NIH Public Access
Author Manuscript
Clin Genet. Author manuscript; available in PMC 2008 December 12.

Published in final edited form as:
Clin Genet. 2008 November ; 74(5): 401–407. doi:10.1111/j.1399-0004.2008.01088.x.

Adaptation to living with a genetic condition or risk: Mini-review

Barbara Biesecker and
National Human Genome Research Institute, National Institutes of Health

Lori Erby
Johns Hopkins School of Public Health, Health, Behavior and Society

Keywords

Adaptation; Living with a genetic condition; Genetics services; Interventions

Clinical geneticists and genetic counselors understand quite well the impact of genetic conditions and risk on individuals, parents and families. The impact is loss; loss of one's previous identity as a healthy person or loss of one's expectations for having a baby without difference or medical compromise. This loss is not unique to genetic conditions or birth defects as it occurs when one receives a diagnosis of a serious acute illness or chronic condition. The diagnosis of any condition that significantly threatens one's health leads to stress. Most affected individuals, parents and families manage the stress, and some demonstrate remarkable resilience. About a third, however, fail to adjust well to the stress of a genetic condition or risk (1,2). These patients can benefit from help offered by their health care providers.

A contemporary definition of genetic counseling concludes with the goal of facilitating adaptation to a genetic risk or condition (3). Genetics health care providers frequently use "adaptation" in describing their patients. For example, "the Smiths seem to be adapting well to John's condition." It is a familiar term that suggests that a patient or family is doing well psychosocially and functionally. Yet in the professional literature it is unclear what is meant by adaptation and how genetics health care providers can facilitate it.

Generally, adaptation refers to the process of coming to terms with the implications of a health threat and the observable outcomes of that process. In the health psychology literature there are a variety of descriptors and definitions of adaptation, complicated by the use of the synonyms "adjustment" and "acceptance." Other concepts closely tied to adaptation are quality of life and psychological well-being. Livneh and Antonak define it as "a)…cognitive reconciliation of the condition, its impact, and its chronic or permanent nature; b) an affective acceptance, or internalization, of oneself as person with a condition, including a new or restored sense of self-concept, renewed life values, and a continued search for new meanings; and c) an active pursuit of personal, social and/or vocational goals, including successful negotiation of obstacles encountered during the pursuit of these goals (4)." The variation and complexity in the process or desired outcomes described as "adaptation" reflect the current empirical and theoretical state of adaptation research. The inconsistency reflects the evolution in conceptualizing what it means for an individual, parent or family to adapt to a genetic condition or risk and for developing, using and studying interventions that may facilitate it.

Adaptation has been studied in adults with a variety of conditions, primarily those with the greatest public health impact; for example, cancer, cardiovascular disease and diabetes (4–9). It has also been studied among adults with disabilities (4). Adaptation of children and parents of children affected with rare conditions including genetic conditions and birth defects has been studied to a more limited degree (10–12). This mini-review summarizes what is known

NIH-PA Author Manuscript
NIH-PA Author Manuscript
NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

about adaptation across chronic diseases and disability, including genetic conditions, and what the evidence suggests for genetics health care providers.

Adaptation as a process

Humans are constitutionally resilient. Resilience is the ability to withstand and rebound from disruptive life challenges, becoming strengthened and more resourceful (13). It entails struggling effectively, working through and learning from adversity and integrating the experience into one's life. The majority of people adapt to a chronic illness or disability over time with little help from health care providers. Yet the more health care providers understand the process, the more opportunity there is to intervene to enhance the process for those who are less successfully adapting; for example, by removing barriers or minimizing predictors of poor adaptation. To do so, providers need to understand what comprises adaptation, how to assess it, and how to intervene.

Adaptation is understood as a multi-dimensional temporal process. At any one point in time, one can be assessed as being more or less well adapted, but that assessment would be expected to change with time. The multidimensionality of adaptation has led to the development of several conceptual models. Comprehensive models account for intra- and inter-personal psychosocial dimensions as well as physical functioning, personality traits, and economic resources (4,14). While each of these domains influence adaptation, we focus on stress and coping models because they represent a central component of adaptation. In these models, important contextual factors such as character traits and economic resources are excluded. While, for example, an optimistic person of higher means may adapt more readily than a pessimistic person of lower means, personality traits and economic status are circumstances largely beyond the control of providers. Stress and coping models highlight concepts that providers can influence. We look first to Shelley Taylor's Theory of Cognitive Adaptation (15).

