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Psychosocial Experiences Associated With Confirmed and Self-Identified Dyslexia: A Participant-Driven Concept Map of Adult Perspectives

Blace Arthur Nalavany[1], Lena Williams Carawan[1], and Robyn A. Rennick[2]

Abstract

Concept mapping (a mixed qualitative–quantitative methodology) was used to describe and understand the psychosocial experiences of adults with confirmed and self-identified dyslexia. Using innovative processes of art and photography, Phase 1 of the study included 15 adults who participated in focus groups and in-depth interviews and were asked to elucidate their experiences with dyslexia. On index cards, 75 statements and experiences with dyslexia were recorded. The second phase of the study included 39 participants who sorted these statements into self-defined categories and rated each statement to reflect their personal experiences to produce a visual representation, or concept map, of their experience. The final concept map generated nine distinct cluster themes: Organization Skills for Success; Finding Success; A Good Support System Makes the Difference; On Being Overwhelmed; Emotional Downside; Why Can't They See It?; Pain, Hurt, and Embarrassment From Past to Present; Fear of Disclosure; and Moving Forward. Implications of these findings are discussed.

Keywords

dyslexia, adult's perspective, psychosocial, experience, concept mapping

There is increasing evidence that as children with dyslexia mature their struggles with language-based tasks including reading, writing, and spelling persist into adulthood (Undheim, 2009; Van Ijzendoorn & Bus, 1994). In other words, despite myths to the contrary, children with dyslexia become adults with dyslexia. Yet compared to the burgeoning etiological and neural studies on the causes of dyslexia and instructional interventions, empirical inquiry into the psychosocial experiences on adults with dyslexia has lagged behind (Hellendoorn & Ruijssenaars, 2000; Ingesson, 2007; McNulty, 2003; Morris & Turnbull, 2006). This is surprising because dyslexia is among the most common of learning disabilities (LD), with a prevalence ranging from 5% to 12% (Shaywitz, 1998). Although there has been a considerable amount of research under the global category of "learning disabled" adults, drawing conclusions from these studies is challenging because many types of LD are lumped together in the analyses. For example, adults with nonverbal disabilities, specific arithmetic disabilities, intellectual disabilities, or a primary diagnosis of ADHD are lumped together as one group. Because many of these disorders have different etiologies (Boetsch, Green, & Pennington, 1996), understanding the unique psychosocial dynamics and effects experienced by adults with dyslexia is lost. Although focusing on the broader category of LD is of

value, this study endeavors to further distinguish and understand the unique social and emotional experiences of adults with dyslexia. Understanding the psychosocial aspects of dyslexia may increase public attention to this often hidden disability and can help professionals, such as policy makers, educators, mental health professionals, and family members intervene in a more empathic and efficacious manner.

Literature Review

The literature review was based on a systematic research synthesis (SRS; Rothman, Damron-Rodriquez, & Shenassa, 1994) of the available empirical literature on dyslexia (Nalavany & Carawan, 2010). A SRS is defined as the retrieval, codification, and integration of empirical knowledge to yield a conceptual rather than statistical meta-analysis of research findings germane to a phenomenon of interest

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(Rothman et al., 1994). This SRS was guided by the following research question: Given the existing research literature, what is the current knowledge base of the psychosocial experiences of adults with dyslexia?

To answer this question, more than 20 online databases (e.g., Academic Search Premier, CINAHL, ERIC, Medline, PsycARTICLES, PsycINFO, SocINDEX, and Social Work Abstracts) were comprehensively searched for peer-reviewed, empirical literature (i.e., qualitative or quantitative studies) with no time limit to December 2009. The search included *dyslexia* as the main keyword and terms encompassing psychosocial aspects of dyslexia (e.g., *psychosocial*, *experience*, *depression*, *anxiety*, *adjustment*, *risk and resiliency*, *emotion*, *coping*, *behavior*, *social*, *self-concept*, and *self-esteem*).

The SRS findings revealed that there is a considerable gap in the literature addressing the psychosocial experiences of adults with dyslexia. Of approximately 600 studies that were retrieved through the initial search, only 30 studies met the criteria and focused on the psychosocial experiences of adults with dyslexia. Because of vast data collected via this SRS, we present an abbreviated summary of the extant research according to methodology (i.e., quantitative, qualitative, and mixed methods). Further linkages of the existing literature with the findings of the present study can be found in the Discussion section.

Quantitative Research

Quantitative research accounts for 43.3% of the empirical literature. Kosmos and Kidd (1991) found significant differences in adults with dyslexia, in comparison to adults without dyslexia, in that they lack self-confidence, are vulnerable to self-defeating thoughts, and are apt to question their ability to cope with stress of establishing boundaries and obtaining goals. Using a control group, Feldman et al. (1993) concluded that individuals with dyslexia from the middle class fair as well as individuals who do not have dyslexia in financial achievement; however, individuals with dyslexia are more likely to report low self-esteem, negative self-image, anxiety, and depression. In a study with 47 adults with dyslexia, Hughes and Dawson (1995) found that half of the participants reported school experiences dominated by fear. In specific, they reported receiving no additional help for reading and writing problems, felt that they were of low intelligence, and had experienced ridicule from teachers for reading and spelling mistakes. Nearly 75% of the participants thought that their school experiences could have been better had someone understood their difficulties. In fact, adults with dyslexia who have histories of committing criminal offenses often report early childhood experiences dominated by stereotyping and invalidation by teachers and even their parents (Daderman, Lindgren, & Lindberg, 2004).

In a study of 18 men with dyslexia and 18 men without dyslexia, Boetsch et al. (1996) found that men who had an understanding of dyslexia as an inherited disability that was not their fault and was distinct from general intelligence had better outcomes on psychosocial measures. They further found that adults with dyslexia reported no more job satisfaction, marital history or satisfaction, and antisocial tendencies than nondyslexic adults. In addition, adults with dyslexia were no more at risk for depressive symptoms and lower global self-worth than controls. However, Boetsch et al. also concluded that men with dyslexia have a greater number of symptoms of emotional distress than men without dyslexia.

A number of studies also reported higher levels of general anxiety and social anxiety (Carroll & Iles, 2006; Jensen, Lindgren, Meurling, Ingvar, & Levander, 1999; Lindgren et al., 2002; Riddick, Sterling, Farmer, & Morgan, 1999), academic anxiety (Carroll & Iles, 2006; Riddick et al., 1999), and significant low self-esteem (Baker & Ireland, 2007; Riddick et al., 1999) among adults with dyslexia as compared to controls. Most recently, important research by White-house, Spector, and Cherkas (2009) studied the genetic link between dyslexia and anxiety in a population-based sample of 940 monozygotic and 903 dizygotic female twin pairs with or without dyslexia. The analyses found a relationship between dyslexia and anxiety, but the association was independent of genetic influences. Rather, the findings showed that the association between dyslexia and anxiety may be mediated by environmental dynamics, such as negative school and/or social experiences.

In a recent national representative sample study from Canada, Wilson, Armstrong, Furrie, and Walcot (2009) examined the mental health outcomes of 14,265 individuals. The primary populations of interest were identified as individuals with self-identified LD or dyslexia. These researchers recognized that the mental health outcomes of individuals with dyslexia may be different from those of individuals who meet the broader category of LD. The analysis of the subgroup of individuals with self-identified dyslexia included 118 males and 85 females. This analysis revealed that in comparison to those without dyslexia, individuals with self-identified dyslexia reported significantly high levels of suicidal thoughts, depression, professional consultation, distress, general mental health issues, and anxiety disorders.

