>
<tr>
<td>Social surrounding</td>
<td>The role of others (outside of the workplace) in the well-being and coping with eye condition, general content with social surrounding, contact with other visually impaired individuals</td>
</tr>
<tr>
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<td>Short questionnaire about educational background, household composition, socio-economic status, religious affiliation, volunteering behavior</td>
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</tbody>
</table>

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Table 3.8: Main code families used in the analysis (alongside demographic information)

<table>
<thead>
<tr>
<th>Code family name</th>
<th>Typology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adaptation and adjustments to vision loss</td>
<td>Adapting and adjusting behavior and emotion to vision</td>
</tr>
<tr>
<td>Career planning and adjustment</td>
<td>Work adjustments and planning in relation to vision</td>
</tr>
<tr>
<td>Challenges in education</td>
<td>Challenges in education related to vision loss</td>
</tr>
<tr>
<td>Emotional challenges</td>
<td>Emotional challenges relating to vision loss</td>
</tr>
<tr>
<td>Supportive workplace</td>
<td>Support and accommodations in the workplace</td>
</tr>
<tr>
<td>Work challenges</td>
<td>Work challenges regarding employment</td>
</tr>
<tr>
<td>Work discrimination</td>
<td>Discrimination in the workplace</td>
</tr>
<tr>
<td>Work and wellbeing</td>
<td>Wellbeing being affected by work related concerns</td>
</tr>
<tr>
<td>Workplace strategies</td>
<td>Strategies to obtain and sustain employment</td>
</tr>
<tr>
<td>Concealment as workplace strategy</td>
<td>Concealment for obtaining and sustaining employment</td>
</tr>
<tr>
<td>Passing behavior strategies</td>
<td>Passing and concealment behavior</td>
</tr>
<tr>
<td>Concealment motivations</td>
<td>Motivation to conceal identity</td>
</tr>
<tr>
<td>Concealment implications</td>
<td>Implications of identity concealment in the workplace</td>
</tr>
<tr>
<td>Revealing motivations</td>
<td>Motivations for revealing or being open about identity</td>
</tr>
<tr>
<td>Revealing implications</td>
<td>Implications of revealing identity in the workplace</td>
</tr>
<tr>
<td>Strategies to revealing identity</td>
<td>Strategies for how participants revealed their identity</td>
</tr>
<tr>
<td>Identity conflict</td>
<td>Identity conflicts between visually impaired and sighted</td>
</tr>
<tr>
<td>Challenges related to visibility</td>
<td>Challenges related to being visible as visually impaired</td>
</tr>
<tr>
<td>Cane use</td>
<td>Cane use and the meanings attached to it</td>
</tr>
<tr>
<td>Guide dog</td>
<td>Guide dog use and the meanings attached to it</td>
</tr>
<tr>
<td>Professional rehabilitation</td>
<td>Professional rehabilitation use and the meanings attached to it</td>
</tr>
<tr>
<td>Assistive technology</td>
<td>Assistive technology use and the meanings attached to it</td>
</tr>
</tbody>
</table>

3.6 Interview Data Results

In this section we will first give an overview of how the participants experienced the process of disclosure in the workplace, and how this process affected their wellbeing. The role of the three themes in the narratives will then be discussed.

3.6.1 Disclosure and Wellbeing

Except for one, all of the participants in this study had disclosed their identity in the workplace. However, not all of the participants did so at the same time: 15 said
they disclosed their identity before or when they were hired, 15 said they disclosed their identity mid-career, and five said they disclosed their identity shortly before leaving the labor market. The majority of the participants reported that they had positive experiences with disclosure, and had a higher overall level of wellbeing thereafter. Eleven of the participants said they experienced both positive wellbeing outcomes related to disclosure (e.g., physical and mental relief) and adverse outcomes related to disclosure (i.e., discrimination in the workplace).

It is important to note that for many of the participants, both disclosure and the benefits of disclosure emerged through a gradual process. That is, not all of the participants disclosed their full condition to all of their coworkers at once, and thus did not experience immediate positive outcomes from disclosing their identity. These benefits seemed to emerge gradually over time for many participants. This gradual process can be explained to a great extent by the pathways suggested in the following section.

3.6.2 Pathways Linking Disclosure in the Workplace to Wellbeing

3.6.2.1 Alleviation of Inhibition

The experience of the alleviation of inhibition was a dominant theme among the participants who self-disclosed, or who were “forced” to disclose their condition because it was worsening, and was thus becoming difficult to conceal. Sixteen of the participants who disclosed their condition after a period of concealment reported that they experienced an alleviation of inhibition following the disclosure, while another three of these participants reported that they experienced a partial alleviation of inhibition following the disclosure. The more control the participants had over how visible their condition was to others—i.e., the more “invisible” their identity was—the more likely they were to try to keep it a secret. The desire to conceal their condition generally stemmed from a fear of unfavorable reactions from employers and coworkers. The participants described their efforts to conceal their condition as having been emotionally and physically taxing:

I hid it (my identity as visually impaired) my entire life, and it was incredibly stressful; at work [it was] incredibly stressful. Put more and more strain on my family my relationships and my social ties until I really couldn't hide it anymore.
they disclosed their identity before or when they were hired, 15 said they disclosed their identity mid-career, and five said they disclosed their identity shortly before leaving the labor market. The majority of the participants reported that they had positive experiences with disclosure, and had a higher overall level of wellbeing thereafter. Eleven of the participants said they experienced both positive wellbeing outcomes related to disclosure (e.g., physical and mental relief) and adverse outcomes related to disclosure (i.e., discrimination in the workplace).

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I hid it (my identity as visually impaired) my entire life, and it was incredibly stressful; at work [it was] incredibly stressful. Put more and more strain on my family my relationships and my social ties until I really couldn't hide it anymore.

So here I am getting heavier cause I've been working 60 hours a week and gaining weight. Very stressed out that they're gonna discover me any day now.

Two of the participants reported that they used medication to deal with the anxiety related to being discovered:

I have an eye problem; I have to deal with my eye problem. But they did put me on some medication that would help with anxiety and depression. Not heavy dosages, but little dosages.

Interestingly, though, most of the participants who had disclosed their condition reported experiencing reduced anxiety and stress:

When you're able to just say ok so my vision is impaired and this is what I need from you or can you help me in this way, it's like all of that angst is just lifted from you. People generally I would say more than 90% of the time are amazingly agreeable and helpful and nice and interested.

So we told everybody etcetera, etcetera (about the condition); that was just a great success. It gave me an opportunity to use my personality, which is apparently really good with people because I just kept my customers. I loved them and my staff and they loved me.

Thus, it seems that concealment was accompanied by a certain degree of stress and anxiety. Generally, the more severe an individual’s condition became, the more difficult it was for her to keep up appearances, and the more anxiety she felt in relation to the act of concealment. In the majority of cases, the disclosure of the identity was associated with relief from anxiety and enhanced wellbeing. However, three of the participants also experienced adverse responses in their work environment (e.g., discrimination, being undervalued). In those cases, while the stress related to concealment was lowered, their overall stress levels did not decline, and their wellbeing outcomes were thus less positive. This ongoing perception of stress was probably related to difficulties they were experiencing in maintaining and sustaining employment.

3.6.2.2 Social Support in the Work Context

All of the participants of this study had disclosed their identity in the workplace at a certain point in their work trajectory. However, not all of them reported that they
received support from coworkers and employers. The individuals who revealed their condition and received support in the workplace from the coworkers with whom they had a close relationship seem to have experienced higher levels of wellbeing. The positive responses took the form of offers emotional or practical support, as in the following cases:

*He [partner in firm] wasn't surprised; he knew that there were some issues but he didn't know the extent of it. He actually tried to learn more about the disease and was helpful and helped me quite a bit, and we remain friends today.*

*I have Janice [assistant]; I use her elbow.*

*If things were going on that you needed to adjust your schedule they were receptive to let you come in and go when you needed to. As long as you got your work done... [it was a] very nurturing kind of environment for all of the staff that worked there; they were supportive.*

However, in the cases in which the participant’s coworkers and employers responded in a less than accommodating fashion, the wellbeing of the participant suffered. Even if some individuals in the workplace responded in a more supportive manner, if there were negative responses as well the overall impact of disclosure on the participant’s wellbeing was negative:

*Some understood but some [did] not. Like the collections manager had a fit... Often people are just dumb about (it), they're ignorant; I should say they're ignorant.*

It is important to note that for some of the participants, the perception of support in the workplace was a motivator for revealing their condition. Individuals who worked in a supportive environment felt more comfortable disclosing their identity at work. For the majority of the participants, being open about their condition resulted in a higher level of wellbeing. However, whether the participants described the disclosure as a positive experience depended on the responses of the confidant(s) to the act of disclosure.

### 3.6.2.3 Using Assistive Devices

There are various devices that can assist people with low vision in their day-to-day functioning, both within and outside of the workplace. However, individuals who
are trying to conceal their identity may avoid using certain types of devices, as doing so may expose their disability. But by avoiding assistive devices, individuals with low vision may find it difficult to maintain their performance at work. Trying to keep up with their peers without accommodations negatively affected the wellbeing of some of the participants:

So the company and the people around me would not know that mistakes were made because they were covered up (laughter). I covered it up. But I knew what was going on and I thought that it was quite dangerous for my clients and so that’s you know... I didn’t want to keep practicing law that way.

Disclosing the condition allowed participants to seek help and accommodations in the workplace:

I contacted the people in the state office that was helping me for the visually impaired; they outfitted me an office with a computer program called zoom text to help me read a little bit larger...Basically they helped me out immensely.

I’m surrounded by tremendous hi-tech equipment that I am researching all the time...I have a reading machine. I get email and send email over the telephone because there is a special thing on AOL that allows you to do that. And I’m running a business of close to a billion dollars.

The participants reported that they felt relief and experienced greater wellbeing as their efficiency improved after these accommodations were made:

Here somebody’s coming to a luxury property like the (name of hotel). They would feel that they deserve to have someone who was fully sighted or without a handicap of any kind. That was unfounded because the truth is that people were happy to see that someone that has this visual impairment actually was doing something about it, and I happened to have a very good-looking dog, a friendly dog and appropriate that the clients actually loved it.

Sometimes the more progressed or the less vision you have to play with the easier things get. Ok? ... As long as you have that piece of macular (peripheral vision) you are always trying to use it and it's difficult. But once it’s gone you are free of that battle to see in that way. For me I had to become a better computer user. A better user of technology. It was a major turning point for me.
Some participants indicated that they disclosed their impairment from the beginning of their employment, because without visible accommodations they would have had difficulties functioning:

Yes, it was always out (identity) because I couldn't function otherwise. I could socially function without people knowing, sometimes if I have the right contact but I cannot function at work without someone knowing. Cause almost any task that I need to do I need an accommodation...

Overall, the use of accommodations reduced the level of effort participants needed to exert to perform on par with their work peers. Using assistive devices improved the participants’ wellbeing and quality of life. Whether they had access to assistive technologies depended to a large extent on whether the participants had disclosed their condition in the workplace.

It is important to note that some individuals disclosed their identity because they were already using devices prior to entering the labor market or a particular work setting. However, for the majority of participants, vision decline was a process that occurred while they were already participating in the labor market, and those individuals were more likely to have taken the aforementioned pathway.

3.7 Discussion

3.7.1 Findings Summary

In this study we used a mixed methods design to study which factors play a role in the relationship between the disclosure in the workplace of a degenerative eye condition and wellbeing. First, based on the literature on this topic, we identified three pathways through which disclosure and wellbeing are linked: the alleviation of inhibition, social support in the workplace, and the use of assistive devices. In the next step we used survey data to test whether these factors mediate the association between disclosure in the workplace and wellbeing. Finally, we used interview data to explore what role the aforementioned factors played in the narratives of the participants.

Both the survey and the interview data suggest that the alleviation of inhibition is a meaningful aspect of the relationship between disclosure in the workplace and wellbeing. Additionally, both the survey and the interview data show that disclosure in the workplace is related to workplace support and to the use of devices. However, we find weaker support for the assumption that workplace support and devices act as a pathway linking disclosure in the workplace and wellbeing. Our analysis of the
survey data indicates that there is no direct association between these two mediating factors and subjective wellbeing. Using the interview data, we demonstrated that these factors are important in the relationship between disclosure and wellbeing, but are less important than the alleviation of inhibition. In the following, we will discuss the contributions of the findings to the literature from three different perspectives: theory, methodology, and policy.

3.7.2 Theory

Our findings correspond in part with the overarching theoretical framework on pathways to benefits from the disclosure of a stigmatized identity by Chaudoir and Fisher (2010). In line with their expectations, we find that the alleviation of inhibition is an important factor in the relationship between disclosure in the workplace and wellbeing.

Device use and workplace support emerged as pathways linking disclosure in the workplace and wellbeing in the interview data only. It is possible that the use of devices and workplace support act as pathways linking disclosure and alternative workplace outcomes, such as workplace productivity. For example, the previous literature on disabilities has pointed out that the use of accommodations in the workplace by individuals with disabilities helps in “leveling out the playing field” between disabled and able-bodied workers (Yeager, Kaye, Reed, & Doe, 2006). Thus, it is possible that these two factors act as a resource for alternative work-related outcomes, rather than as direct contributors to wellbeing. Furthermore, the SPF theory would suggest that the use of assistive devices may contribute to the fulfillment of physical and social needs. For instance, by using assistive devices that make mobility easier, an individual may find it easier to meet her physical needs. The use of assistive technology can help the individual perform better in the workplace, and may therefore help to meet her social needs for behavioral confirmation and status. Future research may investigate device use and workplace support as contributors to the fulfillment of particular aspects of social needs, rather than to overall wellbeing.

3.7.3 Methodology

The mixed methods design used in this study proved to work better than the traditional single method research designs. The quantitative portion of this study allowed us to establish systematically whether the three mediating factors were evident when looking at a larger pool of individuals. The qualitative in-depth interviews confirmed the importance of the pathways linking disclosure and wellbeing that had been identified in the previous literature; and, through the use of the SPF
theoretical framework, allowed us to establish variations within the pathways. For instance, we find that both device use and workplace support contributed to individuals disclosing their condition in the workplace, rather than the other way around. The additional qualitative insights also allowed us to compensate for the cross-sectional nature of the survey data, and to gain insights into the long-term processes of participants.

The lack of statistical evidence for the pathway through workplace social support may also be related to the measurements used in this study. A general scale that does not differentiate between physical and physiological support related to vision loss, and that does not account for both positive and negative support from colleagues and supervisors, was implemented. Previous research on the relationship between social support and wellbeing indicates that both positive and negative social support can have an influence on the wellbeing of individuals with low vision (Reinhardt, 2001). This suggests that positive social support in the workplace might not directly contribute to wellbeing among individuals who are open about their condition, but rather that the absence of negative social pressure may play a role in preventing reduced wellbeing. Future studies may want to account for the number of confidants in the workplace, and the ratio between those who respond positively and those who respond negatively to the disclosure.

### 3.7.4 Policy

Our findings suggest that full disclosure in the workplace relates positively to wellbeing. Policies and regulations, such as the Americans with Disabilities Act (ADA), have provided significant labor market protections for individuals with disabilities. So far, however, the ADA has done little to improve the employment opportunities of individuals with disabilities (e.g., DeLeire, 2000). One potential explanation for why these kinds of laws have so far been ineffective in promoting employment is that they did not include measures to educate employers about the abilities of individuals with disabilities. For instance, the law might require an employer to provide appropriate support for employees with vision loss. But unless an employer believes that the employee is able to do the job, the employer will do the bare minimum required by law. Because of this unwillingness to make accommodations, employees with disabilities often experience physical and mental strain as they attempt to conceal their condition (inhibition). Interventions designed to educate employers about the high performance potential of individuals with disabilities, and to mitigate the potential negative effects of disclosure (e.g., being laid off), would promote disclosure. As we have shown, disclosure not relieves the strain associated with concealment, it is also allows the disabled employee to use devices and benefit from the social support of coworkers. Thus, when they disclose their disability, employees tend to have higher productivity, and are more likely to continue
to participate in the labor market.

### 3.7.5 Concluding Remarks

As we investigated the outcomes related to disclosure behavior, we focused on individuals who were working (or were retired). Studies on adverse outcomes for individuals who have disclosed their disability have tended to focus on “getting a foot in the door;” that is, on the process of becoming employed. This study shows that the wellbeing of individuals who are participating in the labor market improves when they disclose their disability, and that emotional relief contributes substantially to this sense of wellbeing.
Chapter 4

Having Both Hands on the Steering Wheel: Driving Behaviour among White-Collar Workers with Degenerative Eye Conditions*

Abstract

Because people in the United States are highly reliant on cars for transportation, individuals with restricted driving abilities face severe accessibility constraints in the labour market. Guided by the social exclusion framework, we used a qualitative approach to gain insights into the role of car driving and alternative commute modes in the lives of white-collar workers with degenerative eye conditions. The study participants gradually restricted their driving behaviour as the disease progressed. They also exhibited several types of commute solutions, which lent themselves to a variation in the experienced degree of exclusion (both between participants and within participants over time), with changes in vision state and available resources. Another aim of our study was to identify the motivations for driving behaviour. The results showed that while a desire to reduce the risk of an accident motivated the participants to stop driving, certain normative (for men) and practical considerations motivated participants to continue driving. While all of the participants eventually stopped driving due to vision decline, the decision to quit often occurred only after the participants experienced one or more car accidents. Workplace accessibility challenges is a factor that hinders the labour market participation of individuals with degenerative eye conditions, and a lack of alternatives to driving when commuting to work encourages individuals to engage in risky behaviour.

