

Adults with Dyslexia, an Invisible Disability: The Mediational Role of Concealment on Perceived Family Support and Self-Esteem

Blace A. Nalavany*, Lena W. Carawan, and
Stephanie Sauber

*Correspondence to Blace A. Nalavany, School of Social Work, College of Human Ecology, East Carolina University, Greenville, North Carolina, USA. E-mail: nalavanyb@ecu.edu

Abstract

Living with a concealable stigmatised identity, adults with dyslexia are at risk for low self-esteem. The small but growing body of research on adults with dyslexia suggests that perceived family support has a direct influence on the self-esteem of adults with dyslexia. Understanding potential causal mechanisms underpinning the relationship between perceived family support and self-esteem is important to address the needs of this hidden population. To be sure, adults with dyslexia often face complex decisions regarding disclosure. According to theoretical and empirical literature, concealment or chronic fear of and hesitancy towards disclosing their invisible identity paves the way for negative affective states including low self-esteem. The present study examined the mediational effect of how concealment may account for the empirical link between perceived family support and self-esteem. The participants were 224 adults with dyslexia who participated in a web-based survey and predominantly resided in the USA. A bootstrapping analysis (a contemporary approach to mediational analysis) revealed that concealment mediated the relationship between perceived family support and self-esteem. Implications for social work practice and research are discussed.

Keywords: Adults, concealment, dyslexia, mediator, perceived family support, self-esteem

Accepted: July 2013

Introduction

Dyslexia is a common learning disability characterised in many individuals by difficulty in acquiring and processing language. In fact, dyslexia is the most common specific learning disability in the UK (British Dyslexia Association, 2011) and the USA, with estimates of prevalence ranging from 5 to 12 per cent of the population (Shaywitz, 1998). Dyslexia is manifested often through reading, spelling and writing difficulties. We will use the term ‘dyslexia’ to describe the most common learning difference across the UK and the USA.

The field of social work is grounded for advocating and enhancing the lives of all people, especially those who are vulnerable and lack a voice. Certainly, individuals with dyslexia fit among the vulnerable groups living with invisible stigma. Invisible stigmas include a range of conditions, such as HIV/AIDS, drug abuse, cancer, mental disability and mental illness (Ragins, 2008). Although these stigmas differ in several dimensions, they share the common characteristic of having attributes not seen by others that convey an identity devalued in some social settings (Crocker *et al.*, 1998). The field of social work includes a rich history of addressing invisible stigmas, such as individuals with mental illness. This research is informed by both the US Code of Ethics of the National Association of Social Workers (NASW, 2008) and the Code of Ethics for Social Work of the British Association of Social Workers (BASW, 2002), which mandates that social workers should obtain education and seek to understand the nature of social diversity and oppression. The authors suggest that dyslexia fits within the social work mandate, although a comprehensive search in the *British Journal of Social Work* yielded no articles that intentionally focused on dyslexia as identified by the word ‘dyslexia’ being used in the title or abstract of the manuscript. As such, there appears to be a lack of attention devoted to dyslexia, which, as mentioned previously, is known to be a ‘hidden disability’ (Hussein *et al.*, 2008, p. 1593).

Living in a society that associates educational and occupational success with literacy often makes life emotionally challenging for adults with dyslexia (McNulty, 2003). They are often subject to negative perceptions, stereotypes, misunderstandings and discrimination (Denhart, 2008). For example, the 2010 report on Americans’ and Educators’ understandings and attitudes about learning disabilities (LD; in the USA, dyslexia is often referred to as a ‘learning disability’) found that half of the general public believe that dyslexia/LD are the result of laziness and are not true disabilities (Roper Public Affairs & Corporate Communications, 2010). Stereotypes regarding dyslexia include the notion that individuals with this condition are considered to have poor social skills, limited ability and lower intelligence (May and Stone, 2010). Those requesting accommodations are often perceived by non-disabled students, professors and others as cheating or using unfair advantages (Field *et al.*, 2003; Denhart, 2008). These perceptions can affect more than the educational issues of individuals with dyslexia and often

have long-lasting impacts on their self-esteem (Burden, 2008). A competent social worker who understands the depth of pain from early and present experiences of the adult with dyslexia may play a role in the lives of these individuals that is every bit as important as the role of a competent educator.

Individuals with dyslexia have to face continuing emotional challenges throughout their lives, including making the decision to disclose or conceal their disability. The extant literature suggests that concealment gives rise to a host of negative emotional states, including low self-esteem (Pachankis, 2007). While self-esteem refers to the extent to which one experiences one's self as worthy and capable, low self-esteem is experienced as feelings of unworthiness, inadequacies and deficiencies (Rosenberg *et al.*, 1995). Self-esteem plays a foundational role in social and emotional adjustment and well-being in adulthood (Orth *et al.*, 2009; Hunt and Guindon, 2010). Understanding dyslexia and the life experiences that affect self-esteem can position social workers in the role of advocacy and support for this group. The present research informs social workers of the challenges involved in concealing dyslexia and of the way that perceived family support may impact self-esteem through concealment dynamics. Such insight may assist social workers when working with adults with dyslexia and family systems where dyslexia is present.

