A School-Based Self-Management Program for Youth with Chronic Health Conditions and Their Parents

Diane Magyary and Patricia Brandt

The Self-Management Program was a school-based intervention for 65 school-aged children with a chronic health condition and their parents. Through the peer group process, a cognitive-behavioural intervention was used to promote the child’s self-management of the stresses associated with the chronic condition. Groups were also held to support parents in helping the child to use the newly acquired self-management strategies. A pre- and post-test waiting control group design examined treatment effects on therapeutic adherence, child self-responsibility, and child self-efficacy. Children in the intervention group, in comparison to those in the control group, showed significantly higher therapeutic adherence and more self-responsibility in the management of the health condition. By two months, the improvements in self-responsibility had begun to fade as reported by the children, but remained significant as reported by the parents. No significant differences were found on the self-efficacy measure. Goal attainment, child and parent learning, and consumer satisfaction were also found to be evident.

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Introduction

Schools are important centres for providing psychosocial and physical health services to children with chronic health conditions (Meecker, DeAngelis, Berman, Freeman, & Oda, 1986; U.S. Department of Health & Human Services, 1993). Thirty percent of children under 18 years of age are estimated to have chronic conditions (Newacheck, Stoddard, & McManus, 1993). Children with chronic health conditions typically have interrelated physical, psychosocial, and learning problems. Providing psychosocial services within the school setting might improve their accessibility, as only about 20% of children receive services for significant psychosocial problems (Mash & Barkley, 1989).

School-based health programs are best designed to address the commonly experienced needs of children, regardless of the type of chronic condition, as school children are likely to have various types of conditions. Such a non-categorical approach, focusing on the functional needs of children and their families, has been found to be a more meaningful way of designing psychosocial services than an approach based on disease-specific diagnoses (Stein, Bauman, Westbrook, Coupey, & Ireys, 1993).

For youth to cooperate with their parents in caring for their health needs, two major competencies have been found to play a significant role: management of the stresses associated with the chronic condition, and performance of the health-care tasks associated with the condition (McNabb, Wilson-Pessano, & Jacobs, 1986). If interventions are designed to improve only the youth and family’s knowledge and skills relevant to the condition, adherence to the health-care regimen typically remains problematic (Heerman & Wils, 1992; Karoly, 1993). Adherence rates for youth on long-term therapeutic regimens average about 50% (LaGreca, 1989). Adherence difficulties do not uniformly lead to impaired health; however, they are related to extended illness, further cost, and physical complications (Krasnegor, Epstein, Johnson, & Yaffe, 1993; Masek & Jankel, 1982). Development of self-management competencies can serve to facilitate progression of the child’s physical health and psychosocial functioning (Masek & Jankel; Stein & Jessop, 1989).

Self-management interventions have been found to produce behavioural change in children (Delameter, 1993). The majority of intervention studies have targeted health-care tasks associated with a specific condition, particularly diabetes and asthma. They have varied in the type, intensity, and duration of intervention strategies, as well as the outcomes targeted, the age of the youth, and the severity of the disease.
Although these studies have methodological and design limitations, results indicate that the health perceptions and health behaviours of the children can be improved (Agras, 1993; Lewis, Rachelefsky, Lewis, de la Sota, & Kaplan, 1984). The design of most intervention studies directed toward children include only one or two self-management skills, rather than the complete skill package.

Self-management is the ability of the individual to use self-regulatory skills to manage developmental, health, and situational challenges (Karoly & Kanfer, 1982). Self-regulatory skills comprise self-observation, self-instruction, self-monitoring, decision-making, self-evaluation, and reinforcement (Bandura, 1986). Intervention programs that incorporate self-management approaches and target children’s health perceptions and behaviours offer promise for health outcomes (Petosa, 1986; Taggart et al., 1991).

Purpose

The purpose of this study was to evaluate the effectiveness of a self-management, school-based intervention for youth. The following research questions were posed:

- In comparison to the children in the control group, will the children in the experimental intervention group exhibit greater improvement in health perception and health behaviour?
- Will the intervention children and parents achieve their individualized health goals?
- Will the intervention program result in consumer satisfaction and learning?