* This chapter is co-authored with Ori Rubin and Nardi Steverink and has been resubmitted for a second round of reviews to a scientific journal.
Abstract
Because people in the United States are highly reliant on cars for transportation, individuals with restricted driving abilities face severe accessibility constraints in the labour market. Guided by the social exclusion framework, we used a qualitative approach to gain insights into the role of car driving and alternative commute modes in the lives of white-collar workers with degenerative eye conditions. The study participants gradually restricted their driving behaviour as the disease progressed. They also exhibited several types of commute solutions, which lent themselves to a variation in the experienced degree of exclusion (both between participants and within participants over time), with changes in vision state and available resources. Another aim of our study was to identify the motivations for driving behaviour. The results showed that while a desire to reduce the risk of an accident motivated the participants to stop driving, certain normative (for men) and practical considerations motivated participants to continue driving. While all of the participants eventually stopped driving due to vision decline, the decision to quit often occurred only after the participants experienced one or more car accidents. Workplace accessibility challenges is a factor that hinders the labour market participation of individuals with degenerative eye conditions, and a lack of alternatives to driving when commuting to work encourages individuals to engage in risky behaviour.

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4.1 Introduction

The most popular mode of commuting in the United States is driving (McKenzie & Rapino, 2011). This is hardly surprising given the long-standing urban development and planning practices in the U.S., in which driving has long been given priority over walking and access to public transport (e.g., Handy, Cao, & Mokhtharian, 2005). Furthermore, in the U.S. and across western societies, acquiring a driver's license and driving a car are prominent cultural identifiers of maturity, autonomy, and independence; of masculinity (for men); and of citizenship and sociability (Carrabine & Longhurst, 2002; Sheller, 2004; Urry, 2007). In addition to these cultural markers, being able to drive also plays a role in obtaining and sustaining employment. As physical mobility is an important determinant of social mobility (Kaufmann, Bergman & Joye, 2004), it is evident that individuals who do not drive have lower chances of finding employment (Grengs, 2010). Indeed, not driving can detrimentally influence a person's chances of employment, regardless of whether a vehicle is needed to perform job-related tasks (Baum, 2009). Not driving thus hampers the ability of individuals from disadvantaged groups, including individuals with disabilities, to integrate into and fully participate in the labour market. Being shut out of the labour market can in turn lead to social exclusion (e.g., Farber & Páez, 2010; Preston & Raje, 2007). In this paper, we define social exclusion as being completely or partially unable to participate in the labour market and in social activities that are available to the majority of the population due to restrictions in resources and in access to services and rights. Social exclusion is further considered as an accumulative interaction between social problems that occur simultaneously or in sequence (Lucas, 2012). For instance, having a disability may lead to reduced access to transportation, which in turn leads to difficulties in participating in the labour market.

A particularly salient group to consider when examining the role of car driving in social exclusion is white-collar workers with degenerative eye conditions. This group is important for three reasons. First, to our knowledge there are no previous studies that have investigated the effects of driving on white-collar workers with degenerative eye conditions. The existing studies that have investigated the role of commuting in the work context have not distinguished between the type of disability and the type of work (Farber & Páez 2010). Thus, these studies have not specifically examined the experiences of individuals with degenerative eye conditions who compete at higher levels of the labour market (i.e., white-collar workers), and who are at risk of exclusion from participation in society, including in the workforce. The existing research has, however, shown that, while there are alternatives to driving as a means of commuting to work (e.g. walking, public transportation), individuals with severe visual impairments—much like the general population in the U.S. (Giuliano &
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Dargay, 2006)—have a preference for using a private vehicle, either as a driver or a passenger. This is evident from the relatively high numbers of individuals with severe visual impairments who avoid using public transportation by getting rides from others (Gallagher et al., 2011; Golledge, Marston & Costanzo, 1997). The preference for driving is also apparent in the substantial number of drivers with severe visual impairments who are impaired in their ability to drive (Szlyk et al., 2002), but who continue to drive despite the increased risk. This is alarming, because individuals with a severe vision impairment who drive run a much greater risk than the general public of getting into an automobile accident (Ivers, Mitchell & Cumming, 1999; Szlyk et al., 2002; Wang et al., 2003; Wood, 2002). This problem may be partly attributable to inadequate regulation of the vision tests for driver’s licenses in the U.S. (Fishbaugh, 1995). It can also be difficult to restrict or prohibit driving by people who have visual impairments, especially as many of these individuals have incentives to conceal their condition. In the workplace, individuals with visual impairments often assume that both practical aspects of their limitations and the stigma attached to their identity will decrease their chances of obtaining and sustaining employment (Spiegel, de Bel & Steverink, 2016). However, the question of which factors encourage or discourage driving among people with visual impairments remains open.

Second, studying this group provides us with a unique opportunity to gain insights into the various facets of social exclusion related to vision decline, because the lack of optimal tools and solutions likely influences the car driving and transportation choices of these individuals. A core premise of the social exclusion approach is that the lack of access to opportunities (i.e., the inability to commute) is what generates exclusion, rather than the absence of opportunities (Preston & Rajé, 2007). Access to places of employment and services is determined by the mobility landscape. For example, how far do people have to travel to reach their workplace or other desired location? Is public transportation available, and are sidewalks safe for walking? Mobility constraints limit the ability of individuals to actively participate and to access certain commodities (i.e., without work, the individual does not have access to goods). Whereas there are technological solutions that enable some other disability groups (such as those with limb disabilities) who would not otherwise be able to operate a car to engage in conventional driving, there are currently no such tools available to people with visual impairments. Alternatives to car driving can be costly (taxi, private driver), time consuming (public transportation), or burdensome for others (receiving rides) (Golledge, Marston & Costanzo, 1997); and relocation to cities where walking is a feasible commute solution is still considered a challenging solution for individuals with severe vision impairment (Worth, 2013).

Third, Schwanen et al. (2015) have suggested that there is an important gap in the literature on social exclusion, as the social exclusion framework used in most of these studies refers to social exclusion as a dichotomous state. The authors argued that while it is often assumed that a person is in a state of either inclusion or exclusion, in practice social exclusion takes place on a gradient. Individuals with degenerative eye
conditions are of particular interest in this context, as they not only exist on the continuum between inclusion and exclusion; they also move between the two ends of the continuum over time as their vision declines and their available resources change (e.g., being able to afford taxi rides). Yet so far it is not known what shape these processes take and how the individual experiences them.

Based on the above considerations, two questions will be addressed in this study: How do white-collar workers with degenerative eye conditions experience and deal with changes in their perceived abilities and available resources in choosing between car use and alternatives over time? And how do these individuals motivate the choice to stop or to continue driving?

In this study, we use a qualitative approach that enables us to gain insight into the experiences people with degenerative eye conditions have with commuting to work by car and by other modes of transportation, and to identify overarching themes across the narratives of these individuals. This approach also allows us to gain a better understanding of the gradient and the shift over time in the behaviours and the experiences of these individuals, and to relate these trajectories to issues of social exclusion. These findings may ultimately contribute to the development of more focused legal and societal interventions that discourage high-risk behaviour (i.e., driving) among visually impaired individuals, and that minimise the extent to which they are excluded from accessing the modes of transportation they need to commute to work.

4.2 Methods

4.2.1 Ethical Statement

This study implemented guidelines for ethical conduct in qualitative research in the social sciences (Hennink, Hutter & Bailey, 2010), in line with the Declaration of Helsinki. The ethical committee of the sociology department of the University of Groningen has confirmed that the study has been carried out in an ethical manner. Consent for participation was received from all of the study participants; the consent was recorded on tape before the beginning of the interview and in written form thereafter. The participants were encouraged to consult the consent form at the time of their convenience (with the help of others if needed). All of the names and other identifying information have been anonymized.

4.2.2 Sample

We approached participants through a medical research non-profit organization based in the United States. We sent out participation letters requests to individuals
who met the following criteria: the participants had to be at least 40 years old, to have had a degenerative eye condition for at least 10 years, and to have been employed either at the onset of the disease or while the disease was progressing. All of the participants were employed in white-collar positions, and had been diagnosed with either (types of) Retinitis Pigmentosa or Stargardts.

The first author of this paper conducted all of the interviews. The number of participants was determined using the principle of information saturation (Hennink, Hutter & Bailey, 2010). Information saturation is a sampling method that posits that the sample size should be established as the researcher is collecting the data. After each additional interview the researcher examines the input given by the participants on the topic in question, and evaluates whether new information is being introduced. When additional interviews no longer generate new insights, the researcher ceases collecting data. Thirty-six interviews were conducted with the original sample. Four of these participants were removed from the sample for various reasons: two of the participants who suffer from dual sensory loss (also hearing) experienced emotional difficulties with completing the interview, a third interviewee was eliminated because he was not yet experiencing any significant vision loss, and a fourth participant was removed because he was unable to communicate about the topic at hand due to a language barrier. We further recruited four participants through a snowballing procedure. The interviewer stopped recruiting participants when no new insights were provided by additional interviews. Thus, the total number of interviews used in this study is 36.

The majority of the participants were highly educated, and described their socioeconomic status middle class or higher. While some the participants were not working at the time of the interview (unemployed or retired), all of participants had been previously employed in a white-collar position. The general demographic information can be found in Table 4.1.
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The majority of the participants were highly educated, and described their socioeconomic status middle class or higher. While some of the participants were not working at the time of the interview (unemployed or retired), all of participants had experienced vision loss for at least 10 years. All of the participants were employed in white-collar positions, and had been diagnosed with either at the onset of the disease or while the disease was progressing. All of the participants who met the following criteria: the participants had to be at least 40 years old, to have a degenerative eye condition for at least 10 years, and to have been employed either at the onset of the disease or while the disease was progressing. All of the participants had experience with driving, and were asked to describe their driving experiences post diagnosis.

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Table 4.1: Descriptive information about participants

<table>
<thead>
<tr>
<th>Pseudo name</th>
<th>Employment status</th>
<th>Relationship status</th>
<th>Socio-economic class</th>
<th>Age</th>
<th>Diagnosis</th>
<th>Living area</th>
<th>Interview properties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Susan</td>
<td>Retired (worked FT)</td>
<td>Second marriage</td>
<td>Middle</td>
<td>66</td>
<td>37</td>
<td>Urban</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Eleanor</td>
<td>Retired (worked FT)</td>
<td>Married</td>
<td>Middle</td>
<td>59</td>
<td>19</td>
<td>Suburb</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Emily</td>
<td>Retired (worked FT)</td>
<td>Second marriage</td>
<td>Middle</td>
<td>59</td>
<td>20’s</td>
<td>Urban</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Michael</td>
<td>Retired (worked FT)</td>
<td>Married</td>
<td>Upper</td>
<td>60</td>
<td>43</td>
<td>Mid size town</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Greg</td>
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<td>Married</td>
<td>Middle</td>
<td>59</td>
<td>25</td>
<td>Urban</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Kim</td>
<td>Retired (worked FT)</td>
<td>Divorced</td>
<td>Middle</td>
<td>55</td>
<td>41</td>
<td>Mid size town</td>
<td>Phone, snowball</td>
</tr>
<tr>
<td>Josh</td>
<td>FT</td>
<td>Married</td>
<td>Middle-upper</td>
<td>53</td>
<td>15</td>
<td>Suburb</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Rick</td>
<td>PT</td>
<td>Second marriage</td>
<td>Middle</td>
<td>54</td>
<td>27</td>
<td>Suburb</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Oliver</td>
<td>FT</td>
<td>Married</td>
<td>Middle-upper</td>
<td>54</td>
<td>18</td>
<td>Suburb</td>
<td>Phone, original pool</td>
</tr>
<tr>
<td>Joey</td>
<td>FT</td>
<td>Married</td>
<td>Middle-upper</td>
<td>42</td>
<td>19</td>
<td>Urban</td>
<td>Phone, original pool</td>
</tr>
<tr>
<td>Noah</td>
<td>FT</td>
<td>Married</td>
<td>Upper</td>
<td>82</td>
<td>26</td>
<td>Mid size town</td>
<td>Phone, original pool</td>
</tr>
<tr>
<td>Lauren</td>
<td>Retired (worked FT)</td>
<td>Second marriage</td>
<td>Middle-upper</td>
<td>73</td>
<td>40</td>
<td>Urban</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Patrick</td>
<td>FT</td>
<td>Married</td>
<td>Upper</td>
<td>68</td>
<td>18</td>
<td>Urban</td>
<td>Phone, original pool</td>
</tr>
<tr>
<td>Dylan</td>
<td>FT</td>
<td>Divorced</td>
<td>Middle-upper</td>
<td>53</td>
<td>37</td>
<td>Urban</td>
<td>Phone, original pool</td>
</tr>
<tr>
<td>Debra</td>
<td>FT</td>
<td>Single</td>
<td>Middle-upper</td>
<td>55</td>
<td>33</td>
<td>Urban</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Dan</td>
<td>FT</td>
<td>Married</td>
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<td>50</td>
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<tr>
<td>Henry</td>
<td>FT</td>
<td>Married</td>
<td>Upper</td>
<td>67</td>
<td>22</td>
<td>Suburb</td>
<td>In person, original pool</td>
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<tr>
<td>Nick</td>
<td>PT</td>
<td>Married</td>
<td>Middle-upper</td>
<td>59</td>
<td>18</td>
<td>Urban</td>
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</tr>
<tr>
<td>Phil</td>
<td>Retired</td>
<td>Second</td>
<td>Middle-middle</td>
<td>82</td>
<td>27</td>
<td>Urban</td>
<td>In person, original pool</td>
</tr>
</tbody>
</table>
**Full-time = FT. Part-time= PT**

<table>
<thead>
<tr>
<th>Name</th>
<th>Employment Status</th>
<th>Marital Status</th>
<th>Socio-Economic Status</th>
<th>Age (Years)</th>
<th>Initial Experience (Years)</th>
<th>Location</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dick</td>
<td>FT</td>
<td>Divorced</td>
<td>Middle</td>
<td>42</td>
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<td>Urban</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Roger</td>
<td>FT</td>
<td>Married</td>
<td>Middle-upper</td>
<td>52</td>
<td>42</td>
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<td>Phone, snowball</td>
</tr>
<tr>
<td>Ron</td>
<td>FT</td>
<td>Third marriage</td>
<td>Upper</td>
<td>60</td>
<td>17</td>
<td>Suburb</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Adam</td>
<td>FT</td>
<td>Married</td>
<td>Upper</td>
<td>73</td>
<td>39</td>
<td>Suburb</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Benjamin</td>
<td>FT</td>
<td>Divorced</td>
<td>Middle</td>
<td>52</td>
<td>5</td>
<td>Urban</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>James</td>
<td>FT</td>
<td>Married</td>
<td>Upper</td>
<td>70</td>
<td>5</td>
<td>Suburb</td>
<td>Phone, snowball</td>
</tr>
<tr>
<td>Rachel</td>
<td>Unemployed</td>
<td>Married</td>
<td>Middle</td>
<td>52</td>
<td>31</td>
<td>Urban</td>
<td>Phone, snowball</td>
</tr>
<tr>
<td>Justin</td>
<td>FT</td>
<td>Married</td>
<td>Middle-upper</td>
<td>67</td>
<td>20’s</td>
<td>Suburb</td>
<td>Phone, original pool</td>
</tr>
<tr>
<td>Norah</td>
<td>FT</td>
<td>Second divorce</td>
<td>Middle-upper</td>
<td>53</td>
<td>21</td>
<td>Mid-size town</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Gabrielle</td>
<td>PT</td>
<td>Married</td>
<td>Middle</td>
<td>45</td>
<td>26</td>
<td>Urban</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Michelle</td>
<td>FT</td>
<td>Cohabiting</td>
<td>Middle</td>
<td>51</td>
<td>38</td>
<td>Urban</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Carol</td>
<td>Unemployed</td>
<td>Second marriage</td>
<td>Middle-upper</td>
<td>50</td>
<td>30</td>
<td>Suburb</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Gwen</td>
<td>PT</td>
<td>Married</td>
<td>Middle</td>
<td>63</td>
<td>Mid 40’s</td>
<td>Suburb</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Sarah</td>
<td>PT</td>
<td>Divorced</td>
<td>Lower</td>
<td>58</td>
<td>37</td>
<td>Suburb</td>
<td>Phone, original pool</td>
</tr>
<tr>
<td>Katy</td>
<td>PT</td>
<td>Married</td>
<td>Upper</td>
<td>56</td>
<td>23</td>
<td>Suburb</td>
<td>In person, original pool</td>
</tr>
<tr>
<td>Jill</td>
<td>FT</td>
<td>Married</td>
<td>Lower middle</td>
<td>70</td>
<td>17</td>
<td>Suburb</td>
<td>Phone, original pool</td>
</tr>
<tr>
<td>Monica</td>
<td>FT</td>
<td>Married</td>
<td>Upper</td>
<td>77</td>
<td>18</td>
<td>Urban</td>
<td>In person, original pool</td>
</tr>
</tbody>
</table>
4.2.3 Data Collection

The data used in this article are taken from a project that investigates the challenges and achievements that characterise the work lives of white-collar workers with degenerative eye conditions. The life stories of the participants were collected as part of a grounded theory approach. Grounded theory is a systematic methodology that mainly involves inductive data collection. Rather than test specific hypotheses, this method allows the data to shed light on the research problem (Hennink, Hutter & Bailey, 2010). This approach is appropriate for the investigation of the current research questions, because before starting this study we knew too little about the challenges white-collar workers with degenerative eye conditions face in the workplace to formulate hypotheses.

