

Review

# The role of effective communication with children and their families in fostering adherence to pediatric regimens

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## Abstract

Adherence to pediatric health enhancement, disease prevention, and medical treatment, particularly for chronic disease, can be challenging because of demanding regimens, children's progressing developmental stages, and varying family perspectives and relationships. This review examines adherence in the context of communication among providers, pediatric patients, and their families. The focus is on: the delivery of prevention and treatment information; trust in the therapeutic relationship; beliefs and attitudes in shaping acceptance of health care messages; social and cultural norms; building patient and family commitment to behavior change; family habits; barriers and pressures faced by patients and their families; the role of social networks and social support in fostering adherence, and the effects of family cohesiveness and family conflict. The unique challenges of fostering preventive health care and treatment for chronic disease in the context of transition to adolescence are also considered, and effective clinical solutions are reviewed.

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## 1. Introduction

Health promotion, disease prevention, and successful medical management, particularly of chronic disease, can be difficult to attain in pediatric care. Simply adhering to a healthy lifestyle—limiting sun exposure, getting some exercise, eating fruits and vegetables everyday, avoiding smoking, and having recommended physician visits and immunizations—can be challenging enough for healthy children and adolescents. While certain omissions (such as vaccinations and automobile safety belts) can have devastating immediate consequences, for the most part failure of healthy children and adolescents to follow health promotion strategies tends to have more distal consequences such as health problems in later years. For the 7.5 million who have chronic diseases (e.g., asthma, diabetes, cystic fibrosis (CF), rheumatoid arthritis, gastro-intestinal disorders, renal failure), however, the need to adhere every day to medical interventions can sometimes be overwhelming [1,2], making life seem like “an endless cycle of medications, treatments, procedures, and medical visits” ([3], p. 394). For chronically ill children and adolescents, health behavior can be an incessant and awesome daily task, the poor management of which can lead to further morbidity and even death [4].

Adherence (also termed compliance) involves the accurate observance by a patient of a prevention or treatment regimen set out by a health professional. Decades of research on this subject have produced many important findings that have both clinical and research implications [5]. Nonadherence (or noncompliance) can have some very serious consequences. Failure to follow medication prescriptions can be a major cause of the proliferation of drug resistant infections as well as of serious drug reactions and interactions. Noncompliance can waste billions of health care dollars and can even be a cause to withhold treatment such as transplantation [6,7]. Nonadherence can result in limited benefits of care [8] and can compromise the health outcomes of pediatric treatment by as much as 71% (and on average by 33%) [9]. The long-term maintenance of adherence is critically important in chronic disease because disease management is life-long and can pervade every aspect of daily life.

Adherence to pediatric treatment regimens for chronic disease is particularly difficult to achieve. In the treatment of cystic fibrosis, for example, adherence to required dietary regimens can be as low as 12–16% [10]. In insulin-dependent diabetes mellitus (IDDM), adherence is also low, with as many as 25% of patients neglecting their insulin injections, 81% eating an improper diet, and 29% failing to conduct all of their required blood glucose monitoring (sometimes reporting false results to their health professionals) [11]. Although the characteristics of each particular disease and treatment regimen are unique, there are some commonalities across pediatric adherence problems. Generally, the adherence of children and adolescents can be

particularly complex because it frequently involves intricate family relationships and perspectives and because regimens can be demanding both behaviorally and psychologically, particularly when the illness is serious [12]. The demands of treatment can overwhelm the developmental abilities of the child and/or the emotional and physical resources of the family [13]. Other developmental issues can affect adherence as well, such as separation/individuation, limited abilities in risk assessment, conscious risk-taking, and peer group pressures. The day-to-day treatment regimens of the pediatric patient might even be precisely contradictory to the goals of the rest of the family (such as when the child with CF eats high fat, high calorie foods while other family members attempt to lose weight) [2]. Improving pediatric adherence is particularly important, however, because there is evidence that complying with treatment may have an even greater effect on the health outcomes of children than on those of adults [9].

