The role of hope in adaptation to uncertainty: The experience of caregivers of children with Down syndrome

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Abstract

Objective—The goal of this study was to investigate the relationships between perceived uncertainty, hope, and adaptation in caregivers of children with Down syndrome (DS).

Methods—A total of 546 caregivers were recruited from local and national DS groups and from a DS clinic list. A cross-sectional survey examined caregivers' levels of perceived uncertainty, hope, and adaptation. The hope that caregivers had for their child was also measured.

Results—Uncertainty, hope and adaptation were all significantly correlated, with uncertainty and hope independently predicting caregiver adaptation. Caregivers' motivation to reach goals for their child was higher than their ability to think of ways to meet those goals, and their lessened ability to think of ways to reach goals was significantly related to decreased adaptation levels.

Conclusion—Findings from this study suggest that having hope in the face of uncertainty is important in adaptation but that caregivers struggle with having hope related to thinking of ways to reach goals for their child.

Practice implications—The results of this study indicate that perceived uncertainty and hope may be important targets for improving psychological well-being. Interventions that assist caregivers in setting and attaining appropriate goals may be of particular interest.

Keywords

Uncertainty; Hope; Adaptation; Down syndrome; Caregiver; Parent

1. Introduction

Down syndrome (DS) is the most common genetic cause of intellectual disabilities [1]. DS occurs in approximately 1 in 732 infants, or 5400 out of the 4 million infants born each year in the United States [2]. DS is associated with high levels of within-syndrome variability and prognostic uncertainty related to the degree of developmental delay, problem behaviors, and

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other medical issues [3]. Despite having a diagnosis for their child, parents of children with DS often struggle with ongoing uncertainty about their child's condition. Knowing the diagnosis and its associated prognostic possibilities may only reduce uncertainty to a limited extent. In such instances, factors such as hope may play a role in helping a parent adapt to the residual uncertainty surrounding their situation. Despite some knowledge about the psychosocial adaptation of parents of children with DS, much remains unknown about the factors that may be related to their adaptation and how those factors might be amenable to intervention.

This study aims to explore relationships between perceived uncertainty, hope, and adaptation as informed by Lazarus and Folkman's Transactional Model of Stress and Coping [4], Snyder's conceptualization of hope [5], and Mishel's Uncertainty in Illness Theory [6]. The process of psychological adaptation to a stressor is a dynamic process influenced by both personal and environmental characteristics, and has been described generally as psychological well-being in living with a condition [7]. The Transactional Model of Stress and Coping (TMSC) theorizes that the stress associated with being a caregiver is cognitively appraised by evaluating the impact of the child's condition on one's life (primary appraisal) and considering what one can do in response (secondary appraisal) [4]. It is important to consider that many situational factors, the nature of the stressor itself, and other life circumstances change with time; therefore, adaptation is truly a process reflective of these changes [8].

Like the TMSC, Mishel's Uncertainty in Illness Theory discusses a cognitive appraisal process. Whether an uncertain event is appraised as a threat or opportunity will lead an individual to select coping strategies that reduce or foster uncertainty, respectively [6]. Then, the ability of the individual to employ coping strategies that reflect their appraisal of the uncertainty will ultimately aid them in the process of adapting to the uncertainty. It is known that high levels of uncertainty commonly lead to psychological distress such as anxiety, helplessness, and depression [9] and is thus generally something that individuals aim to reduce. Yet some qualitative studies have explored the ability of parents of children with disabilities to find benefits or opportunities when faced with lasting uncertainty [10,11]. It is possible that, for example, a parent's level of hope for their child may play a role in how they appraise prognostic uncertainty as part of the adaptation process, but this has not been studied to date.