Theoretical Basis for the Intervention

The intervention was based on a social-cognitive paradigm (Bandura, 1986) and a stress and coping paradigm (Lazarus & Folkman, 1984). The social-cognitive paradigm influenced conceptualization and implementation of the self-management strategies. Self-management was defined as the use of self-regulatory skills for enhancing stress management and building parallel construction of self-efficacy. Self-regulatory skills were designed to enhance self-observation of psychophysiological reaction to stress; self-monitoring of the events that produce the stress response; self-instruction, to guide oneself in stress management behaviours that reduce, inhibit, or change the stress response; decision-making, to determine which skill is likely to be the most appropriate for the sit-
uation; self-evaluation, to identify the usefulness of the skill used; and self-reinforcement of the effort and outcome reached. Changes in the youth's abilities to self-regulate are linked in theory to self-efficacy, which is defined as the perception that one has the ability to manage daily challenges (Bandura).

The stress and coping paradigm provided the framework for the intervention content. The youth's adherence and physiological responses are influenced by stress (Boardway, Delmpter, Timakowsky, & Gutai, 1993; Johnson, 1990). Stress associated with the chronic condition may occur due to treatments, interactions with peers, conflicts with parents, or fear of relapse. Children's avoidant styles of coping, such as detachment and wishful thinking, have been found to be linked to ineffective management of the chronic condition (Auerbach, 1989). Strategies for the self-management of emotions and alteration of the stressful situation were taught to the children in the intervention.

The intervention incorporated emphases on (1) the full range of self-regulatory skills, (2) the child's health perception and health behaviours, and (3) mind-body linkages. These approaches are consistent with the recommendations for child-oriented cognitive interventions (Beck, 1993; Kazdin, 1993; Mahoney, 1993).

**Method**

**Participants**

Two school districts agreed to participate in the study. School personnel, including nurses, teachers, psychologists, and counsellors, identified children with chronic health conditions. Ninety-two percent of the parents and children who were notified agreed to participate. The remaining 8% declined because of schedule conflicts or the possibility that they would be moving out of the school district in the near future. The 65 children and their parents who agreed to participate met the screening criteria; thus the children involved had no serious mental health or cognitive disorder. Their types of chronic condition were primarily long-term physical illnesses such as asthma, arthritis, cystic fibrosis, diabetes, allergies, recurrent headaches, or chronic abdominal pain. Common reasons for referral to the study intervention were child-adherence and self-management problems or stress responses to the chronic health condition. Every child’s health condition was evaluated by his or her physician, who approved participation in the study.

The mean age of the children was 9.5 years (range 7-13 years). The median grade was Grade 4 (range of Grade 2 to Grade 8). The mean age
of the fathers was 40 years and the mean age of the mothers was 37 years. Fourteen children (21%) came from families whose parents were divorced, separated, or widowed. The majority (92%) of the children were Caucasian. Family income ranged from $5,000 to more than $50,000 per year, with a mean range of $25,000 to $29,000. The average education level for mothers and fathers was technical training beyond high school. The children in this study had no other support services immediately prior to or during treatment.

Design

Approval was obtained from the University of Washington Human Subjects Review Committee, according to whose guidelines the completed parent consents and youth assents noted that all participants would receive the intervention at some time during the study. Thus a quasi-experimental pre- and post-test, waiting control-group design was used. Families were randomly assigned to either the intervention or the waiting control group, except for a few families (11%) who requested to be in the waiting control group because of their schedules. Those families who requested a delay in the intervention were not found to differ significantly from the total sample. No family dropped out of the study. The intervention group comprised 29 children, the waiting control group 36 children. Four intervention groups were treated in the fall, with the waiting control groups treated during the winter.

The subjects were divided into treatment groups of six to eight members, to ensure adequate group process. Children were assigned to a treatment group in accordance with their age and geographic location. Since children represented 17 different schools, the intervention was held in centralized school settings.

Measures of moderating variables that could influence the dependent variable were obtained prior to the intervention. The dependent variables were measured immediately before, immediately after, and two months after the intervention. Data were collected in each family’s home by graduate students in pediatric nursing who had clinical experience with children with chronic health conditions and their families. Data collectors attended a 40-hour training session and participated in biweekly two-hour supervisory meetings. Families were asked not to inform the data collectors of the time period in which they received the intervention, and the data collectors had no contact with the nurses who carried out the intervention.
The study’s research design has particular merit for eight reasons: (1) treatment integrity was monitored throughout the study; (2) the nurses who provided the intervention were not those who collected the evaluation data; (3) child and parent learning from and satisfaction with the program were measured; (4) the child and the parent were independent sources of information for the health outcomes, with agreement of results examined; (5) health outcomes were measured in relation to the child’s particular condition, to assess the program relative to the child’s daily life; (6) the health behaviour of self-responsibility was differentiated into two components – the cognitive process of decision-making and the implementation process of administering the healthcare task; (7) health perception and health behaviour were study outcomes; and (8) moderator variables were measured and statistically controlled for their potential influence on the intervention.