Participants were asked to tell their life story, with an emphasis on the role their visual condition has played in their work trajectory. Otherwise, they were given free rein in telling their story. Deductive methods were also used, but to a lesser degree, as recent studies on grounded theory suggest that research is not done in a vacuum, and that the principles in the literature are always implicitly and explicitly present throughout the research cycle (Heath & Cowley, 2004). For this reason, a set of themes (see Table 4.2) based on broader research on vision impairment has been used as an additional guideline. Participants were asked about these topics directly only if they did not mention them in their narratives.

Twenty-four interviews were conducted face-to-face, while the rest were done by phone. The interviews took an average of 50 minutes. The duration and the richness of the interviews did not vary significantly based on the method of data collection.

Table 4.2: Pre-established discussion topics that have been covered during interviews

<table>
<thead>
<tr>
<th>Themes</th>
<th>General description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background</td>
<td>Experience growing up with eye condition</td>
</tr>
<tr>
<td>Eye condition</td>
<td>Information in disease, coping strategies</td>
</tr>
<tr>
<td>Work life choices</td>
<td>General career description. Career in light of eye condition</td>
</tr>
<tr>
<td>Identity</td>
<td>Self-acceptance, identity as visually impaired</td>
</tr>
<tr>
<td>Social surrounding</td>
<td>Social support from surrounding (private and work), contact with peers with visual impairment</td>
</tr>
<tr>
<td>Demographic information</td>
<td>E.g., household composition, educational background, mobility training etc.</td>
</tr>
</tbody>
</table>

4.2.4 Data Analysis

All of the interviews were fully transcribed. The first author and an additional coder then coded all of the interviews in ATLAS.ti inductively and independently, using the guidelines from Hennink et al. (2010). The authors worked independently to
reduce the potential bias stemming from the fact that the first author is visually impaired. After each of the four additional interviews were coded, the two coders met to determine which of the codes that emerged in the data were most important. These codes were then formed into categories using the following steps. First, similar codes were identified and grouped together inductively into broad category, and were given a descriptive name. Then, based on the particular research questions at hand, the broad categories were broken down into smaller, more meaningful groups of codes. Each category then was made to represent a concept, which was then used in the formulation of a joint “family code book”. These family codes, which were used in the next steps of this analysis, are presented in Table 4.3.

<table>
<thead>
<tr>
<th>Family code category</th>
<th>Concept</th>
</tr>
</thead>
<tbody>
<tr>
<td>Driving general commute challenges</td>
<td>All codes describing commute related challenges participants experience</td>
</tr>
<tr>
<td>Driving and work</td>
<td>All codes describing commute related challenges participants experience in relation to their work lives</td>
</tr>
<tr>
<td>Commute strategies</td>
<td>All codes describing the various commute strategies and commute modes used by participants</td>
</tr>
<tr>
<td>Driving motivations (to continue and to stop)</td>
<td>All codes describing reports of participants motivations behind driving behaviour</td>
</tr>
<tr>
<td>Commute risk behaviour</td>
<td>All codes describing risky driving behaviour reported by participants</td>
</tr>
</tbody>
</table>

To answer our research questions, we made use of the “bigger picture” approach (Hennink et al., 2010). This approach stipulates that the researcher should identify the central story that accounts for the issues in the data (in this case, issues concerning the relationship between labour market participation and driving and commuting), while making use of the family code book. The researcher is then expected to step back from the data and look at the precise accounts of each individual, and at how these individual accounts are linked to each other in the context of the topic at hand (i.e., driving and commuting). Comparing the main overarching themes (from the family code book on the topic of commuting and driving) with the individual accounts (and the variations therein) allowed us to identify behavioural patterns among participants and their overarching motivations. These will be elaborated on in the next section.

4.3 Results

The topic of commuting by car consistently emerged as relevant in the context of work. While no direct questions about commuting were asked, all of the participants mentioned the challenges they faced in work related commute. As the participants brought up the topic of driving and commuting spontaneously, we only have
information on the events they chose to report. We use quotes to illustrate that commuting, and the challenges associated with commuting, were meaningful to the participants. It is, however, likely that the respondents would have addressed these issues in greater detail if direct questions about driving had been asked. For example, they may have reported more car accidents.

### 4.3.1 Changes in Car Use Over Time and Alternatives Used by Participants

Of the 36 participants, 28 reported that they their main commute mode was driving, at least until they reached a certain point in their career. Some of the participants acknowledged, however, that their decision to continue driving was problematic:

...I was still driving but not completely legally. I mean I probably shouldn't have, but I was still able to memorise enough stuff to get my license, but I probably shouldn't have been driving. (Lauren)

The more vision decline participants experienced; the more concessions they made in their driving patterns. For example, some participants said they were driving only in the daytime or in familiar areas. However, most of the participants indicated that they preferred driving to work, even under restricted conditions, to using alternative modes of transportation. This was the case even when the participants were within walking distance of their workplace and other amenities, as in the following case:

*When I was 59 and I saw the visual field that I had was less than 10 degrees I gave up driving. Before that I had given up driving maybe full time two years before that where I was not driving at night and then it moved up to not driving at night and only driving to the gym and the diner. Both back roads both within five minutes of my house.*

(Michael)

After the participants decided that they were no longer able to drive themselves to work, their commute mode shifted according to one of four main patterns (see Table 4.4).
Table 4.4: Process of driving and commute behaviour

<table>
<thead>
<tr>
<th>Pattern description</th>
<th>Total</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 drive → stop working</td>
<td>5</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>2 drive → get rides</td>
<td>14</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>3 drive → relocate &amp; walk, walk or public transport</td>
<td>9</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4 Never used a car for work commute</td>
<td>8</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>36</td>
<td>20</td>
<td>16</td>
</tr>
</tbody>
</table>

Four women and one man exhibited the first pattern. These individuals reported having considerable difficulties in fulfilling their work obligations without being able to drive. For these participants, not being able to drive meant that they were not pulling their weight at work. One participant in particular indicated she needed to drive several times a day to see clients. She recounted what happened after she asked for adjustments in her duties to accommodate her vision loss:

At age 50 things started to turn a bit in my job at a school for developmentally disabled students. I was a case manager for supportive climate, which involved driving all day to different locations. So they kind of tailored that a little bit, but then it just got to be too difficult and it was time to hang up the keys. (Eleanor)

These participants left the labour market when they were no longer able to drive, as is evident from the following case:

Well there were a bunch of different factors [influencing my decision to leave my job]...You have to go to so many potential clients and have several meeting with each one before you can bring in the real clients. So when I could no longer drive that shrunk my ability to bring in new clients the way I was doing. That would have a negative, a severe negative effect on my compensation. (Kim)

Ten men and four women exhibited the second pattern. These individuals replaced driving with getting rides from others (either paid or unpaid). This pattern was much more common among men than among women, as more men had the resources to organise rides. For example, men were more likely than women to have had a partner who was working part time or was a homemaker and was able to provide rides, or to have had a highly compensated position that made it easier for them to afford to pay for rides.
Some participants took their access to rides into account when choosing their place of residence, as is illustrated by the following testimony:

*From the beginning my wife and I planned, wherever we moved, we planned for transportation alternatives. When I moved to my second home from our first apartment it was right near my parents so we had a backup there. I had not only my wife driving but also my mother and father driving. Hence I had mobility.* (Henry)

Getting rides was perceived as challenging by only a few of the participants. One of the participants who reported having difficulties was a woman who was getting rides from her working husband, who also had a busy work schedule:

*So I had to work my schedule so that it was within the realm of his [her spouse’s] work schedule. He is recently retired so now it's not as big of an issue. But for a lot of time it was an issue because I had to go to work when he could drop me at work. So maybe I started working at 8 o'clock but I might have to be at work at like 6.30 in the morning so that he could get to work on time (laughs).* (Gwen)

However, most of the individuals who said they used this commute mode did not indicate that they had great difficulties, as most said they were able to participate rather easily in the labour market.

Four men and five women have exhibited pattern three. These individuals had replaced driving as their main commute mode with either walking or using public transportation. Some of these individuals made the conscious choice to move to an area where they could more easily walk or use public transportation as their main means of getting to work (e.g., from the suburbs to the city), as in this case:

*You know I have been a lot of places but this community [name], it's perfect. I can walk to at least eight restaurants and the bank, and the hospital, and my doctor and the grocery store, and the pharmacy and a couple little stores...I take cabs. I walk to work. I'm a mile from work.* (Norah)

Relocating to a more accessible area was not, however, a solution that was available to all of the participants. Moving closer to work can be expensive, especially as in many areas in the United States there is little or no public transportation or pedestrian infrastructure.

The participants who were working in bigger cities and relocated seem to have had an easier time maintaining their employment status. Others, like this individual, had to move their business to a different location:
So I got through that I am back home trying to practice law by myself out of my home. That was a monstrous thing for me. I couldn’t stand being around the home so I owned the building where my old law firm was and it was only half a mile away from my home so I opened up my own office in August of 2006. (Oliver)

Having control over the location of his work gave this participant more independence and the ability to use his time more efficiently (rather than spending it commuting).

The final pattern consisted of five men and three women who never drove themselves, and who have always relied on a combination of rides from others, walking, and public transportation to get to work. It is important to note that only three of the participants reported making use of government-arranged rides (such as Para-Transit). When talking about their labour market concerns, most of the participants focused less on their commute than on other challenges, such as having limited access to information because of problems they encountered in using assistive technology.

4.3.2 Motivations Behind Continuing and Stopping Driving

While all of the participants eventually either stopped working or substituted driving to work with alternative commuting modes, the majority of participants reported that their decision to stop or to limit their driving was motivated to a great extent by repeated assessments of risk (see Table 4.5).

Table 4.5: Motivations behind driving behaviour

<table>
<thead>
<tr>
<th>Driving motivations</th>
<th>Description</th>
<th>Total</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prolonging driving</td>
<td>Concerns that urge participants to continue driving</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independence &amp; access</td>
<td>The fear of being limited and unable to participate</td>
<td>19</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Normative</td>
<td>A fear of losing an identity associated with driving (being able-bodied, masculinity)</td>
<td>5</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Stopping driving</td>
<td>Concerns that lead participants to stop driving</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced vision and anticipated danger</td>
<td>The anticipation that accidents may follow in the future</td>
<td>19</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>Accidents near accidents</td>
<td>Experiencing or nearly experiencing accidents</td>
<td>9</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>

*Results are based on reports. Not all participants revealed all concerns for driving or stopping with driving and the associated information (such as driving accidents)
They assessed their ability to drive and the potential risk involved by comparing their driving skills to those of others, and by experiencing high-risk driving situations. Participants also relied on others to help them with the decision to stop driving (health professionals or individuals in their close network):

*I basically made the decision that, you know, if [the doctor] told me I was legally blind that I wouldn't drive anymore... I think morally it was the right decision. And I feel that, you know, there are times I wish I could still drive and then there are other times when you’re riding around and some other drivers are crazy. Then I think maybe it isn't such a bad thing that you can’t drive anymore.* (Gwen)

The participants who reported postponing giving up driving despite their declining vision cited two main motivations for the delay. First, for many individuals, not being able to drive imposed practical limitations on their ability to work, such as on their ability to complete their work tasks or to commute to the office within a reasonable amount of time.

The main alternatives to driving, public transportation and walking, were not feasible for the many participants (especially for those individuals who lived outside of large cities) lived too far away from their workplace to walk. Additionally, many of the participants noted that public transportation in the United States is inadequate in a number of ways (e.g., it is not available, it is inefficient, or using it is time consuming). Thus, relying on public transportation to get to work was not an option for many of the participants:

*I couldn't get to the [workplace] without driving. so that's why I had to leave that. They held the job for me for a few months so I can figure it all out but probably around November, that's when we decided that there was just no way that I could keep getting back and forth to the airport at the hours that they needed me. It would take me hours. I would have to take a bus to another bus and then walk a mile.* (Rachel)

The example above illustrates how the inability to drive is perceived as a threat to an individual’s ability to participate in the labour market. This dynamic therefore represents a means of social exclusion from participation in the labour market.

The second motivation the participants cited for continuing to drive was the fear of social exclusion based on the inability of the individual to fulfil normative expectations associated with driving. Only male participants (five drivers and two non-drivers) reported experiencing acute difficulties related to the symbolic meaning of driving; i.e., that no longer being able to drive affected their ability to be a full
participant in society. The following participant reported that he felt that if he could no longer drive he was not fulfilling his role as the head of his household:

_I did stupid things like… I only lived about a half mile from [work] but when I was driving at this time a year when the days get shorter I would follow my [work] partner, follow his headlights home, he would drive by my home and I would turn into my driveway. So here you have two lawyers: one guy who can barely see and the other guy leading with two cars down the road. How ridiculously stupid was that? But it kind of underscores how [...] fearful you can be with this. Cause I’m the breadwinner in my family and I have all these people depending on me for going to school and putting food on the table; and I don't know, you just do things that you look back and go, “Wow, I can't believe I did that”. (Oliver)_

This quote illustrates that for some participants, being able to drive a car is associated with the ability to fulfil societal roles. After this participant realised that the risk was too high he stopped driving and started working from home. And once it became clear that his decision to give up driving would not affect his ability to fulfil his role as a breadwinner, his original resistance to the idea abated. He explained how his attitude towards driving changed:

_I thought the world was going to come to an end when I stopped driving but it didn't. I even said to somebody the other day that, with all the stem cells and all the other research even if I get to the point some day that I can see the faces of my grandkids that... I don't care if I ever drive again I can deal with that. (Oliver)_

This case illustrates well that, even though this individual did not need to drive to commute to work (i.e., the practical dimensions of exclusion were absent), he was tempted to continue driving because he associated driving with masculinity and with being a breadwinner.

Other participants reported that they were uncomfortable with relying on other people for rides, even through a paid car service or cab. For example, the participant quoted below, who stopped driving because he lost all of his usable vision, expressed discomfort with his dependent status:

_I feel it's very important to pay the people who drive me very, very well even though they say, “No, it's all taken care of”... but I still want to pay them just as though I have a private chauffeur; so that's the way that I feel more comfortable with it. I do pay them. But that is what I_
Being concerned with compensating the person who drives him (in this case, a taxi driver) can be seen as a way to reassert his role as a breadwinner, or as a person who can afford such services, rather than as a person who relies on others for transportation.

The fact that men reported experiencing more normative meanings associated with driving can be partially attributed to the relatively high average age of the participants (only two participants were below the age of 50). These men may have relatively traditional ideas about masculinity.

As the majority of the women in this study were also earners, most of the female participants reported trying hard to avoid social exclusion and to sustain their labour market position. While the women did not report having the same normative motivations as men, they did report having practical concerns. Thus, their comments often had a normative undertone related to the loss of independence:

Driving is like when you take away the keys; it's a big independence taken away from you. So that was a big adjustment. (Eleanor)

Unlike the men, most of the women in this study were not the main provider in their household, which may have reduced the level of stress they experienced at the prospect of losing their role as a breadwinner. Nonetheless, even among the women who were the major or the sole contributor (single women) of income to their household, the level of meaning they attached to having to stop driving appears to have been lower than that of men:

I stopped driving probably about six to seven years ago. I forget the exact date. I did stop driving, as the eyes got worse... I had wonderful peripheral field for the disease but it did slowly get worse finally so... I do take the Para-transit bus to and from work. (Sarah)

This case is typical of the experiences reported by the other female participants who were contributing a large share of their household’s income. While giving up driving clearly posed a challenge, these women did not express the same degree of emotional loss or identity conflict as some of the men in the sample did.

While the considerations described above are incentives for prolonging driving, the participants eventually stopped driving after they had either encountered dangerous situations or felt that they might encounter them in the near future. Six of the participants reported having repeated accidents (and three reported experiencing “near misses”). Some of the participants did not stop driving until after they had been...
involved a “high impact” accident, in which they could have hurt themselves or
someone else. This is illustrated in the following case:

Even though I was driving—at that point mostly on the weekends—I knew that there would come a point that I wouldn’t be able to drive. 2003 I couldn't drive anymore. I actually had a freaky experience on the road. I drove up on the sidewalk. I just was happy to get home and at that point I called my middle son and gave him my car. I swore I would never get behind the wheel. It was interesting because the doctor was right, cause he said when it was time to give it up, you would know. Well I now know. So I was without a car, it hurt my ego more than anything else. It hurt my independence. (Dylan)

A number of the participants in this study said that they needed assistance in determining when they should stop driving. However, several also reported that the instructions they were given by health professionals for assessing when they should stop driving were unclear. For example, some participants said that their ophthalmologist (or other eye specialist) told them that they would know when to give up their license. This advice did not appear to be effective, as many individuals ended up waiting to give up driving until they had a clear sign that they were not longer to competent to drive, such as having an accident. In the following, a participant explains how he assessed his driving skills:

I didn't crash or anything but I was driving on the freeway and maybe there was a car on my left. My parents were like, “Oh there's a car”; but the thing with RP [Retinitis Pigmentosa] is you never know what’s normal misses. What are normal misses versus RP misses?... They [other drivers] cut you off with no blinkers, you'd never see, you'd never know. Some things are very normal. You glare at the sunlight, intensified by the RP but it's also not easy for the average person... You never know, is it me now at age 42 is it the RP? I'm at the point where it's shifting. (Dick)

Self-assessment of risk is thus a challenge for participants, and can lead to prolonged risk-taking.