Snyder and colleagues conceptualize hope as a goal-directed cognitive process with determined thinking that involves figuring out the way(s) that a goal can be attained. Their definition of hope is comprised of two domains: a sense of agency (goal-directed determination) and pathways (planning of ways to meet goals) [5]. Goals are central to the theory and are viewed as directing human cognitions. People with high hope often devise one clear route that they are confident in, but will likely have thought of alternative ways of reaching their goal and will be flexible enough to switch to one of the other ways if necessary. The energy or motivation thoughts are the drive behind whether a pathway will be carried out and are important when a person reaches an impediment in trying to reach a goal, because then high levels of goal-directed motivation will allow thoughts to be channeled toward the best alternative pathway. Discussion of the TMSC in relation to facing a serious illness has described Snyder's conceptualization of hope as a "promising variable" that may fit into the TMSC as a secondary appraisal [7]. Studies examining the relationship between hope and adaptive outcomes have found hope to be negatively correlated with anxiety, dysphoria, and depression [12–14] and positively correlated with quality of life, life satisfaction, and well-being [7,15]. Some previous research has shown hope to moderate the relationship between stressful life events and well-being [16] and between disability related stress and maladjustment [17]. Qualitatively, some mothers of children with DS have

described feeling hopeful during the process of adjustment to the diagnosis and mentioned the importance of the process of re-goaling after losing the 'hoped for child' as they adjusted to the idea of having a child with special needs [18]. Likewise, parents of children with DS in another study [19] expressed how hope provided them with a new positive direction and way of living life, remarking on the important role that support groups and getting connected with other parents had in increasing their hopeful thoughts.

Despite qualitative studies and theoretical considerations which suggest that hope is an important part of the process of parental adaptation to uncertainty, quantitative data do not yet exist to support that suggestion. We aimed to examine the relationship of uncertainty and hope with adaptation in caregivers of children with DS at a single point in time. Whether or not hope functions as a moderator between uncertainty and adaptation levels is also of interest as a test of the theoretical framework. Another aim of this study is to describe what caregivers hope for in terms of the goals they have for their children and how that hope relates to caregiver adaptation.

2. Methods

2.1. Study participants and procedures

Participants were recruited from local and national support groups and a mailing to the Kennedy Krieger Institute (KKI) Down syndrome clinic patient list. Individuals were eligible to participate if they were age 18 or older and the primary caregiver of a child of any age with Down syndrome. The participant did not have to be a biological parent but it was required that the child reside with the participant taking the survey. The mean age of caregivers was 41.7 years old (± 8.8), with a range of 21–84. The mean age of the caregivers' children with DS in this sample was 7.8 years old (± 7.8), with a range of infancy to 48 years old. Caregivers were asked a single question about whether or not they were a member or participant in a DS support group; approximately 84% of respondents answered in the affirmative. For the remainder of the participant information, see Table 1.

The study protocol was approved by the IRBs of the National Human Genome Research Institute and the Johns Hopkins School of Medicine. To initiate support group recruitment, support group leaders across the United States were contacted by email to see if they would be interested in sharing information about the survey with their group members; those who responded were sent a contact letter to pass on to their group members. Additionally, contact letters were sent to approximately 1000 homes of patients on the KKI DS clinic list a few months after the support groups were contacted. Approximately 11.3% ($n = 62$) of the study sample was comprised of caregivers reached through the KKI clinic list mailing. The survey was open for recruitment from June 2008 to August 2008. A total of 641 people started the survey and 95 people did not continue beyond the eligibility questions either because they voluntarily quit or they were not eligible to proceed. In order to maximize the amount of data in each analysis, some partially completed surveys were used for certain analyses depending on which section(s) of the survey was complete. Requirements were set for each quantitative measure so that responses were only included in analyses if participants completed at least 75% of each subscale or scale, with the exact cut-off depending on the number of questions in each scale. Missing data were imputed once this cut-off was met. If a participant filled out only certain scales and met the completion requirements for those scales, after imputation those data were included in the appropriate analyses. A total of 546 surveys (85.1%) were eligible for at least one of the analyses. The Cronbach's alphas as measured in the current study can be found in Table 2.

2.2. Study measures

2.2.1. Perceived uncertainty—The Parental Perceived Uncertainty Scale (PPUS) examines parental perceptions about their child's condition [20]. It has four subscales (ambiguity, lack of clarity, lack of information, and unpredictability) consisting of 31 items measured on a 5 point scale. Minor modifications to the scale had previously been made by others in consultation with Mishel to better fit the study population of caregivers, and the modified scale has been previously administered with these changes without apparent effect on the scale's validity in studies involving parents of children with rare chromosome disorders [21] and caregivers of children with pervasive developmental disorders [22]. An item example is "I have lots of questions without answers".

