JoDD
Journal on Developmental Disabilities
Le journal sur les handicaps du développement

Cognitive and Emotional Language Use in Parents of Children with Developmental Disabilities

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Keywords

developmental
disabilities,
parenting,
cognition,
Linguistic Inquiry and
Word Count (LIWC)

Abstract

The present study examined cognitive and emotional language use in narratives of parents of children with Down syndrome (n = 78) versus other developmental disabilities (n = 45). It was hypothesized that parents of children with Down syndrome would make more references to positive emotions and fewer references to negative emotions and cognitive processes. Narratives were examined using the Linguistic Inquiry and Word Count (LIWC) software. Parents of children with Down syndrome made fewer references to tentativeness, insight, causation, and sadness than parents of children with other developmental disabilities. The results suggest that diagnostic uncertainty increases cognitive processing and negative emotions in parents of children with developmental disabilities. Limitations of the analysis of published narratives were discussed.

Parenting a child with a developmental disability may evoke a number of different responses. These may include anger (Atkinson et al., 1995), depression (Orsmond, Lin, & Seltzer, 2007), and sorrow (Mallow & Bechtel, 1999) as well as more positive responses (Trute & Hauch, 1988). The variability of parental responses may be due to a number of factors, including the social support system, the coping styles of the parent(s), and the nature of the child's disability. For example, Florian and Findler (2001) found that the marital adaptation of mothers of children with cerebral palsy was influenced by the size of the family's support network. Regarding coping style, Seltzer, Greenberg, Floyd, and Hong (2004) found better adjustment in parents who adopted a coping style in which they flexibly adjusted their goals in response to their child's disability.

Relatively less is known about how parents adapt to family life with children with different kinds of disabilities. Perry, Harris, and Minnes (2004) compared mothers and fathers of children with one of five types of developmental disability (Down syndrome, fragile X syndrome, Rett syndrome, autism, and unknown etiology) on the Moos and Moos (1981) Family Environment Scale. Although there were few group differences, Perry et al. reported an intriguing finding that increased diagnostic ambiguity was associated with lower levels of perceived family harmony. Similarly, Goldberg, Marcovitch, MacGregor, and Lojkasek (1986) found greater family stress in families of children whose developmental disability was of unknown etiology relative to children with Down syndrome.

In this paper, I examine how different developmental disabilities may lead to different parental experiences. First, I discuss the use of narratives as a means of investigating cognitive, emotional, and social phenomena and review representative studies using this approach. Next, I examine the differences that may exist between parents of children with Down syndrome versus parents of children with other developmental disabilities. I then report a study that examines narratives written by the two groups of parents. Finally, I examine the implications of the current findings with respect to the current literature on families with children with developmental disabilities.

The study of narratives has attracted strong interest within psychology for some time. Bruner (1986) has suggested that stories are, along with arguments, one of the two natural modes of thought. Cognitive psychologists have examined the structure of a well-designed story and its effects on memory (Mandler, 1984), and other scholars have studied how stories emerge in children (McCabe & Peterson, 1991) as well as the role of narratives in psychotherapy (Labov & Fanshel, 1977). More recently, McAdams and colleagues have explored how individuals create meaning by constructing life stories (McAdams, 2001), focusing in particular on turning points in lives (McAdams, Josselson, & Lieblich, 2001).

In this study, I examined parental narratives from a quantitative perspective. In recent years, quantitative analysis of narratives has yielded important insights into how individuals structure their experience (Mehl, 2006; Tausczik & Pennebaker, in press). Pennebaker, Francis, and Booth (2001) developed the Linguistic Inquiry and Word Count (LIWC) software. LIWC receives text files as input and produces measures of several dozen linguistic and psychological variables. Most measures are the percentages of various word types (e.g., articles, emotion words) in the text. Previous studies have explored the relationships between LIWC measures and variables such as personality (Pennebaker & King, 1999), gender (Newman, Groom, Handelman, & Pennebaker, 2008) and depression (Stirman & Pennebaker, 2001).

Carroll (2008) examined cognitive and emotional responses of parents of children with developmental disabilities and parents of typically developing children using the LIWC. Carroll collected samples from books written by parents of children with disabilities and parents of healthy children and found some surprising differences between the two groups of books. Parents of children with disabilities made more references to optimism and fewer references to anger than parents of typically developing children. In addition, they referred to family and home less often than parents of typically developing children. There were also significant differences in the use of pronouns. Parents of children with disabilities used the first person singular and second person plural less often and the first person plural and the third person more often than parents of typically developing children. In other words, they talked about themselves less and their children more.