**Intervention Conditions**

**Intervention administration, content, and format.** The self-management intervention program had three components: (1) a single two-hour family session held in the home prior to treatment; (2) a dozen 75-minute youth-group sessions, held twice a week for six weeks; and (3) three 90-minute parent-group sessions, held biweekly over six weeks. During the home session the group leader helped the child and parent negotiate and develop a contract, using a modified approach to Kiresuk’s (1976) goal-attainment scale. The contract included a concern, a desired goal with a measurable behavioural change, action steps, and positive reinforcement approaches. The contract was relevant for the youth’s health condition and the intervention. It was used during the group intervention as a way to tailor the curriculum to each child’s experience of the chronic condition. The group facilitator telephoned the parents during the intervention to reinforce their participation in the contract and address the matter of any required changes.

**Child-group sessions** were held in the school, to enhance accessibility and normalization of the intervention. Each session had three parts: (1) warm-up and review (15 minutes); (2) knowledge and skill development (45 minutes), with demonstration, practice, and feedback strategies; and (3) application to the home and school setting through homework assignments, role playing, and completion of handouts (15 minutes). Training in self-regulatory skills and reinforcement by peers and group leaders were incorporated into each session. Periodic sessions were devoted to synthesis and integration of learning. The child-intervention content included the following topics: "I can take
care of me” concept; mind-body connection; individual differences in stress responses; thoughts and feelings regarding “stress triggers”; constructive expressions of stress; relaxation to manage stress; problem-solving; communication to elicit help; positive self-talk; and self-management to “take care of me.”

Parent-group sessions were held at a centralized school location. These sessions focused on enhancing parental understanding of child intervention and encouraging parental coaching and reinforcement of the child’s use of the newly acquired self-regulatory skills. The group leader used an educational format to describe the intervention that the children were receiving. The parents, facilitated by the group leader, generated problem-solving and approaches promoting the child’s use of new skills.

Two graduate nursing students led the child groups. A nurse with a doctoral degree facilitated the parent groups. Each nurse had clinical experience working with children with chronic health conditions and their families. Prior to the intervention, the group leaders completed a one-week training session on group process skills and the intervention content.

Intervention integrity. The content and process of the intervention were monitored and sustained by seven approaches, to assure treatment integrity: (1) A curriculum manual, entitled You Can Take Care of Yourself, was developed, including objectives, content, learning activities, and teaching strategies for each session (Cowan, Brandt, & Maggy, 1988). (2) A content checklist for the curriculum was completed by the group leaders at the end of each session. (3) Weekly supervisory meetings were held with the group leaders and the principal investigators. The in-session notes completed by group leaders were used during these meetings as a means of preparing for the next sessions. (4) Each child’s participation as an individual in the group was evaluated after each session by the group leaders on five process dimensions: interest; receptiveness; understanding; involvement in practice exercises in the classroom, home, and school; and completion of homework. (5) Each child and parent session was evaluated on group process dimensions of cohesion, cooperation, communication, productivity, emotional involvement, cognitive involvement, and conflict. (6) After each child and parent session the group leader completed a self-evaluation on leadership roles as instructor, facilitator, supporter, coordinator, communicator, and energizer. (7) The child-group sessions were randomly selected for videotaping early, mid-point, and late in the intervention program. The purpose of videotaping was to facilitate improvements for future
sessions and to provide for a cross-validity check of the group process evaluations by the group leaders. The group evaluation forms for this study were developed using the principles of group process described by Johnson and Johnson (1987).