When a diagnosis of a genetic condition or birth defect is made, for example, parents of an affected child first inquire about what the condition is and why it has occurred. "Why?" refers to understanding the cause within a greater search for meaning. From her research with breast cancer patients and others faced with a health threat, Taylor describes the necessity of finding meaning in the experience as an important early task in adaptation (15). One aspect of finding meaning involves identification of cause, referred to as the formation of causal attributions.

Genetics providers are often involved in discussions with parents about genetic or developmental causes of their child's condition or with adults affected with a genetic condition. Affected individuals and parents of affected children often hold several different causal attributions, such as family history, God's will and stress (16). Each attribution helps them to make sense of what happened, even when the causes seem to conflict. If one believes that a condition arose as a result of stress, for example, one can strive to avoid it in the future. This does not preclude one believing it was God's will that it happened or that genetics played a role.

Further, parents seek to find existential meaning in their child's condition. This process aims to understand WHY they came to be in the situation. When health care providers become involved in the existential journey of their patients they are afforded opportunities to help families integrate scientific understandings of cause with metaphysical or spiritual ones. Taylor's research findings remind us that adults are capable of holding multiple causal attributions and that scientific ones need not trump existential ones. Geneticists help families adapt when they avoid suggesting that a scientific cause is the only or the most important causal attribution.

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

Geneticists are often involved in another task of adaptation described by Taylor as regaining mastery or control over one's life. A diagnosis is initially disruptive and leaves parents or an individual feeling out of control. They seek ways to regain feelings of control by learning as much they can about the condition, taking control over aspects of medical care, joining support groups, striving to achieve a good outcome for themselves or their child, finding the best schools or other resources, and finding ways to meet their own or their child's needs. With respect to families with children affected with a genetic condition, all of these activities have tangible benefits for the child but they also help parents to regain feelings of control over their child's well-being. In a situation where they are not able to control whether the child is affected, they can control aspects of how the condition will affect their child and their family. At the end of this review we discuss ways that genetics providers can suggest opportunities for parents or individuals to regain control as a means of facilitating adaptation.

Ultimately, Taylor describes restoration of self-esteem as a further step in the process of adaptation (15). Studies indicate that those affected with chronic illness are often able to describe personal growth that results from their illness, resulting not only in restoration but even enhancement of self-esteem. Taylor described "positive illusions" or indications of renewal and hopefulness. Parents of children with genetic conditions do not necessarily prefer that their children are affected, but they similarly describe personal growth resulting from their experience, testimony to Taylor's findings.

Overall, Taylor identifies three central components to the process of adaptation-a search for meaning, efforts to regain mastery or control and restoration of self-esteem-that individuals, parents and families accomplish over time. Defining the outcomes of this process helps providers to recognize whether someone has indeed "adapted."

Adaptation as an outcome

How individuals adapt (as a process) and whether they adapt (as an outcome of having a condition) are distinct but related empirical questions. Descriptions of the process of adaptation suggest the existence of an outcome of positive adjustment to chronic illness, but they often fail to reveal observable indicators of the outcome of that process. Stanton and colleagues found at least five concepts related to positive adjustment in a literature review of adaptation to chronic disease (17): successful performance of adaptive tasks, absence of psychological disorder, low negative affect and/or high positive affect, functional status and appraisals of satisfaction or well-being. These concepts are measured distinctly using, for example, successful achievement of illness-related activities, absence of depressive symptoms, positive psychological well-being or high quality of life. These concepts, captured at any one time, can be thought of as a function of the complex multi-dimensional interplay among components of the adaptation process. Like the process, each outcome can be described as having intra- or interpersonal dimensions.

Intra-personal dimensions of adaptation outcomes are cognitive (self-esteem), affective (lack of depressive symptoms) and behavioral (functional status). *Inter-personal* dimensions relate to relationships with family and friends. These various dimensions are interrelated. For example, depressive symptoms may be correlated with low self-esteem. Researchers concur that adaptation is not merely the absence of pathology (18). A lack of depressive symptoms, for example, is not sufficient to suggest positive adaptation. Thus, assessment of adaptation state involves several dimensions of parents' or individuals' lives, including self-esteem, positive affect, successful coping and successful re-integration into the lives of family and friends.