Qualitative Research

The majority of the research on the psychosocial aspects of adults with dyslexia is qualitative in design, with 46.7% classified as such. Although qualitative research is limited in generalizability, the conclusions gleaned from the qualitative studies on adults with dyslexia are consistent with the findings of many quantitative studies. The research by McNulty (2003) is particularly noteworthy because it is one of the few studies that compares and contrasts the life experience of adults with dyslexia and integrates such experiences into a comprehensive framework. Using the life story approach to qualitative

research with 12 adults with dyslexia, McNulty stressed that during their early and middle school years children subsequently identified as dyslexic are prone to question their academic intelligence and to lose motivation as a repercussion of their unexplained learning challenges. Participants also reported incredibly embarrassing experiences in school and self-esteem and emotional insecurity problems continuing through adulthood. Niches in late adolescence and young adulthood seemed to buffer stressful experiences with dyslexia and enhance self-esteem.

In case studies on seven adult males with dyslexia, Saunders and Barker (1972) found patterns of marital distress and a tendency to keep the learning challenges a secret from their families, employers, and friends. Interestingly, anxiety was highest when they struggled with keeping pace with job-related tasks and when their children started to read in school. Similarly, in an in-depth case study of a 35-year-old man, Lenkowsky and Saposnek (1978) concluded that parents who were unsupportive because of their misunderstanding of a child's dyslexia may have profoundly affected the child into adulthood in the form of marital and family-related stress. Later stress in adulthood may be related to the adult's tendency to keep the dyslexia a secret because of profound shame associated with his or her learning challenges as well as difficulty with social cues. An adult man with dyslexia reported that despite achieving high academic goals and success, he was still prone to strong emotional reactions of frustration, embarrassment, and anger (Mautner, 1984). Other case studies have also reported that anxiety, low self-esteem, and a pervasive feeling of being overwhelmed with coping with dyslexia was characteristic of individuals with dyslexia (Arkowitz, 2000; Migden, 1990).

Several authors have used larger samples in more traditionally focused qualitative studies that resulted in parallel findings. Scott, Scherman, and Phillips (1992) interviewed several males and females with dyslexia and concluded that despite the large amount of effort put forth the participants were challenged to complete their goals, which led to extreme frustration. Another component of their frustration was their general awkwardness in social situations. In a study by Riddick (2003), nearly 70% of 14 teachers with dyslexia reported painfully negative experiences in primary and secondary school. Their past experiences with dyslexia enhanced the teachers' ability to be empathic to children with disabilities. Price and Gale (2006) and Morris and Turnbull (2006) found that nurses with dyslexia experience anxiety around the decision to disclose their dyslexia, stress when completing tasks, and low self-esteem. Reporting the use of a grounded theory approach with only seven adults with dyslexia, Illingworth (2005) concluded that participants use a variety of compensatory strategies to overcome barriers. Still the participants remained cautious about when and to whom they disclosed their dyslexia. This decision was about the fear of the perceived

stigma that is attached to individuals with dyslexia. Just recently, using thematic analysis methodology, Stampoltzis and Polychronopoulou (2009) explored the personal and educational experience of 16 young adult Greek students with dyslexia in higher education. Eleven themes were identified in this study. These themes are congruent with those of McNulty (2003) and others yet highlight the inherent stressors and necessary coping strategies associated with being a college student with dyslexia.

Mixed Research

Although only 10% of the studies qualified as mixed-methods research, the findings are consistent with the conclusions drawn for the quantitative and qualitative research. Ingesson (2007) explored 75 teenagers' and young adults' descriptions of their psychosocial experiences while growing up with dyslexia. Of the participants, 40% had experienced early years of school with feelings of low self-worth. This largely resulted from being teased and bullied because of their difficulties with dyslexia. A frequent comment was, "I felt inferior to others" (p. 580). Conversely, others were quite skilled at making friendships, possibly as a means to compensate for their challenges with dyslexia. As they grew older, the feelings of low self-esteem subsided as they choose occupations that were consistent with their unique strengths and often avoided college. Hellendoorn and Ruijssenaar (2000) interviewed 27 adults about their personal experiences with dyslexia. Participants reported mostly negative school memories and current social and emotional problems stemming from their dyslexia yet appraised themselves as having tenacity and resolve. A dilemma for nearly half of the adults was the decision to disclose their dyslexia to colleagues at work and to people they meet socially. In a follow-up study on psychosocial factors of 31 young Norwegian adults, Undheim (2003) found a majority of the adults in this study reported anxiety about being viewed as stupid, chronic feelings of low self-esteem, and psychiatric problems.

Present Study

In addition to the paucity of research on the psychosocial experiences of adults with dyslexia, the findings of this SRS also reveal that the extant literature lacks conceptual models that select, organize, and present these psychosocial experiences within a comprehensive framework. The vast majority of the research is composed of individual case histories, comparison of adults with dyslexia to those without dyslexia on key variables of interest, and basic descriptions of within-group experiences. To be certain, most of the foregoing research presents "linear" or one-dimensional descriptions of adults' experiences with dyslexia. Conceptual models that explore, describe, and/or explain linkages between and

among key variables or themes of interest in a meaningful way are lacking. This is not to suggest that the existing knowledge base is of limited utility, but quite the contrary. This "first-generation" research can serve as a foundation for "second-generation" research efforts (see the Discussion section for more elaboration on this point) and serves as the impetus for this study.

As the empirical literature concerning the psychosocial experiences of adults with dyslexia is in its embryonic stage, qualitative and mixed-methods studies that explored and depicted adults' personal accounts of their experience with dyslexia became an influential source of inspiration for our research. The findings from these studies are particularly compelling because they advance unique participant-driven conceptualizations of the psychosocial experiences of dyslexia. These conceptualizations complement quantitative research by providing for a richer, more in-depth understanding of adults' experiences with dyslexia. However, the majority of the research on the psychosocial experiences of adults with dyslexia has been driven by the conceptualizations of professionals. Because adults' worldviews in organizing, naming, and conceptualizing their experiences with dyslexia were not included in previous research, the findings from prior studies incompletely reflect the adults' subjective experience of dyslexia.

The purpose of the present study was to deepen our understanding of adults' experiences with dyslexia by producing a methodologically rich, conceptual model of the psychosocial experiences of dyslexia as understood by adults. Using their own words, we attempted in this study to select, coalesce, organize, and depict the experiences of adults with dyslexia within a parsimonious yet comprehensive conceptual framework. This study sought to answer the following research question: How does dyslexia affect, influence, or impact one's life as an adult? This study describes a two-phase application of an alternative methodological approach, concept mapping, to produce a conceptual model of adults' experiences with dyslexia.

Developed by Trochim (1989), concept mapping is a mixed-methods participatory approach, designed for the management and interpretation of a specific type of qualitative data. Social science researchers increasingly have used concept mapping for depicting the dynamics of a phenomenon of interest as it is experienced by a group of participants (Bedi, 2006; Hepworth & Paxton, 2007; Kadambi & Truscott, 2008). Concept mapping combines the inherent strengths of qualitative and quantitative analyses utilizing a structured process focused on a topic or construct of interest. It involves input from participants that seeks to yield an interpretable pictorial view of their ideas and concepts and how these are interrelated (Kane & Trochim, 2007). The intent underpinning concept mapping is congruent with participatory research methodologies that emphasize empowerment

(Petrucci & Quinlan, 2007) and the direct involvement of people with LD in social science research (Aldridge, 2007).

Method

Participants

Item-generation participants. During the initial phase of the study, a group of 15 individuals participated in the first phase of concept mapping called item generation (to be discussed in the Procedures section). Of the participants, 8 were former students of a private school (located in the United States) for children and adults with dyslexia who responded to an announcement placed at the school and 7 of the participants were recruited through an advertisement placed on the listserv of a university department (located in the United States) for disability services. Participants were included in the study if they met the following criteria: minimum age of 24 years old, documented diagnosis of dyslexia, or self-identified dyslexia (screening of participants is described below). The minimum age of 24 was selected because as Gerber (2009) noted, the majority of research on adults with LD is biased toward early adulthood. We wanted participants who have lived long enough to reflect on varied experiences of living with dyslexia as an adult.

