

# Adaptation to Chronic Physical Conditions: Why Should We Ask the Children, and How?

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## Abstract

Paediatric research and practice often centre upon adult perspectives rather than those of children and adolescents themselves. This paper argues for a need to explore children's own views of living with a chronic condition, an approach consonant with a view of children as active copers and constructors of their experiences rather than victims and passive health care recipients. It also accords with social ecological and systemic approaches to illness, and with multi-informant approaches to clinical child psychology. The value of multiple methods and their implications for gaining information from children are discussed. The quantitative methods typically employed in paediatric psychology research have an important place, though care must be taken in choice of instruments, as those devised for healthy children may unfairly pathologise those with chronic conditions or overlook issues important for them. The value of qualitative methods is also increasingly recognised in this field, not only because of their usefulness in exploring little-understood phenomena and rare conditions, but because of an increasing desire to understand the lived experiences of children and adolescents. Finally, case studies have an important role, especially as we begin attempts to convert research findings into clinical practice. Asking the children can both complement and challenge the perspectives of the adults charged with their care.

## Children's Adaptation to Chronic Physical Conditions

Increasing numbers of children in industrialised societies are living with chronic physical conditions: as medical and surgical techniques improve, more children with life-threatening physical conditions, such as diabetes and cancer, are surviving, while the prevalence of some conditions, such as asthma, is increasing (Newacheck & Taylor, 1992). Such conditions often involve a strong element of self-management by the child and family such as the need to eat and exercise appropriately and take medications. There may be frequent medical appointments, surgeries or unpleasant treatments such as injections, bone marrow aspirations or chemotherapy. Some children whose condition is less life-threatening, but has functional and social implications (such as cleft lip) face many similar issues. This paper argues that paediatric psychology researchers should be doing more to gain the perspectives of children themselves on living with such conditions.

A frequently-cited definition of a chronic physical condition is one that: interferes with daily functioning for more than 3 months in a year, or; causes hospitalisation for more than 1 month in a year, or; is thought at diagnosis to be likely to have either of these results (Pless & Pinkerton, 1975). The numbers of children concerned varies according to what conditions and degree of severity are included, and figures ranging from 5% to 30% are variously quoted. A US survey in 1992 estimated that 31% of children under 18 have a chronic condition, consisting of 20% with a mild condition (which is not very bothersome or limiting of activities), 9% with a moderately bothersome or limiting condition and 2% where the condition is severe, in being frequently bothersome and limiting (Newacheck & Taylor, 1992).

A large body of research has emerged over the last thirty years investigating the psychosocial adaptation of these children, although the direct translation of these findings into clinical practice is much rarer. Initial research focused upon examining whether children with chronic conditions were more at risk of psychosocial difficulties than other children. Overall, they seem to be twice as likely as other children to have emotional or behavioural problems in the clinical range (Lavigne & Faier-Routman, 1992). Nevertheless, the majority copes well, and more recently, there has been a move towards determining what factors contribute to better psychosocial adaptation. We should note that estimates of the severity of a condition are not independent of psychosocial functioning (Newacheck & Taylor, 1992): if a child functions very well despite having a chronic condition, the condition will, by definition, be less bothersome and limiting. So we could view the aim of psychosocial interventions to be to reduce the burden of illness and help to move more children into the milder categories of severity.

## Systemic Approaches: The Child as Informant

Today, models of children's adaptation to chronic conditions are typically based upon social ecological and systemic approaches. These recognise that multiple factors, both internal and external to the child, are mutually interactive and impinge upon the child's medical condition and psychosocial adaptation (Shute & Paton, 1992). Among the relevant variables are maternal and child coping; family functioning; child's cognitive ability, self-esteem and peer relationships, and; physical and treatment factors (Wallander, Thompson & Alriksson-Schmidt, 2003). Information from any single informant about a child's adaptation is therefore likely to provide a limited perspective. For example, while parental and

child perceptions of adaptation tend to be positively correlated, this is at a moderate level (Gannoni, 2003), and the unique and shared information from different informants are both important for understanding children's adaptation (Sanson, Finch, Matjacic, & Kennedy (1998). Multi-informant approaches are now advocated in paediatric psychology research, which parallels accepted practice in clinical child psychology, as those familiar with Jerome Sattler's texts (e.g., Sattler, 2002) or the Achenbach System of Emotional and Behavioral Assessment (Achenbach & Rescorla, 2001) will be well aware.