Literature review

Concealment of an invisible stigma

Goffman (1963) defined stigmas as socially repugnant, deviant or abhorrent attributes that disgrace an individual's social identity. Stigmatised individuals may be perceived by others as possessing undesirable attributes that underscore their character, physical body or group membership. Stigmas are socially constructed and often form the basis for stereotypes, prejudices and discrimination. Individuals with invisible stigmas are confronted with excruciating decisions in choosing if, when, how and to whom to disclose their stigma. According to Derlega and associates (1993), disclosure refers to 'what individuals verbally reveal about themselves to others' (Derlega *et al.*, 1993, p. 1). While there has been considerable research on disclosure, the present study focuses on concealment. Although the term 'concealment' is used in the present study, existing literature uses other terms, such as 'identity denial' (Ragins, 2008), 'preoccupation' (Pachankis, 2007), 'fear of disclosure' (Chaudoir and Quinn, 2010), 'perceived stigma' (Corrigan, 2004) and 'anticipated stigma' (Quinn and Chaudoir, 2009) to describe the difficulty of keeping an invisible stigmatised characteristic a secret. At the core of these theoretically similar concepts is the extent to which individuals believe that others will shun, stereotype, discriminate or stigmatise them if they were to reveal their stigmatised identity.

Goffman's (1963) pioneering research revealed that they are vigilant of the negative stereotypes and myths associated with their group and may, consequently, internalise the stereotypes allocated to their stigmatised group. Individuals with invisible stigmas may develop a chronic fear of and hesitancy toward disclosing their identity to others and may conceal or otherwise keep their identity secret from others (Chaudoir and Quinn, 2010).

Smart and Wegner (1999) explain that keeping secrets can activate a set of cognitive processes that lead to a preoccupation with the secret and, as a result, intrusive thoughts that the secret keeper is trying to suppress may repeatedly enter the mind, causing what is conceptualised as a 'private hell' (Smart and Wegner, 2000). Pachankis (2007) further suggests that the cognitive preoccupations described by Smart and Wegner (1999) are combined with other cognitive implications, such as avoidance and suspiciousness to foster negative affective states including anxiety, depression, hostility, guilt, shame and low self-esteem. Quinn and Chaudoir (2009) found that increased anticipated stigma is directly related to self-reported health outcomes and psychological distress in a sample of adults who possessed various forms of stigmatised identities including but not limited to mental illness, medical conditions and sexual orientation. Similarly, Chaudoir and Quinn (2010) found that fear of disclosure (i.e. concealment) of an invisible stigmatised identity exerted a direct negative influence on self-esteem in a sample of young adults with invisible stigmatised identities.

Concealment and self-esteem

The decision to conceal dyslexia from others may be a compelling life experience for adults with dyslexia and can be a safeguard from hostile encounters. For example, college students with dyslexia have reported experiences of discrimination after disclosing dyslexia to receive accommodations (Denhart, 2008). In addition, employment discrimination upon disclosure in the workplace (Tanner, 2009) has also been reported. Yet, do experiences with discrimination and stigmatisation alone account for why nearly half of adults with dyslexia conceal their disability in employment (Gerber, 2012) and non-work settings (Hellendoorn and Ruijsenaars, 2000)? We reason that Smart and Wegner's (2000) concept of 'private hell' as discussed earlier could be applied to adults with dyslexia. In a recent study on adults with dyslexia, the decision to disclose across work and non-work settings was coloured by secrecy, fear of rejection, apprehension and uneasiness (Nalavany *et al.*, 2011b). Individuals with a concealable stigmatised identity who internalise the negative stereotypes and myths associated with their invisible identity may come to anticipate prejudice, discrimination and stereotyping if their identity were known (Quinn and Chaudoir, 2009). Thus, individuals with a concealable stigmatised identity do not have to genuinely experience invalidation to experience distress—they simply have to anticipate that it may

happen to them in the future (Earnshaw *et al.*, 2011). In terms of dyslexia, a small but growing body of research supports that the fear of feeling vulnerable (Valle *et al.*, 2004), the fear of being ridiculed or victimised (Morris and Turnbull, 2006) and the fear of being perceived as intellectually inferior (Gerber, 2006) are common reasons for concealing dyslexia. It is plausible that anticipating discrimination and being consumed by keeping dyslexia secret from others across life contexts might result in a host of negative emotional states and low self-esteem as theorised by Smart and Wegner (2000) and Pachankis (2007).

Perceived family support and self-esteem

In this study, perceived family support (PFS) is referred to individuals' perception that they are cared for, validated and assisted by their families. We conceptualise the kinship group known as family to include not only parents but siblings, spouse and/or other family members who are perceived as giving unconditional support. Research indicates that social support is thought to be effective only to the extent that one perceives it (Turner *et al.*, 2000).

Challenges associated with dyslexia have been found to continue into adulthood (McNulty, 2003). These challenges may include graduating from college, obtaining and keeping a job and concealment decisions (Hellendoorn and Ruijsenaars, 2000; McNulty, 2003). Feelings of not belonging to a certain niche, disillusionment, fear of failure or inferiority and difficulty in expressing emotions are additional issues reported by adults with dyslexia (Hellendoorn and Ruijsenaars, 2000). McNulty (2003) and Nalavany, Carawan and Rennick (2011*b*) found that a unique set of emotional experiences (feelings of sadness, anxiety, exhaustion and painful memories) encapsulates the life of adults with dyslexia and may be directly linked to low self-esteem (Nalavany and Carawan, 2012).

While dyslexia is often viewed through an educational lens, current thinking suggests that view is short-sighted, as education is only one component in the life of the adult with dyslexia (Wilson *et al.*, 2009; Gerber, 2012). Adults are more likely to feel less stigmatised, report fewer emotional challenges and are more satisfied with adult life, which may enhance their self-esteem, when they receive unconditional support from their family members throughout the lifespan (Logan, 2009; Stampoltzis and Polychronopoulou, 2009; Nalavany and Carawan, 2012). For example, because individuals with dyslexia may experience life transitions and issues as particularly difficult, parents often continue to play a longer and more substantial supportive role. This support may include encouraging these individuals as they struggle with post-secondary school success, helping them pursue an employment career, coping with increasing job and social demands, and making decisions to self-disclose. Ultimately, ongoing family support beyond childhood can play a foundational role in enhancing adults' self-esteem.