2.2.2. Hope level—We used the Trait Hope Scale [5] which is based on Snyder's conceptualization and consists of four items to measure agency (goal-directed determination), four items to measure pathways (planning of ways to meet goals), and four distracter items. The combination of the eight real items results in a measure of a person's dispositional hope. Respondents were asked to use a scale (1 = definitely false to 8 = definitely true) to assign a number to each item, resulting in a summed total score. The trait hope scale has previously been used in populations of caregivers of children with renal/liver transplants and of children with intellectual disabilities [14, 23]. In order to measure hope specifically related to the child, the scale was given a second time as a "hope for child" measure in a way that protected the properties of the original trait hope scale (referred to as "hope" or "hope for self") and involved modifying the wording of the 12 items so that they ask about agency and pathways related to the child. For example: "I energetically pursue my goals" from the agency subscale of the hope for self version compared to "I energetically pursue my goals for my child" from the hope for child version, and "I can think of many ways to get myself out of a jam" from the pathways subscale of the hope for self version compared to "I can think of many ways to get my child out of a jam".

2.2.3. Adaptation—The 20 items scale used in this study was developed by coauthors Drs. Lori Erby and Barbara Biesecker in conjunction with Dr. Bryce Reeve and collaborators from the PROMIS Collaboration [24]. This scale measures four domains of adaptation: social integration, self-esteem, positive stress response, and spiritual/ existential impact. Each sub-domain consists of five items. Participants were asked to rate their level of agreement or disagreement with each item on a 5-point scale. For example, "Being a caregiver of a child with DS has …" "helped me take things as they come"(positive stress response), "helped me become a better person" (self-esteem), "helped me know who I can count on in times of trouble" (social integration), and "helped me develop a deeper sense of purpose in life" (spiritual/existential impact). A confirmatory factor analysis provided strong support for the four sub-domains. Not all 20 items contribute substantially to each domain but the items load onto the factors as designed.

2.2.4. Goals for child (focus of hope)—Open-ended questions about what caregivers hope for with regard to their child were included in the survey. Participants were first asked to write generally about the goals they have for their child. They were then prompted to write about their goals for their child in the following categories: social skills, behavior, education/ learning, independence, mental health, physical health, and other. After each category, they were asked "On a scale of 1–6, how likely are you to pursue the goals that you listed in this category?" which measures the agency (motivation) domain of hope. A parallel question was asked with regard to pathways of hope: "On a scale of 1–6, how easy is it for you to think of different ways to pursue the goals that you listed in this category?" While quantitative data from this section of the survey will be presented, the qualitative data will be analyzed for future publication.

2.3. Analysis strategy

Data were analyzed using SPSS 16.0 (Statistical Package for the Social Sciences). The primary outcome variable was adaptation to being a caregiver of a child with DS. The five demographic variables that were initially categorical were dichotomized after preliminary bivariate analyses with the key predictor variables were not significant. The decision to dichotomize was also made due to the overly disproportionate distribution across most of the categories. The variables were dichotomized as follows: "Race" (white vs. not), "Relationship to child" (biological mother vs. not), "Education (some college or less vs. college degree or more), "Marital status" (married vs. not), "Annual income" ($70,000 or less vs. greater than $70,000).

The key predictor variables (uncertainty, hope, and adaptation) as well as age of child and caregiver age remained as continuous variables in the analyses. Each demographic variable was tested to see if it had a significant relationship with adaptation using Pearson's correlation, ANOVA, or t-tests as appropriate, before conducting the multiple regressions. For the goals section, Pearson's correlations were obtained to see if caregivers' agency and motivation levels in each goal category was related to their overall level of adaptation or hope for child. To see if there were differences in mean agency and pathways scores between the goal categories, t-tests were performed for each possible goal category pairing. To see if the correlations observed between caregivers' agency and adaptation differed from the correlations observed between the corresponding pathways levels and adaptation, we used Fisher's r to z transformation.