We present next Lazarus and Folkman's Transactional Theory of Stress and Coping in which adaptation is the outcome that follows from primary and secondary appraisals and coping

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

(19). Appraisals are perceptions of one's ability to manage the stress of a health threat, and they lead to choices of coping strategies. Lazarus and Folkman's model is the most widely used model to frame research on adaptation to a chronic health threat. There exists significant empirical evidence for its usefulness in predicting coping and adaptation (20). Findings suggest that appraisals are important predictors of adaption and ones that providers can enhance. For example, if a patient cannot envision a strategy to manage their condition, a provider could help to identify one that the patient feels s/he could implement.

Maes and colleagues elaborated on Lazarus and Folkman's model with the addition of the influence of individuals' life goals on adaptation to a condition (21). The more one's central life goals are threatened by the condition, the more stressful the situation may be and the more difficult it will be to adapt. Thompson and colleagues further expanded the model to include family functioning in an effort to understand family adaptation to the stress of a condition (22). Studies of families with children affected with cystic fibrosis and sickle cell anemia provide support for the expanded model with the model's variables accounting for up to 68% of the variance in familial adaptation to these conditions (23).

Zimmerman and Tansella expanded the Transactional Stress and Coping Model to a biopsychosocial model (24). Indicators of neuroendocrine and immune function appear as biological responses to stress and mediators of the relationship between coping and adaptation. The model further includes affect in recognition of Taylor's positive illusions, which in her theory appear as outcomes of adaptation but can also serve as moderators of the process. The biopsychosocial model is new and relatively untested but includes an expanded group of predictors, suggesting further the limitations of linear or simple models and the complexity of assessing the components of adaptation and their inter-relationships.

Overall, adaptation is a dynamic process that is difficult to capture at a single point in time. However, understanding how a patient is functioning according to several different outcomes at a given time point provides some evidence of how effectively the patient is managing the stress of their condition. Despite expected variation over time, longitudinal studies of children with cystic fibrosis and their mothers have demonstrated relative stability in adaptation assessed over multiple time points (23), supporting some value in cross-sectional assessments.

Adaptation to chronic illness

Several studies have examined adults' adjustment to chronic illness across different conditions (25). Overall, individuals affected with chronic illness have comparable levels of adjustment, and these levels have been shown to be more positive than those of depressed outpatients (4). Similarly, social support has been shown to be associated with positive adaptation across chronic conditions (8,26–28).

Two broad conclusions can be drawn from the descriptive studies on adjustment to chronic illness (17). First, most individuals adjust well to chronic illness over time. Researchers caution however that this could be due to shifting comparison standards so that affected individuals compare themselves to others affected with the same condition rather than to unaffected individuals or to to their former selves. Taylor and Brown attribute this to the pervasive human tendency toward positive self-evaluation (29). It is also possible that chronic illness has a somewhat circumscribed, rather than a global, impact for most people (17). Secondly, considerable variability has been shown in psychological adjustment across studies and across individuals. The variation may be attributed to differences in outcome measures. Yet some variation may be explained by the differences in variables in the stress and coping models, such as the effectiveness of coping strategies and the availability of social support.

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

Adaptation to genetic conditions

Overall, far more studies have assessed distress among children and adults living with genetic conditions than have addressed the process or outcomes of adaptation. In a meta-analysis of 87 studies on adaptation of children to chronic physical illness, including cystic fibrosis and sickle cell anemia, adjustment problems including somewhat lower self-esteem were identified with greater frequency (30).

Occasionally studies reveal that coping is ineffective at managing the stress of a genetic condition. A recent study of adaptation to vision loss among 33 adults with retinitis pigmentosa found that participants had difficulties in health care-related, vocational, social and familial domains. When compared to diabetic patients, they were more poorly adapted (31). Similarly, a study of adults with myotonic dystrophy demonstrated severely impaired adaptation (32). Adaptation is more difficult in progressive disorders as individuals have to adapt to a moving target. One may adapt to a certain state of the condition, but when it worsens it adds new stress and initiates a cyclical process.

Studies of adaptation to genetic conditions have been largely descriptive but some explore variables that predict positive outcomes. Studies of adults with cystic fibrosis and spina bifida identify effective coping strategies that result in better interpersonal relationships and social functioning (33). Studies of parents of children with cystic fibrosis, sickle cell anemia, fragile X syndrome, and “rare” disorders also identify effective coping as a predictor of relatively positive adaptation to their child’s condition (11,12,22). Findings generally emphasize the usefulness of emotion-focused coping for situations that cannot be altered and of task-focused coping for aspects that can be addressed (34). Collectively, these researchers call for additional studies into identification of factors that predict less adaptive outcomes to identify interventions that can enhance the process, highlighting the need for familial interventions.