4.4 Discussion

In this study we used qualitative methods to gain insights into 1) how white-collar workers with degenerative eye conditions experience and deal with changes in their perceived abilities and their resources over time when choosing whether to drive
to work or to use alternative modes of transportation; and 2) how they motivate the choice to continue or to stop driving.

Concerning the first question, we found that the majority of participants continued to drive after their eye condition was diagnosed, and even as their visual decline advanced. While it is generally acknowledged in the literature that people with low vision and blindness face disadvantages associated with not being able to drive (Marston & Golledge, 2003), few studies have looked at the preferences of and the actual commute modes used by people who are visually impaired, including driving (Gallagher et al., 2011; Golledge, Marston & Costanzo, 1997).

The findings indicate that the majority of participants in this study, and especially the men, tried to find modes of transport that helped them avoid social exclusion. For example, many of the participants reported that they went from continuing to drive as before, to driving only under certain conditions, and then to being driven by others.

However, the wide range of commute mode solutions cited by the participants illustrates that social exclusion is not a dichotomous state. The shifts between commute modes reflect the gradient in the degree of social exclusion within the narrative of each individual participant, and between the participants. For instance, the participants who exhibited the first pattern of behaviour left the labour market as soon as they stopped driving, which is indicative of a high level of social exclusion. By contrast, the participants who had access to rides to work were able to maintain their labour market position, and thus experienced little social exclusion. However, the individuals who relied on rides had a higher degree of dependence on others than the individuals who moved to be closer to their work. This gradient in the experience of social exclusion is in line with previous research that stressed the importance of investigating social exclusion on a continuum (Schwanen et al. 2015).

Our results for the second research question regarding the reasons for continuing to drive show that, in line with the social exclusion framework, the participants were motivated to continue driving by practical and normative concerns. From a practical point of view, many participants perceived that being unable to drive would hamper their independence and their access to amenities. From a normative point of view, we found that the meanings attached to driving and the desire to retain the breadwinner role led many of the male participants in particular to continue to drive.

The normative motivations for continuing to drive are related to the meaning attached to the commute mode. Our results regarding these motivations are in line with the findings of previous studies. A study in the UK showed that many older individuals, who grew up with a strong norm of self-resilience, stopped participating in activities that could only be reached by car when they could no longer drive (Schwanen, Banister, & Bowling, 2012). Furthermore, Gardner and Abraham (2007), who studied the role of the car among the general population, suggested that the instrumental motivations (closely related to practical motivations) and the affective motivations (closely related to socio-cultural motivations) for driving should not be treated as mutually exclusive, but should instead be considered together.
The finding that only male participants reported strong normative motivations for driving may point to the traditional cultural attributes in western societies associated with driving a car, such as manhood and masculinity (Carrabine & Longhurst, 2002; Sheller, 2004; Urry, 2007). These normative expectations may also relate to findings that that men tend to evaluate their driving competence more highly than women (Ruechel & Mann, 2005; Siren & Meng, 2013).

While their assessment of the risks they faced by continuing to drive eventually led the participants to stop driving, many of the participants reported that they were not certain when they should quit. This uncertainty led some participants to continue driving until they had been involved in one or more car accidents. These results are in line with those of previous studies on older populations with visual impairments, which indicated that many of these individuals engage in risky driving behaviour (Szlyk et al., 2002). The period during which people with visual impairments restrict their driving appears to be important, as continuing to drive while impaired may have grave consequences for the safety of these individuals and of those around them. This period seems to be prolonged in part because individuals are often told by health professionals that they will know when to stop driving. As most people are motivated to continue driving for both practical and normative reasons, it is important that health professionals guide the decision to stop driving more strictly.

While this study makes some important contributions, it also has some limitations. First, the participants in this study were not asked directly about their car usage or commute mode, but rather about their work trajectories and the challenges they encountered in this context. This can be seen as both as an advantage and a drawback of the study. On the one hand, our approach clearly shows that commuting plays a very important role in obtaining and sustaining work for individuals with degenerative eye conditions, and that being able to get to work greatly affects their labour market participation. On the other hand, the full extent of this problem cannot be assessed here because the topic of driving was not a focal point of this data collection.

Second, the data collection was done using two methods: i.e., face-to-face and by phone. While this can be perceived as a drawback, the average length of the interviews was similar regardless of the method used. Thus, while we acknowledge that variation in the method of data collection can affect the quality of the data collected, we are confident that this is not the case here.

Future research may try to quantify some of the issues dealt with in this paper on a larger scale, such as the experiences of socio-cultural and practical exclusion, and relate them to the likely employment trajectories of this sub-group. In addition, future research should focus on the questions of whether and how driving behaviour and perceptions of car use differ by residential context (i.e., suburban, urban, rural), and area of residence. As the visual requirements and regulations for drivers differ between states in the U.S. (Fishbaugh, 1995), researchers should examine how these regulations are related to commuting behaviour among this population.
To summarize, our study illustrates that while driving is often neglected in the literature on the commuting behaviour of people with vision impairments, it is a central commute mode among individuals experiencing vision decline. As the number of individuals affected by vision loss (one in 28 adults over the age of 40 in the United States: Eye Diseases Prevalence Research Group, 2004) is rising, it is important to consider the possible consequences of social exclusion for the health and the overall well-being of this group. Existing policies aimed at accommodating the commuting needs of this group have primarily focused on paid transportation alternatives, which, as was demonstrated here, often are not time-efficient or normatively appealing for the user, or cost-effective for the provider. Policies that incentivise car-pooling within the workplace may be a suitable intermediate solution, allowing individuals who are unable to drive to continue to participate in the labour market.
Chapter 5

We're all in the Same Boat: Individual Outcomes Associated with Participation in Networking Groups among Individuals with Degenerative Eye Conditions*

Abstract

This study aimed to gain insights into the relationship between participation in peer networking groups and individual outcomes among individuals with degenerative eye conditions. Two theoretical frameworks were used: homophily and social comparison theory. In Study 1 we tested the role of homophily and peer similarity on experiential and structural dimensions. Partial support was found for the expectation that the two dimensions relate positively to satisfaction with group participation and to subjective wellbeing.. In Study 2 we qualitatively illustrated that individuals had a preference for engaging in contact with others who were coping well and struggling less, thus showing a preference for upward comparison. Downward comparison preferences were less evident and were more common with regard to the severity of the condition. Dissimilarity with regard to age and employment status inhibited identification processes and induced either the avoidance of contact or the process of assuming the role of a mentor to others with degenerative eye conditions.

* This chapter is co-authored with Nardi Steverink and is currently in preparation for submission to a scientific journal.
Abstract
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5.1 Introduction

When an individual experiences an adverse life event, such as an illness or a status transition, she may seek to join a networking group (or support group) that is tailored to the particular hardship she is experiencing. Certain types of networking groups, such as groups for women with breast cancer or individuals with HIV, are rather common, and participation in them has been widely studied (e.g., Klemm et al., 2003; Spirig, 1998). However, we know relatively little about many other kinds of groups, such as groups for individuals with degenerative eye conditions. We are unaware of any studies that focus on these groups. The existing studies that examined the general population of individuals with visual impairment focused on either older individuals (Thomas & Urbano, 1993), adolescents (Kef & Deković, 2004), or broad groups of individuals with various disabilities, without distinguishing separate effects (Finn, 1999). Thus, these studies give us little insight into the particular characteristics of these types of networking groups and the associated individual outcomes related to participation in them for adults with degenerative eye conditions.

It is important that we gain more knowledge about peer group participation among individuals with degenerative eye conditions because of the gradient change (transition) in identity that occurs with such progressive conditions. Visual impairment and blindness are highly stigmatized identities (Goffman, 1963). The gradient identity change makes it possible for individuals to postpone assuming the identity, and to develop tools for dealing with their increasing visual limitations. But to avoid being subject to social exclusion, it is crucial that individuals start to develop these tools before their eyesight becomes very limited. For instance, if an individual does not learn how to use assistive technology, she might have a hard time sustaining her position in the labor market when her sight worsens. Peer contact may help the individual in developing physical and mental coping strategies that may prove useful as the condition progresses. However, because of the stigma associated with such conditions (Goffman, 1963), the individual may experience distress and discomfort when interacting with peers, especially when the contact forces her to confront her impairment. Thus, having contact with visually impaired peers can have both positive and negative consequences for the individual. Given the progressive nature of these conditions and the potential benefits individuals can derive from having contact with peers, it is important that we gain more knowledge about when peer network contact is beneficial or rather detrimental for individual outcomes.

In this paper we address the following questions: When are individuals with degenerative eye conditions satisfied with participation in peer networking groups? And, when do individuals with degenerative eye conditions experience overall wellbeing benefits from participation in such groups? This study represents a first step in investigating this otherwise understudied group. We chose the aforementioned outcomes because they relate to the broad subjective experiences of the individual,
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Chapter 5 | We’re all in the same boat

and provide us with a more general overview of these issues, which can help to pave the way for research on more specific mental health outcomes, such as depression.

The literature thus far points to two main theoretical frameworks for tackling our questions. First, there is evidence to suggest that homophily (McPherson, Smith-Lovin, & Cook, 2001)—i.e., similarity between individuals—is important for individual outcomes. Positive outcomes from peer support have been shown to be related to similarity between individuals. Both experiential similarity (when the individuals who are interacting have similar attributes related to the transition) and structural similarity (when the individuals who are interacting have similar demographic attributes that are not related to the transition) have been shown to contribute to satisfaction with contact and to wellbeing (Lin, Woelfel, & Light, 1985; Suitor, Keeton, & Pillemer, 1995; Suitor & Keeton, 1997; Wright, 2000).

Second, social comparison processes (Festinger, 1954) have been shown to play an important role in whether contact yields positive or negative outcomes for the individual. On the one hand, having contact with peers fosters social comparison processes that can help the individual embrace the disability or condition as part of her identity, become more open about the condition, and accept her limitations. This kind of peer contact can also assist the individual if she is grieving or is having emotional difficulties (Mazanderani, Locock, & Powell, 2012). On the other hand, studies have shown that adverse outcomes can occur if the group members are incompatible. Individuals who reported having good mental health prior to participation in support groups with peers might experience depression (Uccelli, Mohr, Battaglia, Zagami, & Mohr, 2004) or fear and angst (Locock & Brown, 2010) as a result of exposure to individuals who are coping poorly with their condition.

The paper is divided into two studies. In the first study we investigate our research questions from a sociological perspective guided by homophily principles; i.e., by investigating the role of peer similarity (McPherson, Smith-Lovin, & Cook, 2001) in individual outcomes. Thereafter, we approach the question from a social-psychological perspective guided by the social comparison theory (Festinger, 1954). In Study 1 we make use of survey data that allow us to test various aspects of similarity against each other. In Study 2 we make use of qualitative interview data that give us insight into the social comparison experiences of individuals with degenerative eye conditions, and into the patterns and variation among participants.

5.2 Study 1: A Homophily Approach to Peer Networks

The homophily approach stipulates “birds of a feather flock together.” This means that individuals not only have a preference for engaging in contact with others who are similar to themselves, but that the degree of similarity will predict the likelihood that the contact will prove to be long-lasting, resulting in, for example, marriage or long-term friendship (see McPherson, Smith-Lovin, & Cook, 2001).
Furthermore, research on homophily within support group networks shows that homophily is also related to satisfaction with the contact and with the length of the contact (Wright, 2000). Thus, with these findings in mind, we might assume that individuals who have contact with peers who are similar would perceive these interactions as positive, and would derive wellbeing benefits from the interaction.

To ensure that our concept of similarity is sufficiently nuanced, we follow Suitor, Keeton, and Pillemer (1995), who distinguish between two aspects of similarity: experiential and structural similarity. Experiential similarity refers to whether individuals are experiencing similar status transitions (i.e., from being able-bodied to being disabled). Studies have shown that individuals who have experienced a specific hardship in the past are better positioned than others to provide emotional support to individuals who are currently experiencing the same hardship (Suitor, Keeton, & Pillemer, 1995). This finding suggests that experiential similarity would tend to foster mutual support between peers, and would thus enhance the benefits of peer contact. In this study we distinguish between two aspects of experiential similarity within the specific status transition of vision loss: how an individual is coping with the condition, and the severity of the individual’s condition (visual decline). We hypothesize that similarity in coping with the condition and in the degree of condition severity will associate positively with the degree to which an individual is satisfied with group participation and also to overall higher subjective wellbeing (H1).

Structural similarity refers to similarity in terms of demographic characteristics outside of the status transition (i.e., vision loss). Individuals tend to attribute to others who are similar to themselves in terms of structural dimensions similar viewpoints, values, and perceptions. Thus, when individuals are more similar in terms of structural dimensions it may be assumed that will be better able to relate to and understand one another with regard to their experiences surrounding the particular status transition (Suitor, Keeton, & Pillemer, 1995). Similarity in terms of structural dimensions within the context of social support was found to predict changes in depressive moods (Lin, Woelfel, & Light, 1985), the length of participation in different support-related networking groups (Suitor & Keeton, 1997), and satisfaction with group participation (Wright, 2000).

Following Suitor, Keeton, and Pillemer (1995), we investigate aspects of structural similarity that are associated with similar socialization patterns within the status transition at hand, and that will lead the individual to experience the transition in a similar manner. In this study we focus on age and employment status as structural aspects of similarity. We expect age to contribute to how individuals experience the status transition, as it is likely that people who are around the same age are going through life transitions at around the same time (such as seeking a partner). We further expect employment status to be an important factor given the role that vision impairment plays in hindering labor market participation. In short, when individuals have similar characteristics they are more likely to understand each other’s experiences. Thus, we hypothesize that similarity in age and in employment status...
will associate positively with the degree to which an individual is satisfied with group participation and also to the degree of overall higher subjective wellbeing (H2).

5.3 Method

5.3.1 Ethical Statement

Consent was obtained from all of the participants in both Study 1 and Study 2. The procedures of these studies have been evaluated as being ethical by the ethical board of the sociology department of the University of Groningen.

5.3.2 Survey Data Description

We administered an online survey with the following selection criteria: the individuals had to have a degenerative eye condition, be over age 18, and be living in the United States. The participants were recruited through a medical nonprofit organization for individuals with sight impairment, through various social media (email lists, Facebook) and through the National Federation for the Blind. The survey was filled out by 143 individuals, of whom 82 indicated that they were participating in social network groups for individuals with visual impairments. These individuals are used in this analysis.

5.3.3 Measures

Satisfaction with group participation is measured with the following item: “How satisfied are you with your participation in this (these) group(s)?” The answer categories range from one to five, whereby one indicates that the respondent is very satisfied and five indicates that the respondent is very dissatisfied. The item has been reversed such that a score of five indicates the highest degree of satisfaction.

Subjective wellbeing is measured using three scales that are often used together to measure subjective wellbeing (Pavot & Diener, 1993): life satisfaction, positive affect, and negative affect. Life satisfaction was measured with the Satisfaction With Life Scale (SWLS, Diener, Emmons, Larsen, & Griffin, 1985). This is a five-item scale consisting of items such as: “In most ways my life is close to my ideal.” The answer categories range from one to five, whereby one indicates that the respondent strongly disagrees and five indicates that the respondent strongly agrees (Cronbach’s alpha=.93). We measure positive and negative affect using the 10-item PANAS scales (Thompson, 2007). In the question on positive affect, participants are asked to indicate how they felt over the last two weeks on items such as “alert” and “determined” (Cronbach’s alpha=.84). Similarly, in the question on negative affect, participants are asked to indicate how they felt over the last two weeks on items such as
as “afraid” and “nervous” (Cronbach’s alpha=.84). The answer categories range from one to five, whereby one indicates “very slightly to not at all” and five indicates “extremely.”

Degree of similarity is measured with the following question: “On average, how similar to you are the individuals in this (these) group(s), on a scale of 1 (not at all) to 5 (very similar), in terms of [aspect].” The following aspects are rated: “struggles with eye condition,” as a proxy for coping; and “disease severity,” as an indicator of experiential aspects of similarity. Additionally, age and employment status (employed, not employed, retired, house keeper, student) are rated as indicative of structural aspects of similarity.

We further control for the degree of difficulty individuals have with daily activities using the first 10 items of the Visual Functioning Questionnaire (VFQ-25, Stelmack, Stelmack, & Massof, 2002). An example of an item is: “How much difficulty do you have reading ordinary print in newspapers?” The answer categories range from one, “no difficulty at all;” to six, “stopped doing this” (Cronbach’s alpha=.83). Finally, we look at how many years ago individuals started experiencing difficulties with their vision decline. A summary of the descriptive statistics is shown in Table 5.1.

<table>
<thead>
<tr>
<th>Table 5.1: Descriptive statistics</th>
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<td>Group satisfaction</td>
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<td>Life satisfaction</td>
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<td>Positive affect</td>
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<td>Coping similarity</td>
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<td>Severity similarity</td>
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<td>Age similarity</td>
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<td>Employment similarity</td>
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<td>Years since deterioration</td>
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<td>Difficulties with activity</td>
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</table>

5.3.4 Analysis

We used the SEM command for path modeling to run our OLS regression models in STATA.13. We chose to use this command because it provides us with an optimal platform for dealing with missing values using the Maximum Likelihood for Missing Values (MLMV) technique.
5.4 Results

When we look at the correlation matrix (Table 5.2) we can see that all of the correlates are .6 or lower, which reduces our concerns related to multicollinearity. Thus, we proceed to testing our hypotheses.