Table 1 presents the characteristics of the all the participants. The participants were primarily women (73.3%) and ranged in age from 25 to 66 years ($M = 42.5$, $SD = 11.9$). The sample was Caucasian (80.0%) or African American (20.0%). The majority of participants were employed full-time (71.4%) and had completed an AA or bachelor's degree (53.4%). No significant differences in age were noted between the two groups.

Sorting and rating participants. All item-generation participants were invited to participate in the second phase of concept mapping called sorting and rating (to be discussed in the Procedures section). Of the original 15 participants, 11 (73.3%) completed the sorting and rating tasks. To garner a larger sample size for the sorting and rating tasks, 38 additional adults responded to a newspaper advertisement or announcements placed on the listserv of a university department for disability services, a newsletter associated with the National Association for Adults with Special Learning Needs, and a bulletin posting at the 2008 International Dyslexia Association conference. Through a prescreening telephone interview, participants were eligible for the study if they met the same criteria as described above for the item-generation participants (i.e., 24 years or older, documented history of dyslexia or self-identified dyslexia). Potential participants were mailed a recruitment packet containing the consent form, instructions for the sorting and rating task, a DVD that visually illustrated the sorting and rating tasks, a demographic and educational history questionnaire, a rating questionnaire, and a checklist of dyslexia symptoms. Of the 49 participants who were mailed packets, 39 completed the tasks (79.6%)

Table 1. Descriptive Characteristics of Item-Generation and Sorting and Rating Participants

Variables	Item-Generation Participants (n = 15)	Sorting and Rating Participants (n = 39)
Age (in years; *M*, *SD*)	42.5, 11.9	44.4, 14.4
Gender		
Female	73.3	61.5
Male	26.7	38.5
Race/ethnicity		
Caucasian	80.0	87.2
African American	20.0	10.3
>Hispanic/Latino		>2.6
Income		
<10,000	13.3	10.5
10,000–20,000	13.3	23.7
20,001–35,000	26.7	26.3
35,001–50,000	13.3	15.8
>50,001	33.3	23.7
Employment status		
Unemployed but looking	7.1	11.8
Employed part-time	14.3	20.6
Employed full-time	71.4	50.0
Retired	7.1	17.6
Education		
High school diploma or equivalent	6.7	10.8
Some college	20.0	18.9
AA degree	26.7	27.0
Bachelor's degree	26.7	29.7
Master's or doctoral degree	20.0	13.5
Diagnosis		
Documented dyslexia	73.3	64.1
Documented learning disability	20.0	10.3
Self-identified dyslexia	6.7	25.6

Note: Values are percentages unless otherwise noted and may not total to 100% due to rounding.

and returned their packets to the researchers. As shown in Table 1, the majority of the participants were female (61.5%) and ranged in age from 24 to 73 years (*M* = 44.4, *SD* = 14.4). The sample was primarily Caucasian (87.2%) or African American (10.3%). The majority of participants were employed full-time (50.0%) and held an AA (27.0%) or bachelor's degree (29.7%). There were no significant differences in age and gender between the Phase 1 and Phase 2 participants.

Screening of Participants

Participants provided information (e.g., place of diagnosis, evaluator credentials, age of diagnosis, assessment documentation) to support a genuine diagnosis of dyslexia and not an alternative LD label such as "specific learning disability."

As stated previously, of the 15 individuals who participated in the item-generation phase, 8 (53.3%) were former students of a private school for students with dyslexia whereas 3 participants provided verification of a formal diagnosis of dyslexia. As such, 73.3% of the item-generation participants had a formal diagnosis of dyslexia. Of the remaining 4 participants, 3 provided verification of a formal diagnosis of a LD and 1 self-identified as dyslexic. As for the 39 participants in the second phase of this concept mapping study, 25 (64.1%) responded affirmatively to a specific diagnosis of dyslexia, 4 (10.3%) provided information to support a formal diagnosis of a LD, and 10 (25.6%) self-identified as having dyslexia. Self-identified dyslexia was confirmed with a positive response to the questionnaire question, "Do you suspect that you have dyslexia?" All participants thus self-identified as having dyslexia regardless of having a formal diagnosis of dyslexia or LD or not.

All participants, whether formally diagnosed with dyslexia or not, completed a checklist of dyslexia symptoms. The checklist was developed by a professional with nearly 40 years of experience in the assessment and instruction of children and adults with dyslexia. The checklist was originally used as a screening tool by case managers to identify the possibility of dyslexia in welfare to work clients (Hardman, 2000). The checklist was found to have a 94% accuracy rate in subsequent testing for diagnosis of dyslexia. The checklist was composed of yes–no questions designed to indicate possible dyslexia. Questions on the checklist are consistent with symptoms of dyslexia as defined by Pennington (1991) and the *Revised Adult Dyslexia Checklist* (Vinegrad, 1994). The checklist contains questions about verbal memory, difficulty with directions, spelling, reading and language, familial history of dyslexia, and other symptoms. In our study, 93.0% of the total sample gave 10 or more yes responses to the 20 questions included in the checklist.

Although the majority of participants had verifiable documentation of dyslexia, the use of a checklist and self-report may emerge to be less reliable than a battery of tests. However, self-identification has been shown to be a valid measure of reading difficulties (DeFries, 1989; Gilger, 1992; Schulte-Korne, Deimel, & Remschmidt, 1997). Self-identification was used in the International Adult Literacy Survey (Vogel & Holt, 2003) and most recently in the Canadian Community Health Survey: Mental Health and Well-Being, Cycle 1.2 (Wilson et al., 2009). In arguing for the validity of self-identification for dyslexia, Wilson et al. (2009)

> reasoned that although some individuals may self-identify as LD who, in fact would not meet acceptable criteria, those who also identify as Dyslexic would more likely typify those who meet the narrow criteria of reading difficulties within the more heterogeneous category of LD. (p. 26)

Although the authors were aware of limitations associated with a checklist and self-report, it should be stressed that because of the potential of high participant burden in concept mapping research (described below), a more comprehensive assessment was thought to be beyond the purpose of this study. The researchers were more concerned with participants' definitions and perceptions of their dyslexia rather than how professionals would diagnose them.

Procedures

The process of concept mapping involves a series of systematic yet flexible steps (Petrucci & Quinlan, 2007). Included are planning (developing the focus question and recruiting participants), brainstorming qualitative statements in response to the focal question to produce ideas around a particular concept, sorting and rating the statements, analyzing the results statistically by using Concept Mapping software, computing concept maps (i.e., a visual representation, or map, of the conceptual relationships among the set of qualitative statements), and utilizing the maps to guide strategic planning. We describe the item-generation and sorting and rating phases in the following section

Phase 1 (Item Generation)

Although all participants were invited to take part in both an interview and a focus group, only three individuals participated in both. The remainder of the participants chose to take part in either the individual interview or the focus group. Six individual interviews and two focus groups of six participants each were conducted in two southern cities in the United States. Participants were sent or given a recruitment packet that contained the information described above. Participants were given a $20 U.S. postal money order as an incentive to participate in the study.

We used participant-generated photography with individual participants and a collage creation during each of the focus groups as a method for participants to tell their own stories using a combination of visual, kinesthetic, and verbal language. We make the argument that incorporating photography and art as a way to generate ideas in the individual and focus group interviews is a method that accommodates the unique needs of this group. Previous research suggests the many individuals with dyslexia are more creative and visually oriented as compared to individuals without dyslexia (Everatt, Steffert, & Smythe, 1999; Wolff & Lundberg, 2002). This in part may explain why multisensory approaches have long been advocated by special education professionals (Joshi, Dahlgren, & Boulware-Gooden, 2002; Oakland, Black, Stanford, Nussabum, & Balise, 1998; Orton, 1937). Multisensory approaches connect the visual, auditory, and kinesthetic senses and may dramatically enhance language skills

and academic performance of people with dyslexia (Birsh, 2005). Therefore, the use of art and photography fits with the strengths of this population. The rationale and relevance in using photography and art with adults with dyslexia in this concept mapping study have been described in detail elsewhere (Carawan & Nalavany, 2010).