Of particular interest to the present study, these two groups of parents differed on cognitive and emotional variables. With regard to cognitive variables, the parents of children with developmental disabilities referred more often to certainty and less often to tentativeness. Parents of children with developmental disabilities made more references to optimism and fewer to anger. One limitation of this study was that it included parents of children with many different kinds of disabilities. If diagnostic uncertainty influences parental experience, then we might expect to see cognitive and emotional differences in the narratives of parents of children with relatively clear-cut versus more ambiguous diagnoses.

In this study, I examine the narratives written by parents of children with Down syndrome (hereafter, PCDS) and parents of children with other developmental disorders (hereafter, PCDD). Down syndrome was singled out for two reasons. First, unlike many other developmental disabilities, Down syndrome has a relatively clear diagnosis and prognosis. Diagnosis may be confirmed through genetic studies shortly after birth, and health issues (e.g., heart problems, articulation issues) are relatively well understood. In contrast, conditions such autism, pervasive developmental disorder, and cerebral palsy are associated with a wider range of outcomes and thus, for the parents, greater levels of uncertainty. In addition, Down syndrome, compared to other genetic conditions that may lead to disabilities in children, is relatively common. Thus, resources are available for families of children with Down syndrome whereas support systems for families dealing with less common childhood conditions may be more difficult to secure.

Two hypotheses were tested in this study. First, it was hypothesized that PCDS authors would make fewer overall references to cognitive processes than PCDD authors. The assumption was that diagnostic uncertainty may increase cognitive processing and thus may lead to more frequent references to solving problems, drawing conclusions, and related cognitive processes. In particular, it was expected that parents of children with Down syndrome would make more references to certainty and fewer to tentativeness. Second, it was hypothesized that PCDS authors would make more references to positive emotions and fewer to negative emotions than PCDD authors. The assumption is that the relatively greater uncertainty in the DD group would be experienced as negative emotions.

Method

Participants

Seventy-eight PCDS narratives and forty-five PCDD narratives were included in the study. Sixty-two of the PCDS narratives were taken from Soper (2007) and sixteen from Klein and Schive (2001). The forty-five PCDD narratives were from Klein and Schive (2001). I chose the Soper book due to the large number of narratives related to Down syndrome and the Klein and Schive because it provided narratives related to a number of different conditions.

The forty-five PCDD narratives included seven instances of autism, six of cerebral palsy, and two of spina bifida. The remainder included a wide range of disabilities such as cri du chat syndrome, Angelman syndrome, fragile X syndrome, Marfan syndrome, and craniosynostosis. Several of the contributions dealt with disabilities that were not clearly diagnosed or identified.

All but three of the narratives from the two books were included in the study. Two authors contributed to both volumes, and I used only one story from each author. One other contribution was excluded because it was coauthored by two parents and thus did not represent the voice of a single parent.

Most of the essays in Klein and Schive (2001) and all of the essays in Soper (2007) were written by mothers. The two sets of narratives were comparable in terms of length and linguistic complexity. The mean length of the essays was 1154 words (*SD* = 479 words) for the PCDS group and 1037 words for the PCDD group (*SD* = 385 words). The PCDS group averaged 15.1 words per sentence (*SD* = 2.8 words) whereas the PCDD group averaged 15.5 (*SD* = 2.5 words). The percentage of words captured by the LIWC dictionary, a measure of how common the language used in a text is, was 90.1% for the PCDS group (*SD* = 2.4%) and 90.4% for the PCDD group (*SD* = 2.3%).

Table 1. Examples of LIWC variables

Variable	*Examples*
Cognitive	
Causation	*because, conclude, effect, hence*
Insight	*consider, grasp, know, think*
Discrepancy	*ideal, normal, should, wish*
Inhibition	*abstain, block, constrain, hesitate*
Tentative	*guess, maybe, perhaps, possible*
Certainty	*absolute, always, never, sure*
Inclusion	*along, both, each, we*
Exclusion	*but, except, unless, without*
Positive Emotions	*glad, happy, silly, sweet*
Negative Emotions	
Anxiety	*afraid, nervous, obsess, tense*
Anger	*fight, hate, kill, temper*
Sadness	*alone, cry, grief, sad*

Procedure

Narratives were scanned, cleaned up, and submitted to the most recent version of LIWC (Pennebaker, Booth, & Francis, 2007). LIWC receives text files as input and produces measures of about 80 linguistic and psychological variables. Most measures are the percentages of various word types (e.g., articles, emotion words) in the text.