Perceived family support, concealment and self-esteem

While it has been established that PFS and concealment may impact self-esteem, to the best of our awareness, no study has specifically addressed how these variables may operate together as they relate to adult dyslexia. One key advance in this direction that might be applicable to adult dyslexia is theoretical work on invisible stigmas. [Ragins \(2008\)](#) proposes a model that in part suggests that the decision to disclose a stigmatised identity is made within a powerful context of the support received in the individual's environment, including parents and family. Although Ragins's model has not been applied to adults with dyslexia, the extant literature suggests that this model could be tenable for this population.

[Ragins \(2008\)](#) theorises that positive family support may help reframe one's perception of possessing a flawed identity and seeing oneself in a more positive light. This validation facilitates disclosure decisions and, in turn, according to [Smart and Wegner \(2000\)](#) and [Pachankis \(2007\)](#), enhances self-esteem and well-being. Recently, one study found a connection between positive PFS and positive emotions surrounding one's experience with dyslexia ([Nalavany and Carawan, 2012](#)). Since concealing a stigmatised identity is manifested in an array of negative emotions ([Pachankis, 2007](#)), it is plausible that PFS may also directly mitigate the fears and negative affective states that accompany disclosure decisions, thus enhancing self-esteem.

Rationale of the current study

The purpose of this study was to examine the directional pathways between the constructs of PFS, concealment and self-esteem within a testable mediation model. First, it was hypothesised that higher levels of PFS would significantly predict lower levels of concealment or less apprehension, avoidance and shame associated with disclosure. Second, it was hypothesised that higher levels of concealment would predict lower levels of self-esteem. Third, our primary hypothesis is that PFS would indirectly enhance self-esteem via the positive influence PFS would have on concealment. This study attempts to further the knowledge of the experiences of living with dyslexia and to influence social work practice and research.

Methods

Survey development and procedures

This study involved a cross-sectional, web-based survey of adults with dyslexia. The purpose of the project was to identify the experiences that facilitate or hinder adults with dyslexia in living successful and satisfying lives. We systematically followed proposed guidelines for web-based survey research

(Dillman, 2000) and web-based survey research for individuals with disabilities (Cook *et al.*, 2007). Based on our pilot testing and given the visual processing challenges of some individuals with dyslexia (Laasonen *et al.*, 2012), horizontal and vertical scrolling was kept to a minimum. Participants were also able to re-access the survey link and use text-to-speech software.

The project website included an URL link to the survey. The web-survey was anonymous in design. Adults age twenty-one years and older with diagnosed or self-reported dyslexia were eligible for the University Institutional Review Board-approved study and were recruited with non-random sampling methods (e.g. social media, organisations that advocate for individuals with dyslexia and alumni from a private school exclusively for boys with dyslexia) due to the difficulty with gaining access to this population (Gerber, 2009).

Measures

Independent variable: family support

Perceived family support was measured by the Provisions of Social Relations (PSR) (Turner *et al.*, 1983) family support dimension, which is capable of capturing both tangible and emotional support. Six items (e.g. 'My family lets me know they think I am a worthwhile person') are rated on a five-point scale ranging from (1) *Not at all like me* to *Very much like me* (5). The items were summed, with higher scores reflecting more family support. The Cronbach's alpha reliability of this measure was 0.88.

Dependent variable: self-esteem

Self-esteem was measured using the Self-Esteem Rating Scale (SERS) (Nugent and Thomas, 1993). The SERS is a forty-item instrument designed to provide a measure of self-esteem as a multifaceted concept capable of assessing problematic as well as positive dimensions of self-esteem in adults. The SERS has excellent psychometric properties (Nugent and Thomas, 1993). The items are rated on a seven-point Likert scale, with total scores ranging from -120 to +120. Positive scores reflect higher self-esteem. The items focus on a range of areas that are important as they relate to dyslexia, including overall self-worth, social competence, problem-solving ability, intellectual ability, and self-competence and worth relative to others (e.g. 'I feel confident in my ability to learn new things'; 'I feel that other people are smarter than I am'). The Cronbach's alpha reliability of this measure was 0.97.

Mediator variable: concealment

Based on a previous concept-mapping study (2011), the data that comprise the mediator variable, Concealment, were based on a cluster composed of

four statements identified as 'Fear of Disclosure'. Concept mapping is suitable for the development of scale domains or factors (Kane and Trochim, 2007). Participants were instructed to rate the items, given their personal experience with dyslexia. Items were rated on a seven-point scale ranging from (1) *Strongly disagree* to (7) *Strongly agree*. Additional items were assessed for their use in the present study.

Based on the confirmatory factor analysis and reliability analysis (Nunnally and Bernstein, 1994), five items were summated (four of the original cluster items) to represent a Concealment indicator, whereby higher scores reflect elevated levels of secrecy, fear of rejection, apprehension and uneasiness about disclosing one's dyslexia to others across work and non-work contexts. The Concealment indicator demonstrated very good internal consistency yielding an alpha coefficient of 0.90. Two sample items are 'My dyslexia is a secret' and 'I keep up my guard about having dyslexia because I feel that people might hurt my feelings'.

Control variables

We include several covariates in the mediation analysis: ADD, ADHD, a current diagnosis of depression or anxiety, current age at time of survey (in years), gender and attendance at a regular public school or a private school specifically for students with dyslexia/LD. These variables have been shown to be related to indices of adjustment (Riggs and Han, 2009) while private school attendance appears to promote positive emotional experiences and self-esteem in adulthood (Nalavany et al., 2011a).