A multi-informant approach to research in this area implies that it is important to gather information from children themselves, yet much paediatric research centres upon adult perspectives. Wallander and Varni (1992) noted limited resources and logistical restrictions leading to heavy reliance on gathering data from mothers. Over a decade later, they are still noting an over-reliance on maternal reports as being a limitation in the field (Wallander et al., 2003). This is an understandable situation, as reliable and valid instruments that are developmentally appropriate and convenient to administer to children are not always available. This is especially so when condition-specific issues need to be addressed, and instruments may have to be modified or specially devised. For example, for one study, we found no instrument to measure perceived family and peer support for the various aspects of adolescents' management of their cystic fibrosis, and had to modify one previously developed for diabetes (Graetz, Shute & Sawyer, 2000). Another example is that, in attempting to devise a child report questionnaire for measuring coping with chronic illness, Spirito found difficulty in obtaining reliable measures, and argued that an interview format might work better (Spirito, 1996). Interviewing and observation, as alternative methods of data collection from children, have some specific strengths (Sattler, 2002), but are time-consuming, especially within the context of large-scale, multifactorial studies. Interviewing children also takes considerable skill and requires specialised training (McConaughy & Achenbach, 2001). The temptation to rely upon a parent-completed questionnaire is therefore strong, and this is usually the mother, as she is the one likely to bring the child to appointments. Fathers, as well as children, therefore tend to be left out of the picture (Gannoni, 2003).

Children's peers are another neglected source of data on adaptation. Work on the peer relationships of children with chronic conditions is relatively sparse (Wallander et al., 2003) despite the acknowledged fact that peer relationships play a crucial part in current and future functioning (Parker, Rubin, Price, & DeRosier, 1995). While it is possible to gather data from the target child, the parent or the teacher, about peer relationships, the peers themselves are a unique source of information. However, in Australia at least, it has become increasingly difficult to carry out research using sociometric measures: we have found that ethics committees increasingly disallow it, because of concerns about potentially damaging effects on participants. This is another way, then, in which children's valuable perspectives are not being heard.

In the paediatric setting, the persistence of a paternalistic mode of care might be one reason for neglecting children's views (Garth & Aroni, 2003). One aspect of this might be a desire to protect them from what are seen as sensitive issues. It has been suggested (in the context of grief and loss) that this approach has more to do with protecting adults in maintaining a view of children as happy and innocent creatures, while leaving children isolated (Irizarry, 1987). A lack of interest in children as informants in paediatric settings is evidenced through a dearth of research on child-practitioner, as compared with adult-practitioner, communication; this is especially the case for children with disabilities (Garth & Aroni, 2003). Client empowerment and participation in clinical practice have come much more to the fore recently, with arguments being made that, in keeping with the UN Convention on the Rights of the Child, children too have right to be heard (Davis, 1998; Garth & Aroni, 2003). Similarly, in the realm of research, we have seen a movement in recent years, promoted by postmodern perspectives, to empower participants, including children (Davis, 1998). Research on coping with illness and medical treatments, by children and adolescents (La Greca, Siegel, Wallander, & Walker, 1992), is one indication of a move in the direction of seeing children as active copers and constructors of their experiences rather than as passive recipients of health care.

It is argued here, then, that children's own perspectives on their situation form an important, but neglected, part of a multi-informant approach within a systemic view of chronic physical conditions. A move in this direction is supported by a philosophical shift in favour of the empowerment of children, both as paediatric patients and as research participants. This gives rise to ethical issues concerning informed consent, confidentiality and protection (Davis, 1998), though these are not addressed in this paper.