Photographs were used with the participants who were individually interviewed. The participants were asked to "take 12 or more pictures of anything that would help people understand your dyslexia" and to "take part in a two hour interview at a time that is convenient for you." Each interview was audiotaped and transcribed. In the actual interview we asked an initial grand tour question: "How does dyslexia affect, influence, or impact you as an adult?" The researcher presented the photos one by one to the participant, which provided an opportunity for her or him to share personal insights about each image. Researchers numbered and often wrote words or direct quotes on the back of each photo. Discussing the photographs often led to unexpected information or deeper discussions than what the particular picture showed. During the process, it became clear to us that the use of prompts that we had prepared (e.g., "What are the specific emotional, behavioral, and social experiences encountered as a person with dyslexia?") was unnecessary.

An art project was used in the focus groups to assist in the process of describing what it is like to be an adult with dyslexia. Focus group participants were asked to take part in a 2-hour focus group where they describe their experience of dyslexia both verbally and through the creation of a collage. The process was audiotaped, and one of the researchers facilitated the process while the other researcher recorded notes on a laptop.

Participants were divided into small groups of three and given a variety of magazines, scissors, tape, glue, markers, crayons, and construction paper. Each group was asked to create a collage that would describe their experiences with dyslexia as an adult. The prompts developed for the focus group were not needed as the art collage activity triggered deep discussion about participants' emotional, social, and behavioral experiences with dyslexia from childhood to adulthood. Although each focus group was originally scheduled for 2 hours, an additional half hour was needed for all participants to share their experiences.

The individual and focus group interviews were audiotaped and transcribed verbatim. Several strategies were used to render a nonredundant and inclusive set of statements to be used in the sorting and rating phase. First, the research team independently extracted relevant statements from the participants' accounts. Relevant statements were defined as any statement conveyed by the participants that represented a dynamic or effect associated with dyslexia, including temporal, psychological, interpersonal, educational, familial, affective, cognitive, or behavioral experiences. The use of

photography and art elicited more than 1,200 statements from participants. In comparison to previous concept mapping studies that utilized an open-ended focus statement format, we found only two studies (Bedi, 2006; Donnelly, Donnelly, & Grohman, 2005) that remotely approached the number of statements that were generated in our study. Kane and Trochim (2007) suggested a guideline that the number of statements be less than 100 because large numbers of statements present practical restraints for participants. In our experience participants were often overwhelmed by their everyday life, so we sought to keep statements to a manageable but representative set. We reduced the original set of statements to 75 (Table 2) through a stratified random selection process. In the selection process, we randomly selected 25 statements from focus groups, 25 statements from the individual interviews with males, and 25 statements from the individual interviews with females. It was important for the voices of each group to be included in the final set of 75 statements while preserving the different methodologies for item generation. Next, the research team employed Giorgi's (1985) four-level scheme as a methodological guideline to qualitatively analyze the 75 statements. It was our intention to preserve participants' language and highlight the domain of their experience of being an adult with dyslexia. Finally, we invited the focus group and individual interview participants to reflect on, modify, and made final decisions about the statements. In cases where a statement was found to be too confusing to modify, another statement was selected to replace it.

Phase 2 (Sorting and Rating)

In Phase 2, 39 participants completed a sorting and rating task associated with the previously collected data. Participants were given a $5 gift certificate as an incentive. For the sorting task, each of the 75 statements generated from the qualitative analysis was printed on a card; each card denoted one participant-identified statement or experience related to being an adult with dyslexia. Participants were asked to group the statements "into piles that make sense and fit together." No boundaries were placed on participants' sorting strategies other than that they should not place each item card alone, place all cards in one pile, create a miscellaneous category, or sort the statements on the basis of importance (Kane & Trochim, 2007). Each participant decided how many piles to create and what each category (or concept) contained. Next, participants were asked to give each pile a phrase that they believed most accurately represented the statements in it and to write the phase on the outside of an unmarked envelope. The participants placed each pile in the envelope and sealed the envelope before returning the responses to the lead researcher. Participants also responded to a questionnaire composed of the 75 items. Participants rated on a 7-point Likert-type scale ranging from 1 (*strongly disagree*) to 7

(*strongly agree*) how well each item described their personal experience with dyslexia. The purpose of the rating task was to facilitate identification of the most and least common experiences of dyslexia within the participant group.

Data Analyses and Generation of the Maps

We used Concept Systems software to perform a nonmetric multidimensional scaling (MDS) and hierarchical cluster analysis with the data from the sorting task (Petrucci & Quinlan, 2007; Trochim, 1989). The analysis produced a statistic called a "stress value" representing the goodness of fit of the MDS map solution and ranged from 0 (*perfectly stable*) to 1 (*perfectly unstable*; Kruskal & Wish, 1978). We also computed a bridging value ranging from 0 to 1 for each statement and cluster as part of the concept mapping analysis. The bridging value reflected whether the statement was sorted with others that were close to it on the map or whether it was sorted with items that were farther away on the map. As an indicator of having been sorted with the same statement or group of statements most often, we view those statements with lower bridging values more similarly across participants than statements with higher bridging values (i.e., those statements sorted with different statements by each participant).

Most commonly, the research team decides how many clusters the statements should be grouped in for the final solution because hierarchical cluster analysis can give many possible cluster groups as there are themes or statements. We intentionally incorporated member checking, however, into deciding the final cluster solution. According to Lincoln and Guba (1985), member checking "is the trustworthiness criterion analogous to internal validity in conventional studies" (p. 374) and is "the most crucial technique for establishing credibility" (p. 314). In our study, trustworthiness was established in three ways: (a) the original participants' language was honored as much as possible in all statements, (b) participants provided feedback on the randomly selected statements, and (c) participants gave their opinion on how many clusters best represented their experience and the phrase to describe the contents of each cluster.

Findings

We evaluated several potential cluster solutions (ranging from 3 to 12). We considered that participants on average sorted the statements into 7.1 piles (range = 3–12, *SD* = 2.2). As such, cluster solutions between 6 and 10 were given most weight (Bedi, 2006). Sorting and rating participants provided feedback, and a 9-cluster solution was unanimously selected. Feedback from participants was solicited in the following ways: focus group, telephone interview, and email contact. The MDS procedure resulted in a final stress value of .21, which is considered stable (Kruskal & Wish, 1978)

Table 2. Clusters and Corresponding Bridging Values and Ratings of Adults' Psychosocial Experiences With Dyslexia