Table 5.2: Correlation matrix of dependent, independent and control variables

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<td>1. Group satisfaction</td>
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<td>2. Life satisfaction</td>
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<td>3. Positive affect</td>
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<td>4. Negative affect</td>
<td>-.18</td>
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<td>5. Coping similarity</td>
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<td>6. Severity similarity</td>
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<td>7. Age similarity</td>
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<td>9. Years since deterioration</td>
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<td>-.25</td>
<td>-.04</td>
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<td>10. Difficulties with activity</td>
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</tbody>
</table>

*p*-values in parentheses

We expected to find that having similar degree of coping would be positively related to satisfaction with group participation and a high level of overall subjective wellbeing (i.e., a positive association with life satisfaction and a positive affect, and a negative association with a negative affect). As can be seen from Table 5.3 only one significant association was found, and it was in the opposite direction of the one we expected: namely, having similar degree of coping was shown to be negatively associated with life satisfaction ($\beta = -.29$, $p = .037$). We discuss this unexpected finding in more detail in the conclusion section.
Table 5.3: Association between similarity, subjective wellbeing and satisfaction with group participation

<table>
<thead>
<tr>
<th></th>
<th>Model 1 Group satisfaction</th>
<th>Model 2 Life satisfaction</th>
<th>Model 3 Positive affect</th>
<th>Model 4 Negative affect</th>
</tr>
</thead>
<tbody>
<tr>
<td>R square</td>
<td>.20</td>
<td>.19</td>
<td>.06</td>
<td>.06</td>
</tr>
<tr>
<td>Constant</td>
<td>4.26 (.000)</td>
<td>3.49 (.000)</td>
<td>5.55 (.000)</td>
<td>2.14 (.000)</td>
</tr>
<tr>
<td>Coping similarity</td>
<td>-.20 (.133)</td>
<td>-.29 (.037)</td>
<td>-.14 (.350)</td>
<td>-.18 (.142)</td>
</tr>
<tr>
<td>Severity similarity</td>
<td>.31 (.007)</td>
<td>.31 (.009)</td>
<td>.05 (.357)</td>
<td>-.04 (.389)</td>
</tr>
<tr>
<td>Age similarity</td>
<td>-.01 (.902)</td>
<td>.04 (.358)</td>
<td>.00 (.497)</td>
<td>.11 (.383)</td>
</tr>
<tr>
<td>Employment similarity</td>
<td>.20 (.049)</td>
<td>.05 (.323)</td>
<td>-.09 (.492)</td>
<td>-.05 (.347)</td>
</tr>
<tr>
<td>Years since deterioration</td>
<td>-.26 (.005)</td>
<td>-.22 (.021)</td>
<td>-.03 (.368)</td>
<td>-.07 (.292)</td>
</tr>
<tr>
<td>Difficulties with activity</td>
<td>-.09 (.174)</td>
<td>-.19 (.033)</td>
<td>-.17 (.068)</td>
<td>.20 (.035)</td>
</tr>
</tbody>
</table>

N=82, standardized coefficients are presented with p-values in parentheses; p-values of results which are in line with the expectations are one-tailed.

We further expected to find that having a similar degree of visual impairment would be positively related to satisfaction with group participation and to wellbeing. While we found the expected associations for satisfaction with group participation ($\beta=0.31$, $p=0.007$) and for life satisfaction ($\beta=0.31$, $p=0.009$), we found no significant associations between having a similar degree of visual impairment and positive or negative affect.

Regarding the structural similarity indicators, we expected to find that similarities in age and employment status would be positively related to satisfaction with group participation and to overall subjective wellbeing (i.e., a positive association with life satisfaction and a positive affect, and a negative association with a negative affect). We found no support for our expectations regarding age. For similarities in employment status, we found only one significant association: namely, having a similar employment status was shown to be positively associated with satisfaction with group participation ($\beta=0.20$, $p=0.049$). Having a similar employment status was not found to be associated with any of the three components of subjective wellbeing. Thus, we find only partial support for Hypotheses 1 and 2.
5.5 Conclusions

Making use of homophily principles, we attempted to investigate whether similarity between participants in networking groups for individuals with degenerative eye conditions is associated with higher levels of satisfaction with group participation and higher levels of subjective wellbeing. We distinguished between two similarity dimensions: experiential and structural.

In line with previous literature (Suitor & Keeton, 1997; Wright, 2000), we found partial support in our findings for the association between the two dimensions of homophily (i.e., experiential similarity and structural similarity) and satisfaction with group participation. However, our findings regarding the association between the two similarity dimensions and the subjective wellbeing indicators are less clear. While similarity in terms of the severity of the condition was found to be positively associated with life satisfaction, none of the similarity aspects were found to be significantly associated with the other two dimensions we used to measure subjective wellbeing; namely, negative and positive affect. Furthermore, having a similar coping strategy was found to be significantly associated with life satisfaction only, and in the negative direction. This finding is contrary to our expectations.

A possible reason for this contradictory finding is that the homophily principle may not be the best concept to use when seeking to understand the mechanisms that underlie the positive or negative outcomes related to peer contact in the case of the specific status transition considered here; namely, degenerative eye conditions.

Unlike many other status transitions that have been studied in the past (such as the shift from being married to being divorced, or from being employed to being unemployed), the identity of individuals with a degenerative eye condition develops over time. Moreover, as we noted in the introduction to this paper, blindness is a highly stigmatized identity, as loss of sight is the most feared type of sensory loss among the general population (Dickerson, Smith, & Moore, 1997). These concerns may feed back to why homophily may not be a sufficient explanation for the effects of peer networking group participation on individual outcomes among this population. Homophily principles do not address the degree to which a person identifies with her peers. The issue of identification is crucial in this context: if an individual does not identify herself as being a peer to others because she is unwilling to accept the identity, or because of a lack of compatibility with group members, then exposure to the group may be perceived as threatening and may induce negative outcomes for the individual. Identification may also partially explain our findings. While the severity of the condition cannot be influenced by the individual (i.e., the disease progression is not under the control of the individual), the person can choose the strategy she uses for coping with the impairment. It is possible that the impact of exposure to
individuals who have similar coping strategies depends on the degree to which an individual accepts her identity and perceives others as peers. An individual who copes poorly with her condition likely has not yet accepted her identity, and would thus perceive exposure to others who cope in a similarly poor way as a negative experience.

Thus, to gain a better understanding the role of similarity, we should seek to gain more insight into the circumstances under which the individual assumes the identity of being a person with a degenerative eye condition, and is willing to recognize others with the same condition (including its challenges) as peers. For this reason, studies that have looked at peer relationships among individuals who experience health decline often make use of social comparison theory (Festinger, 1954) to assess the role of peer identification and how peers view each other (Bennenbroek, Buunk, van der Zee, & Grol, 2002; Taylor et al., 2007). Thus, in Study 2 we will investigate whether social comparison theory can shed more light on the findings of Study 1. This framework may help us gain a deeper understanding of how different comparison characteristics—which we refer to here as similarity aspects—are experienced by individuals with degenerative eye conditions, and help or hinder the wellbeing of these individuals when they participate in networking groups.

5.6 Study 2: A Social Comparison Approach to Networking Group Participation

A social-psychological theoretical framework often used to investigate peer relationships is social comparison theory (Festinger, 1954). This theory suggests that the individual strives to have an accurate assessment of herself. Her objective is thus to make this assessment using the most accurate tools available to her. However, in the absence of strictly objective tools, the individual will compare herself with others. Social comparison processes are assumed to take place in relation to others who are similar to the individual in terms of the attribute she seeks to evaluate (in our case, having a degenerative eye condition).

After the comparison objects have been identified (a person or a group), the individual engages in one of two processes: upward comparison or downward comparison (Taylor & Lobel, 1989). Upward comparison is meant to assist the individual who strives to better herself in reaching a goal related to the attribute in question. For instance, an individual who has been recently diagnosed with a degenerative eye condition will want to compare herself with an individual who has a similar condition and is coping well with the impairment. Observing and learning from someone who copes well with her condition can inspire the individual to improve her coping strategies and achieve a higher level of wellbeing.

An individual may also feel compelled to engage in downward comparison. This type of social comparison can be attributed to ego-enhancing motivations, as it allows
the individual to evaluate herself as functioning on a higher level or as being better off than her peers. For instance, an individual with a degenerative eye condition may compare herself with individuals who are coping relatively poorly with the impairment, as such a comparison may serve to enhance her wellbeing.

Studies of cancer patients have shown that while cancer patients tend to rate their condition as being better than that of other patients (for a review, see Taylor & Lobel, 1989), and thus engage in downward comparison processes, they show a preference for receiving information about, and engaging in contact with other cancer patients who are well adjusted and are coping well (Bennenoek, Buunk, van der Zee, & Grol, 2002; Taylor et al., 2007). If we apply these findings to the current context, we may assume that an individual with a degenerative eye condition would have a preference for having contact with individuals who have eyesight that is worse than her own, while still having a preference for having contact with individuals who are coping well with their physical condition.

In their Identification Contrast Model, Buunk and Ybema (1997) have, however, suggested that whether an individual will experience an upward or a downward comparison as positive or negative depends to a great extent on the degree to which a person identifies with the comparison target, and thus to what extent she has already assumed the identity; in this case, of an individual with a vision impairment. Social comparison processes primarily take place in the form of contrasts or comparisons. When an individual does not assume her identity fully or does not perceive others as being her peers, then contrasting takes place and two alternatives outcomes are possible. Either this person will engage in upward comparison processes that lead to feelings of subsidiarity, or an individual will engage in downward comparison processes that lead to feelings of superiority. Given that the second outcome is more attractive, we can expect that the individual will be more likely to engage in a downward than an upward comparison process. When identification does take place, then upward comparison processes may become more attractive, as these processes tend to support the goal-enhancing motivations that will likely benefit the individual in the long run in dealing with her progressing disability.

5.7 Method

5.7.1 Sample

We approached participants through a U.S.-based non-profit organization that conducts research on vision impairment. To be eligible to participate, the respondents had to be over age 40, have had a degenerative eye condition for at least 10 years, and have been employed at the onset of the disease or during its progression.

We used saturation information to reach the number of participants (n=36). Four interviews were removed from the study. Two of the participants (with dual sensory
loss) were removed from the study because they had an emotional reaction to the interview, which led to the interviews being terminated early. A third case was removed due to language barriers, and a fourth case was excluded because the respondent did not yet have any serious symptoms. Four more participants were reached through a snowballing procedure. When no new insights were provided, the first author stopped looking for additional participants. This procedure resulted in a final sample of 36 participants.

Only one study participant had no contact with other individuals who identify as visually impaired. Twenty-five participants were taking or had taken part in a networking group. One other participant had no informal contacts with other visually impaired people other than his father and son. He did, however, express an interest in having contact. Eight participants reported that in their relationships with other visually impaired individuals their main role was as a mentor or a provider of support. Twenty-eight participants had a form of Retinitis Pigmentosa, and eight participants had Stargards. The youngest participant was age 42 at the time of interview, and the oldest participant was age 82. The average age of the participants was 59.

### 5.7.2 Data Collection

The participants were asked to tell their life story, with a focus on the role their vision loss played in their work trajectory. The participants were given free rein in telling their story, but were prompted to discuss the main themes (see Table 5.4) addressed in this study. One of these themes was the role of peers. The majority of the interviews were done face-to-face, and the rest were done by phone (24 and 12, respectively). The average length of an interview was 50 minutes.

<table>
<thead>
<tr>
<th>Themes</th>
<th>General description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background</td>
<td>Growing up experience, growing up experience with eye condition</td>
</tr>
<tr>
<td>Eye condition</td>
<td>Type, degree of vision loss, coping, behavioral strategies in different settings</td>
</tr>
<tr>
<td>Work life choices</td>
<td>Career description, interplay between eye condition and career choices, dealing with work environment</td>
</tr>
<tr>
<td>Identity</td>
<td>Self-acceptance, identity as visually impaired</td>
</tr>
<tr>
<td>Social surrounding</td>
<td>The role of others (outside of the workplace) in the well-being and coping with eye condition, general content with social surrounding, contact with other visually impaired individuals</td>
</tr>
<tr>
<td>Demographic information</td>
<td>Short questionnaire about educational background, household composition, socio-economic status, religious affiliation, volunteering behavior</td>
</tr>
</tbody>
</table>
5.7.3 Data Analysis

All of the interviews were fully transcribed. Using guidelines from Hennink, Hutter, and Bailey (2010) the data were coded inductively in ATLAS.ti by the first author and an additional coder. The data were coded independently. After each additional four interviews were coded, the two coders reported on the main emergent codes and reached a consensus on which codes were most important. The codes were subsequently assigned to categories: i.e., similar codes were identified and then grouped together under a descriptive name. These broader categories were subsequently broken down into smaller, more meaningful code groups based on the research question. At this stage the categories represented the concepts that comprise the “joint family code” (see Table 5.5).

Table 5.5: Main code families used in the analysis

<table>
<thead>
<tr>
<th>Code family name</th>
<th>Typology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adaptation and adjustments to vision loss</td>
<td>Adapting and adjusting behavior and emotion to vision</td>
</tr>
<tr>
<td>Career planning and adjustment</td>
<td>Work adjustments and planning in relation to vision</td>
</tr>
<tr>
<td>Challenges in education</td>
<td>Challenges in education related to vision loss</td>
</tr>
<tr>
<td>Emotional challenges</td>
<td>Emotional challenges relating to vision loss</td>
</tr>
<tr>
<td>Coping with vision loss</td>
<td>Different coping mechanisms with vision loss (e.g. avoidance, upward comparison, downward comparison)</td>
</tr>
<tr>
<td>Contact with other visually impaired individuals</td>
<td>Description of contact with other visually impaired individuals</td>
</tr>
<tr>
<td>Contact with other visually impaired individuals: negative</td>
<td>Negative perceptions or experiences with contact with other visually impaired individuals</td>
</tr>
<tr>
<td>Contact with other visually impaired individuals: positive</td>
<td>Positive perceptions or experiences with contact with other visually impaired individuals</td>
</tr>
<tr>
<td>Identity conflict</td>
<td>Conflict between visually impaired and sighted identity</td>
</tr>
<tr>
<td>Role models: being one and having one</td>
<td>On acting as and having a visually impaired role model</td>
</tr>
<tr>
<td>Support family and peers</td>
<td>Social support received from family and peers</td>
</tr>
</tbody>
</table>
The family codes were used in our “bigger picture” analysis approach (Hennink, Hutter & Bailey, 2010). In this approach, the researcher identifies the central story that accounts for the research question being investigated (in this case, the relationship between individual outcomes and peer contact, and the role of social comparison processes), while also making use of the family codebook. In the next phase the researcher takes a step back and considers the individual accounts of participants, looking for both similarities and differences between the accounts. The final step is the identification of patterns through a comparison of the central story with the individual accounts. We found patterns of upward and downward comparison. In the analysis we have further distinguished between how these processes were experienced based on the different comparison dimensions: namely, on the experiential and the structural dimensions of comparison.

5.8 Results

5.8.1 Upward and Downward Social Comparison Processes with Regard to Experiential Aspects

The participants reported on two comparison points: the degree to which others were coping emotionally and physically with the condition, and the severity of the condition. Sixteen participants reported having an interest in having contact with peers if the contact was with individuals who were coping well. Thus, a substantial number of participants showed a preference for upward comparison social interaction opportunities. This is evident from the following testimony:

*I came in contact with other people whose eyesight was at least as limited as my own if not more so; and seeing them function in a very fulfilling way gave me an enormous amount of support and determination and hope.* (Female, 66)

This quote illustrates that this participant clearly sees the individuals she had come into contact with as her peers, and hence as comparison targets rather than as contrast subjects. Engaging in upward comparison processes in turn enhanced her wellbeing.

The following report is of a participant who had come into contact with others with vision impairment only after a long period of isolation as he struggled to accept his condition:

*This [blind] friend that I met he told me how he could make his own beer and he made this waterfall and I said nooo… I went to his house*
and I said, ‘You did this and you can't even see!’ It gave me a lot of hope that if he could do it then I could do it. (Male, 52)

This individual did not come into contact with others who were visually impaired until he had started to accept his identity. Exposure to others at that stage was a means of goal enhancement; i.e., he engaged in upward comparison processes. Having contact with others who were impaired in terms of their vision but not in terms of their overall abilities allowed him to raise his expectations of his own abilities.

Seven of the participants reported having difficulties communicating with other visually impaired people because they perceived that many were maladjusted and coping poorly. Thus, these participants showed disdain for downward social comparison opportunities.

The following participant reported that she had participated in networking groups. However, she indicated she had mixed feelings about the people she came into contact with:

They're [other visually impaired people] a pain in the ass. Because a lot of times they want things done for them. They're spoiled they're coddled. I don't go out all the time with visually impaired... Sometimes I'd rather be by myself with my dog. I don't need the party. (female, 70)

This quote shows this participant was distancing herself from “them”—i.e., the other visually impaired individuals. Thus, she was engaging in contrasting behavior. She showed a preference for spending time alone rather than with others whom she described as being as less adjusted; thereby avoiding contact that would have led to downward comparison processes.

Another participant reported having a similar experience:

I have a bit of an aversion to people who want to dwell in the struggle. I have difficulty with that. I will go there [group meeting] for a little while but I will not stay there... Just like in anything there are people who need to do that. That's what they need to do. It's not what I need to do. (female, 55)

None of the participants reported experiencing downward comparison benefits from being in contact with maladjusted peers. These reports illustrate that participants not only prefer to minimize contact with peers who are less well adjusted or are coping poorly; they want to have contact with peers who are better adjusted—i.e., they have a preference for upward comparison contact opportunities.