Sixty-two percent of the children attended the maximum of 12 sessions; 38% missed one or two sessions. On average, 90% of the curricular content was delivered as planned. Mean ratings of individual child participation in the group process ranged from moderately high to very high on interest, receptiveness, and understanding. Completion of homework and practice of strategies at home or in school were consistently rated low to moderate. Mean ratings of the child-group process dimensions ranged from moderately high to high. Mean ratings of parent-group sessions ranged from moderate to high. The group leaders’ ratings of group process were consistent with the evaluation of the videotapes conducted by an independent rater. Self-performance ratings by the respective group leaders were moderate to high. No significant differences on performance were found across the group leaders or across the groups of children or parents.

Measures

Measures were obtained on the following: family and child characteristics, child health behaviour, child health perception, health-goal attainment, child and parental learning, and child and parental satisfaction with the intervention.

Family and child characteristics. Potential moderators of the intervention effects were selected on the basis of theoretical and empirical work. The child’s mother completed the measures of child and family characteristics. Family characteristics selected were family income, education, and stresses. Income and educational variables were viewed as resources that influence the child’s experience of stress and interest in learning (Lazarus & Folkman, 1984). Family stresses influence the nature of the child’s environment and interactions with others, and thus may affect the potential for the child’s behavioural and attitudinal change (Campbell, 1990; Rutter, 1994). Two types of family stress were identified via questionnaires with established validity and reliability. The family’s major life changes were measured using the Family Inventory of Life Events (FILE), by McCubbin, Patterson, and Wilson (1981). Situational stresses related to the child’s chronic condition were measured using the Impact of the Illness on the Family (Stein & Riessman, 1980).
Child characteristics identified as potential moderators were age, gender, and severity of illness. *Gender* differences with respect to chronic health conditions have been reported in the literature. For example, female teens with a disability, and their parents, have been found to experience more difficulty performing daily activities than their male counterparts (Walker & Greene, 1991). *Age* affects adherence differently, according to the chronic condition. Adherence has been found to decrease with age in children with diabetes (Anderson, Auslander, Jung, Miller, & Santiago, 1990) and to increase with age in children with cancer (Manne, Jacobson, Garfinkle, Gerstein, & Redd, 1993). *Severity of illness* may alter the child’s self-efficacy in association with the lack of predictability in ongoing experiences and the development of learned helplessness (Kutner, Delameter, & Santiago, 1990). The Healy Scale was adapted for this study to measure the degree to which the child’s chronic health condition interfered with daily functioning (Healy, McAreavey, & Von Hippiel, 1978).

**Health behaviour outcomes.** Therapeutic adherence and self-responsibility were measured using a structured clinical interview entitled “Health Adherence and Management Interview” (Magyary, 1988a). The child was interviewed independently of the parents.

The Health Adherence and Management Interview was advantageous in two ways. First, the format allowed for the interview to be conducted in relation to a variety of health conditions, in contrast to instruments that focus on a specific disease. Second, self-responsibility was delineated into two components: decision-making and administration. Measuring responsibility for decision-making separate from administration delineates the child’s developmental progression of self-responsibility and clarifies how individual families manage the condition (Wysocki, Meinhold, Cox, & Clarke, 1990). For example, a child with a chronic health condition may not share responsibility with a parent for decisions about a medication dosage, but rather be totally responsible for administering it.

A percentage score was generated by the Health Adherence and Management Interview for three variables: therapeutic adherence, self-responsibility for decision-making, and self-responsibility for administration. The percentage for the *adherence* score was obtained by having the respondent specify which of the following health-care components were relevant to the child’s condition: medication, special treatment procedures, monitoring procedures, exercise, modification of daily activity, diet, coping strategies, and scheduled visits/phone calls to health professionals identified by the respondent. The number of times
per week the health-care component was prescribed, as well as the number of times per week the health-care component was actually implemented, were identified by the respondent. The frequency of implementation was divided by the frequency of prescription to generate a percentage adherence score for each of the prescribed components. The percentage scores were then averaged across the health-care components.

The self-responsibility score on decision-making was obtained by asking the respondent to rate on a grid the extent to which the child actively participated in decision-making in each identified health-care component. The 10-point grid scale, with 10 as high, was converted into a percentage score for each identified component. A mean percentage for self-responsibility in decision-making was generated by averaging the scores for the identified health-care components. At the follow-up points, the respondent was asked to note any changes on the previously rated grid.

The self-responsibility score on administration was obtained by asking the respondent to repeat the above procedure, but now marking the extent to which the child participated in the administration of each identified component. A mean percentage score was then calculated for self-responsibility for administration.