Mediation analytic strategy

The mediation model (Figure 1) was tested using a non-parametric re-sampling method called bootstrapping to evaluate direct and indirect effects (Hayes, 2009; Preacher and Hayes, 2004). We used an SPSS macro (available for download at www.quantpsy.org) that accompanies the paper by Preacher and Hayes (2004) and allows for the inclusion of control variables.

In evaluating mediation, it is important to differentiate between various effects and their consequent weights. According to Figure 1, the *total effect* (un-standardised regression coefficient or weight of path *c*) of an independent variable (i.e. PFS) on a dependent variable (i.e. self-esteem) is derived from a *direct effect* (weight of path *c'*) of the independent variable (i.e. PFS) on the dependent variable (i.e. self-esteem) and a mediated or *indirect effect* (weight of path *ab*) of the independent variable (PFS) on the dependent variable (self-esteem) through the hypothesised mediator (Concealment). Weight path *a* denotes the direct effect of the independent

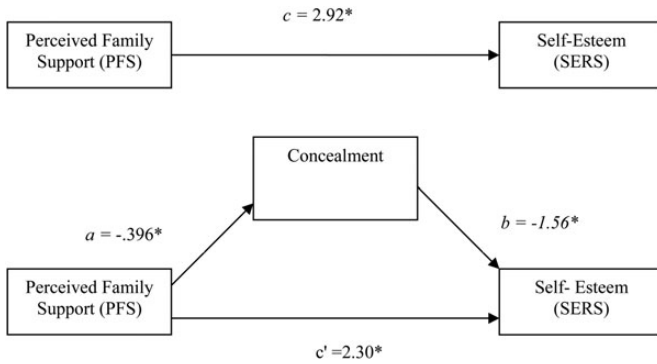


Figure 1 Model of the mediational role of concealment in the relationship between perceived family support (PFS) and self-esteem
 PSR, Provisions of Social Relation; global self-esteem (SERS), Self-Esteem Rating Scale. Un-standardised regression coefficients are denoted by each path. * $p < 0.001$.

variable (PFS) on the mediator (Concealment), while weight path b signifies the direct effect of the mediator (Concealment) on the dependent variable (self-esteem), while removing the influence of the effect of the independent variable (PFS) and any control variables. The indirect or mediated effect is the product of path a and path b , which is equal to the difference between the total (path c) and direct (path c') effects of the independent variable on the dependent variable (Preacher and Hayes, 2004).

Point estimates and 95 per cent confidence intervals are produced for the indirect effect. The estimate of the indirect effect is statistically significant when zero is not contained in the 95 per cent confidence interval (Preacher and Hayes, 2004). This corresponds to an alpha level for significance at 0.05. We described the extent of mediation by examining the un-standardised indirect effect (Hayes, 2009) and by calculating the proportion mediated, which is the ratio of indirect effect to total effect (Shrout and Bolger, 2002).

Results

Participants

A response metric called a completion rate (the number of participants who consented to participate by completing the first survey page divided by the number of participants who completed the last survey page) is often reported in web-based surveys that are open-ended and anonymous in design (Eysenbach, 2004). A total of 228 participants completed the entire survey, while twenty-two individuals partially completed the survey. This represents a 91.2 per cent completion rate. The findings described herein are only from those who completed the survey. We omitted one participant

who was under age twenty-one and three participants who did not provide their birth data, yielding an analysis sample of 224 participants who predominantly resided in the USA.

The majority of the participants (83.1 per cent) responded 'yes' to having a specific diagnosis of dyslexia, while all participants self-identified as having dyslexia. The majority of the participants were male (64.7 per cent), Caucasian (87.5 per cent), had earned at least a bachelor's degree (60.7 per cent) and were working full or part time (62.1 per cent). Only 10.3 per cent reported to be current full- or part-time students.

Bivariate analyses

Pearson's and biserial correlation coefficients were used to examine correlations among continuous and dichotomous variables. Intercorrelations among study variables and means and standard deviations are presented in Table 1.

Mediation analyses

As hypothesised and depicted in Figure 1, higher levels of PFS predicted lower levels of Concealment (path *a*), while higher levels of Concealment predicted lower self-esteem (path *b*). It should be stressed, however, that independent tests of total (path *c*, Figure 1) and direct effects (paths *a* and *b*, respectively) are not a prerequisite for a significant indirect or mediated effect (Hayes, 2009). With this in mind, the bootstrapping results revealed that the indirect effect (i.e. path *ab* or the difference between the total and direct effects) of PFS on self-esteem through Concealment was significant, with a point estimate of 0.616 and a 95 per cent confidence interval excluding zero ($CI_{0.95} = 0.282, 1.10$). This indirect effect held over and beyond the control variables, including the significant effect of anxiety/depression ($b = -21.07, p < 0.0001$) and private school attendance ($b = 16.50, p < 0.001$) on self-esteem. Put differently, as PFS increases by one unit, self-esteem increases by 0.616 units (or between 0.275 and 1.12 units, given the confidence interval) as a result of PFS's negative effect on Concealment (i.e. promotes more comfort and ease in disclosing one's dyslexia) which in turn positively affects self-esteem, while holding the control variables constant. Examination of the proportion of effects mediated shows that 21.1 per cent of the total effect of PFS on self-esteem is mediated by Concealment.