Several broad conclusions can be drawn from the literature on adaptation among children, parents and families affected with genetic conditions. First, findings suggest that the disorder (severity) does not predict adaptation. While the amount of stress generated depends in part on the chronicity, lethality, and severity of the condition, there are mediators of these variables, including the ability and desire to access the cognitive resources needed to adapt. Second, while the majority of affected individuals adapt well, there are those who are less successful at coping and would benefit from interventions. Third, children’s adaptation parallels that of their parents, specifically the mother’s. Yet there is little agreement on degree of adaptation in children among informants. Parents, siblings and health care providers assess information about children’s adaptation differently. To understand adaptation in children, multiple informants need to be studied. One approach is to study adaptation within families.

Well-designed studies using newer methods such as social network models will capture the complex structure of communication and familial interactions amongst members. Findings can be used to develop interventions aimed at the less adaptive interactions.

Similar to our cautions from the literature on adaptation to chronic illness, the ways adaptation is defined and measured varies significantly among studies and limits our ability to fully understand the process or its outcomes. While most recent studies of adaptation to genetic conditions consider adaptation to be a multi-dimensional concept, studies vary in both their choice of dimensions and measurement scales, selecting from a menu of distinct measures of psychological distress, self-esteem, physical or social functioning, or general sense of well-being. Much of this work has emphasized measures of psychological distress (including symptoms of depression or anxiety), which may more appropriately be viewed as the result of more or less successful adaptation rather than as a measure of adaptation itself. If evidence-based recommendations are to be made with regard to the most effective interventions for

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

improving adaptation, there is a clear need for a multi-dimensional outcome measure that could capture an individual's level of adaptation to living with a genetic condition at a given time point. Based on the expanded stress and coping models, such a measure should capture both intrapersonal and interpersonal outcomes of the process, including cognitive and emotional responses to the condition as well as the condition's impact on self-esteem, social relationships, and the search for spiritual or existential meaning.

Remaining empirical questions

The research summarized is significantly limited by its inconsistencies in conceptualizing adaptation, study design, lack of evidence-based theoretical frameworks, and in choice of outcome measures. Findings from these studies therefore are limited in their empirical and clinical implications. Concepts from evidence-based theories of adaptation should continue to be assessed and revised in well-designed studies according to their effects on adaptation. These studies of adaptation should be framed by central theories across diseases to provide consistency in understanding concepts that influence adaptation using comparable outcomes. Studies should maximize use of validated measures and minimize the social desirability of responses. The more expanded biopsychosocial model of adaptation would provide further understanding of biological indicators of stress and their role as mediators. Adaptation studies should expand beyond individual to include familial adaptation with well-designed multi-dimensional approaches such as social networks. Other models of familial adaptation expanding upon stress and coping theories will benefit from path analysis and other tests of the models themselves and the inter-relatedness of the constructs. In sum, improvements in the definitions, models, constructs, outcomes and assessments of the models of adaptation will all contribute to our understanding of this complex process.

Recommendations for health care providers

Based on the understanding that psychological adaptation to illness occurs through a dynamic process, multidimensional interventions for improving adaptation outcomes have been developed. Studies have tested the effectiveness of a clinical intervention on adaptation and largely demonstrate greater adaptation (22). Such interventions have ranged from the use of an interactive website to specific individual or group counseling sessions (35–40). Although the design and emphasis of these programs have varied depending upon the age of the target population and the nature of the targeted illness, each has attempted to have an impact in several key psychological processes suggested by the theoretical understanding of adaptation: finding meaning, fostering a sense of personal control, restoring self-esteem, and reappraising personal resources. The existing evidence suggests that these interventions are able to positively affect patient outcomes such as feelings of self-worth, depression, anxiety, and physical functioning. Although evaluations have focused on comprehensive, multi-component interventions designed to simultaneously affect more than one aspect of the adaptation process, elements of these interventions can be incorporated into routine genetics practice.

Interventions designed to assist in the process of finding meaning within the illness experience have provided structured mechanisms for patients to tell the story of their illness, either through directed writing exercises, shared video journals, or verbal processing (34,36,41). This experience of talking or writing about the personal journey allows individuals opportunity for cognitive restructuring that facilitates the development of meaning. By inviting patients to share their personal experiences with genetic conditions, geneticists and genetic counselors not only foster the process of finding meaning, but may also be able to help individuals to integrate the scientific explanations for illness with other causal explanations.