Health perception outcome. Self-efficacy was defined as the child’s perception that daily life stresses could be handled by his or her learning and using self-management strategies. The Youth Self-Efficacy Scale (YES), by Magyary (1988b), consists of 31 items with a yes/no format. A percentage score was generated, with high scores indicating high self-efficacy. The internal consistency coefficients (Cronbach’s alpha) on the YSES across three time points ranged from .83 to .91. Construct validity was demonstrated by correlations of $r (65) = .30, p < .01$ between the YSES and the Child Health Locus of Control Instrument (O’Brien, Bush, & Parcel, 1989), and $r (65) = .24, p < .05$ between the YSES and the self-worth subscale on the Perceived Self-Competence Instrument, by Harter (1985). These validity results suggest that self-efficacy as measured by the YSES is related to other measures of the self-system but appears to have conceptual distinctness from self-worth and health locus of control.

Health goal attainment. An adaptation of the Goal Attainment Form, by Kiresuk (1976), was completed by the parents at the last assessment time. During the home session, the health goal was negotiated by the parent and the child and the desired level of attainment was
determined using a five-point scale, 1 indicating “much less than expected” and 5 indicating “much more than expected.”

**Child and parent learning.** Measures of child and parent learning of the intervention curriculum were developed for this study. Child learning was measured in three ways. First, each child evaluated his or her own learning at the end of the intervention by means of a 17-item questionnaire; the extent to which the child applied program knowledge and skills to daily living and learned to “take good care of myself” was measured. Second, parents evaluated the child’s learning by rating on a five-point scale (5 as high) the extent to which the child demonstrated knowledge and skills before and after treatment. Third, the group leaders evaluated the child’s knowledge and mastery of skills by means of a 49-item checklist, with a rating scale of 1 (minimal evidence) to 5 (considerable evidence). Parental learning was measured at the last parent session by means of a 10-item questionnaire.

**Consumer satisfaction.** Measures of Child’s Satisfaction and Parent’s Satisfaction with the intervention program were obtained at the last assessment by using Likert-scaled items and several open-ended questions. Parents completed the ratings separately from the children.

## Results

**Preliminary Analyses**

**Data collectors.** At each assessment, the data collectors noted whether they knew if subjects were assigned to the intervention or to the waiting control group. The percentage of data collectors who indicated they did not know subject assignment was as follows: 91% pre-treatment, 77% immediately post-treatment, and 42% at two months post-treatment. Those data collectors who knew the subject placement stated that a family member had provided the information. ANOVA analyses indicated that the pre-treatment and post-treatment outcome measures did not differ across the five data collectors.

**Covariates: child and family characteristics:** T-tests were used to determine whether the intervention and waiting control groups differed on interval variables. Chi square tests were used for the categorical level moderator variables. Significant differences were found for child’s gender ($\chi^2 (1, N = 65) = 4.01, p < .04$) and major family life changes ($t (65) = 2.20, p < .03$). Families in the intervention group had more female than male children and had experienced more major family changes. While child gender was significantly related to nearly half of the outcomes, major family changes were rarely related to any
of the outcomes, and child gender and family stress were significantly but minimally, interrelated ($r (65) = .21, p < .05$). Thus child gender was selected as a covariate to test for intervention efficacy. No significant differences were found between the intervention group and the control group on maternal or paternal educational level, total family income, the impact of the child’s health condition on the family, the child’s severity of health condition, or age. Hence these variables were not used as covariates.

**Covariates: pre-test scores for dependent variables.** No significant differences were found when $t$-tests were used to determine whether the intervention group differed from the waiting control group on pre-test scores for dependent variables. However, pre-test scores on outcomes were used as covariates because of their high correlation with the two post-tests across time. The correlation coefficients ranged from $r (65) = .51$ to $r (65) = .89$, with $p < 0.01$, with $p$ ranging between 0.01 and 0.001.

**Intervention Effects**

**Health behaviours and health perception.** One factor analysis of covariance was used to evaluate treatment effects using the pre-test scores and the child gender as covariates. A one-tailed significance test was used (see Table 1). Because of the exploratory nature of the study, each post-treatment time point was evaluated separately to avoid confounding one time point by the other. Missing data for any single analysis ranged from 0% to 6% of the sample. Only patterns of findings were determined noteworthy for discussion, as significant findings due to chance may occur because of the number of analyses.