Discussion

While the profession of social work has traditionally addressed the needs of people with concealable stigmatised identities such as HIV status, gay and lesbian, and individuals with persistent mental illness, this study brings

Table 1 Means, standard deviations, percentages and correlations matrix of all variables

Variable	M (SD) or %	1	2	3	4	5	6	7	8	9
<i>Dependent variable</i>										
1. SERS	51.17 (40.77)		0.50**	-0.51**	0.10	0.26**	0.37**	-0.25**	-0.09	-0.37
<i>Independent variable</i>										
2. PFS	25.02 (5.54)			-0.29**	-0.10	0.18**	0.23**	-0.23**	-0.10	-0.18**
<i>Mediator variable</i>										
3. Concealment	19.85 (8.79)				-0.14**	-0.19**	-0.18**	0.17**	0.03	0.15*
<i>Control variables</i>										
4. Age	49.06 (14.55)					0.14*	0.06	-0.14*	-0.10	-0.14*
5. Gender (male)	64.7%						0.56**	-0.01	-0.03	-0.12
6. Private school education	42.4%							-0.08	-0.05	-0.14*
7. ADD	17.4%								0.16*	0.25**
8. ADHD	6.7%									0.17*
9. Anxiety/depression	21.4%									

PFS, Perceived Family Support (Provisions of Social Relations); SERS, Self-Esteem Rating Scale. * $p < 0.05$; ** $p < 0.01$.

to light a new population that is also subjected to discrimination and injustice—adults with dyslexia. Adults with dyslexia tended to have higher self-esteem because PFS decreased concealment which subsequently facilitated positive self-esteem. PFS helped directly lessen the degree of fear, uneasiness and shame about disclosing one's invisible stigma—dyslexia—to others. In turn, the more one is self-confident in disclosing dyslexia, the more self-esteem is enhanced. The finding held even when controlling for two significant predictors of self-esteem—private school attendance and a diagnosis of anxiety/depression. According to [Ragins's \(2008\)](#) disclosure of a stigmatised identity model, the presence of supportive family and ally relationships has a direct effect on the disclosure process. Family members may provide support for disclosure decisions in several unique ways, including advocacy, acceptance and validation. Just as securely attached children find 'felt security' in the form of a 'holding environment' in times of emotional distress ([Bowlby, 1977](#)), families can provide a similar kind of solace through affirmation and acceptance throughout the lifespan. This finding also held true in an earlier study ([Nalavany et al., 2011b](#)) of adults with dyslexia. One theme suggested that parental support continued to be essential long after high school. Statements such as 'Parental support can make a difference in self-esteem' and 'Parents encourage our success in different ways' point to the importance of family support throughout adulthood. Validation from family can increase the adults' hopes of encountering other supportive relationships, lessen concealment and inspire them to disclose to others ([Ragins, 2008](#)). With the stronghold of concealment lessened, self-esteem is indirectly enhanced. Based on our findings, it is possible that family support may directly lessen the [Smart and Wegner \(2000\)](#) concept of 'private hell' and [Pachankis's \(2007\)](#) preoccupation with and cognitive burden associated with concealing one's invisible stigma. Being at peace with their learning difference, individuals may take more risks in revealing their dyslexia to others, which, in turn, enhances self-esteem.

Limitations

Several limitations of this study should be acknowledged. The first concern is the ability to generalise these findings due to sample biases inherent in online surveys. We are unable to determine the degree to which our sample is representative of the general population of adults with dyslexia. Nonetheless, the completion rate of 90 per cent is indicative of the advantages of this method in researching adults with dyslexia. Second, the degree of discrimination genuinely experienced over the life course is likely to predict self-esteem. Including experiences of discrimination will be important to consider in future research on dyslexia. Finally, an important consideration in the interpretation of our findings is that the correlational structure of our data precludes firm conclusions about the causality of study variables. One

possibility is that the order of causation among our variable can be reversed such that concealment and self-esteem could be reversed—that self-esteem mediates the relationship between PFS and concealment. Longitudinal data collected over developmental periods along with multiple-source reports (e.g. parents, family and the adult with dyslexia) will yield greater insights on causal effects among study variables. However, it should be stressed that our model was based on the extant literature on concealable stigmatised identities. Our dependent variable, self-esteem, is also cited in the extant literature on adult dyslexia as a common outcome (McNulty, 2003; Burden, 2008).

Implications and conclusions

Perhaps our strongest implication for social work practice and future research is that the critical role parents and family have in their child's early life may be just as compelling in adulthood. The need for support throughout the entire lifespan from social workers cannot be overlooked. Social workers can be an important link in educating, coaching and supporting parents and other family members in realising the value that continuing family support has throughout the lifespan, especially the transition to adulthood as it pertains to concealment. According to Ragins (2008), environmental support including family increases the centrality—or self-acceptance—of the stigmatised identity, which promotes disclosure. In other words, fostering the development of a strong sense of identity regarding one's learning differences can ease the emotional burden and shame that often accompany keeping one's invisible stigma a secret from others. An important implication is that both the family and the social worker need to understand that it is often the family who first provides the all-important view of the adult with dyslexia that goes beyond the stigma that is associated with dyslexia. This family experience can assist adults in seeing their strengths, gifts and inherent value. It is important to recognise the family as the expert. This view sets the stage for adults with dyslexia to accept themselves beyond cultural stereotypes and myths, and may enable them to be confident and self-assured in taking risks revealing their identity to others. This process indirectly enhances self-esteem. On the other hand, our findings suggest that the lack of PFS increases the negative stigma associated with dyslexia and subsequently undermines self-esteem. Social workers, therefore, should be mindful of the need for alternative sources of support for this group. For example, the research on invisible stigmatised identities supports the value of a support network that includes similar others (Ragins, 2008). In this case, similar others can be other adults with dyslexia. The support from other adults who have dyslexia can provide the empathy and validation (Dale and Taylor, 2001; Nalavany *et al.*, 2011b) that may be missing from the lack of ongoing family support. Here again, the social work professional

is trained in group work and bringing together support networks which fit well within the needs of this group.