Cluster and Item	Bridging Value	Rating (M)
Cluster 1: Organization Skills for Success		
23. I find ways to make life with dyslexia easier.	0.25	6.26
19. I need goals.	0.23	6.13
59. I have to break up tasks into manageable pieces.	0.29	6.05
51. I have to find a way to not put too much pressure on myself.	0.52	6.00
1. Managing time is important but difficult.	0.44	5.97
9. Routine is so important.	0.34	5.74
67. I don't care what's going on, I have a need to be organized.	0.56	5.67
25. I need a plan to do any task better.	0.29	5.56
7. To get my degree I have to take a lighter course load.	0.39	5.05
Average	0.37	5.83
Cluster 2: Finding Success		
50. It's important to work with your strengths.	0.17	6.82
12. Perseverance and hard work are necessary to be successful.	0.25	6.79
41. Having a job that I like is important to me.	0.27	6.77
75. It's important to validate (recognize your strengths) yourself.	0.20	6.72
71. Do not let anyone tell you that you cannot be successful.	0.22	6.67
16. I have an amazing work ethic.	0.22	6.56
27. It's important for me to recognize that I do learn differently.	0.22	6.49
68. It's important to self-esteem to have things in your life that you are good at.	0.17	6.38
2. I may have dyslexia but I am an intelligent person.	0.17	6.33
45. It's important not to let others invalidate you.	0.21	6.15
22. Physical activities (e.g., fishing, weightlifting, basketball, pool, running) reenergize my mind. They are therapeutic and peaceful.	0.37	5.85
32. Having a hobby (e.g., cooking, gardening, reading) that I love and that I am good at is important to my self-esteem.	0.27	5.77
4. Reading takes extra time and energy but it's something I want to do.	0.27	5.18
18. Making an A on a test validates me as a person and gives me self worth.	0.35	4.90
Average	0.24	6.24
Cluster 3: A Good Support System Makes the Difference		
10. Parental support can make a difference in self-esteem.	0.27	6.51
64. Unlike my childhood experiences, I want other children to experience a life of confidence and success.	0.89	6.41
53. Close and extended family support can be important to future success.	0.22	6.26
55. Dyslexia has helped me want to give back and help others who are struggling.	0.58	6.21
38. The support of friends can be important to future success.	0.34	6.18
69. Having a tutor that is understanding and capable can make the difference between success and failure.	0.31	6.18
66. Parents encourage our success in different ways.	0.44	6.05
34. Advocating or helping others who have disabilities gives me self worth and makes me feel good about myself.	0.42	5.82
6. I'm no longer embarrassed at disclosing my dyslexia to significant others (e.g., spouse, girlfriend, partner).	0.74	5.56
11. My life started to change for the better when a teacher took special interest in me.	0.50	5.56
8. A support group for individuals with dyslexia can be helpful.	0.61	5.41
33. My parents' advocating for my educational needs was important.	0.68	4.77
Average	0.50	5.91
Cluster 4: On Being Overwhelmed		
63. It's frustrating not to complete tasks.	0.30	6.18
31. I have to work at relaxing.	0.60	5.72
40. I am in a constant tug of war with my energy, for example self care, keeping house, school, work, or social relationships.	0.19	5.59
60. When I can't find the help I need, I get stressed out and angry.	0.18	5.46
26. Coping with dyslexia can lead to exhaustion.	0.18	5.44
36. I have problems concentrating on tasks.	0.37	5.26
3. I'm overwhelmed when given several tasks to do.	0.39	5.15
42. If I get behind in whatever I need to accomplish then I'm doomed.	0.28	4.77
46. I don't know where to begin to clean up papers; I can't even begin because it is so overwhelming.	0.25	4.62

(continued)

Table 2. (continued)

Cluster and Item	Bridging Value	Rating (*M*)
62. Eating too many sweets causes me to have scattered thinking and my thoughts to race . . . almost like an addiction.	0.28	3.72
24. My whole world seems out of control like being in a wind tunnel.	0.15	3.31
Average	0.29	5.02
Cluster 5: Emotional Downside		
56. Even as an adult I experience sadness about my dyslexia.	0.06	5.21
13. I have concerns, worries, and anxieties about others understanding what I'm trying to communicate.	0.12	5.08
5. I experience a lot of anxiety and stress regarding my dyslexia.	0.07	4.95
52. I sometimes wish that the dyslexia would go away because sometimes it hurts.	0.05	4.82
43. I'm subject to depression and I'm sure it is a result of the frustration that I felt as a child.	0.01	4.15
21. I've been in counseling or therapy because of experiences related to my dyslexia.	0.18	3.33
Average	0.08	4.59
Cluster 6: Why Can't They See It?		
65. Other people don't see the amount of hard work that someone with dyslexia puts forth to accomplish the same task.	0.31	6.62
70. Just because I am not doing the best that I want doesn't mean I am not doing my best.	0.29	6.51
54. Even filling out a job application takes good writing and spelling skills.	0.23	6.49
39. It's discouraging and frustrating to work harder than others and not see the same results.	0.14	6.26
30. I have trouble with standardized or formal testing.	0.14	5.79
Average	0.22	6.33
Cluster 7: Pain, Hurt, and Embarrassment From Past to Present		
48. Negative childhood experiences with dyslexia can influence adult life.	0.11	6.38
14. There can be social, physical, and/or communication barriers to living with dyslexia.	0.18	6.23
58. The pain from harsh, negative messages from parents in childhood can affect you negatively in adulthood.	0.22	6.00
44. As a child with dyslexia, school experiences can be hurtful, embarrassing, and scary.	0.00	5.90
49. I struggled with feeling different in grade school.	0.00	5.82
35. It is really embarrassing when teachers point out that you read or write at a low level.	0.17	5.74
20. Growing up I felt extremely sad due to my experiences with dyslexia.	0.07	5.08
28. Although I needed special accommodations in school, my job, or other educational settings, I didn't feel comfortable asking for help.	0.17	4.72
61. It was predicted by school officials that I would be a school drop out.	0.07	3.72
15. I keep up my guard about having dyslexia because I feel threatened that people might hurt my feelings.	0.10	3.38
Average	0.11	5.30
Cluster 8: Fear of Disclosure		
57. I never liked disclosing that I have dyslexia.	0.25	4.36
17. I don't tell anyone at work that I'm dyslexic.	0.32	3.79
29. I don't feel that there's reason to tell anybody that I'm dyslexic because there are so many connotations.	0.38	3.74
47. My dyslexia is a secret.	0.24	2.77
Average	0.30	3.67
Cluster 9: Moving Forward		
74. Because it is difficult to see dyslexia, it is often difficult for some people to recognize it . . . it's a silent disability.	0.58	6.33
72. I wish people including myself would not see dyslexia as negative.	0.92	6.00
37. Sometimes you have to fight to get disability services in schools.	0.49	5.33
73. I tell people up front that I've got a learning disability.	1.00	3.82
Average	0.75	5.37

Note: Participants (*N* = 39) rated each item according to how well each item described their personal experience with dyslexia, using a 7-point scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*).

and is below the average stress value of .29 as reported by Trochim (1993).

The concept map describing the psychosocial experiences of adults with dyslexia appears in Figure 1. The 75 statements (or experiences) from the qualitative reduction in Phase 1 appear as different points on the map. Points that are closer together denote statements that more frequently sorted together than were statements represented by points farther apart. The cluster boundaries represent statements that were more frequently sorted together in the same pile and less often sorted with statements in other piles.
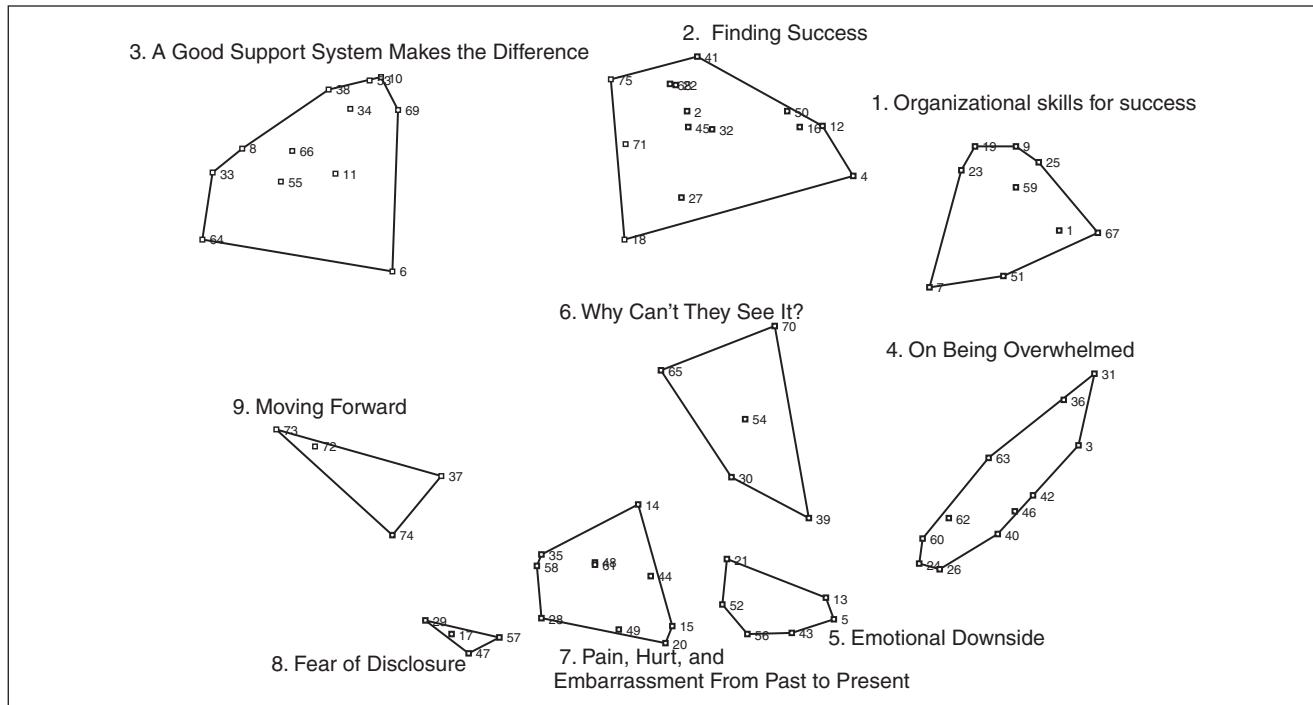
Figure 1. Concept map of the 75 participant-driven experiences with dyslexia