When the participants were asked about interacting with peers with a higher or a lower degree of vision impairment, the responses were slightly different. Some
participants reported feeling better when they encountered individuals who had worse vision than their own:

> People with RP [retinitis pigmentosa] like us I find that their vision is more impacted to the degree that they can't see the person that they are talking to. They can just tell shapes and things like that, whereas I feel lucky because I can still see 20/20 and everything seems like it's ok. (Female, 51)

This quote shows that while downward comparisons in terms of coping and the degree of psychological adjustment are not beneficial for the individual, downward comparisons in terms of the severity of the condition can be.

Nevertheless, it is important to note that very few participants reported experiencing benefits from downward comparisons in terms of the severity of the condition. As is illustrated in the following quote, having a similar degree of visual decline is experienced as a peer identification mechanism through which the individual feels supported:

> It was such a comfort in a sense to be able to bump into someone and have them completely understand. Oh I don't mind. Or we're dancing in the dinner dance and, oh, I might step on your toe, or that kind of thing. And everybody understands. Whereas on the streets god forbid you walk into somebody and they would kill you. (Female, 59)

### 5.8.2 Upward and Downward Social Comparison Processes with Regard to Structural Aspects

Six participants directly reported having difficulties with structural dissimilarities between themselves and their peers. In particular, the participants said they had difficulties identifying with people of a different age or a different employment status (i.e., whether the individuals were employed and in what type of occupation).

The report below is from an individual who had participated in a group, but who quit the group after a relatively short period of time. He made the following observations about the people he encountered:

> Some of the participants in these groups have been [struggling] with employment; dealing with their jobs [and with] getting benefits. I sometimes felt guilty: I was patting myself on the back for accepting what I have and fighting for it. I don't know how many people do that. (Male, 67)
This quote illustrates that this individual was focusing on the differences rather than on the similarities between himself and the other group participants, and was thus engaged in a downward comparison process. On the one hand, he benefited from the downward comparison because it gave him a sense of superiority. On the other, it appears that this contact was not beneficial for him, as he stopped engaging in group activities.

An additional finding related to identification based on structural aspects of similarity concerns mentoring. Eight participants showed a strong tendency to differentiate themselves from the other visually impaired peers whom they met in group settings. Instead of avoiding contact with peers altogether, they assumed the role of supporter or mentor, either within the context of group activities or on an individual basis. Many of these individuals reported that they felt they had not met a true peer with whom they could identify (i.e., in terms of structural dimensions other than the visual impairment). When the following individual was asked why he avoids having contact with others, he said:

*If they're [the visually impaired persons] very successful and they are not whining and they are not sorry for themselves [then contact can take place].... Like [name of successful businessman who is blind] my friend... he's running a big company. Yes people like this I am talking [with and] I associate with. But I just don't want to be in any group of people that sees it [the condition] as an impairment to their lives. I deny it.* (Male, 68)

This quote illustrates that it is necessary for this individual to first be able to perceive others as comparison targets (as opposed to contrasting targets) in order to engage in true peer contact (as opposed to as a hierarchical contact).

Being older or younger than their peers was also a deterrent for identification and for sustaining contact: *There won't be anyone [in the group] in their 30's. No one in their 20's, no one in their 30's... Probably the median age is 75...* (Male, 42).

The following individual reported his experiences with looking for peers with guide dogs at the time when he received his guide dog:

*[I heard] that it's not only that there are [people with retinitis pigmentosa] there but there are actually people that have [guide] dogs. When I questioned and asked about it they were different: one of them is a woman that is on her fourth dog and is in her mid 80s... You know I would love to talk to another person who is a professional who's got this [eye condition].* (Male, 54)

This participant had an interest in making contact with peers who were similar to him in age and employment status, and with whom he could share his struggles and
experiences. Having contact with an individual who had a guide dog but was much older or was no longer participating in the labor market did not meet this need.

5.9 Conclusions

In Study 2 we followed up on the findings of Study 1 by seeking to gain deeper insight into the complex phenomena of peer identification and contact, and the associated outcomes for the individual. Identification was recognized as an important step in light of the stigmatized identity in question, and in light of the gradual process involved in assuming this identity (i.e., the rate of decline).

In line with previous research, we found that when it comes to experiential aspects, most individuals reported a preference for upward comparison opportunities (Bennenbroek, Buunk, van der Zee, & Grol, 2002; Taylor et al., 2007). Downward comparison processes were reported to a lesser extent and were experienced positively only with regard to disease severity; i.e., individuals benefited from contact with others who had worse vision. However, this was the case only if their peers were coping well. If their peers were coping poorly, then the individuals developed a disdain for contact.

The inability to identify with others based on structural aspects (age and employment status) led individuals to either avoid contact or assume a mentoring position. Individuals who acted primarily as mentors or providers of support were less prone to identify with their peers, and were thus more likely to engage in downward comparison processes. It appears that individuals who occupied a higher position in the hierarchy (as a mentor rather than as a person who was seeking help or peer contact) had fewer reservations about having contact with other visually impaired people who were coping less well, and experienced fewer adverse outcomes when they had contact with others than individuals who were trying to form peer relationships.

5.10 General Discussion

5.10.1 Findings Summary

We carried out two studies in order to gain insight into the question of to what extent peer network group characteristics are related to satisfaction with group participation and subjective wellbeing among individuals with degenerative eye conditions. In Study 1 we took a sociological approach. Making use of survey data, we tested whether principles of homophily played a role in individual outcomes. We looked at two aspects of experiential similarity: namely, similarity in coping strategies and similarity in disease severity. We also examined two aspects of structural
similarity: namely, employment status and age. The results regarding satisfaction with group participation were in the expected direction. One element of experiential similarity (i.e., disease severity) and one element of structural similarity (i.e., employment status) were both positively associated with group satisfaction. The results regarding wellbeing were mixed. On the one hand similarity in disease severity was found to be positively associated with life satisfaction (one of the three indicators of subjective wellbeing). On the other, contrary to our expectation, coping similarity associated negatively with life satisfaction, which was unexpected. Furthermore, none of the similarity aspects associated significantly with positive and negative affect (two of the three indicators of subjective wellbeing). Thus, only one indicator of subjective wellbeing—namely, life satisfaction—was found to be associated with the similarity aspects. These results indicate that the relationship between these aspects and overall subjective wellbeing is weak.

These results motivated us to try to tackle our research problem by taking a deeper look at the individual cognitive experience of peer identification. In Study 2, we used interview data to explore which aspects of social comparison processes—namely, upward and downward social comparison processes—were reported to play a role in individual outcomes, and whether identification with peers is important for determining whether individuals will engage in upward comparison processes. We were able to add nuance to the results by examining two aspects of comparison characteristics: i.e., those related to the experience (experiential) and those related to additional demographic characteristics (structural). We noted that participants had a general preference for upward comparison processes, and were willing to establish contact with peers only if those peers were coping well with their condition. Having contact with individuals who were coping well was perceived as being rewarding and motivational, while having contact with individuals who were coping poorly was perceived as being a negative experience; most likely because the participant was unable to identify with those peers. This result may also shed some light on the results of Study 1, as it suggests that there is a negative association between coping similarity and subjective wellbeing. It is possible that individuals who cope poorly have difficulties assuming the disability identity, and hence do not derive as much satisfaction from having contact.

Identification concerns were also evident when it came to structural dissimilarities in terms of age and employment status. Only the individuals who acted as mentors were less affected by identification concerns in contact formation. This result may again be attributed to the fact that these individuals did not identify with the visually impaired people they mentored as peers, but rather differentiated themselves from these peers. Members of this group also seemed to benefit from downward comparison processes.
5.10.2 Theoretical and Methodological Approach

In this paper, we took two theoretical approaches: a sociological approach of homophily and similarity (McPherson, Smith-Lovin, & Cook, 2001; Suitor, Keeton and Pillemer, 1995), and a social-psychological approach through social comparison theory (Festinger 1954; Taylor & Lobel, 1989). Both theories have pros and cons from our perspective. The homophily approach gave us the opportunity to quantitatively test the role of similarity in satisfaction with group participation and subjective wellbeing, and to lay the groundwork for considering both experiential and structural aspects of similarity in identification processes with peers. The social comparison approach in turn allowed us to delve more deeply into why certain aspects of similarity were less beneficial than others. This theoretical framework, together with the qualitative approach, provided us with insights into the variation in (experiential and structural) aspects of peer identification, and into how those aspects relate to upward and downward comparison opportunities, and the benefits and the disadvantages thereof. The second approach gave us some additional clarity on the antecedents of the complex role of similarities in coping strategies, suggesting that individuals have a preference for upward comparison opportunities.

While the mixed methods approach of this study is an excellent means of gaining initial insights into the topic of benefits from peer networking outcomes among individuals with degenerative eye conditions, there are a few drawbacks that should be mentioned.

An important drawback of Study 1 is that the survey data only provided us with insight into the outcomes of individuals who, at the time of the survey, were currently participating in networking groups (as opposed to those who were no longer participating in such groups). This was partially compensated for in Study 2, as we also had access to individuals who were no longer participating in networking groups. With these insights, we were better able to disentangle which elements hinder contact, and which elements are associated with dissatisfaction with participation.

A second drawback relates to the interview data of Study 2. The interview data provide insightful initial findings about the role of social comparison in individual outcomes among this population. However, they give us insight into the experiences of the individual who is interviewed only, and not of his or her peers. Future research may benefit from examining ego and network information that make it possible to identify more precisely the mechanisms through which individuals derive benefits from having contact with peers.
5.10.3 Policy Implications

This study takes a first step in evaluating the role of peer characteristics in the informal peer networks of individuals with degenerative eye conditions. Further research is needed to provide us with a complete picture of the role of peer characteristics in group satisfaction and in the wellbeing of these individuals. However, we cautiously draw the conclusion that, while achieving optimal group composition is challenging—i.e., it is difficult to achieve a composition that allows all participants an opportunity for upward comparison processes—there are some steps that could be taken. First, similarity on certain experiential and structural grounds is an important initial step for encouraging individuals to join networking groups. Second, having mentoring figures in groups can be a powerful tool, as this type of contact benefits both the mentor (downward comparison) and the person being mentored (upward comparison). Finally, before an individual can perceive others as being her peers, it is important that she has accepted her identity. Without identification, group processes may lead individuals to focus on their differences rather than their similarities, thus leaving little room for goal enhancement processes to take place. For this reason it would be beneficial to develop programs to help these individuals accept their identity and encourage them to focus on the similarities rather than the differences between themselves and their peers.
5.10.3 Policy Implications

This study takes a first step in evaluating the role of peer characteristics in the informal peer networks of individuals with degenerative eye conditions. Further research is needed to provide us with a complete picture of the role of peer characteristics in group satisfaction and in the wellbeing of these individuals. However, we cautiously draw the conclusion that, while achieving optimal group composition is challenging—i.e., it is difficult to achieve a composition that allows all participants an opportunity for upward comparison processes—there are some steps that could be taken. First, similarity on certain experiential and structural grounds is an important initial step for encouraging individuals to join networking groups. Second, having mentoring figures in groups can be a powerful tool, as this type of contact benefits both the mentor (downward comparison) and the person being mentored (upward comparison). Finally, before an individual can perceive others as being her peers, it is important that she has accepted her identity. Without identification, group processes may lead individuals to focus on their differences rather than their similarities, thus leaving little room for goal enhancement processes to take place. For this reason it would be beneficial to develop programs to help these individuals accept their identity and encourage them to focus on the similarities rather than the differences between themselves and their peers.
6.1 Introduction

As we have identified in the first chapter of this dissertation, an individual who has a stigmatized identity is likely to be faced with prejudice and discrimination from her surroundings. To avoid being confronted with such adverse outcomes, an individual who has the ability to conceal her stigmatized identity is likely to keep her identity a secret (Goffman, 1963).

Concealing a stigmatized identity can hold both positive and negative consequences for the individual. On the one hand, concealing a stigmatized identity may reduce the likelihood that the individual will be confronted by prejudice and discrimination. On the other hand, concealing a stigmatized identity may also lead to adverse outcomes such as reduced self-acceptance and reduced wellbeing.

An especially interesting group to be studied with respect to identity management – the manner and the degree to which an individual chooses to reveal her stigmatized identity to her surroundings – is individuals with degenerative eye conditions. People who are diagnosed with a degenerative eye condition may expect to lose their eyesight over the course of time, but at an unknown pace. Being aware of the consequences of stigma, they may choose to conceal their identity at first, but will eventually have to adapt and renegotiate their identity management in different settings.

The primary focus of this dissertation is on the workplace context. The focus on the workplace is important because individuals with visual impairment are known to suffer from high levels of discrimination in the labor market (Corrigan & Matthews, 2003). In light of the reduced chances experienced by individuals with visual impairment in the workplace, the experiences of those who have an invisible stigmatized identity and can choose how to manage their identity (i.e. those with degenerative eye conditions), are of great interest. Exploring this context is of special interest because the perceived benefits of concealment may come not only at a high psychological cost (as is common with concealment of stigmatized identities) but may also be physically taxing to conceal (i.e., by avoiding the use of assistive devices).

With the various studies in this dissertation (Chapters 2 through 5) we aimed to identify and investigate the struggles and triumphs faced by adults with degenerative eye conditions, in light of their invisible stigmatized identity. We wanted to gain a deeper understanding of the considerations underlying certain behaviors and choices, which directly or indirectly relate to identity management. Moreover, we aimed to better understand how these behaviors and choices influenced their career trajectories and overall subjective wellbeing. While the main focus of this dissertation is on the workplace context, we further sought to gain more insight into the role of peer relationships among individuals with degenerative eye conditions, and how contact relates to subjective wellbeing.
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Due to the exploratory nature of this dissertation, and our interest in disentangling mechanisms and validating them with an understudied group, a mixed methods approach has been taken. Two studies (Chapters 2 and 4) are inductive and qualitative in nature. These studies make use of life-stories of white-collar workers with degenerative eye conditions. The two remaining studies (Chapters 3 and 5) incorporate a mixed methods approach using the qualitative life-stories interviews and quantitative survey data on individuals with degenerative eye conditions. This method is used to gain insights into the applicability of general theories on the topic of disclosure and identity, on the group of those with degenerative eye conditions, and to gain insights into variations and discrepancies that arise from these theories.

In this final chapter, we will reflect on the extent to which these aims have been met. We will do so by first presenting a summary of the findings of the separate studies. Thereafter, a general discussion of the theoretical, methodological, and policy implications of this dissertation will be provided, while addressing shortcomings and opportunities for future research. This chapter concludes with final remarks.

6.2 Summary of Studies Findings

Chapter 2: Keeping up appearances: The role of identity concealment in the workplace among adults with degenerative eye conditions and its relationship with well-being and career outcomes

Individuals who have a stigmatized identity may expect to experience prejudice and discrimination from their social surrounding, and in the workplace in particular (Goffman, 1963). Individuals with concealable disabilities, such as those with degenerative eye conditions, thus often hold a preference for concealing their identity or for engaging in passing behaviors – behaviors that allow the individual to assimilate to the majority group. The manner in which individuals choose the manage their identity depends on the chosen career path, the position an individual has in the labor market, and on the degree to which her eyesight has deteriorated.

In this qualitative study we aimed to describe the interplay between passing patterns and work trajectories among individuals with degenerative eye conditions and to identify behavioral patterns. We then further wanted to examine the wellbeing outcomes associated with the different behavioral patterns.

We explored the variation in patterns in relation to disease progression and career phases, and sought to ascertain whether wellbeing patterns emerge, which relate to the different patterns of career trajectories and identity management (disclosure vs. concealment). We have identified five different patterns of identity concealment and passing strategies (i.e., behaviors the individual engages in to mask her stigmatized identity) in the workplace, which were linked to various work trajectories among individuals with degenerative eye conditions: 1) no career
adjustments, concealed condition throughout career; 2) revealed condition after adjusting career plans; 3) increasingly open about their condition over the course of their career; 4) engaged in career planning, always open about their condition; and 5) engaged in limited career planning, always open about their condition.

The five patterns identified in this study illustrate that there are multiple manners in which individuals tackle identity management, stigma, and career planning over time. These various strategies, in turn, yield different career trajectory patterns for participants and, even more importantly, relate differently to overall subjective wellbeing. Participants who exhibited patterns of less clear career planning, in addition to more passing and concealment behavior, suffered from higher work-related stress and lower self-acceptance. At the same time, participants who exhibited patterns with more career planning, and less passing and concealment behavior, showed higher self-acceptance and experienced overall fewer struggles over the course of their career. Thus, an important conclusion of this study is that, while concealment behavior has been perceived by many participants as crucial for career development, it can also be harmful for the individual, as it induced stress and low self-acceptance.

Our findings further illustrate that concealment is not the only pathway to positive career outcomes. Careful career planning upon diagnosis, which takes into account future visual decline and associated restrictions, can be an important driver of positive professional outcomes as well as heightened wellbeing among participants. So, for those who carefully plan around their future visual restrictions, disclosure in the workplace does not have to act as a long-term hindrance in the workplace, and may even contribute to overall wellbeing.