Geneticists may also be able to assist with patients' needs to gain control over some aspect of the genetic condition. While the ability to control the course of the condition or even some

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

symptoms may be limited, patients benefit from finding a sense of control in other ways (38, 39,42,43). Within the context of a genetics visit, the geneticist has the opportunity to strategize with the patient about controllable aspects of their condition. The provider can help the patient identify concrete ways of gaining some control, including finding information about the condition, managing what information about the condition is disclosed to others, developing positive responses to stressful situations, or making treatment and management decisions that are consistent with the patient's goals. Patients may also benefit from brief interventions designed to enhance their feelings of self-worth (35,38,42,43). Through the process of listening to the patient's illness experience, a geneticist may be able to help identify and emphasize the patient's personal strengths. For instance, a patient that is frustrated with a lack of athletic prowess may be redirected to focus on achievements in academics or social endeavors.

Another way in which genetics providers can promote the psychological adaptation of their patients is through assisting with the process of reappraising personal resources that may facilitate the development of active coping strategies (40,42,44). For example, genetics providers can help parents or adults assess their strengths in managing health-related stress. Finding examples of past successes can help individuals to identify strategies that they can apply to current or future challenges.

Although geneticists are faced with time pressures when managing each patient's visit, the appropriately-timed use of any one of the interventions described above may facilitate a patient's on-going process without greatly extending the length of the visit. A one-time intervention can have an effect on an individual's adaptation as the skills presented can be effectively adopted in the absence of a long-term relationship with a patient. While many patients may also benefit from referral to more intensive multi-dimensional psychological interventions, the strategies described above can be used by genetics providers within regularly scheduled visits to help facilitate positive psychological adaptation for patients with genetic conditions and their family members.

In the rapidly evolving field of clinical genetics, more risk information and diagnoses will be shared and the need for adaptation expanded to a greater sector of the general population. The uncertain nature of new genetic risk and diagnostic information will add a layer of difficulty in achieving adaptation. Uncertainty challenges the identification of effective coping resources and interferes with positive adaptation. We can expect the adaptation process to become more difficult for those receiving genetic information that poses a threat to their health and well-being. Thus, the need for better studies and effective interventions, particularly for managing uncertainty, will be increasingly important to the future of effective clinical genetics practice.

"I believe in adaptation… But adaptation is not the same as becoming tolerant of or inured to something. Adaptation allows for creative possibilities." Donald Rosenstein, M.D., Clinical Director, NIMH/NIH, father of a son, Kobe, who has autism (45).

Acknowledgements

Part of the research for this manuscript was funded by the intramural research program of the National Human Genome Research Institute, National Institutes of Health.

References

1. Barakat LP, Linney JA. Children with physical handicaps and their mothers: The interrelation of social support, maternal adjustment and child adjustment. Journal of Pediatric Psychology 1992;17:725–739. [PubMed: 1484335]
2. Canam C. Common adaptive tasks facing parents of children with chronic conditions. Journal of Advanced Nursing 1993;18:46–53. [PubMed: 8429167]