We present participant statements within each cluster and descriptive statistics for each statement and cluster in Table 2. The 9 distinct cluster themes are Organization Skills for Success; Finding Success; A Good Support System Makes the Difference; On Being Overwhelmed; Emotional Downside; Why Can't They See It?; Pain, Hurt, and Embarrassment From Past to Present; Fear of Disclosure; and Moving Forward. Each cluster is identified by a number, but the number assigned to each cluster (see Figure 1 and Table 2) is arbitrary. Interpretation of the clusters is understood by the average bridging, rating values, and visual representation of each cluster. The average bridging value of the 9 clusters in this study is 31.8, which is considerably below that obtained by several recent concept mapping studies (Bedi, 2006; Kadambi & Truscott, 2008; Rush & Harrison, 2008). This suggests the themes have a cohesive representation on the concept map. Average rating values denote how participants felt the statements within each cluster related to their personal experiences with dyslexia. Average participant rating values could be important to understanding the experience of the participants.

Cluster 1

Organization Skills for Success seems to represent ways adults "find ways to make life with dyslexia easier" by systematically prioritizing, organizing, and accomplishing goals while simultaneously attempting not to put "too much pressure" on themselves. Participants agree to the relevance of

organizational creativity in living successfully with dyslexia, as it had the fourth highest average rating ($M = 5.83$).

Cluster 2

Finding Success included items that suggest the keys of living successfully with dyslexia embrace working with and validating one's "strengths," securing a job that brings satisfaction, a commitment to "perseverance and hard work," an honest appraisal of one's learning challenges, and ignoring people who believe "you cannot be successful" or "invalidate you." Finding Success also involves the importance of engaging in physical activities or hobbies that enhance self-esteem. Although Finding Success ranked second in terms of average rating, of the 75 statements, this cluster included 5 of the highest rated statements, with "It's important to work with your strengths" ($M = 6.82$) being the highest rated statement. As such, Finding Success in one's inner life is perhaps the most compelling factor in living successfully with dyslexia.

Cluster 3

The visual representation (Figure 1) of Cluster 3, A Good Support System Makes the Difference, suggests that this is an aspect of participants' experience with dyslexia that is quite distinct from other identified themes. This cluster ranked third in terms of its average rating value ($M = 5.91$). The statements in this cluster reflect how "parental support," "close and

extended family support," the "support of friends," and the mentoring relationship with just one tutor or teacher "that is understanding and capable" and genuinely interested in success of the individual with dyslexia make a difference between "success and failure." Not only is social support necessary in one's life, but it is also important to self-worth to help "others who have disabilities" and "give back and help others who are struggling."

Cluster 4

Visual inspection of Cluster 4 (Figure 1), On Being Overwhelmed, suggests that this cluster is the polar opposite of Cluster 1 (Organization Skills for Success). The statements in this cluster include the frustration involved in "not complet[ing] tasks," the "exhaustion" that is associated with coping with dyslexia, and the need to "work at relaxing." As one participant stated, "I am in a constant tug of war with my energy." Cluster 4 ranked seventh in terms of its average rating value ($M = 5.02$).

Cluster 5

As the most conceptually cohesive cluster in terms of its low average bridging value, Emotional Downside contained statements that related to the deleterious emotional effects of dyslexia as experienced in adulthood—from depression (e.g., "I experience sadness about my dyslexia"; "I'm subject to depression") to anxiety about communicating clearly to others and a pervasive feeling of "anxiety and stress" regarding one's dyslexia. Cluster 5 ranked seventh in terms of its average rating value ($M = 4.59$).

Cluster 6

This cluster (Why Can't They See It?) ranked first in terms of its average rating ($M = 6.33$). As such, the statements within this cluster were of extreme relevance to the participants. The statements within this cluster seem to be connected to participants' feelings about the lack of public awareness and understanding shown from others. One example was the participants' strong perceptions that others do not recognize the "amount of hard work" a person with dyslexia puts forth to "accomplish the same task" as compared to a person without dyslexia. Participants reported feeling like their efforts were misunderstood by others (e.g., "Just because I am not doing the best that I want doesn't mean I am not doing my best") and experience discouragement and frustration when working "harder than others and not see the same results."

Cluster 7

Pain, Hurt, and Embarrassment From Past to Present embodies perhaps the more egregious experience associated with dyslexia. The items within this cluster represent how past negative experiences in general "can influence adult life," how past "negative messages from parents in childhood" can have profound emotional affects in adulthood, and how grade school experiences "can be hurtful, embarrassing, and scary" perhaps when their self-concept and self-worth are invalidated by teachers or peers. There is also a pervasive feeling of insecurity and anxiety in living with dyslexia ("There can be social, physical, and/or communication barriers"). Cluster 7 ranked sixth in terms of its average rating value ($M = 5.30$).

Cluster 8

Fear of Disclosure represents the difficult decision adults with dyslexia must make in deciding to disclose their dyslexia. Statements within this cluster seemed to be connected to adults' apprehension in disclosing their dyslexia in general ("I never liked disclosing that I have dyslexia") and choosing to conceal their dyslexia at all costs ("I don't feel that there's reason to tell anybody that I'm dyslexic because there are so many connotations"). Cluster 8 ranked ninth in terms of its average rating value ($M = 3.67$).

Cluster 9

Given the overall high bridging values for the items constituting Moving Forward, it appears that the items fit together because each statement could possibly be placed in any of the other clusters. Cluster 9 ranked fifth in terms of its average rating value ($M = 5.37$). The first two statements were rated quite high ($M = 6.33$ and $M = 6.00$, respectively). Similar to Cluster 6, this cluster contained statements that represent the social misunderstanding of dyslexia (e.g., "Because it is difficult to see dyslexia, it is often difficult for some people to recognize it . . . it's a silent disability" and "I wish people including myself would not see dyslexia as negative") as well as discriminatory experiences in academic settings (e.g., "Sometime you have to fight to get disability services in schools").

Discussion

This study represents the first formal research attempt to depict a coherent conceptual model of the psychosocial experiences of adults with dyslexia in the language of the participants, as the item generation and interpretation of the data were undertaken by the participants. It is widely understood that the typical implementation of concept mapping involving the generation of statements, sorting and rating, and interpretation of the statistically derived maps has strong potential for participant burden (Kane & Trochim, 2007). Yet this study went beyond the customary implementation of concept mapping. The methodology used in this concept mapping study had unique strengths in that we used innovative, multisensory approaches (i.e., photography and art projects) to generate

participants' ideas about their experiences with dyslexia. To the best of our knowledge, this is the first concept mapping study that used both individual interviews and focus groups to triangulate the data and obtain information. That nearly 80% of potential participants completed the sorting and rating tasks speaks to the resolve adults with dyslexia have in wanting their experiences validated and known. The obtained statistics were also considerably stronger than most concept mapping studies of similar intent. Collectively, participants were directly incorporated in all aspects of this research, thus ensuring that the findings and implications well represented the perceptions of the participants.