The findings of this study indicate the need for future research in three areas. First, because the extant research has excluded the voices of parents and family members of adults with dyslexia (Hellendoorn and Ruijsenaars, 2000), future research should include their perspective. We posit that their experience in living with a family member with dyslexia throughout the life course gives them expert status and can therefore inform and give direction to practice and policy. Second, the field is in need of an intentional model that more clearly describes and depicts the role of family in relationship to concealment, self-esteem and overall well-being, since all three factors have such impact on the quality of one's life. Although Ragins's (2008) model in part informed the conceptualisation of this study, it is vital to note that this is only a beginning and that this model may not completely capture the experience of adults with dyslexia. For example, Ragins (2008) notes that 'Supporters and allies are individuals who do not have a stigma but who consciously and deliberately support those who do' (Ragins, 2008, p. 203). Although not the focus of the current research, it is important to also reflect upon the role inherited dyslexia may have in understanding the main findings. A growing body of research suggests that dyslexia tends to run in families. Approximately 33–66 per cent of children with dyslexia have at least one parent with dyslexia (van Bergen *et al.*, 2012). On the other hand, approximately 6–16 per cent of children with dyslexia are children of parents without dyslexia (van Bergen *et al.*, 2012). The evidence suggests that perhaps a high percentage of our study participants come from families with intergenerational dyslexia. To what degree, if any, does a parent with dyslexia influence an offspring's view of dyslexia and self-esteem? Because of their experience, parents with dyslexia may be powerful role models who ultimately help their offspring view dyslexia in a more positive light by helping them recognise their ability to be creative, resourceful and determined (Logan, 2009; Eide and Eide, 2011; Nalavany *et al.*, 2011*b*). Addressing the topics of intergenerational dyslexia, concealment and overall well-being can shed more light on this phenomenon through future research. In the present study, we added one open-ended question at the end of our online survey. This open-ended question resulted in a surprising amount of qualitative data about the experience of being a parent with dyslexia and having a child/children with dyslexia. These data inform our next study, which will look at the role of intergenerational dyslexia in families.

Finally, it is important to stress that, although concealing one's dyslexia had a significant direct and indirect negative impact on self-esteem, the reality is that a concealable stigma does not take place solely within a vacuum or within the individual. As Chaudoir and Fisher (2010) note, 'the reality is that disclosure can increase the objective frequency with which people are targets of social rejection, prejudice, and discrimination and not simply subjective perceptions of these events' (Chaudoir and Fisher, 2010, p. 248). To be sure, the

disabling aspect of dyslexia is viewed as a consequence of social interaction (Denhart, 2007). Consistently with the social model of disability, 'the environmental and social barriers that exclude people from mainstream society are imposed on top of any impairment experienced' (Brewster, 2004, p. 25). For example, it is accepted in Western society that reading and writing ability is considered a measure of intelligence and that those who struggle with reading and writing or read with assisted devices such as audio tape or write via a dictation device are regarded as intellectually inferior (Denhart, 2007). Indeed, being stereotyped as stupid, cheating, lazy and mentally incapacitated often leads to blatant acts of injustice and discrimination and often contributes to feelings of shame and rejection over and beyond their language-based challenges. Thus, given that disclosure does bring forth the threat of potentially deleterious outcomes (Chaudoir and Fisher, 2010), it is vital to keep in mind that concealment may serve as a protective function to intolerant environments (Pachankis, 2007). Social work practice, policy and research can look back to its historical roots and move beyond the stereotypical view that asks 'What is wrong with this individual with dyslexia?' Instead, the social work community has an opportunity to embrace its mission by addressing 'environmental forces that create, contribute to, and address problems in living' as outlined in the NASW Code of Ethics (2008) for individuals with dyslexia. Likewise, the BASW Code of Ethics (2002) states that 'Social work practice addresses the barriers, inequities and injustices that exist in society'. Given the lack of attention social work has seemingly devoted to individuals with dyslexia, we challenge the field to live up to its reputation and coveted mission to 'enhance human wellbeing and help meet the basic human needs of *all* people' (BASW Code of Ethics, 2002, emphasis). This includes intentionally promoting and advocating for the social justice of adults with dyslexia.

While the purpose of this manuscript is to highlight the interrelationships among PFS, concealment and self-esteem in adults with dyslexia, a secondary objective is to bring attention to the need for social work to embrace this invisible population. With this in mind and in conclusion, tentative implications for social work are threefold. There is a need for our profession to explore and understand dyslexia, to recognise the stigma associated with dyslexia and to strengthen family awareness in their role of promoting a positive self-image which decreases the need to conceal one's identity and therefore promotes healthy self-esteem. In other words, the family accepts and sees them as 'whole' and accepts them for who they are. What could be more important for the adult with dyslexia: for families to understand or for social workers to promote?

Acknowledgements

We thank the participants for their commitment and passion for this research. We thank the anonymous reviewers for their helpful comments in revising

this manuscript. Financial support for this study was provided by a Research Start-Up Grant from the Division of Research and Graduate Studies, East Carolina University, to the first author, B.A.N.