## Multiple Methods

As well as being multi-informant, clinical research with children is moving in the direction of using multiple methods. However, in studying adaptation to chronic conditions an over-reliance on paper-and pencil methods (with mothers, as noted previously) has been observed (Wallander et al., 2003). A move towards the use of more diverse data-gathering methods that include children as informants is in line with accepted practice in clinical child psychology, where there is a recognition that any one method of data-gathering has its weaknesses as well as its strengths, as in the case of Sattler's famous "four pillars of assessment" (Sattler, 2002). The quantitative methods typically employed in paediatric psychology research have an important place, though care must be taken in choice of instruments, as those devised for healthy children and adolescents may unfairly pathologise those with chronic conditions (Wallander et al., 2003) or overlook issues important for them. This last point is apparent, for example, in our research on teasing experienced by young people with craniofacial anomalies, where a common measure

of peer aggression fails to capture some of the specific negative peer behaviours experienced by this population (Carroll & Shute, 2005).

The current emphasis on testing complex models of adaptation, using multiple methods and informants, creates some pragmatic problems. In order to collate sufficient participants with chronic physical conditions for studies, multi-site studies are increasingly advocated (Wallander et al., 2003). It is becoming more difficult to place quantitative papers based on fewer variables and smaller samples in top journals, and I fear that PhD students, unless they are attached to specialist research centres with considerable funding and networks of influence, will find it increasingly difficult to publish their work in these journals. I mention this because some of the exciting paediatric psychology research with child informants that I am citing in this paper is being carried out by PhD students in single-site studies.

Having said that, there is some return to the notion that useful research can be carried out, in paediatric psychology, with small numbers of participants, through case studies. The Journal of Pediatric Psychology, established at the end of the 1970s, originally published many case studies and few empirical studies, but over the years, this situation reversed completely, with most papers consisting of large-scale research studies and few case reports (none at all in 1989, for example) (Drotar, La Greca, Lemanek, & Kazak, 1995). This was seen to reflect an increasing divide between paediatric psychology research and practice, and led to a call for more case studies to be submitted, given their advantages such as describing rare clinical phenomena, illustrating new methodologies in practice and to call attention to unmet clinical needs (Drotar et al., 1995).

The value of *qualitative* methods is also beginning to be recognised in this field. These have a particular place in exploring little-understood phenomena and rare conditions (Fiese & Bickham, 1998). There is also recognition that such methods are necessary if we want to understand the lived experiences of children and adolescents. Metaphorically, it has been said that while quantitative methods survey the landscape, qualitative methods mine the depths (McCracken, cited in Brannen, 1992). Clinical expertise in working with children and adolescents is invaluable for carrying out such research since gathering data through methods such as individual interviews and focus groups presents special challenges when the participants are children. I find it interesting that clinically experienced students of mine who have carried out qualitative research projects invariably comment afterwards that they have gained new insights into the lives of their client group and their families. They find this to be true even after working with these families for years and discussing their issues with them clinically. Certain issues just do not seem to emerge within the constraints of normal clinical practice; time and space and the asking of certain pertinent questions seem to be needed. Thus, just as lessons

for research with children can be learned from clinical practice, so can qualitative research usefully feed back into clinical practice in paediatric psychology.

Despite the increasing use of qualitative methods in psychological research, they remain controversial. The problem still arises that one can face journal reviewers and thesis examiners who do not appreciate the philosophical underpinnings of qualitative methods, and evaluate them against inappropriate quantitative standards. The explicit use of identified standards of rigour for qualitative research, such as those articulated by Sandelowski (1986) goes some way towards addressing this problem.

### **“Accentuate the positive”**

I would like to finish by noting that the emphasis of quantitative research in paediatric psychology has been on pathology and difficulty. Questionnaires such as the Child Behavior Checklist and Youth Self Report, invaluable as they are, are mainly aimed at discovering whether or not the child or adolescent has problems that fall into the clinical range. Instruments to measure anxiety, depression, etc., are relatively easy to find, as are clinical interview schedules aimed at discovering whether a child meets the diagnostic criteria for a particular psychiatric condition as defined within DSM or the ICD. Instruments based upon a strengths approach are much rarer. The parent-rated Behavioral and Emotional Rating Scale (Epstein, Harniss, Pearson, & Ryser, 1999) is an exception, and has been used by Roberts in her PhD on coping by young people with craniofacial anomalies (Roberts, 2005). Paediatric psychology is certainly not exceptional in its focus on pathology and, indeed, some in this field have raised warnings about the dangers of pathologising children who are reacting in normal ways to their abnormal situation. As Martin Seligman (1998) has argued, psychology as a whole has for many years had this negative focus, and the Positive Psychology movement, aimed at investigating virtues and strengths, as well as weaknesses, is becoming more influential.