Children in the intervention group, in comparison to those in the waiting control group, exhibited significantly higher scores on therapeutic adherence. This finding was corroborated by both child and parent report at the immediately post-treatment and two months post-treatment points. Children in the intervention group also exhibited more self-responsibility than controls in management of the chronic condition, as measured on both self-responsibility outcomes—decision-making and administration of the health-care regimen. This pattern of results was evident based on the child report immediately post-treatment and the parental report at both time points. No significant differences were found on the child self-efficacy measure. These results were stable when analyses were compared with and without outliers—scores greater than three standard deviations from the mean. Clinical significance of the results is discussed in the next section.
Table 1  One-Factor Analysis of Covariance:  
Child health outcome percentage score

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Health goal attainment. On the health-goal attainment scale, every parent noted at least one change in child health perception or health behaviour as a result of the intervention. The majority of parents reported two or more improvements. Scores ranged from “expected change” to “much more than expected change.” Typical examples of health goals negotiated between child and parent are as follows: improvement in health-related symptoms; increase in age-appropriate responsibility for health-care tasks; and increase in positive behavioural responses to the health condition. Parents reported a significant decrease in the frequency and severity of the child’s health problems after treatment ($t (29) = 10.72, p < .00$).
Child and parent learning. Child learning results were consistent across independently derived sources of evaluations: child, parent, and group leaders. Nearly all of the children reported a moderate to high level of acquired self-management knowledge and skills. Children reported attempts to transfer and use the newly acquired skills in the home and school setting, but consistent mastery of skills was rarely reported. The majority of parents reported a moderate to high level of child learning after the intervention. Parent ratings showed a significant increase from pre-treatment to post-treatment on child health knowledge and health-appropriate behaviours ($t\ (29) = 6.52$, $p < .001$). Mean score ratings by the group leaders on child learning indicated "considerable evidence" that children understood new information and attempted to apply this knowledge to specific skills. Knowledge and skills scores correlated at $r\ (29) = .87$, $p < .001$. Although group leaders rated as high the children's use of new skills during the child group sessions, they rated as moderate the generalization of new skills to daily living. Child, parent, and group leader ratings on child learning were significantly correlated in a positive direction with the majority of scores on the outcome measures.

Results on parent learning were similar to the data patterns on child learning. Parents reported a high level of understanding of the intervention curriculum and a moderate level of ability to transfer this understanding to daily living. Parents requested additional assistance in fostering the transformation of the child's learning into sustained behavioural patterns.

Consumer satisfaction. All the children and all the parents rated the intervention as very informative, relevant, and useful. Many children and parents indicated that more initial and follow-up sessions were needed to facilitate generalization of newly acquired skills to daily living. The majority of children and parents believed that in future interventions the school personnel should be involved, to facilitate transfer of the child's newly acquired skills to the school environment.

Patterns among Outcomes

Intercorrelations between child-reported and parental-reported score on the corresponding outcomes were significant. The correlational coefficients ranged from $r\ (29) = .36$ to $.52$ at the $p < .05$ to $.001$, a two-tailed level of significance. Although the parental and child outcomes were related, they appeared to be somewhat independent, since a minimal degree of variance (13% to 27%) was shared.
The intercorrelations among the majority of parent-reported outcomes were significant. The Pearson correlations ranged from .38 to .58 ($p < .01$ to .001). In contrast, the majority of intercorrelational patterns among the child-reported outcomes were not consistently significant.

**Discussion**

A summary of the results and implications for further research are discussed in relation to the intervention utility, efficacy, strength, and conceptualization (Seligman, 1995; Yeaton & Sechrest, 1981). In relation to utility of the self-management intervention, children and parents perceived the intervention as useful to their lives. The high attendance rate also attests to the intervention’s value. Children and parents frequently remarked that holding the intervention in the school setting increased its accessibility and conveyed the message that management of a chronic health condition is one of the many life skills taught in school.