References

- Bowlby, J. (1977) 'The making and breaking of affectional bonds', *British Journal of Psychiatry*, **130**, pp. 201–10.
- Brewster, S. (2004) 'Insights from a social model of literacy and disability', *Literacy*, **38**(1), pp. 46–51.
- British Association of Social Workers (BASW) (2002) *The Code of Ethics: British Association of Social Workers*, Brighton, BASW.
- British Dyslexia Association (2011) *Dyslexia and Specific Learning Difficulties in Adults*, available online at <http://www.bdadyslexia.org.uk/about-dyslexia/adults-and-business/dyslexia-and-specific-learning-difficulties-in-adu.html>. (accessed June 2013).
- Burden, R. (2008) 'Is dyslexia necessarily associated with negative feelings of self-worth? A review and implications for future research', *Dyslexia*, **10**, pp. 188–96.
- Chaudoir, S. R. and Fisher, J. D. (2010) 'The disclosure processes model: Understanding disclosure decision making and postdisclosure outcomes among people living with a concealable stigmatized identity', *Psychological Bulletin*, **136**, pp. 236–56.
- Chaudoir, S. R. and Quinn, D. M. (2010) 'Revealing concealable stigmatized identities: The impact of disclosure motivations and positive first-disclosure experiences of fear of disclosure and well-being', *Journal of Social Issues*, **66**, pp. 570–84.
- Cook, J. A., Grey, D. D., Fitzgibbon, G., Batteiger, D., Caras, S., Dansky, H. and Priester, F. (2007) 'Challenges in defining respondent populations in a Web survey of individuals with psychiatric disabilities', in T. Kroll, D. Kerr, P. Placek, J. Cyril and G. Hendershot (eds), *Towards Best Practices for Surveying People with Disabilities*, New York, Nove Science Publishers.
- Corrigan, P. W. (2004) 'How stigma interferes with mental health care', *American Psychologist*, **59**(7), pp. 614–25.
- Crocker, J., Major, B. and Steele, C. M. (1998) 'Social stigma', in S. T. Fiske, D. T. Gilbert and G. Lindzey (eds), *The Handbook of Social Psychology*, New York, McGraw Hill.
- Dale, M. and Taylor, B. (2001) 'How adult learners make sense of their dyslexia', *Disability & Society*, **16**, pp. 997–1008.
- Denhart, H. (2007) 'On the nature of dyslexia: A new frontier: A radically different interpretation of medical research', in *The State of Our Children and Dyslexia: A Portland Report of a National Issue*, Portland, Oregon, Boys & Girls Clubs of Portland Metropolitan Area.
- Denhart, H. (2008) 'Deconstructing barriers: Perceptions of students labeled with learning disabilities in higher education', *Journal of Learning Disabilities*, **41**, pp. 483–97.
- Derlega, V. J., Metts, S., Petronio, S. and Margulis, S. T. (1993) *Self-Disclosure*, Thousand Oaks, CA, Sage.
- Dillman, D. A. (2000) *Mail and Internet Surveys: The Tailored Design Method*, Toronto, John Wiley & Sons.
- Earnshaw, V. A., Quinn, D. M. and Park, C. L. (2011) 'Anticipated stigma and quality of life among people living with a chronic illness', *Chronic Illness*, **8**, pp. 78–88.

- Eide, B. L. and Eide, F. F. (2011) *The Dyslexic Advantage: Unlocking the Hidden Potential of the Dyslexic Brain*, New York, Hudson Street Press.
- Eysenbach, G. (2004) 'Improving the quality of web surveys: The checklist for reporting results of internet e-surveys (CHERRIES)', *Journal of Medical Internet Research*, **6**(3), pp. e34. Retrieved from <http://www.jmir.org/2004/3/e34/>.
- Field, S., Sarver, M. D. and Shaw, S. F. (2003) 'Self-determination: A key to success in post-secondary education for students with learning disabilities', *Remedial and Special Education*, **24**, pp. 339–49.
- Gerber, P. J. (2006) 'Acceptable loss and potential gain: Self-disclosure and adults with learning disabilities', *Thalamus*, **24**(1), pp. 49–55.
- Gerber, P. J. (2009) 'Transition and adults with learning disabilities', in J. M. Taymans (ed.), *National Institute for Literacy, Learning to Achieve: A Review of the Research Literature on Serving Adults with Learning Disabilities*, Washington, DC, The National Institute for Literacy.
- Gerber, P. J. (2012) 'The impact of learning disabilities on adulthood: A review of the evidenced-based literature for research and practice in adult education', *Journal of Learning Disabilities*, **45**, pp. 31–46.
- Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*, New York, Simon and Schuster.
- Hayes, A. F. (2009) 'Beyond Baron and Kenny: Statistical mediation analysis in the new millennium', *Communication Monographs*, **76**, pp. 408–20.
- Hellendoorn, J. and Ruijsenaars, W. (2000) 'Personal experiences and adjustment of Dutch adults with dyslexia', *Remedial and Special Education*, **21**, pp. 227–39.
- Hunt, B. and Guindon, M. H. (2010) 'Alcohol and other drug use and self-esteem in young adults', in M. H. Guindon (ed.), *Self-Esteem across the Lifespan: Issues and Interventions*, New York, NY, Routledge/Taylor & Francis Group.
- Hussein, S., Moriarty, J., Manthorpe, J. and Huxley, P. (2008) 'Diversity and progression among students starting social work qualifying programmes in England between 1995 and 1998: A quantitative study', *British Journal of Social Work*, **38**, pp. 1588–609.
- Kane, M. and Trochim, W. M. K. (2007) *Concept Mapping for Planning and Evaluation*, Thousand Oaks, CA, Sage.
- Laasonen, M., Salomaa, J., Cousineau, D., Leppamaki, S., Tani, P., Hokkanen, L. and Dye, M. (2012) 'Project DyAdd: Visual attention in adults with dyslexia and ADHD', *Brain and Cognition*, **80**, pp. 311–27.
- Logan, J. (2009) 'Dyslexic entrepreneurs: The incidence, their coping strategies and their business skills', *Dyslexia*, **15**, pp. 328–46.
- May, A. L. and Stone, C. A. (2010) 'Stereotypes of individuals with learning disabilities: Views of college students with and without learning disabilities', *Journal of Learning Disabilities*, **43**, pp. 483–99.
- McNulty, M. A. (2003) 'Dyslexia and the life course', *Journal of Learning Disabilities*, **36**, pp. 363–81.
- Morris, D. and Turnbull, P. (2006) 'Clinical experiences of students with dyslexia', *Journal of Advanced Nursing*, **54**, pp. 238–47.
- Nalavany, B. A. and Carawan, L. W. (2012) 'Perceived family support and self-esteem: The mediational role of emotional experience in adults with dyslexia', *Dyslexia*, **18**, pp. 58–74.
- Nalavany, B. A., Carawan, L. W. and Brown, L. (2011a) 'Considering the role of traditional and specialist schools: Do school experiences impact the emotional well-being and