3. Results

3.1. Descriptive statistics and bivariate relationships

The means, standard deviations, and ranges of the main study variables are presented in Table 2. The hope for child and hope for self scales were highly correlated (Pearson's correlation = 0.654, p-value < 0.001), and there was no significant difference between their mean values (mean difference = 0.026, p-value = 0.435). There was no significant difference between the mean agency and pathways values in the hope for self scale (mean difference = −0.045, p = 0.153); however, in the hope for child scale, mean agency was significantly higher than mean pathways (mean difference = 0.297, p < 0.001). Bivariate analyses showed that only one demographic variable was significantly associated with adaptation scores at the p < 0.05 level. As the age of the caregiver increased, adaptation levels were found to decrease (p = 0.022). As hypothesized, hope for self was found to be positively associated with adaptation, r = 0.326, p < 0.01, indicating that caregivers with greater hope are better adapted to their child's condition. Analyses also revealed that uncertainty was negatively associated with both hope for self (r = −0.319, p < 0.01) and adaptation (r = −0.188, p < 0.01).

3.2. Multivariate analyses

3.2.1. Adaptation regression model—Since adaptation was significantly associated with both hope for self and uncertainty in bivariate analyses, we also wanted to examine the strength of these relationships while controlling for potential confounders. In the multivariate regression model, independent variables that had a significant bivariate relationship with adaptation at the p < 0.2 level were regressed on adaptation. Those variables included the two key predictor variables (hope and uncertainty) as well as two demographic variables (age of parent and whether a person was a support group member). The regression model was constructed by entering all four of those variables and then using backwards elimination with p < 0.05 as the cut-off for inclusion in the model (Table 3). Both of the demographic variables were eliminated from the model, with only hope and

uncertainty remaining. The R^2 for the regression model was 0.130, indicating that hope and uncertainty are significant independent predictors of adaptation, together accounting for 13% of the variance in adaptation.

3.2.2. Moderation analysis—In order to test the hypothesis that the relationship between uncertainty and adaptation will vary by degree of hope, hope for self was dichotomized at the mean and an interaction variable was created by multiplying mean uncertainty by dichotomized hope (0 or 1). When regressed on adaptation along with the main effects of uncertainty and hope, the interaction variable was found to be non-significant ($p = 0.798$, $n = 526$), indicating that the relationship between uncertainty and adaptation did not significantly vary by degree of hope.

3.2.3. Level of hope—In six different categories, caregivers were asked to write about the goals that they have for their child in that category and were also asked two questions that parallel the domains of hope: agency (goal-directed determination) and pathways (planning of ways to meet goals). The agency subscale in the goals section was correlated with the agency values in the hope for child scale, and the pathways subscale in the goals section was correlated with the pathways values in the hope for child scale ($p < 0.01$) in all of the goal categories. Also, both subscales in the goals section were correlated with total hope for child ($p < 0.01$). Mean pathways scores were significantly lower than the agency scores in each of the goal categories ($p < 0.001$). Pearson's correlations were obtained to determine if caregivers' hope for their child in the goal categories was related to their level of adaptation (Table 4). In each of the goal categories, the pathways subscale was correlated with caregiver adaptation, whereas the agency subscale was not significantly correlated with adaptation in any of the goal categories. The differences between these sets of correlations were statistically significant based on comparisons made after implementing Fisher's r to z transformation.

4. Discussion and conclusion

4.1. Discussion

Despite the challenges that caregivers of children with DS face, the participants in this study had a fairly high level of hope both in terms of dispositional hope for self and hope for child. The caregivers in this study had higher mean hope levels than mothers of children with chronic physical conditions, namely spina bifida, cerebral palsy, and diabetes [17], and had higher hope than parents of children with externalizing disorders [25]. The caregivers in this study had lower mean perceived uncertainty surrounding their child's condition than parents of children with rare chromosome disorders [21] and caregivers of children with pervasive developmental disorders [22].

It was shown in this study that both of the key predictor variables, hope and uncertainty, were significantly associated with caregiver adaptation. Hope has previously been found to be positively correlated with other outcome variables such as quality of life, life satisfaction, and well-being [7,15]. It also fits within the theoretical TMSC framework that having hope would increase one's adaptation to a stressor, but no research has determined the nature of the relationship with a theoretically derived multiple domain measure of adaptation such as the one used in this study. In this population, caregivers who had higher perceived uncertainty had both lower hope and adaptation, suggesting from a theoretical perspective that caregivers of children with DS in this study perceived the uncertainty as more of a threat than an opportunity.