Twelve LIWC variables were selected for this study: positive emotions, the three subcategories of negative emotions (anxiety, anger, and sadness) and the eight subcategories of cognitive mechanisms (insight, cause, discrepancy, tentativeness, certainty, inhibition, inclusion, and exclusion). Examples of the twelve variables are shown in Table 1.

Results

Means for each LIWC variable for each author were calculated. Although some of the LIWC categories had low base rates, the distributions of the categories were sufficiently similar to normal distributions to justify parametric tests. A one-way multivariate analysis of variance (MANOVA) examined the effects of family type on the 12 LIWC variables. The MANOVA was significant, F(12, 110) = 5.41, p = .001. Tests of between-subjects effects (see Table 2) indicated that the PCDS group made fewer references to insight (p = .001), tentativeness (*p* = .001), exclusion (*p* = .001), cause (*p* = .034), and sadness (*p* = .021). The groups did not differ on positive emotions or certainty.

Discussion

The results support the cognitive hypothesis. PCDS authors made fewer references than PCDD authors on four of the eight cognitive variables in LIWC. PCDS authors made fewer references to tentativeness (*depend, hope, indefinite),* insight (*discover, explain, understand*), and exclusion (*exclude, not, versus*). In addition, PCDS authors made somewhat fewer references to cause (*hence, infer, reason*). It appears that PCDD authors are engaging in considerable cognitive effort to understand the nature of their child's disability and the effect of the disability on their family. In particular, these parents seem

Table 2. LIWC measures for Down syndrome (DS) and other developmental disability (DD)

	DS[a]		DD[b]			
Variable	*M*	*SD*	*M*	*SD*	*F*	*d*
Insight	2.74	.78	3.54	.91	26.86**	.94
Cause	1.24	.45	1.43	.54	4.59*	.38
Discrepancy	2.08	.74	2.08	.71	.02	.00
Tentativeness	1.99	.62	2.76	.91	31.64**	.99
Certainty	1.54	.59	1.44	.47	1.04	.19
Inhibition	.57	.32	.62	.28	.77	.17
Inclusion	5.96	1.26	5.90	1.32	.06	.05
Exclusion	1.94	.68	2.53	.85	17.74**	.77
Positive Emotions	3.77	1.01	3.96	1.12	.97	.18
Anxiety	.55	.31	.62	.44	.83	.16
Anger	.25	.25	.34	.26	3.41	.35
Sadness	.54	.35	.73	.55	5.44*	.41

[a] $n = 78$ [b] $n = 45$ * $p < .05$ ** $p < .001$

to be focused on the tentative nature of their children's diagnoses.

The exclusion subcategory deserves special mention. Suedfeld (1985) has suggested that individuals may cope with negative life events by a process of differentiation (recognizing different dimensions or perspectives on a given situation) and integration (the recognition of trade-offs, syntheses and other ways of integrating different points of view). Suedfeld and Bluck (1993) examined letters written by individuals who had experienced positive and negative life events and found an increase in differentiation and integration following the negative events, although not the positive events. The prevalence of exclusion words in the PCDD authors may reflect recognition of the ways in which their child or their family may differ from other children or families, as a first step in constructing a different type of family.

The results provide partial support for the emotion hypothesis. PCDS authors made fewer references to sadness, although the groups did not differ with respect to anxiety, anger, or positive emotions. The results are consistent with Perry et al. (2004) and Goldberg et al. (1986) in suggesting that diagnostic ambiguity may lead to more negative experiences in parents of children with developmental disabilities.

These results support and extend Carroll (2008). Carroll found that parents of children with developmental disabilities expressed greater amounts of certainty and less tentativeness than parents of typically developing children. In addition, parents of children with disabilities expressed more optimism and less anger. However, Carroll's study did not differentiate between different types of disabilities. It appears that PCDS authors in the present study are most similar to the parents of children with disabilities studied by Carroll (2008), as both display relatively low levels of negative emotions and tentativeness. In contrast, the PCDD authors in the present study appear to be more cognitively active and less emotionally positive than the parents studied by Carroll (2008).

This pattern of findings may be considered in light of recent scholarship on the narrative study of lives. McAdams and Bowman (2001; see also McAdams, 2001) have examined turning points in lives, emphasizing the themes of redemption. Redemption sequences occur when individuals are able to turn negative life events into more positive outcomes. For example, the death of one's father may lead a family to become closer or an exhausting workload may cause an individual to recognize the need for more balance in one's life.