- self-esteem of adults with dyslexia?', *British Journal of Special Education*, **38**(4), pp. 191–200.
- Nalavany, B. A., Carwan, L. W. and Rennick, R. (2011b) 'Psychosocial experiences associated with confirmed and self-identified dyslexia: A participant-driven concept map of adult perspectives', *Journal of Learning Disabilities*, **44**, pp. 63–79.
- National Association of Social Workers (NASW) (2008) *Code of Ethics*, Washington, NASW Press.
- Nugent, W. R. and Thomas, J. W. (1993) 'Validation of the Self-Esteem Rating Scale', *Research on Social Work Practice*, **3**, pp. 191–207.
- Nunnally, J. C. and Bernstein, I. H. (1994) *Psychometric Theory*, New York, McGraw-Hill.
- Orth, U., Robins, R. W., Trzesniewski, K. H., Maes, J. and Schmitt, M. (2009) 'Low self-esteem is a risk factor for depressive symptoms from young adulthood to old age', *Journal of Abnormal Psychology*, **118**, pp. 472–8.
- Pachankis, J. E. (2007) 'The psychological implications of concealing a stigma: A cognitive– affective–behavioral model', *Psychological Bulletin*, **133**, pp. 328–45.
- Preacher, K. J. and Hayes, A. F. (2004) 'SPSS and SAS procedures for estimating indirect effects in simple mediation models', *Behavior Research Methods, Instruments, & Computers*, **36**, pp. 717–31.
- Quinn, D. M. and Chaudoir, S. R. (2009) 'Living with a concealable stigmatized identity: The impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health', *Journal of Personality and Social Psychology*, **97**, pp. 634–51.
- Ragins, B. R. (2008) 'Disclosure disconnects: Antecedents and consequences of disclosing invisible stigmas across life domains', *Academy of Management Review*, **33**(1), pp. 194–215.
- Riggs, S. A. and Han, G. (2009) 'Predictors of anxiety and depression in emerging adulthood', *Journal of Adult Development*, **16**, pp. 39–52.
- Roper Public Affairs & Corporate Communications (2010) *Measuring Progress in Public and Parental Understanding of Learning Disabilities*, Washington, DC, Custom Research North America.
- Rosenberg, M., Schooler, C., Schoenbach, C. and Rosenberg, F. (1995) 'Global self-esteem and specific self-esteem: Different concepts, different outcomes', *American Sociological Review*, **60**, pp. 141–56.
- Shaywitz, S. (1998) 'Current concepts: Dyslexia', *New England Journal of Medicine*, **338**, pp. 307–12.
- Shrout, P. E. and Bolger, N. (2002) 'Mediation in experimental and nonexperimental studies: New procedures and recommendations', *Psychological Methods*, **7**, pp. 422–45.
- Smart, L. and Wegner, D. M. (1999) 'Covering up what can't be seen: Concealable stigma and mental control', *Journal of Personality and Social Psychology*, **77**, pp. 474–86.
- Smart, L. and Wegner, D. M. (2000) 'The hidden cost of hidden stigma', in T. F. Heatherton and R. E. Kleck (eds), *Social Psychology of Stigma*, New York, Guilford Press.
- Stampoltzis, A. and Polychronopoulou, S. (2009) 'Greek university students with dyslexia: An interview study', *European Journal of Special Needs Education*, **24**(3), pp. 307–21.
- Tanner, K. (2009) 'Adult dyslexia and the "conundrum of failure"', *Disability & Society*, **24**, pp. 785–97.
- Turner, R. J., Frankel, B. G. and Levin, D. M. (1983) 'Social support: Conceptualization, measurement, and implications for mental health', *Research in Community Mental Health*, **3**, pp. 67–111.

- Turner, R. J., Sorenson, A. M. and Turner, J. B. (2000) 'Social contingencies in mental health: A seven-year follow-up study of teenage mothers', *Journal of Marriage and the Family*, **62**, pp. 777–91.
- Valle, J. W., Solis, S., Volpitta, D. and Connor, D. J. (2004) 'The disability closet: Teachers with learning disabilities evaluate the risks and benefits of "coming out"', *Equity & Excellence in Education*, **37**, pp. 4–17.
- van Bergen, E., de Jong, P. F., Plakas, A., Maassen, B. and van der Leij, A. (2012) 'Child and parental literacy levels within families with a history of dyslexia', *Journal of Child Psychology and Psychiatry*, **53**(1), pp. 28–36.
- Wilson, A. M., Armstrong, C. D., Furrie, A. and Walcot, E. (2009) 'The mental health of Canadians with self-reported learning disabilities', *Journal of Learning Disabilities*, **42**, pp. 24–40.