On the face of it, it might seem strange to ask parents and children about the positive aspects of living with a serious chronic condition, yet this can lead to some surprising findings and yield information that has the potential to be used in clinical practice (Gannoni, 2003; Roberts, 2005). It represents a move away from conceptualising these children and their families as victims of the child's condition. I suggested at the beginning that one view of the aim of psychosocial interventions is to reduce the burden of illness and help to move more children into the milder categories; taking a positive psychology approach suggests that this is not enough, and that we should also be seeking to understand ways in which having a chronic physical condition can be a blessing as well as a burden.

Three recent empirical projects by my PhD students are illustrative of the issues raised here. The motivation for all of

them was clinical, with two of them being carried out by clinicians with long experience in working with the client groups in question. Dr. Anne Gannoni carried out a qualitative study with children with several different chronic illnesses; this study complemented a more traditional quantitative study and yielded rich insights into how the young people, and their parents, perceived both the negative and positive aspects of the child's adaptation to a chronic illness (Gannoni, 2003; 2005). Rachel Roberts has also conducted research using complementary quantitative and qualitative methods, with young people with craniofacial anomalies (CFAs) and their parents. The quantitative aspect has provided information about how various coping strategies contribute to the psychosocial adaptation of these young people, while the qualitative part has yielded young people's and their parents' perceptions of the challenges and benefits of having a CFA (Roberts, 2005); the qualitative information provided the basis for the development of a questionnaire for clinical and research use with this population, incorporating both positive and negative aspects. Finally, using quantitative methods, Pam Carroll has challenged the common assumption that young people with CFAs are more teased than other children (Carroll & Shute, 2005) and has developed case studies that explore ways of working clinically with children and families when such victimisation does occur (Carroll, 2005). An overall theme of these projects is that asking young people with chronic conditions about their own experiences, whether through qualitative or quantitative methods, can both complement and challenge the perspectives of adults charged with their care.