## 2. Communication is a central element in adherence

There exist hundreds of empirical papers and reviews of the literature on adherence demonstrating that how well people follow treatment recommendations is a very complex issue. The present qualitative review of pediatric adherence and communication is based upon a complete search of all empirical and review articles and book chapters on pediatric adherence indexed in PsychLit and Medline from 1968 to the present. This review examines research and writing on pediatric adherence that interfaces with work on issues of communication (of health professionals, patients, and their families) and examines relevant factors such as the patient's disease, the type of regimen and beliefs held about it, the patient's (and family's) habits, experiences, and supports, and the health professional–patient–family relationship [14]. More detailed quantitative meta-analyses and further review of both pediatric and adult patient studies in this very extensive literature are presented elsewhere [5,9,15].

The adherence literature does suggest that the issue of communication permeates the adherence construct in several important ways and that adherence is dependent upon a number of factors that relate directly or indirectly to communication. We examine this evidence here, including how patients and their families interact with their health professionals, what patients and their families know and believe about their regimens, how pediatric regimens fit into family life, and how social support and family interaction patterns can affect the actions taken to improve the health and quality of life of children and adolescents.

### 2.1. The delivery of preventive and treatment information

Effective health professional–patient communication is critically important to fostering adherence and positive health outcomes. The presentation of information to the

family is vital to observance of the regimen; giving information to the child is essential to helping him or her cope with illness [12]. Education is most effective if it is focused on full understanding of the precise behaviors that are to be modified and the means and behavioral skills by which to modify them [2,10,16]. In order to adhere, patients and their families must accept the importance of taking medication precisely as it is prescribed, and of reporting side effects to the health professional. Written summaries of medications, and methods for assessing and tracking adherence to them, have been found to be very useful. These measures are, however, generally lacking in pediatric chronic illness care, and patient education is rarely documented in the pediatric medical chart [17].

### 2.1.1. Building trust in the therapeutic relationship

For several reasons, adherence depends on trust in the health professional–patient relationship. Reporting of adherence behavior (such as blood glucose testing) is likely to be distorted when children or adolescents and their families feel judged or unsupported [18]. Discrepant, yet unshared perspectives, of the family and the physician can lead to family attempts at adaptive noncompliance [19,20]. Conversely, physicians' informativeness, interpersonal sensitivity, and partnership-building are associated with more truthful adherence reporting, better adherence, greater satisfaction, and more positive evaluations of health care quality (particularly among anxious parents) [21,22]. Effective self-management requires a reciprocal relationship between physician and patient. Faithfulness to the recommendations depends upon the health professional being viewed as an ally who works in collaboration and cooperation with the patient and family [23]. So far, however, minimal research attention has been paid to the direct effect on adherence of the relationship between health professional and child (or adolescent).

### 2.1.2. The role of beliefs and attitudes

Beliefs and attitudes are among the most well-studied predictors of adherence to preventive and treatment regimens; the findings of research on social cognitions and health are among the clearest available. Parents' beliefs in the seriousness of their children's conditions, or in the severity of the complications their children might suffer if they fail to adhere, relate positively to taking health actions in order to cooperate with prevention and treatment [24–27]. Conversely, however, parents' beliefs that adherence (such as to a dietary regimen for diabetes) can be dangerous (e.g., lead to hypoglycemia) vastly increase the chances of nonadherence [23]. Interestingly, there is some evidence that the sicker parents believe their children are, the *less* well they follow recommended care for them [28,29]. This finding has potentially serious implications, and future research should focus attention on fully understanding its origin, meaning, and repercussions. Generally, research on social cognition has offered some understanding of parental adherence, but as yet

little is known about children's own health beliefs. Do they reflect those of their parents, and how do these beliefs change and affect behavior as children develop? This is a critically important issue because clinical information toward the goal of enhancing adherence needs to be tailored to what both families and the young patients themselves know and believe about disease and medical treatment [10].