Evidence of intervention efficacy was found for the attainment of health goals and improvement on the outcomes of therapeutic adherence and child self-responsibility. The child’s learning during the intervention was found to be significantly and positively related to therapeutic adherence and self-responsibility. Despite these positive results, the strength of the intervention dosage needed to be enhanced for the child self-responsibility outcome. Treatment efficacy was sustained for therapeutic adherence but not self-responsibility, as reported by the child. The significant improvement in self-responsibility behaviours, as reported by the child, had begun to fade by the time of the two months post-intervention follow-up. Although the parents perceived sustained change at this point, they concurred with the children that increased initial and follow-up sessions would have helped to reinforce the child’s use of self-management skills in the home. In addition, the intervention possibly would have been strengthened had the child group sessions and parent group sessions been augmented by more individualized family sessions. Parents and children found that the process of contracting for a mutually agreed upon health goal was both rewarding and challenging. They believed that more practice and professional guidance would help solidify the skills developed during contracting. Strengthening the skills of family members, in relation to the child’s condition and in the context of family dynamics, may enhance the ongoing use of these new skills (Anderson & Coyne, 1993).

Involvement of school personnel was viewed as a means of strengthening the intervention. If school personnel were to participate in the intervention, the efforts of children could be reinforced, and they could
receive feedback on their attempts to use new skills in the school environment. Other child interventions have found that generalization and maintenance effects are more readily obtained when the consequences of positive behaviors and monitoring occur naturally in the school as well as in the home (DuPaul & Eckhart, 1994). Further investigation is needed to enhance our understanding of which intervention strategies will sustain and reinforce the generalization of new behavior patterns (McGinnis, 1993).

The intervention program raised issues regarding the reconceptualization of responsibility for health management. During the intervention, it became strikingly apparent that child self-responsibility is best understood in the context of joint responsibility by parent and child. A critical element for the successful attainment of the contracted health goal was found to be the ability of parent and child to negotiate the distribution of responsibilities. For many parent and child dyads, joint management, with a gradual increase in the youth’s responsibilities for the health condition, was the contracted goal. The group leaders discovered that few parents viewed the child’s participation in health management with clear parameters or developmental considerations. Some parents expected to transfer responsibilities to a child who was not prepared to accept them or who did not show readiness indicators. Others were reluctant to relinquish responsibilities to the child. The progression of responsibilities for health management needs to be more fully understood with respect to group norms as well as individual differences among children and parents (Giodano, Petrila, Banion, & Neuenkirchen, 1992). Discovering strategies that promote effective sharing of responsibilities among youth and parents will be valuable, given that the health status of children is influenced by supportive family environments (Follansbee, 1989).

Measurement of responsibility for joint management poses a challenge for intervention studies. In our study, the parent’s and the child’s perceptions of responsibility were not always consistent. Other researchers have also found parent and child reports on child behavior to differ (Achenbach & Edelbrock, 1983). There may be a variety of explanations for these differences. In our data set, perhaps parents identified small changes in the child’s behavior, whereas the children overlooked changes. In this instance, child-reported data may be less reliable, given that the various dimensions of self-management were not consistently interrelated as an overall construct. Another hypothesis is that the child’s perception of change is more accurate than the parents. In this study, children frequently reported frustration with using newly acquired self-management responsibilities in the school.
tions are not observed by parents. Thus children may perceive differently, since they are summarizing their behaviours across situations. Research needs to be directed toward the reasons for differences between parent and child perceptions of child behaviours.

Another issue raised by this study is the conceptualization of self-efficacy. The lack of change in self-efficacy may be best understood from a developmental and interactional perspective. The child’s environment interacts with the child’s mastery and interpretation of experiences to develop and sustain belief patterns incorporated into the self-system (Harter, 1988). Thus treatments intended to alter a child’s self-schema require great strength and long duration (Kazdin, 1993). Too often, the effort, time, and intensity required to alter one’s self-schema are underestimated (Fonagy & Target, 1996; Seligman, 1994). Perhaps self-efficacy needs to be conceptualized as a secondary outcome contingent on the sustained improvement of primary outcomes such as health behavioural patterns of adherence and management. A causal modelling perspective may contribute to our understanding of the interrelationships of primary and secondary outcomes.

In summary, the design of intervention studies aimed at improving child health perceptions and behaviours needs to consider the complexities involved, as well as the strength of the intervention required for change to occur and be sustained over time. In today’s health-care climate of cost-containment and economy of time, there may be a tendency to underestimate the comprehensiveness needed. A course of treatments designed to improve adherence and self-responsibility over time may be more cost-effective than one treatment so brief that the benefits dissipate quickly.

References


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