Chapter 3: What are the pathways linking the disclosure of a degenerative eye condition in the workplace and wellbeing? A mixed methods approach

While disclosure of a stigmatized identity is known to be associated with many positive individual outcomes, such as higher self-esteem, more energy, and lower stress levels (Corrigan & Matthews, 2003; Clair, et al., 2005; Derlega, Metts, Petronio, & Margulis, 1993; Jourard, 1971), little is known about the mechanisms behind this relationship, especially within the workplace context. Individuals with degenerative eye conditions are an interesting case for exploring the link between workplace disclosure and wellbeing benefits, because of the gradient shift these individuals experience in their identity over time (from fully sighted to visually impaired). Identifying the pathways between disclosure in the workplace and wellbeing benefits can help promote workplace disclosure and is, hence, the focus of this study.

We predicted three pathways between workplace disclosure of a degenerative eye condition and wellbeing benefits, namely the pathways through: 1) the alleviation of inhibition, 2) workplace social support, and 3) the use of assistive devices.
Chapter 6 | Discussion

We found partial support for our predictions. Specifically, both the survey and interview data exhibited support for the pathway through the alleviation of inhibition (i.e., the emotional relief tied to not having to conceal one’s identity). Our results suggested that concealing a stigmatized identity, especially one that is linked to a progressive health condition, can be physically and mentally straining for the individual. Revealing such a stigmatized identity is hence important for reducing emotional strain and thereby inducing overall subjective wellbeing.

The other two pathways, i.e., through workplace social support and through the use of assistive devices, are not supported by the survey data, but are partially supported by the interview data. The interview data suggest that workplace social support and the use of assistive devices are meaningful in two ways. First, these factors – although to a lesser extent than the alleviation of inhibition – do act as pathways between workplace disclosure and wellbeing benefits. Some participants reported that once they revealed their identity, they experienced higher workplace social support and/or started using assistive devices, which contributed to their overall wellbeing. Second, high levels workplace social support and the use of assistive devices have been reported by some participants to have preceded the act of disclosure, and to have, consequently, contributed to their decision to disclose their identity at the workplace. So, these two factors may also enhance the likelihood of disclosure taking place.

Two main conclusions can be drawn from this chapter. First, all three factors seem to play a role in the relationship between workplace disclosure and wellbeing benefits. Thus, we found support not only for the psychological (the alleviation of inhibition) and social (social support) pathways suggested by others (Chaudoir & Fisher, 2010; Beals et al., 2009), but also for the physical pathway (the use of assistive devices) deduced from the social production function theory (Lindenberg, 1996; Ormel et al., 1999).

Second, while all three factors relate to disclosure and disclosure benefits, they may relate to them in different ways. For instance, while certain individuals may disclose their condition because they experience high levels of social support in their work environment, others may experience increased social support as a result of workplace disclosure. Distinguishing these pathways can help disentangle the various motivational processes, that individuals encounter when faced by the dilemma of disclosure.

Chapter 4: Having both hands on the steering wheel: Car driving behavior in white-collar workers with degenerative eye conditions

Car driving is an important status symbol in Western societies, and in the USA in particular (e.g., Carrabine & Longhurst, 2002; Sheller, 2004; Urry, 2007). Not driving, hence, can act as an important factor in inducing social exclusion, especially in the labor market (Grengs, 2010). Due to their shifting identity (between sighted and
visually impaired) individuals with degenerative eye conditions face increasing driving restrictions. With this study we aimed to gain more understanding of how white-collar workers with degenerative eye conditions experience and deal with changes in their perceived abilities and available resources in choosing between car use and alternatives over time. We further wanted to investigate how these individuals motivate the choice to stop or to continue driving.

The majority of participants kept holding their driver’s license after having been diagnosed with their condition. Driving increased the degree of mobility experienced by participants and, by implication, the degree of experienced social inclusion, rendering driving an attractive commute solution. As the condition progressed, participants gradually shifted from driving behavior to alternative commute solutions in the context of labor market activities: 1) exiting the labor market, 2) being driven by others, and 3) relocating for the purpose of having access to public transportation or living within walking distance of the workplace.

These commute solutions were associated with a variety of experienced degrees of exclusion. The type of solution chosen was dependent on the visual decline individuals experienced, as well as the shift in resources that were available to them at different points in time (e.g. a spouse that is able to drive them). This finding is important as it stresses the importance of investigating social exclusion and the implications thereof as a gradient process. Not taking the gradient in social exclusion into consideration would result in oversimplification of the processes and the consequences of transport social exclusion. This in turn may result in oversimplified advice being extended to policy makers.

Additionally, our results showed that the shift towards giving up driving depended on two factors: the expected risk participants attached to this behavior, and the practical value and normative value (for men) that participants attributed to driving. More specifically, factors restricting driving lie within a risk assessment individuals engage in, but the perceived benefits of driving may cloud individuals’ judgment regarding their own ability to drive, and to sustain driving behavior. The benefits of driving relate to both practical concerns (e.g., how will I be able to efficiently commute to work without driving?), as well as normative concerns (e.g., how will my work connections view my competence if I do not drive?).

Understanding that not only practical but also normative motivations guide the decision to continue driving is important in understanding and predicting risky driving behavior. Thus, commute solutions that do not take both practical and normative concerns into account may still induce risky driving behavior.
Chapter 5: Experiential and structural similarity and social comparison processes in networking groups of individuals with degenerative eye conditions: A mixed methods approach

In this study we wanted to gain knowledge about peer networking groups of individuals with degenerative eye conditions. The focus on this group and topic are important because individuals who have been diagnosed with such a progressive condition may greatly benefit from learning and sharing with others who are coping with the same condition. However, the gradient transition between sighted to visually impaired may render the individual sensitive to exposure to peers with the same condition, as it may also induce fear and anxiety. With this study we aimed to disentangle under which circumstances peer network participation is positively or negatively related to satisfaction with participation, and to overall subjective wellbeing among individuals with degenerative eye conditions.

Chapter 5 presents the results of two sub-studies. In Study 1, the role of homophily in peer similarity regarding experiential and structural dimensions was tested using survey data. We expected to find that higher homophily on both dimensions would be associated with higher satisfaction with group participation and higher subjective wellbeing. We found partial support for our expectations. The results regarding experiential similarity suggest that there is a positive association between condition severity similarity, and satisfaction with participation in peer groups and life satisfaction (a sub dimension of subjective wellbeing). The expectations regarding the role of coping similarity were not supported by the data. Instead, a negative association between coping similarity and life satisfaction was found. The results regarding structural similarity suggested that there is a positive association between employment status similarity and satisfaction with peer group participation. Our expectations regarding age similarity, however, were not substantiated. So, there are only limited conditions under which similarity was positively related to satisfaction with participation in peer networking groups and to subjective wellbeing. A possible reason for these restricted findings is that homophily might not be the most adequate theoretical tool for investigating adverse status transitions that have a gradient nature to them, i.e., the individual is not able-bodied or disabled, but rather may experience his or her status to lie on somewhere in between these two states. We, therefore, sought a theoretical framework which holds, as a focal point, self-identification, identification with others and consequent social comparison.

In Study 2, interview data were used to explore the role of social comparison processes in satisfaction with peer group participation and with subjective wellbeing. The interview data illustrated that participants showed an overall preference for engaging in contact with others who were coping well with their condition, and thus an overall preference for upward comparison. Downward comparison benefits were evident primarily with regards to the severity of the condition. Age and employment
status dissimilarity inhibited identification processes and induced individuals to avoid peer contact, due to dissatisfaction with contact and a general negative feeling they associated with peer contact. Only one group seemed to not be negatively affected by downward comparison with peer contact, namely: individuals who took up mentoring roles.

Two main conclusions can be drawn from this study. First, we have learned that upward comparison, as opposed to downward comparison, is a preferred state among this population regarding peer contact. Participants reported willingness and satisfaction from engaging in contact with “contrasting” subjects that is, downward comparison subjects, primarily if these participants engage in mentoring roles.

Second, identification may influence the degree to which individuals with such a condition can benefit from contact. Individuals who have accepted their identity as visually impaired seem to be more open for accepting others with the same condition as comparison targets and as peers.

In sum, the findings suggest that within the context of networking groups, for those with a degenerative eye condition, the benefits of homophily may be restricted, as individuals primarily prefer to be exposed to others who cope well, which does not necessarily coincide with the individual’s personal performance level. Thus, when considering peer contact among individuals with disabilities, and especially among individuals who identify on the spectrum between able-bodied and disabled (such as those with degenerative eye conditions), social comparison theory may be a more suitable approach. Our results indicated that considering identification processes is an important factor in understanding whether or not individuals will benefit from peer contact.

6.3 Overarching Contributions and Discussion of the Theoretical, Methodological and Policy Implications

6.3.1 Theory

Two important notions regarding stigma theory and the management of a stigmatized identity have been brought to the front in this dissertation. First, stigma theory (Goffman, 1963) suggests that concealment as opposed to disclosure of a stigmatized identity, when possible, is a preferable solution as disclosure may entail grave consequences for the individual. Whether or not individuals will conceal their identity, thus will depend on whether they have the resources to do so. An individual who possesses the physical resources to conceal her identity (i.e., can see well enough to pass as sighted), or/and who has the social, psychological and financial resources to conceal her identity (e.g., by having a private driver to conceal inability to drive), will choose to conceal her identity (Goffman, 1963). Our findings, however, portray a different picture. In this dissertation we have illustrated that, while some of the
participants reported initially experiencing negative consequences associated with disclosure, the vast majority of participants reported experiencing over time higher levels of wellbeing after disclosure than when they concealed their identity. Thus, concealment on the long run did not act as a preferable state, but rather as a hindrance of wellbeing, experienced through stress and low self-acceptance.

Our findings relate closely to previous findings that show that disclosure of an invisible stigmatized identity can actually contribute to both physical and psychological benefits (Corrigan & Matthews, 2003; Clair et al., 2005; Derlega, Metts, Petronio, & Margulis, 1993; Jourard, 1971).

Thus, stigma theory provides us with valuable tools for determining the initial response to stigma that can be anticipated among those who are diagnosed with a degenerative eye condition. However, it falls short in providing us with the tools to tackle the nuances in the personal context and the changes therein, which determine the expected long-term costs and benefits associated with concealment and disclosure among this group.

Second, stigma theory shows us that identity management can take many forms. A person can have her identity fully concealed or fully disclosed, but she may also be on the spectrum somewhere in between these two states. She may be aware of her visual limitations being visible to her surroundings, but she may choose to try and “pass” as normal, by avoiding the use of a cane or a guide dog. Over the course of time she may shift between these states, depending on the degree to which she is able to conceal her identity (see previous point). Thus identity management should be seen as a gradient state.

While case studies on the topic of identity management have illustrated in the past that identity indeed is a gradient state (e.g., Brune, 2012; Wilson, 2012; Siebers, 2004; Samuels, 2003), empirical studies on this topic often tend to investigate identity management as a dichotomous state (e.g., Ellison, Russinova, MacDonald-Wilson, & Lyass, 2003; Griffith & Hebl, 2002).

Furthermore, the notion of identity as a gradient state is often not taken into account in theoretical frameworks, which directly or indirectly investigate concerns of individuals who have stigmatized identities. A good example of this is the social exclusion theoretical framework. Scholars who have investigated social exclusion thus far, tended to define social exclusion as a dichotomous state (e.g. Levitas, 1996). However, since social exclusion is dependent on the individual’s identity, and hence also the gradient shift therein, it is important to consider social exclusion too as a gradient. For instance, if we consider the case of transport social exclusion, a person that has a degenerative eye condition is expected to experience different levels of social exclusion dependent on: 1) the degree of visual loss she has experienced so far and, 2) the resources she has to compensate for her vision loss such as a partner that can drive her. The need to consider social exclusion as a gradient is not only relevant for the group we focus on in this dissertation, but for many other stigmatized identity
transitions, such as the transition between young and old, or from being financially stable to being poor.

Our approach to social exclusion is in line with recent critique made by Schwanen et al. (2015) on the drawbacks of dichotomizing research on social exclusion. They suggest that a dichotomous view on social exclusion provides skewed findings about social exclusion and that it is important to incorporate systematic analysis tools, which still provide room for interpreting ambiguity and variation.

In this dissertation we have taken a first step at an empirical exploration of identity and identity management as gradient processes. We have shown that the individual continuously negotiates her identity and its management. Each stage associates to different career trajectory and wellbeing outcomes (Chapter 2). We have further illustrated that where a person is on the gradient between “normality” and having a stigmatized identity, relates to different types of passing behaviors, and to different degrees of social exclusion (Chapter 4).

### 6.3.2 Methodology

In this dissertation both qualitative interview data and quantitative survey data have been used. The qualitative interview data (used in Chapters 2 and 4) were of a semi-structured nature and allowed us to explore the dominant factors that play a role in the lives of working age adults who have degenerative eye conditions. This method of exploratory data collection was preferred, as this group has been understudied and little was known about it.

A mixed methods approach was taken in Chapters 3 and 5. We made use of a mixed methods approach for two main reasons. First, it is useful when the researcher wants to have the ability to generalize while also gaining a detailed understanding of an under-studied phenomenon and group (Cresswell, 2013). Second, using qualitative and quantitative methods alongside each other helps provide a more comprehensive analysis of the research problem at hand (Cresswell, 2013).

In Chapter 3 we used both interview and survey data in order to explore various theoretical links between disclosure and wellbeing benefits with the qualitative and the quantitative data. We first wanted to see whether we could identify these links in the narratives of the participants (the qualitative data) before we proceeded to hypotheses testing. This was an essential step because we were applying general theories on the sub group of individuals with degenerative eye conditions and wanted to start with a more exploratory approach.

In Chapter 5 a mixed methods approach was taken as well, however, in a different way to Chapter 3. In Chapter 5 we started by testing a sociological theoretical framework (homophily) to tackle our research problem, which was testable using our quantitative survey data. This approach, however, led to puzzling results (see summary on Chapter 5) so we proceeded to taking a social psychological
approach (social comparison) to our research problem, which we could investigate using the qualitative data.

Both in Chapter 3 and 5, the mixed methods approach allowed us to identify not only overarching patterns, but also discrepancies between the qualitative interview data and the quantitative survey data. Insight into both commonalities and discrepancies provides us with tools for strengthening our theoretical and analytical tools. The aforementioned strength of our methodological approach can be illustrated with an example of a discrepancy as discussed in Chapter 3. In this chapter, both the survey data and the interview data suggested that the alleviation of inhibition might be able to explain the link between workplace disclosure and wellbeing benefits. However, some discrepancies between the qualitative and quantitative analysis were found. While workplace social support and the use of assistive devices were not found in the quantitative analysis to link the relationship between workplace disclosure and wellbeing benefits, in the qualitative analysis we found partial support for this link. The interview data provided us with a possible explanation for the survey data findings, by introducing an additional causal link. That is, while workplace social support and the use of assistive devices acted as links between disclosure and wellbeing benefits for some participants, for other participants these factors acted as reasons to disclose their identity. So, these data also illustrated that for some study participants, social support and the use of assistive devices preceded the act of disclosure, and encouraged them to disclose their condition, hence playing a different role in the link between disclosure and wellbeing benefits. If we had only relied on the quantitative analysis we would have come to the conclusion that workplace social support and the use of assistive devices are not important in linking disclosure and wellbeing benefits. Thus, the qualitative interviews helped us get a more nuanced understanding of what the role of these two factors might be.

Notwithstanding the advantages of the methods used, two drawbacks of our research design and sample selection should be noted. First, the aim of this dissertation was exploratory. Various important pathways have been identified. However, more in-depth research into the identified themes is needed to draw more general conclusions. For instance, we have identified that commute and driving were important factors among participants. The next step would be to design a study that specifically targets risky driving behavior of this group, in order to understand how widespread this concern is among this group and how policy makers and health professionals can best tackle it.

Second, investigating the population of those with degenerative eye conditions as a unique group holds challenges with regards to sample selection. While a desirable state would be to have a normal distribution of individuals on the scale of workplace disclosure, our survey sample is under-representative of those who were currently fully concealing their at the workplace. This sample selection drawback can be explained by the fact that individuals who conceal their identity in the workplace might be less inclined to take part in research on the topic of disclosure, as they may
have not accepted their identity yet. The interview data and the life-stories approach could bridge this drawback to some extent, as the majority of individuals who took part in this portion of the study had concealed their identity during some time in their careers, and could retrospectively report on their experiences. However, retrospective data also hold the drawback that individuals may have false or biased memories about how they experienced events that had occurred in the past.

Future research investigating the topic of disclosure among this group would benefit from using similar data collection techniques to those used in studies among individuals with other concealable and stigmatized chronic diseases, such as letting health professionals and medical doctors collect data (e.g., Gielen et al., 2000; Serovich, 2001).

6.3.3 Policy Implications

The final topic we will discuss is policy implications. The outcomes of this dissertation touch upon an important question for policy makers: is current policy in the US, targeted at the inclusion of individuals with disabilities, effective in the context of individuals with degenerative eye conditions?

The Americans with Disabilities Act (ADA) is the most prominent act in the US in force to protect those with disabilities in the labor market (Walk, Ahn, Lampkin, Nabizadeh, & Edlich, 1993). Previous research has shown that various regulations within this act have worked to the detriment of those with disabilities.

Initial findings showed that the employment level among the populations of those with disabilities has decreased since the enactment (Acemoglu & Angrist, 1998). While it is not certain that this decline follows exclusively from the ADA (Kruse & Schur, 2003), there are no clear positive trends identified as a result of this act. In the following we will present recommendations, which may help improve current policy protecting individuals with degenerative eye conditions in the workplace, and in social participation as a whole.

