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## Identity, career trajectories and wellbeing outcomes

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## 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\*

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### 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.

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## 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

trajectory. People with these conditions may, for example, avoid social activities with low lighting, or avoid using a cane in public (e.g., Moore, Constantino & Allen, 2000). Among the general public, vision loss is one of the most feared sensory losses, and is one of the least understood disabilities. The prevalence of inaccurate 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). Previous studies have shown that individuals who experience vision loss tend to suffer from a lower quality of life than people with other chronic conditions (Langelaan, de Boer, & Nispen, 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

Name and pattern	Age	Eye condition	Diagnosis	Eye-sight	Marital status and children	Education	Interview
1 Susan	66	RP	37	10 degrees of central vision	Second marriage	College	In person, original pool
1 Eleanor	59	RP	19	10 degrees central vision. Uses cane	Married with two children	College	In person, original pool
1 Emily	59	RP	20's	Central vision remaining	Second marriage. Two children	College	In person, original pool
1 Michael	60	RP	43	Central vision remaining	Married. One child	College	In person, original pool
1 Greg	59	RP	25	Restricted central vision. Uses cane	Married. Two children	College	In person, original pool
1 Kim	55	RP	41	8 degrees. Uses cane	Divorced. In a relationship. One child	College	Phone, snowball
2 Josh	53	RP	15	5 degrees central vision. Uses cane	Married. Five children	College	In person, original pool
2 Rick	54	RP	27	5 degrees vision.	Married second time.	College	In person, original

				Uses cane	Three children		pool
2 Oliver	54	RP	18	Negligible central vision. Uses cane	Married. 2 children	College	Phone, original pool
2 Joey	42	RP	19	Functionally blind. Uses cane	Married. One child	College	Phone, original pool
2 Noah	82	RP	26	Functionally Blind. Uses cane	Married. Two children	College	Phone, original pool
2 Lauren	73	Stargardts	40	Good peripheral vision	Married second time. Two children	Masters	In person, original pool
3 Patrick	68	RP	18	Functionally Blind	Married. Two children	College	Phone, original pool
3 Dylan	53	RP	37	Functionally Blind	Divorced. Three children	College	Phone, original pool
3 Debra	55	Stargardts	33	Some peripheral vision	Never married in a relationships	College incomplete	In person, original pool
3 Dan	50	RP	13	Some usable peripheral vision	Married. Two children	College incomplete	In person, original pool
3 Henry	67	RP	22	Functionally Blind. Uses cane	Married. One child	College	In person, original pool
3 Nick	59	RP	18	Functionally Blind. uses guide dog	Married. One child	College	In person, original pool
3 Phil	82	Stargardts	17	Functionally blind. Uses cane	Married second time. Three step children	College	In person, original pool
3 Dick	42	RP	27	restricted central vision	Divorced in a relationship	Masters	In person, original pool
3 Roger	52	Rods Cons degeneration	42	Functionally Blind. Uses cane	Married. Two children	Medical doctor	Phone, snowball
4 Ron	60	Form of RP	17	Some 'foggy' functional vision	Married third time. Five children	College	In person, original pool
4 Adam	73	RP	39	Restricted central vision. Uses cane	Married. Two children	College	In person, original pool
4 Benjamin	52	Stargardts	5	Some peripheral vision	Divorced. One child	Masters	In person, original pool
4 James	70	Stargardts	5	Functionally Blind. Uses cane	Married. One child	PhD	Phone, snowball



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

**Table 2.2:** Pre-established discussion topics that have been covered during interviews

Themes	General description
Background	Growing up experience, growing up experience with eye condition
Eye condition	Type, degree of vision loss, coping, behavioral strategies in different settings
Work life choices	Career description, interplay between eye condition and career choices, dealing with work environment.
Identity	Self-acceptance, identity as visually impaired
Social surrounding	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.
Demographic information	Short questionnaire about educational background, household composition, socio-economic status, religious affiliation, volunteering behavior (available upon request)

### 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)

<b>Code family name</b>	<b>Typology</b>
Adaptation and adjustments to vision loss	Adapting and adjusting behavior and emotion to vision loss
Career planning and adjustment	Work and career adjustments and planning (or lack thereof) in relation to vision loss
Challenges in education	Challenges in education related to vision loss
Emotional challenges	Emotional challenges relating to vision loss
Supportive workplace	Support and accommodations at work
Work challenges	Work challenges regarding obtaining and sustaining employment
Work discrimination	Discrimination in the workplace
Work and wellbeing	Reports on wellbeing being affected by work related concerns
Workplace strategies	Strategies individuals obtain and sustain employment
Concealment as workplace strategy	Concealment acting as a strategy for obtaining and sustaining employment
Passing behavior strategies	Passing and concealment behavior
Concealment motivations	Motivation to conceal identity
Concealment implications	Reported positive and negative implications (both physical and mental) of identity concealment in the workplace
Revealing motivations	Motivations for revealing or being open about identity
Revealing implications	Reported positive and negative implications (both physical and mental) of revealing identity in the workplace
Strategies to revealing identity	Strategies for how participants revealed their identity
Identity conflict	Participants reports on identity conflicts between being visually impaired and sighted
Challenges related to visibility	Challenges participants perceive related to being visible to others as visually impaired.
Cane	Use of a cane or a guide dog and the meanings attached to it
Guide dog	Use of a cane or a guide dog and the meanings attached to it
Professional rehabilitation	Use of a professional rehabilitation programs and the meanings attached to it
Assistive technology	Use of assistive and the meanings attached to it

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.



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 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

<p><b>1. No career adjustments, concealed condition throughout career</b></p> <p>Make career training and career path choices without consideration of eye condition.</p> <p>Reveal their condition at the end of career trajectory. Retire early.</p> <p>High stress during career trajectory, increased wellbeing and self-acceptance after retirement.</p>	<p><b>4. Engaged in career planning, always open about their condition</b></p> <p>Participants make career training and career path choices that they experience as accommodating to their condition.</p> <p>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).</p> <p>Participants report high wellbeing levels in the workplace and high self-acceptance in and out of the workplace context.</p>	<p><b>2. Revealed condition after adjusting career plans</b></p> <p>Make career training and career path choices not considering eye condition.</p> <p>Experience increased difficulty and stress. Decide to reveal their condition and make adaptations in their career planning to accommodate vision restrictions.</p> <p>Report high content with their later career choices, self-acceptance and general wellbeing.</p> <p><b>5. Engaged in limited career planning, always open about their condition</b></p> <p>This pattern consists only of women. Their main occupation was caretaking for family members or housekeeping.</p> <p>These women were always open about the condition in the workplace (when working).</p> <p>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.</p>
<p><b>3. Increasingly open about their condition over the course of their career</b></p> <p>Career training and career path choices are reported as compatible with vision restrictions.</p> <p>Participants conceal their condition for a part of their career for various reasons (such as pride, fear of injustice).</p> <p>Participants reveal their condition due to increased difficulties in task completion or fear of underperformance.</p> <p>Most participants experience relief and stress reduction.</p>		

## 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.