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

3. Resta R, Biesecker B, Bennett RL, Blum S, Hahn SE, Strecker MN, Williams JL. A new definition of genetic counseling: National Society of Genetic Counselors' Task Force Report. Journal of Genetic Counseling 2006;15(2):77–83. [PubMed: 16761103]
4. Livneh H, Antonak R. Psychological adaptation to chronic illness and disability: A dimensional perspective. Psychological reports 2005;97:577–586. [PubMed: 16342588]
5. van't Spijker A, Trijsburg RW, Duivenvoorden HJ. Psychological sequelae of cancer diagnosis: A meta-analytical review of 58 studies after 1980. Psychosomatic Medicine 1997;59:280–293. [PubMed: 9178339]
6. Anderson BL, Anderson B, deProsse C. Controlled prospective longitudinal study of women with cancer: I. Sexual functioning outcomes. Journal of Consulting and Clinical Psychology 1989;57:683–691. [PubMed: 2600238]
7. Anderson BL, Anderson B, deProsse C. Controlled prospective longitudinal study of women with cancer: II Psychological outcomes. Journal of Consulting and Clinical Psychology 1989;57:692–697. [PubMed: 2600239]
8. Ell, K.; Dunkel-Schetter, C. Social support and adjustment to myocardial infarction, angioplasty, and coronary artery bypass surgery. In: Shumaker, SA.; Czajkowski, SM., editors. Social support and cardiovascular disease. New York: Plenum; 1994. p. 301-332.
9. Cox DJ, Gonder-Frederick L. Major developments in behavioral diabetes research. Journal of Consulting and Clinical Psychology 1992;60:628–638. [PubMed: 1506511]
10. Thompson SC, Nanni C, Levine A. Primary versus secondary and central versus consequence-related control in HIV-positive men. Journal of Personality and Social Psychology 1994;67:540–547. [PubMed: 7965603]
11. Bailey DB, Sideris J, Roberts J, Hatton D. Child and genetic variables associated with maternal adaptation to fragile X syndrome: a multidimensional analysis. American Journal of Medical Genetics A 2008;146(6):720–729.
12. Dellve L, Samuelsson L, Tallborn A, Fasth A, Hallberg LRM. Stress and well-being among parents of children with rare diseases: a prospective intervention study. Journal of Advanced Nursing 2006;53(4):392–402. [PubMed: 16448482]
13. Rolland JS, Walsh F. Facilitating family resilience with childhood illness and disability. Current opinions in pediatrics 2006;18:527–538.
14. Thompson, RJ.; Gustafson, KE. Adaptation to chronic childhood illness. Washington DC: American Psychological Association; 1996. Models of adaptation to chronic illness; p. 133-156.
15. Taylor S. Adjusting to threatening events: A theory of cognitive adaptation. American Psychologist 1983;38:1161–1173.
16. Costanzo ES, Lutgedorf SK, Bradley SL, Rose SL, Anderson B. Cancer attributions, distress, and health practices among gynecological cancer survivors. Psychosomatic Medicine 2005;67(6):972–980. [PubMed: 16314603]
17. Stanton, AL.; Collins, CA.; Sworowski, LA. Adjustment to chronic illness: theory and research. In: Baum, A.; Reverson, TA.; Singer, JE., editors. Handbook of Health Psychology. New Jersey: Lawrence Erlbaum; 2001. p. 387-403.
18. Diener, GM.; Larsen, RJ. The experience of emotional well-being. In: Lewis, M.; Haviland, JM., editors. Handbook of emotions. New Jersey: Lawrence Erlbaum Associates; 1993. p. 405-415.
19. Lazarus, RS.; Folkman, S. Stress, appraisal, and coping. New York: Springer; 1984.
20. Zakowski SG, Hall MH, Klein LC, Baum A. Appraised Control, coping, and stress in a community sample: A test of the goodness-of-fit hypothesis. Annals of Behavioral Medicine 2001;23:158–165. [PubMed: 11495216]
21. Maes, S.; Leventhal, H.; De Ridder, DTD. Coping with chronic diseases. In: Zeidner, M.; Endler, N., editors. Handbook of coping: Theory, research, applications. New York: Wiley; 1996. p. 221-251.
22. Thompson RJ, Gustafson KE, George LK, Spock A. Change over a 12-month period in the psychological adjustment of children and adolescents with cystic fibrosis. Journal of Pediatric Psychology 1994;19:189–203. [PubMed: 8051602]
23. Thompson, RJ.; Gustafson, KE. Adaptation to chronic childhood illness. Washington DC: American Psychological Association; 1996. Psychological adjustment of children with chronic illness; p. 57-86.