First, one possible means to increase the usefulness of protective policy would be by enlarging the scope of people who can make use of it. The findings of this dissertation point to an important pitfall of this type of policy, namely: it is targeted at individuals who have disclosed their identity in the workplace. Governmental assistance in the workplace often requires the employee to disclose her disability to her employer or to human resources in order to get access to assistive devices (e.g., a larger screen, or text to speech devices). Those who wish to conceal their identity may hence be limited in the assistance they can acquire under this act.

This issue has been acknowledged by Santuzzi et al. (2014), who stress the importance of providing channels of assistance that are also useable for those with invisible disability and wish to keep their identity concealed in the workplace. Policy makers could accommodate individuals who have not yet disclosed their identity in
the workplace by, where possible, cutting out the employer as the middleman when it comes to government assistance in the workplace, such that an individual can request directly from the source that provides it. Adapting policy to accommodate also those who do not yet wish to disclosure their condition in the workplace, would make workplace protection policy more accessible to the broader population of individuals with degenerative eye conditions.

Second, an important area for policy improvement is in the field of commute. Our findings point to two main drawbacks when it comes to commute-related policy: the commute solutions are impractical and they are normatively excluding. Regarding the impractical concerns, the study participants under-used public transportation and special transport provided to individuals with disabilities, because these commute modes are often inaccessible (e.g., too few services at a given location) or are too time consuming (e.g., a person may need to wait for multiple hours before receiving service). Previous studies show that mobility-related regulations within the ADA have worked to the detriment of those with disabilities (Lewyn, 2000). As part of the ADA regulations, transportation providers (i.e., public transportation and specialized transportation for those with disabilities) have been required to increase the quality of services they provide to individuals with disabilities. The new regulations, therefore, have increased the costs for transportation providers, which have, in turn, led to restrictions in the availability of these accommodations for those who need them.

Regarding the normative concerns, study participants have shown a preference for commuting in more normatively inclusive transportation modes, that is either driving or being driven in a car by others.

Policy makers should invest in tackling both practical and normative concerns when developing policy for commute accommodations for this population. In light of the importance of keeping up appearances expressed by participants, and the preference participants showed for commuting in a car (even if being driven), policy promoting car-pooling would be an attractive solution for this population. It would further provide an answer both for practical and normative concerns these individuals may have.

The next step scholars should take, in order to assess whether a one size fits all policy is helpful in accommodating individuals who have various concealable chronic conditions, is to provide an overview of the similarities and discrepancies between different groups with concealable chronic conditions, and the challenges they face in light of stigma. Such insights would inform policy makers as to the degree that policy specialization is required, and the ways in which policy makers can service the larger target group of individuals with disabilities and chronic conditions under one act.
6.4 Final Remarks

With this dissertation, we aimed to identify and understand the struggles and triumphs faced by adults with degenerative eye conditions in the light of stigma. We have done so, by improving our understanding of the role of stigma and the motivations guiding identity management behavior of individuals with degenerative eye conditions. We have illustrated that identity management concerns play an important role in guiding the behavior of individuals with degenerative eye conditions in the workplace context (Chapters 2, 3 and 4) and in their contact with each other (Chapter 5). The behaviors individuals engage in, in turn, related differently to the two main outcomes we targeted: career trajectories and overall subjective wellbeing.

The results presented in this dissertation are valuable on two levels. First, they act as a first step in gaining more understanding of the broader research topic of integration and wellbeing of individuals with chronic or progressive conditions. Finally, this research project also provides tools for policy makers for accommodating individuals with degenerative eye conditions, who face the challenges related to identity management within the workplace context, and in life as a whole.
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Samenvatting – Dutch Summary

Mensen met een gestigmatiseerde identiteit hebben een verhoogd risico om gediscrimineerd te worden of met vooroordelen te maken te krijgen. Concreet kan dit betekenen dat de persoon in kwestie benadeeld wordt bij een sollicitatieprocedure, of met sociale uitsluiting te maken krijgt vanwege een gebrek aan begrip in zijn of haar omgeving.

Stigma theory leert ons dat individuen die dit soort negatieve gevolgen willen vermijden er voor kiezen om deze identiteit geheim te houden. Een voorwaarde hiervoor is uiteraard dat de gestigmatiseerde identiteit te verbergen valt.

Het verbergen van een gestigmatiseerde identiteit kan zowel positieve als negatieve gevolgen hebben. Enerzijds kan het verbergen van de identiteit er voor zorgen dat het individu minder snel in aanraking komt met discriminatie of vooroordelen. Anderzijds kan het verbergen van de identiteit tot andere negatieve gevolgen leiden, zoals een gebrek aan zelfacceptatie of stress. Dit laatste kan vervolgen leiden tot psychische problemen die een negatieve invloed hebben op het welzijn van het individu.

De mate waarin, alsmede de manier waarop, een persoon met een gestigmatiseerde identiteit ervoor kiest om deze identiteit voor de omgeving te verbergen staat bekend als identity management. Mensen met een degeneratieve oogaandoening zijn een interessante groep om identity management te onderzoeken.

Individuen met een dergelijke aandoening kunnen ervan uitgaan dat hun gezichtsvermogen zal gaan verslechteren, maar het is onduidelijk op welke termijn deze verslechtering zal optreden. Aangezien mensen met deze diagnose zich vaak bewust zijn van de negatieve gevolgen van stigmatisering kunnen ze er voor kiezen om in eerste instantie de aandoening - en daarmee hun gestigmatiseerde identiteit - te verbergen. Echter, naarmate hun gezichtsvermogen verslechtert en het lastiger wordt om de aandoening te verbergen kunnen individuen zich gedwongen voelen om hun identiteit voor de omgeving (tot op zekere hoogte) aan te passen. Dit betekent dat het individu wordt gedwongen om zijn of haar identity management te heroverwegen.

In dit proefschrift wordt voornamelijk identity management in de context van de werkplek onderzocht. Deze omgeving is relevant vanwege de hoge mate van discriminatie die er plaatsvindt ten aanzien van individuen met visuele beperkingen. In het algemeen ervaren mensen met dit soort beperkingen dat ze minder kansen hebben op het werk. De ervaringen van individuen die deze visuele beperking hebben - maar bij wie deze (nog) niet opvalt - zijn in het bijzonder van belang, omdat zij er voor kunnen kiezen om hun beperking op de werkplek verborgen te houden. Het onderzoeken van de werkplek als context is ook belangrijk vanwege het feit dat de positieve effecten die mensen met een visuele beperking toeschrijven aan hun verhullende gedrag gepaard kunnen gaan met hoge kosten. Deze kosten hebben betrekking op het psychische welzijn van het individu, maar kunnen ook fysiek van aard zijn wanneer het gebruik van hulpmiddelen wordt vermeden.
Mensen met een gestigmatiseerde identiteit hebben een verhoogd risico om gediscrimineerd te worden of met vooroordelen te maken te krijgen. Concreet kan dit betekenen dat de persoon in kwestie benadeeld wordt bij een sollicitatieprocedure, of met sociale uitsluiting te maken krijgt vanwege een gebrek aan begrip in zijn of haar omgeving. *Stigma theory* leert ons dat individuen die dit soort negatieve gevolgen willen vermijden er voor kiezen om deze identiteit geheim te houden. Een voorwaarde hiervoor is uiteraard dat de gestigmatiseerde identiteit te verbergen valt.

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Samenvatting

Dit proefschrift bestaat uit verschillende studies. Het doel van Hoofdstukken 2 tot en met 5 is om de uitdagingen en successen waarmee volwassenen met een degeneratieve oogaandoening te maken krijgen te identificeren en te onderzoeken in relatie tot hun onzichtbare gestigmatiseerde identiteit. Binnen het kader van hun identity management zijn verbanden blootgelegd tussen de gedragspatronen van deze individuen en hun mate van succes om een visuele beperking te verbergen, of juist te onthullen. Daarnaast is onderzocht hoe het verbergen van een visuele beperking zowel de gevolgde carrièrepaden als het algehele welzijn van het individu beïnvloedt. Naast het bestuderen van de arbeidsmarkt voor mensen met een gestigmatiseerde identiteit is het tweede doel van dit proefschrift om inzicht te verkrijgen in de contacten tussen individuen met degeneratieve oogziekten. Concreet is in kaart gebracht welke factoren de tevredenheid over contact met lotgenoten beïnvloeden en hoe dit gerelateerd is aan het welzijn van het individu.

Vanwege het beperkte aantal studies dat tot op heden is verricht naar individuen met degeneratieve oogziekten is het onderzoek voor dit proefschrift gedeeltelijk exploratief. Zo zijn de resultaten die staan beschreven in Hoofdstukken 2 en 4 op inductieve wijze verkregen en kwalitatief van aard. De data voor deze hoofdstukken komen uit interviews met werknemende respondenten die een degeneratiewe oogaandoening hebben. De nadruk in de interviews lag op de levensloop van deze mensen. Voor het onderzoek in Hoofdstukken 3 en 5 is gebruik gemaakt van een mixed-methods benadering. Deze aanpak betekent dat in deze studies kwalitatieve data met kwantitatieve enquête-data zijn gecombineerd. De enquêtes zijn afgenomen bij volwassen respondenten met een degeneratiewe oogaandoening.

De studies uit dit proefschrift (weergegeven in Hoofdstukken 2 tot en met 5) zijn samengevat in Hoofdstuk 6. Uit de studies kunnen twee overkoepelende conclusies worden getrokken. Ten eerste kan worden geconcludeerd dat identiteit en identity management een belangrijke rol vervullen voor mensen met degeneratieve oogziekten. Echter, in tegenstelling tot wat de stigma theory suggereert is het verbergen van de ziekte niet altijd de gewenste strategie voor deze groep op de lange termijn. Bovendien ervaren degenen die de aandoening aan hun omgeving bekend maken niet per se de verwachte negatieve gevolgen naarmate de aandoening erger wordt, zoals een vermindering van arbeidsmarktkansen. Daarnaast komt uit dit onderzoek naar voren dat er juist voordelen aan het onthullen kunnen zijn verbonden, zoals een toename in zelfacceptatie en een vermindering van stress.

Ten tweede suggereert de resultaten dat identity management moet worden beschouwd als een strategie met verschillende gradaties. Een individu kan zijn of haar identiteit volledig verhullen of onthullen voor de omgeving. Echter, in veel gevallen positioneren individuen met een visuele beperking zich niet als gehandicap of niet-gehandicap, maar bevinden ze zich ergens op een spectrum tussen deze twee extremen. Deze nuancering is belangrijk, omdat de wijze waarop individuen zich binnen dit spectrum positioneren inzichten kan bieden met betrekking tot relevante gevolgen zoals sociale uitsluiting. Zo zal voor degenen die zich subtiel positioneren
tussen een gestigmatiseerde en een niet-gestigmatiseerde identiteit sociale uitsluiting meer geleidelijk plaatsvinden. Bovendien zal dit proces verschillen al naar gelang de specifieke omgeving; uitsluiting van de arbeidsmarkt kan bijvoorbeeld optreden omdat een persoon niet in staat is om auto te rijden.

Deze conclusies hebben belangrijke implicaties voor beleid. Er bestaan meerdere wetten met als doel om mensen met een handicap op de arbeidsmarkt te beschermen, maar deze bescherming geldt alleen voor personen die hun identiteit als gehandicapt op de werkplek willen delen. Dit houdt in dat mensen die beschermd willen worden (bijvoorbeeld tegen discriminatie) eerst hun identiteit bekend moeten maken aan hun leidinggevende. Het openbaar maken van dit type identiteit is een langdurig proces en dus is dit soort regelgeving niet noodzakelijk hoewel toepassing op mensen die er nog niet klaar voor zijn om met hun identiteit naar buiten te treden. Het zou daarom zinniger zijn om beleid te ontwikkelen waarin de mate van onthulling van de gestigmatiseerde identiteit meegenomen wordt.

Tot slot is het van belang dat beleid niet alleen op praktische oplossingen is gericht, maar ook op oplossingen met een meer normatief karakter. Een goed voorbeeld van deze laatste categorie is autorijden. In veel Westerse landen is autorijden niet alleen belangrijk vanuit praktisch oogpunt, maar ook vanuit een normatief perspectief. Zo is het in de VS heel belangrijk om een auto ter beschikking te hebben om daarmee te laten zien dat men volwaardig deelneemt aan de maatschappij. Oplossingen voor personen met een gestigmatiseerde identiteit die enkel gericht zijn op praktische zaken, zoals verbeterde beschikbaarheid van het openbaar vervoer, zijn op zichzelf niet voldoende om ervoor te zorgen dat de doelgroep hier ook gebruik van maakt. Beleid dat zowel de praktische als normatieve aspecten in acht neemt, zoals bijvoorbeeld het promoten van carpooling, zal vermoedelijk meer gewaardeerd worden door de doelgroep en dus effectiever zijn dan zuiver praktische oplossingen.
Acknowledgements

This is the fun part where I get to say thank you to everyone who stood by me and helped me in the process of producing this dissertation. The list of individuals is long, so bare with me.

First, I would like to thank the members of the reading committee, Geert Van Hove, Marleen Janssen and Ute Bültmann for taking the time and effort to read and review my dissertation. I would like to acknowledge my supervisors Nardi Steverink and Rafael Wittek. Thank you for letting me follow my gut and interests and for believing in my project. Our long discussions, your input and advice have been a great contribution to the final project and are greatly appreciated.

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Thank you to Vera, for the many hours of coding, discussions and negotiations, which helped make this dissertation a better product. Ori, thank you for sharing your expertise in transportation with me and for your frequent and useful advice and friendship. Tina and Wesley, thank you for your helpful advice and countless help with revisions. You are the best friends ever and I owe you a lot! Thank you also to Melinda, Liesbet, Lea, Diana and countless more who have contributed to the contents of this dissertation. Thank you to the ICS members, and to the members of the HAPS research group, for all the stimulating discussions and the fruitful forum days. I would also like to thank the organizational team, Saskia, Monique, and Henry, thank you for helping me along the way.

My time in Groningen wouldn't be as wonderful as it was without the great office mates I have had over the years: Gina, Christoph and Tina. You have been a delight. I have enjoyed each and every musical we have put up together. Members of the fish-day committee should also not go unmentioned, Nicola, Jornt and the rest it has been a pleasure! Thank you to my housemate and partner in crime Beau to Andre, An, Georges, Javi, Adolfo, Reza, Vladi, Pariya, Ruta, Betta and all my musical and gaming friends. It's been a blast.

This dissertation is also dedicated to my loving family who stood by me through thick and thin. To my mother in particular who has been the brains and wheels behind the data collection for these studies, who has driven me to countless interviews and who has supported me in setting up this project, thank you. Not many PhD students can say that their parents have been so involved in their projects. To my supportive and teasing partner Jakob. Every girl needs a younger Frisian man to put everything in perspective. You have been my anchor during the final stages of this undertaking, emotionally, professionally and humorously.
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About the Author

Tali Spiegel was born in Miami, Florida USA, on March 25, 1986. Upon obtaining her Bachelors degree in Behavioral science at Tel-Aviv Jaffa College in 2008, she moved to the Netherlands to follow the Sociology and Research Master at Utrecht University. She obtained her research master in 2011 and her master thesis was awarded the best Dutch demography master thesis of 2011. In September 2011, she started her PhD at the Interuniversity Centre for Social Science Theory and Methodology (ICS), at the Sociology Department of The University of Groningen. As part of this project she has conducted an extensive data collection in the USA between October 2013 and June 2014. In September 2015, she took up a lectureship position at the Sociology Department of Utrecht University.
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The ICS series presents dissertations of the Interuniversity Center for Social Science Theory and Methodology. Each of these studies aims at integrating explicit theory formation with state of the art empirical research or at the development of advanced methods for empirical research. The ICS was founded in 1986 as a cooperative effort of the universities of Groningen and Utrecht. Since 1992, the ICS expanded to the University of Nijmegen. Most of the projects are financed by the participating universities or by the Netherlands Organization for Scientific Research (NWO). The international composition of the ICS graduate students is mirrored in the increasing international orientation of the projects and thus of the ICS series itself.


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239 Rozemarijn van der Ploeg (2016). *Be a buddy, not a bully? Four studies on social and emotional processes related to bullying, defending, and victimization*. ICS-dissertation, Groningen.

An individual who has a stigmatized identity is likely to be faced with prejudice and discrimination from her surrounding. To avoid being confronted with such adverse outcomes an individual who has the ability to conceal her stigmatized identity from her surrounding is highly likely to keep her identity a secret.

An especially interesting group with respect to identity management – the manner and the degree to which an individual chooses to reveal her stigmatized identity to her surroundings – is individuals with degenerative eye condition. Individuals who are diagnosed with a degenerative eye condition may expect to lose their eyesight over the course of time but at an unknown pace. Being aware of the consequences of stigma thus they may choose to conceal their identity at first, but will eventually have to adapt and renegotiate their identity management in different settings.

With the four studies in this dissertation we aimed to identify and investigate the struggles and triumphs faced by adults with degenerative eye conditions in light of their invisible stigmatized identity. We wanted to gain a deeper understanding of their considerations underlying certain behaviors and choices, which directly or indirectly relate to identity management. Moreover, we aimed to better understand how these behaviors and choices influenced their career trajectories and overall subjective wellbeing. The main focus of this dissertation is on the workplace context due to high unemployment rates among this group and reported discrimination in the workplace. In addition, insights into the role and functions of peer relationships among individuals with degenerative eye conditions and how these relate to subjective wellbeing are presented.

Tali Spiegel obtained her research master’s degree in sociology and social research at Utrecht University and conducted her dissertation research at the Interuniversity Centre for Social Science Theory and Methodology (ICS), and the Department of Sociology of the University of Groningen.