There may be a number of reasons why the interaction variable was not significant in our study. Perhaps hope moderates the relationship between perceived uncertainty and a

different outcome (satisfaction with life, for example) or between a different stressor (anxiety, for example) and adaptation, but not between the particular variables of uncertainty and adaptation. It is also possible that the role of hope is something entirely different than theorized in this study, perhaps functioning instead as a mediator between uncertainty and adaptation or even as a secondary appraisal to a stressor [7] whereby coping would mediate the relationship between hope and adaptation. However, that has not yet been well explored by empiric research. Finally, since these caregivers of children with DS did not perceive relatively high amounts of uncertainty surrounding their child's condition and were overall fairly well adapted, it is possible that the role of hope as a moderator might emerge as significant in other populations of caregivers where there is more variance in perceived uncertainty and adaptation.

In our multivariate analysis, caregivers' level of hope was found to be the most significant predictor of overall adaptation when controlling for any potential confounders, and perceived uncertainty was also found to be a significant independent predictor. These results suggest the important role that both hope and perceived uncertainty play in caregiver adaptation, which had not previously been examined by research in this or similar populations.

A significant difference was observed between agency and pathways scores in the hope for child scale, but there was no such difference seen in the hope for self scale, which parallels our data showing that caregivers' pathways scores were significantly lower than their agency scores in each of the goal categories. It seems, then, that while caregivers' dispositional hope is composed of similar amounts of motivation and ability to think of ways to reach goals, caregivers of children with DS find it easier to be motivated to pursue goals for their child than to think of ways they might achieve those goals. Also, pathways measurements in the goal categories were positively correlated with caregiver adaptation whereas agency was not associated with adaptation in any of the goal categories, suggesting that caregivers' ability to think of ways to reach goals is the more important aspect of hope for child in terms of its relationship with adaptation. It is also interesting to consider that in the goal categories section, the agency scores were actually significantly higher than the pathways scores even though the agency scores were not correlated with adaptation. Perhaps these caregivers struggle most with the pathways component of hope for their child, causing those scores to be lower, and that this struggle is one that directly relates to their ability to adapt to the child's condition.

4.1.1. Limitations—Due to the cross-sectional nature of this study, assessments can only be made about how the variables are associated with one another, rather than being able to determine the direction of the relationships. Also, despite the effort to recruit caregivers from a source other than support groups, only a small portion of the participants were recruited directly from the clinical population and some of those individuals were also members of support groups. Our population was also overwhelmingly white, female, married, and well-educated. These caregivers may differ from other caregivers of children with DS especially in terms of their education, income, and perhaps age. We previously noted that some individuals submitted only partially completed surveys, most often failing to complete one or more of the demographic questions. For those for whom information was available, we found that individuals submitting partially complete responses had lower levels of hope and adaptation than those submitting complete responses (data not presented). We are also limited in our ability to study adaptation since we measured it at only one point in time rather than being able to study it as a process over time. Also, because the aims of this study were exploratory in nature and focused on examining the relationships between the key variables, other constructs potentially important to the adaptation process were not measured. Certain types of coping, such as engaged or accommodative coping, may be

particularly relevant to the key variables in this study because of their conceptual relationship to hope, and should be explored in future studies [13,26].

4.2. Conclusions

This cross-sectional study explored the relationships between perceived uncertainty, hope, and adaptation, revealing that all three key variables are significantly related to one another. Uncertainty and hope were found to be predictors of variance in caregiver adaptation, with hope being the largest contributor to the variance in adaptation, which has implications for future research on these concepts. Although future studies are needed, strategies aimed at strengthening hope and reducing perceptions of uncertainty may increase caregiver adaptation. Studies that examine how hope is discussed or communicated within clinical interactions would also be particularly useful in better understanding how health care providers can most appropriately intervene with patients. Uncertainty and hope interventions based in cognitive behavioral theory may be particularly appropriate in increasing psychosocial adaptation. Such strategies teach individuals to take a larger challenging goal and from it create sub-goals that are easier to attain, which is a process consistent with hope theory [5,27].