Arrangement and Ratings of Clusters

One strategy for discussing a concept map is to examine the placement and adjacency of the map's clusters. Clusters at the top area of the concept map suggest that intrapersonal attributes such as "It's important to work with your strengths" (Statement 50 from Cluster 2), positive social support systems such as "Parental support can make a difference in self-esteem" (Statement 10 from Cluster 3), and compensatory strategies such as "I find ways to make life with dyslexia easier" (Statement 23 from Cluster 1) are essential for living successfully with dyslexia.

The rating question asked the participants to rate how well the items described their personal experiences with dyslexia. Of these clusters, Finding Success consisted of five of the highest rated statements. The items within this cluster are very similar to the "success attributes" (e.g., Self-Awareness, Perseverance) in adults with LD found by Goldberg, Higgins, Raskind, and Herman (2003). The items in this cluster also greatly overlap with the themes of Alternative Compensation and Gifted Overcompensation in adults with dyslexia found by McNulty (2003) and are consistent with research on the association between employment satisfaction and successful outcomes among adults with LD found by Hellendoorn and Ruijssenaars (2000).

The participants in this study noted the support, guidance, and encouragement provided by significant others, such as parents, extended family, friends, tutors, and teachers in making positive differences in their lives (Cluster 3). Although the relevance of support over the course of their lives is a common finding in the extant literature (Dale & Taylor, 2001; Goldberg et al., 2003; Hellendoorn & Ruijssenaars, 2000), the pivotal support role of parents as a protective factor in the lives of adults with dyslexia is not well understood and needs further investigation (Hellendoorn & Ruijssenaars, 2000). A recent study by Logan (2009) examined dyslexia in entrepreneurs and corporate managers. The findings indicate a higher incidence of dyslexia in the entrepreneurs than the corporate managers. The success of the entrepreneurs with dyslexia was associated with a mentor or role within family businesses. The role model was often identified as the father. Logan reasoned that because dyslexia is hereditary, there was a possibility that the fathers also had dyslexia. In this case, the fathers would have been "very powerful role models" (p. 343).

In Cluster 1, participants recognized that developing creative methods for coping with dyslexia and setting specific yet obtainable goals were critical to their success and are consistent with the research on well-adjusted adults with dyslexia (Goldberg et al., 2003; Illingworth, 2005; Kirby, Silvestri, Allingham, Parrila, & La Fave, 2008). At the same time, participants spoke of how overwhelming (Cluster 4) it was for them to cope with dyslexia, complete tasks, and negotiate various aspects of their lives. McNulty (2003) noted the continued challenges adults with dyslexia experience in completing tasks in their jobs or college. Because it takes more time and energy for adults with dyslexia to manage their lives, whether it is at home, school, or work, many of our participants reported feelings of exhaustion. Descriptions of fatigue among adults with dyslexia have been noted in the research (Goldberg et al., 2003; Scott et al., 1992).

Clusters at the extreme bottom area of the map (i.e., Clusters 4 [previously discussed], 5, 7, and 8) represent the more deleterious experiences with dyslexia. Cluster 7, the highest rated cluster of the bottom half of the cluster map, is gripping, with such statements as "Negative childhood experiences with dyslexia can influence adult life" (Statement 48). Many participants recollected school experiences that were "hurtful, embarrassing, and scary" (Statement 44). Being embarrassed by teachers who misunderstood their learning challenge (Statement 35), struggles with social relationships, and repeated experiences of public humiliation perhaps contributed to feelings of being "different" (Statement 49) and "extremely sad." Indeed, McNulty (2003) reported that many adults with dyslexia describe their early school experiences as "traumatic" (p. 371). Painful experiences in school and with parents in childhood are not easily forgotten. Such invalidating childhood experiences can leave emotional scars through adulthood (Hughes & Dawson, 1995; Ingesson, 2007; Mautner, 1984; Riddick, 2003).

High levels of low self-esteem, stress, anxiety, and depression in the lives of adults with dyslexia are echoed in several studies on adults with dyslexia (Boetsch et al., 1996; Hellendoorn & Ruijssenaars, 2000; Jensen et al., 1999; McNulty, 2003; Riddick et al., 1999; Undheim, 2003; Wilson et al., 2009). Although the participants in our study reported current feelings of sadness, stress, and anxiety regarding their dyslexia, this cluster was rated among the lowest. This suggests that many of the participants have successfully compensated with their dyslexia through perseverance and positive sources of support and a variety of adaptive coping skills.

Although some participants revealed their dyslexia to a supervisor or to a person they felt should know, examination

of the rating score (approximately neutral) suggests that the choice to disclose one's dyslexia is not an easy decision (Cluster 8). Indeed, a host of research has shown that approximately 50% of adults disclose their dyslexia to colleagues or supervisors (Hellendoorn & Ruijssenaars, 2000; Madaus, Zhao, & Ruban, 2008; Morris & Turnbull, 2006; Riddick, 2003).

Our participants unequivocally stressed that social misunderstanding of dyslexia (Cluster 6) permeated and transformed perceptions that people have toward individuals with dyslexia. The relevance that social perceptions are so compelling resulted in the highest rated theme. Participants seemed frustrated that their hard work went unnoticed and that other individuals might hold negative stereotypes about their efforts. At the same time, they held themselves to high standards and felt deflated when their expectations were not met. The most interesting feature of the map is the centrality of Cluster 6. According to Trochim (1993), examination of concepts placed in the central region of the map can illuminate perceptions that are important to interpreting the entire concept map. The low bridging value suggests that the experiences in Cluster 6 were frequently sorted together but also were sorted within different conceptual dimensions of the map. Similarly, statements in Cluster 9 call attention to our participants' yearnings for public validation and understanding of dyslexia. One practical interpretation of the placement of Cluster 6 and the themes in Cluster 9 is that adults with dyslexia perceive social and environmental barriers as excluding them from mainstream society over and beyond their personal struggles with dyslexia. Consequently, these social barriers color the lens through which they ascribe meaning to their dyslexia. To be certain, previous research into the life experiences of adults with dyslexia has not tapped into the central role social perceptions have in their lives as clearly as this study.

Limitations of the Study

Although the results of this study highlight many vital implications, as with all research this study possessed several limitations. First, this study was exploratory, descriptive, and inductive rather than confirmatory, causally oriented, or deductive. The purpose of this study was to further understand adults' psychosocial experiences with dyslexia as perceived by adults and does not claim to suggest causal processes with respect to this phenomenon. Second, although this study included 39 participants in the second phase, which is more that the usual amount of participants in concept mapping studies of similar purpose, it is unclear whether these participants' experience with dyslexia is representative of a larger section of the population.

Given that nonrandom sampling was utilized to recruit participants, generalizability is limited to the demographics of the participants as the themes of psychosocial experiences with dyslexia could differ across age, gender, ethnicity,

educational background, family dynamics, and region of living. Future research using a larger number of participants would explore to what degree these findings are consistent and generalizable, although using a large sample with this specific methodology would be challenging. On this note, given the aforementioned literature review, the majority of research on adults with dyslexia includes adult males (Nalavany & Carawan, 2010) and rarely includes adults older than age 30 (Gerber, 2009). With the average age of 43.5 and females composing a majority of the participants, our study adds to the limited knowledge of the psychosocial experiences of adults with dyslexia. Third, because the sample was positive selection, it is also possible that participants may have seen their involvement as an opportunity to share their experiences about dyslexia as a central force in their lives. It is unclear whether the findings would be consistent in some respects to those who may view their dyslexia as less influential.