### 2.1.3. Social/cultural norms and adherence

Parents typically establish behavioral norms and model health behaviors and coping skills for their children. Poor parental coping can impede adherence efforts (for example, if parents are unorganized about monitoring glucose testing or are squeamish about insulin injections) [23]. Parental anxiety can be transmitted to a child and affect his or her ability to engage in self-care, and depression in the main caregiver (typically the parent) can diminish adherence [30]. Peer group modeling, and cultural and social normative expectations by peers, can also affect diligence about following treatment. The treatments themselves can interfere with school performance, and restriction of activity can affect pediatric patients' self-esteem [31] and limit the potentially positive role of peers as normative influences who are supportive of adherence [31].

Effective communication about adherence-related norms and behavioral expectations within the family is essential because the patient's development itself brings changes in beliefs, attitudes, social interaction patterns, self-direction, autonomy, and dependency needs [32]. Developmental and physical growth patterns, family influences, emotional precipitants, environmental risks, coping styles, and cultural influences can affect both physical and emotional distress [33–36]. Developmental changes may present significant challenges in clinical practice because a child may change drastically over time as he or she progresses in knowledge, skill, and attitudes toward the disease and its daily management, and as parental supervision is reduced and responsibility transferred to the adolescent [10]. Adolescent depression can result from the demands of chronic illness, and in turn increase morbidity by threatening adherence, creating a vicious cycle [4]. Continued involvement, oversight, and enforcement of behavioral norms by caretakers are essential [23,35,37]. Direct, effective communication with health professionals is indispensable to establishing them as normative influences for pediatric patients [35].

### 2.1.4. Family commitment and overcoming barriers to adherence

The family is the psychological unit of health maintenance and treatment [4,12]. Pediatric chronic disease regimens can be prolonged and stressful, and can adversely affect quality of life among pediatric patients and their families. Successful communication toward the goal of adherence includes determining the extent to which the family can cope with the regimen (e.g., its scheduling, discomfort, side effects, and costs). Short-term regimens can often be encouraged and

supported with simple methods (e.g., problem solving, supplemental instructions) while more difficult long-term maintenance may require cognitive modification and behavioral management strategies (such as modeling, self-monitoring, evaluation, and reinforcement) [10].

Family communication and family commitment are essential to adherence, and it is vital to view the family as a system. In the care of children with cancer, for example, families with many siblings, and consequently more demands on their social, emotional, and financial resources, have lower rates of adherence than do families with few children [38]. Assistance (such as reducing the complexity, side effects, and costs) can be essential to integrating treatment regimens into family life [13,31,32,37,39]. Further, there is growing awareness of the effects of illness on sibling relationships [1]. Some well siblings may develop impressive maturity because of illness in one member of the family, but chronic illness can place tremendous pressure on well children, and can sometimes create serious challenges to adjustment.

## 2.2. Social and family support

Communication with and support from caring family members and friends can be vital to pediatric adherence. Supportive others can provide information and help, and can serve as facilitators, cheerleaders, and esteem builders. Practical support from parents (for example, for choosing and preparing healthy foods, testing blood sugar levels, going to medical appointments) and emotional support from friends can do a great deal to assist children who have chronic diseases [3,27,32,40–43]. Over-protection can cause social isolation, however, and interfere with the development of personal competency [37].

Family closeness, parental warmth, and the positivity and cohesiveness of family interaction patterns strongly affect adherence [23,40,41,43–45]; this is particularly true among adolescents, whose attempts at individuation may require adjustment by all family members [10,46]. Conversely, family conflict, negative feelings in the family, and poor psychological adjustment can serve as powerful factors in patient nonadherence by interrupting the practical aspects of behavioral management and the emotional support needed to adhere, as well as by being upsetting and stressful [10,23,43,47–49]. The provision of social support for the family from outside sources can contribute to coping, particularly by reducing role strain and parental depression. Social support likely does not actually buffer the stress of childhood illness, particularly when it is serious (such as in the case of cancer or cystic fibrosis) [1,12].