4.3. Practice implications

In this study, perceived uncertainty was negatively associated with caregiver age and also was a significant predictor of psychosocial adaptation. Although directionality could not be assessed, uncertainty theory and stress and coping theories classify uncertainty is an antecedent of adaptation [4,6], therefore techniques aimed at reducing uncertainty may help caregivers adapt to their child's condition. This study provides further evidence of the unique contribution of hope in psychosocial adaptation in caregivers of children with DS. While more research is needed to develop specific hope interventions, in general, health care providers can aim to facilitate discussions around what caregivers are hoping for and assess to what extent having that hope is adaptive for them. Hope is most likely to be adaptive when it is generated by the individual rather than the health care provider and if it is congruent with the individual's value system [28]. Our data indicate that the ability of caregivers to think of ways to reach the goals they have for their child was associated with adaptation whereas motivation was not; therefore, caregivers may especially benefit from assistance by health care providers in identifying new pathways or opportunities related to goals for their child and reinforcing the ones they have come up with on their own.

Acknowledgments

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Table 1

Demographic characteristics of study population.

Demographic characteristics	n	%
Race		
White	423	94.0
Asian	10	0.022
Black/African American	8	0.017
American Indian/Alaska Native	7	0.016
Native Hawaiian/Pacific Islander	2	0.004
Ethnicity		
Not Hispanic or Latino	400	93.9
Hispanic or Latino	26	6.1
Relation to child		
Biological mother	406	91.0
Biological father	22	4.9
Adoptive mother	12	2.7
Adoptive and biological mother	2	0.4
Foster mother	1	0.2
Sister	1	0.2
Grandmother	1	0.2
Guardian	1	0.2
Highest level of education completed		
Post-graduate	152	34.5
Completed college	160	36.3
Some college	83	18.8
Technical school	15	3.4
High school/GED	31	7.0
Elementary/junior high	0	0
Marital status		
Married	398	89.0
Separated/divorced	28	6.3
Single/never married	13	2.9
Widowed	8	1.8
Annual income		
Greater than $70,000	269	61.8
$50,001–70,000	87	20.0
$30,000–50,000	50	11.5
Less than $30,000	29	6.7
Child's gender		
Male	236	54.0
Female	201	46.0
Time of child's diagnosis		

Demographic characteristics	*n*	*%*
Postnatal	366	85.3
Prenatal	63	14.7
DS support group membership		
Member	361	83.8
Non-member	70	16.2

Table 2

Main study variables.

Variable	Mean ± SD	Range	Cronbach's alpha	*n*
Perceived uncertainty	2.17 ± 0.515	1.03–4.19	0.902	488
Hope (for self)	6.63 ± 0.875	2.88–8.0	0.883	544
Hope (for child)	6.64 ± 0.900	3.0–8.0	0.865	475
Adaptation	4.23 ± 0.593	1.5–5.0	0.938	528

Table 3

Adaptation multiple regression model ($n = 421$).

Model (R² = 0.130)	Unstandardized coefficients		Standardized coefficients Beta	t	Sig.
	B	Std. error			
(Constant)	3.089	0.281		10.985	<0.001
Hope	0.216	0.033	0.309	6.483	<0.001
Uncertainty	−0.132	0.054	−0.116	−2.440	0.015

Table 4

Correlations of caregiver adaptation with hope in goal categories.

Hope in goal category (Agency)	Correlation with adaptation	p-Value	n	Hope in goal category (Pathways)	Correlation with adaptation	p-Value	n	z-Score for comparing 2 correlations	2 Tailed p-value
Social skills	0.076	0.108	451	Social skills	0.279	<0.001	448	−3.139	0.0017
Behavior	0.032	0.503	431	Behavior	0.257	<0.001	430	−3.365	0.0008
Learning/education	0.070	0.148	432	Learning/education	0.212	<0.001	432	−2.135	0.0328
Physical health	0.033	0.499	433	Physical health	0.169	<0.001	431	−2.026	0.0428
Mental health	0.055	0.275	391	Mental health	0.222	<0.001	389	−2.373	0.0176
Independence	0.045	0.357	421	Independence	0.191	<0.001	422	−2.147	0.0318