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

24. Zimmerman C, Tansella M. Psychosocial factors and physical illness in primary care: Promoting the biopsychosocial model in medical practice. Journal of Psychosomatic Research 1996;40:351–358. [PubMed: 8736415]
25. Cassileth BR, Lusk EJ, Strouse TB, Miller DS, Brown LL, Cross PA, Tenaglia AN. Psychosocial status in chronic illness: A comparative analysis of six diagnostic groups. New England Journal of Medicine 1984;311:506–511. [PubMed: 6749208]
26. DeVellis, BM.; Revenson, TA.; Blalock, SJ. Rheumatic disease and women's health. In: Gallant, SJ.; Keita, GP.; Royak-Schaler, R., editors. Health care for women: Psychological, social, and behavioral influences. Washington DC: American Psychological Association; 1997. p. 333-347.
27. Blanchard CG, Albrecht TL, Ruckdeschel JC, Grant CH, Hemmick RM. The role of social support in adaptation to cancer and to survival. Journal of psychosocial oncology 1995;13:75–95.
28. Helgeson VS, Cohen S. Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research. Health Psychology 1996;15:135–148. [PubMed: 8681922]
29. Taylor SE, Brown JD. Illusion and well-being: A social psychological perspective on mental health. Psychological Bulletin 1988;103:193–210. [PubMed: 3283814]
30. Lavigne JV, Faier-Routman J. Psychological adjustment to pediatric physical disorders: A meta-analytic review. Journal of Pediatrics 1992;17:133–158.
31. Jangra D, Ganesh A, Thackray R, Austin L, Ulster A, Sutherland J, Levin AV. Psychosocial adjustment to visual loss in patients with retinitis pigmentosa. Ophthalmic Genetics 2007;28(1):25–30. [PubMed: 17454744]
32. Antonini G, Soscia F, Giubilei F, De Carolis A, Gragani F, Morino S, Ruberto A, Tatarelli R. Health-related quality of life in myotonic dystrophy type 1 and its relationship with cognitive and emotional functioning. Journal of Rehabilitation Medicine 2006;38(3):181–185. [PubMed: 16702085]
33. Abbott J, Hart A, Morton A, Gee L, Conway S. Health-related quality of life in adults with cystic fibrosis: the role of coping. Journal of Psychomatic Research 2008;64(2):149–157.
34. Walker JG, Jackson HJ, Littlejohn GO. Models of adjustment to chronic illness: Using the example of rheumatoid arthritis. Clinical Psychology Review 2004;24:461–488. [PubMed: 15245831]
35. DeMaso DR, Gonzalez-Heydrich J, Dahlmeier Erickson J, Pagan Grimes V, Strohecker C. The Experience Journal: A computer-based intervention for families facing congenital heart disease. Journal of the American Academy of Child and Adolescent Psychiatry 2000;39(6):727–734. [PubMed: 10846307]
36. Scott JL, Halford WK, Ward BG. United we stand? The effects of a couple-coping intervention on adjustment to early stage breast or gynecological cancer. Journal of Consulting and Clinical Psyhchology 2004;72(6):1122–1135.
37. Beale IL. Scholarly literature review: Efficacy of psychological interventions for pediatric chronic illnesses. Journal of Pediatric Psychology 2006;31(5):437–451. [PubMed: 16162841]
38. Wagner JL, Smith G. Psychosocial intervention in pediatric epilepsy: A critique of the literature. Epilepsy and Behavior 2006;8:39–49. [PubMed: 16246636]
39. McLaughlin TJ, Aupont O, Bambauer KZ, Stone P, Mullan MG, Colagiovanni J, Polishuk E, Johnstone M, Locke SE. Improving psychologic adjustment to chronic illness in cardiac patients: The role of depression and anxiety. Journal of General Internal Medicine 2005;20:1084–1090. [PubMed: 16423095]
40. Last BF, Stam H, Onland-van Nieuwenhuizen A, Grootenhuis MA. Positive effects of a psycho-educational group intervention for children with a chronid disease: First results. Patient Education and Counseling 2007;65:101–112. [PubMed: 16870387]
41. Smyth JM, Stone AA, Hurewitz A, Kaell A. Effects of writing about stressful experiences on symptom reduction in patients with asthma or rheumatoid arthritis: A randomized trial. Journal of the American Medical Association 1999;281(14):1304–1309. [PubMed: 10208146]
42. Thompson RJ, Gustafson KE, Gil KM, Godfrey J, Bennett Murphy LM. Illness specific patterns of psychological adjustment and cognitive adaptational processes in children with cystic fibrosis and sickle cell disease. Journal of Clinical Psychology 1998;54(1):121–128. [PubMed: 9476716]
43. Hocking MC, Lochman JE. Applying the transactional stress and coping model to Sickle Cell Disorder and Insulin-Dependent Diabetes Mellitus: Identifying psychosocial variables related to adjustment

NIH-PA Author Manuscript

NIH-PA Author Manuscript

NIH-PA Author Manuscript

and intervention. Clinical Child and Family Psychology Review 2005;8(3):221–246. [PubMed: 16151619]

44. Livneh H, Wilson LM, Duchesneau A, Antonak R. Psychosocial adaptation to epilepsy: The role of coping strategies. Epilepsy and Behavior 2001;2:533–544. [PubMed: 12609387]
45. www.npr.org.