## 3. Conclusion

Research evidence supports the important role of effective communication in fostering adherence to preventive and chronic disease treatment regimens in the care of

children and adolescents. In the physician–patient relationship as well as in family interactions, trust, emotional support, and communication clarity are essential to the patient’s observance of necessary health practices to prevent and control disease. Various elements of communication are uniquely important depending upon characteristics of the disease condition, the patient, and the family. More research is needed, however, on the precise ways in which adherence and health care outcomes of various conditions depend upon such aspects as how debilitating the condition is, the degree to which it is life threatening, and how much behavioral adjustment is required of the patient and family members. Research on the complexities of communication in pediatric settings promises to shed valuable light on the most effective strategies for helping patients and their families to achieve enhanced health and better quality of life.

## 4. Practice implications

Research involving clinical interventions targeted at improving communication, health behavior, and adherence in the pediatric setting tends to be relatively sparse, although adherence to prevention and treatment is complex and determined by a multitude of factors [2,50–53]. Some elements of patient care are clear from the existing research, however. Patients and their families need to fully comprehend what they are being asked to do, and should be encouraged to ask questions, to clarify their understanding, and to provide feedback about their experience with the regimen. Through sensitive questioning, clinicians should explore sources of patient resistance and strive to enhance patients’ beliefs in the efficacy and benefits of treatment. The influence of others (extended family, friends, cultural group) should be understood fully. Messages about adherence should be clear, and should establish the normative role of the health care provider in supporting intentions to bring about behavior change. Finally, once it is clear that patients and families *intend to try* to follow the regimen, the clinician should help them to anticipate and overcome frustrating barriers so that they will be *able* to do so (for example, by simplifying the regimen, reducing or eliminating side effects, enhancing treatment organization and coordination, and reducing costs). The clinician should provide or arrange for supports in the form of physical assistance and emotional nurturance (e.g., support groups).

Interventions to improve pediatric health behavior need to be *broad in form and strategy* (e.g., combining cognitive reframing, constructive thinking and planning, family therapy, and behavioral management including goal setting, shaping, and rewards). Interventions should *target specific health behaviors* (e.g., diet rather than global adherence). If a program for adherence and behavior change is too broad in its target, or implemented too quickly, it may not be as effective as if the intervention is systematic and long term. The health regimen should also be tailored to provide individualized

solutions to practical problems as well as to characteristics of the child and family including: the disease condition and regimen, family beliefs, barriers, past history of adherence, past effects of poor adherence, developmental issues in the child, coping, and both intra-psychic and interpersonal dynamics [51]. Family management of adherence is indispensable. The regimen (e.g., a healthy diet) can become the family norm, and with information and encouragement the family can develop skills to become active participants in the child's care [4,19]. Special programs such as therapeutic summer camps can provide additional training, social support, normalization, and problem solving [23].

Tailoring the regimen to the specific demands of the disease is essential [4]. Educational strategies work best for some diseases, and behavioral and multi-component strategies work best for others. For example, organization and body awareness are particularly important in the care of asthma while Juvenile Rheumatoid Arthritis and IDDM require multi-component behavioral (and cognitive-behavioral) management [10]. In the care of many illnesses, stress management is as important as skill-building because stress can contribute to further morbidity (e.g., causing further metabolic disturbances in IDDM and further airway obstruction in asthma). Interventions that include hypnosis, biofeedback, and other relaxation modalities have promise for fostering health behaviors and for improving health [10].

Ultimately, long-term health behavior and chronic illness management require pediatric patients to learn to care for themselves [53,54]. New technologies can help empower patients and their families by providing personal medical records, customized health information systems, and email interaction with physicians' offices [52]. Clinicians can also provide information about accurate and useful health websites (such as those that provide ideas for healthy eating or teach behavioral principles). More than half of internet users have searched the internet for health information, and reliable web-based programs both encourage patient empowerment and connection with others through chat rooms and message boards [52]. Of course, it is important for the physician to be involved so that the accuracy of web-based information can be assessed. In general, user-centered pediatric information technologies can be very effective if they are contextualized within the existing child health care delivery system [54].

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