Implications

Considering risks, strengths, and resiliency. It is clear that life with dyslexia is about the whole person and every facet of her or his life—education, work, leisure, and relationships. Their internal being and external circumstances all affect who they are and how they live their lives. For many, by the time of adulthood, dyslexia has become a risk factor to success and a well-lived life. Uneasiness around disclosure, past and present pain, constant need of but seemingly elusive organizational skills, insensitive and misunderstood social perceptions, and the constant search for support can all contribute to intense emotional reactions, including anger, frustration, depression, and stress. Yet resilient individuals who accept their dyslexia and have a growing awareness of their personal strengths can lead a meaningful and successful life. Although there is no common definition of resilience, Doll and Lyon (1998) define resilience as "successfully coping with or overcoming risk and adversity, or the development of competence in the face of severe stress and hardship" (p. 348). Clearly this study depicts ongoing examples of overcoming risk and adversity throughout the lifespan.

Throughout the study, participants recognized the importance of being self-aware of dyslexia. This acceptance of their disability enabled them to identify and use personal strengths in their quest for success. Recognizing personal strengths, having a positive support system, and developing compensatory strategies were all building blocks related to success for the adult with dyslexia. Having the ability to identify personal strengths in the face of what may seem to be overwhelming odds can be important in the everyday tasks of life. For example, recognizing that one is competent with computers and can help family members and friends correct computer problems can be a strength. In addition, understanding that

physical activity or other hobbies can contribute to one feeling centered and in control can combat anxiety and stress and raise self-worth. Another strategy is learning to organize one's life. For example, setting specific but obtainable goals requires recognizing that these goals might be affected by one's difficulty in completing tasks or experiencing the fatigue that occurs from the extra energy it often takes for adults with dyslexia to accomplish everyday responsibilities.

The importance of being able to identify the factors that create both risk and resilience is necessary to the lifelong health and well-being of these individuals. In fact, a host of authors advocate for a risk and resiliency framework for intervening on behalf of adults with LD (Goldberg et al., 2003; Speckman, Goldberg, & Herman, 1993; Wong, 2003). Educators, therapists and counselors, bosses, criminal justice and social support professionals, and family members need to be aware of and open to the strengths and risks encountered by this group. With knowledge comes the ability for the professional to assist the adult with dyslexia to approach life from a strengths perspective and to weigh risks with self-knowledge. For example, will someone be more successful attending a community college as a student in a college transfer program rather than beginning at a larger 4-year institution? Adults with dyslexia may have varying strengths and risk factors, which lead to more or less resiliency. It is important to identify the common threads found throughout their lives that can assist or hinder success.

As Goldberg et al. (2003) stress, "Learning disabilities do not go away—they are a life long condition" (p. 234) regardless of the effort of teachers, counselors, and parents to rectify them. Dyslexia is not diminished, nor does it go away when one reaches adulthood. In fact, the challenges that often start when a child with dyslexia begins school can become more complicated as the child grows into adulthood. According to the participants in this study, adults with dyslexia experience problems with knowing when and if they should disclose to employers, the need for continued help with organizational skills, and the sadness and/or anger that is often a part of the dyslexia experience for adults. Successfully navigating an education, job, and multiple relationships can be a challenge for anyone but, as this study suggests, most certainly presents added stress and anxiety for an adult with dyslexia. In addition to recognizing that dyslexia does not go away in adulthood, perhaps the most compelling and often overlapping implications from this research suggest that many of the participants are driven to find their own meaning of success, that society's perceptions of dyslexia often create social and environmental barriers to success and personal growth, and that there is a tremendous and continuing need for supportive services that can enhance the lives of adults with dyslexia.

Because dyslexia does not resolve with time, the need for supportive services across the lifespan is paramount. The frustration that comes with not being able to find support services and the public disregard and misunderstanding of dyslexia came up repeatedly in this study. It appears that the emphasis of the field of LD to focus educational support for this population is shortsighted (Goldberg et al., 2003; Raskind, Goldberg, Higgins, & Herman, 1999; Wilson et al., 2009). Although many of the participants in this study reflected histories of pain associated with living with dyslexia, there was an overall belief that educational professionals and mental health counselors do not understand the deep emotional and social pain that occurs from dyslexia. This implies that mental health professionals need more adequate training in the treatment of the effects of dyslexia that begin in childhood and do not disappear in adulthood. Support services that include counseling, support groups, a depth of awareness for teachers and tutors, and family groups that are able to offer both emotional support and cognitive learning strategies are all important to the well-being of adults with dyslexia.

The job of professionals in the field of LD also includes bringing more public attention to this population by heightening awareness in both the professional and public domain to make the invisible more visible. The following statements exemplify the feelings of participants about the social perceptions of dyslexia: "Just because I am not doing the best that I want doesn't mean I am not doing my best." "Because it is difficult to see dyslexia, it is often difficult for some people to recognize it . . . it's a silent disability." These statements call attention to our participants' yearnings for public validation and understanding of dyslexia. They also point to the need for professional and public recognition and understanding of this group.

The clusters and ratings provide preliminary implications, but it is also important to reflect on the focus group *interactions* because the qualitative statements were generated by the focus groups and individual interviews. It was quickly apparent that the participants felt safe in the focus groups and were able to share their vulnerabilities of being adults with dyslexia. For example, several things became clear: Isolation is a factor in living with dyslexia as an adult, adults with dyslexia gained strength from each other within the group, and the group took on a life of its own. The support and freedom they felt to tell their stories and discuss their experiences during the focus group meetings created an emotionally charged experience for everyone in the room. The validations that resulted from interactions around the numerous and compelling accounts of experiences of living with dyslexia as an adult highlighted the need for ongoing support. The intense energy that emerged from the group was completely unexpected by participants and researchers. Based on this finding, the importance of the validation that comes from interacting in a group process with individuals who understand what it is like to live with dyslexia cannot be overestimated. Therefore, professionals should consider developing support groups for adults with dyslexia.

Even though we believed that the use of photography and art would prove to be a good method for gaining in-depth

information from our participants, we were not prepared for the amount and depth of rich data that came from the ease and fit of this methodology when doing research with adults who have dyslexia. The results of this study provided compelling evidence that underscored our belief that researchers have to be willing to step out and think about what method fits with the population that they are working with, both to learn about and to help.

Future research. As the findings of the SRS suggested and as Gerber (2009) eloquently argued, the research on adults with LD "has not adopted a conceptual model to investigate adult issues" (p. 245). The researchers are conducting a larger-scale study to further investigate whether the concept map produced in this study can be a statistically valid and reliable measure of adults' perspectives, whether such experiences with dyslexia vary according to age, gender, and various experiences, and whether life experiences differ with regard to specific types of LD. Researchers are encouraged to move the field toward "second-generation" research. This may be accomplished by proposing and testing conceptual models that explore, describe, and explain the risk and resiliency factors in the lives of adults with dyslexia and LD. In this way, more sensitivity to provide informed practice for adults with dyslexia or LD can be realized.

Conclusion

This study has provided an innovative way of modeling the subjective perspective of adults' experiences with dyslexia. It is hoped that this study can serve as a catalyst to opening up this new area of understanding. This study supports the views that dyslexia does not go away, that negative social perceptions about dyslexia continue to affect adults with dyslexia, that there is a need for services across the lifespan, and that professionals need to be able to identify strengths and risks while working from a strengths and resiliency perspective. Their willingness to share their most private and personal experiences of their lives with dyslexia speaks to their resolve to help others who have dyslexia and their desire to inform families, the public, and professionals about the realities of being an adult with dyslexia. The overwhelming need of participants to be involved in this study was both surprising and humbling to the researchers. It was apparent that participants yearned to tell their stories and to have someone acknowledge the life experiences of being an adult with dyslexia. To be sure, this is the most compelling outcome of all.

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