## References

- Achenbach, T.M. & Rescorla, L.A. (2001). *Manual for ASEBA School-age scores and profiles*. Burlington VT: University of Vermont, Research Center for Children, Youth, and Families.
- Brannen, J. (1992). Combining qualitative and quantitative approaches: An overview. In J. Brannen (Ed.), *Mixed methods: Qualitative and quantitative research*. Aldershot: Ashgate.
- Carroll, P. (2005). Assumptions about teasing of children with craniofacial anomalies, and recommendations for intervention. *Paper presented to the 40<sup>th</sup> APS Annual Conference, Melbourne, Sept/Oct 2005*.
- Carroll, P., & Shute, R. (2005). School peer victimization of young people with craniofacial anomalies: A comparative study. *Psychology, Health and Medicine, 10* (3), 291-304.
- Davis, J.M. (1998). Understanding the meanings of children: A reflexive process. *Children and society, 12*, 325-335.
- Drotar, D., La Greca, A.M., Lemanek, K., & Kazak, A. (1995). Case reports in pediatric psychology: Uses and guidelines for authors and reviewers. *Journal of Pediatric Psychology, 20* (5), 549-565.
- Epstein, M.H., Harniss, M.K., Pearson, N., & Ryser (1999). The behavioral and Emotional Rating Scale: Test-retest and inter-rater reliability. *Journal of Child and Family Studies, 8*, 319-327.
- Fiese, B.H., & Bickham, N.L. (1998). Qualitative inquiry: An overview for pediatric psychology. *Journal of Pediatric Psychology, 23*, 2, 79-86.
- Gannoni, A. (2003). Children's adaptation to a chronic illness. Unpublished PhD thesis, Flinders University, South Australia.
- Gannoni, A. (2005). Children's perspectives on their chronic illness. *Paper presented to the 40<sup>th</sup> APS Annual Conference, Melbourne, Sept/Oct 2005*.
- Garth, B., & Aroni, R. (2003). 'I value what you have to say'. Seeking the perspective of children with a disability, not just their parents. *Disability and society, 18* (5), 561-576.
- Graetz, B., Shute, R.H., & Sawyer, M. (2000). An Australian study of adolescents with cystic fibrosis: Perceived supportive and nonsupportive behaviors from families and friends and psychological adjustment. *Journal of Adolescent Health, 26*, 64-69.
- Irizarry, C. (1987). *The inner world of the child*. Paper presented to conference on the Social Context of Child Abuse, sponsored by S. Australian Office of the Govt Management Board and & Dept. of Premier & Cabinet, Dec., 1987.
- La Greca, A.M., Siegel, L.J., Wallander, J.L., & Walker, E. (Eds), (1992). *Stress and coping in child health*. New York: Guilford.
- Lavigne, J.V., & Faier-Routman, J. (1992). Psychological adjustment to pediatric physical disorders: A meta-analytic review. *Journal of Pediatric Psychology, 17*, 2, 133-157.
- McConaughy, S.H. & Achenbach, T.M. (2001). *Manual for the semi-structured clinical interview for children and adolescents* (2<sup>nd</sup> edn). Burlington VT: University of Vermont, Research Center for Children, Youth, and Families.
- Newacheck, P.W., & Taylor, W.R. (1992). Childhood chronic illness: Prevalence, severity, and impact. *American Journal of Public Health, 82*, 3, 364-371.
- Parker, J.G., Rubin, K.H., Price, J.M., & DeRosier. M.E., (1995). Peer relationships, child development and adjustment: a developmental psychopathological perspective. In: D. Cicchetti and E. Cohen (Eds), *Developmental Psychopathology, Vol 2: Risk, disorder and adaptation*. New York: Wiley.
- Pless, I.B., & Pinkerton, P. (1975). *Chronic childhood disorder – Promoting patterns of adjustment*. London: Henry Kimpton.
- Roberts, R. (2005). The experience of living with a craniofacial condition: Child, adolescent and parent perspectives. *Paper presented to the 40<sup>th</sup> APS Annual Conference, Melbourne, Sept/Oct 2005*.

- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8 (83), 27-37.
- Sanson, A., Finch, S., Matjacic, E., & Kennedy, G. (1998). Who says? Associations among peer relations and behaviour problems as a function of source of information, sex of child and analytic strategy. In: P.T. Slee and K. Rigby (Eds), *Children's peer relations*. pp.183-204. London: Routledge.
- Sattler, J. (2002). *Assessment of children: Behavioral and clinical applications*. 4<sup>th</sup> edn. San Diego: Sattler.
- Seligman, M. (1998). Building human strength: Psychology's forgotten mission. *APA Monitor*, 29 (1), available 22/05/03 at <http://www.apa.org/monitor/jan98/pres.htm>
- Shute, R.H., & Paton, D. (1992). Understanding chronic childhood illness: Towards an integrative approach. *The Psychologist*, 5, 390-394.
- Spirito, A. (1996). Commentary: Pitfalls in the use of brief screening measures of coping. *Journal of Pediatric Psychology*, 21, 4, 573-575.
- Wallander, J.L., Thompson, R.J., & Alriksson-Schmidt, A. (2003). Psychosocial adjustment of children with chronic physical conditions. In: M.C. Roberts (Ed), *Handbook of pediatric psychology*, pp. 141-158. New York; Guilford.
- Wallander, J.L., & Varni, J.W. (1992). Adjustment of children with chronic physical disorders: Programmatic research on a disability-stress-coping model. In: A. La Greca, L. Siegel, J. Wallander, & E. Walker (Eds), *Stress and coping in child health*, pp. 279-298. New York: Guilford.