There are some resemblances between the redemption sequences found by McAdams and Bowman and the narratives studied here. For example, one PCDS narrative concludes:

> But as we head into year two of Aidan's life, I've long since realized that our luck did not run out the day he was born. Not at all. In many ways, our lives have been transformed. We have found loving support from people who used to be strangers. We look at the world differently and consider ourselves lucky to be able to. We have an appreciation for a slower pace; we take greater delight in each small step. And we have a newfound understanding of the preciousness of all people. (Dwight, 2007, p. 9)

A similar redemptive theme is apparent in a PCDD author, albeit with a tinge of sadness:

> The sorrow, although unwelcome, can be a pathway to an unconditional love that grows from a realization of the intrinsic beauty of each child's existence. We parents of children with disabilities can feel fine about ourselves when we grasp this and give up superficial achievement-based values. For Tariq, as for most children with disabilities, there has been no miracle, despite all my striving and wishes. I was powerless to change him, but he has changed me so much that I have no idea who I would be without him. I am okay without the baseball and the model airplanes. I did get a close, warm relationship with my son-and a touch of wisdom. No way would I give that up. Still, there are times that I won't deny wishing we could sit down and really talk. (Naseef, 2001, p. 209)

McAdams and Bowman also emphasize that redemption sequences are most commonly found in individuals with a high degree of generativity; that is, these are individuals who wish to contribute in positive ways to the next generation (McAdams, Diamond, de St. Aubin, & Mansfield, 1997). It may be that both PCDS and PCDD authors choose to share their stories to assure others that the experience of parenting a child with a developmental disability has its joys as well as its challenges.

The present results may be helpful in identifying appropriate support systems for families with different types of disabilities. Considerable research has indicated that the provision of an appropriate support system may play a role in how parents respond to children with developmental disabilities (Perry, 2004). However, the types of support systems may vary with the type of disability. Parents with children with Down syndrome may primarily need information regarding the diagnosis and prognosis of the syndrome. Fortunately, there are a number of resources available to assist parents.

In contrast, parents of children with less clear-cut diagnoses such as autism or pervasive developmental disorder may need different and more extensive support. These parents may receive conflicting messages from different professionals as well as information in the popular media that may be misleading or wrong (see, for example, Fitzpatrick, 2009). The present study suggests that these parents may spend considerable effort in trying to determine the cause of their child's disability as well as the therapeutic alternatives that may help their child. The stress associated with this effort may lead to the relative frequency of negative emotions found in this study. These parents may benefit from therapeutic opportunities that are targeted at the stressful nature of their situation. Further study of the role of uncertainty in parental experience is warranted.

There are several limitations to this study. Although PCDD authors may differ as a group from PCDS authors, there is obviously considerable variability in the experiences of parents within the former category. The present sample of narratives precluded any analyses within this category, but future research on a larger number of narratives should examine this issue. In particular, the experience of parents of children with well-defined but less common disabilities, such as Angelman syndrome, would be interesting to pursue.

Another limitation is that this study was not directly comparable to Carroll (2008), due to the changes in the LIWC. For example, using the earlier edition of the LIWC, Carroll (2008) found that parents of children with developmental disabilities tended to be more optimistic than parents of typically developing children. The newer version of the LIWC does not include subcategories of positive emotions. In addition, the inclusion and exclusion variables are considered as subcategories of cognitive words in the 2007 but not the 2001 version of the LIWC.

It should also be mentioned that word count approaches, such as the LIWC, are not sensitive to linguistic context. Sentences such as "My situation makes me angry" and "However, I seldom get angry" will be coded identically for the anger category. Similarly, the LIWC does not provide information about the distinction between "I was angry" and "The doctor grew angry with me." Thus, the LIWC provides a measure of how frequently words in a given category appear but not how they function in particular sentences.

Finally, the titles of the two books used in this study suggest that they were written to provide inspiration for parents of children with developmental disabilities. The narratives in these books might not be representative of the experience of all parents of children with disabilities. More generally, there may be selective pressures for publishers to present positive or uplifting stories about families of children with developmental disabilities.

In sum, these results suggest that the experience of parenting a child with a developmental disability depends to a significant extent on the nature of the disability. Parents of children with Down syndrome are faced with considerable challenges but these challenges are relatively more clear-cut than those faced by parents of children with less clear diagnoses. It may be useful to explore how the support systems for different groups of parents may need to differ as well.

Author Note

An earlier version of this paper was presented at the Association for Psychological Science convention in San Francisco, May, 2009.

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