

Opening and Closing PANDORA'S BOX

discussing sensitive topics
with children and their families

**a manual for child and adolescent
health care providers**

Naomi Weinstein, Cheryl Bobe, and David Mandell
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Children of Alcoholics Foundation
164 W. 74th Street
New York, NY 10023
(646) 505-2065

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Andrew C. Phillips
Director, Children of Alcoholics Foundation

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INTRODUCTION

Nearly every day, a patient growing up in a troubled family passes through the door. Sometimes the clinician is aware of the problems at home, other times, he or she is less sure. But no matter how hidden the problem is, chances are the patient will have health problems as a result of the chaos, inconsistency, conflict and stress of his or her home environment.

In 1994, the Children of Alcoholics Foundation surveyed members of the American Academy of Pediatrics' (AAP) State Tobacco, Alcohol and Drug Coordinators, and members of the Committee on Substance Abuse to identify the issues most difficult to discuss with patients and their families. The results were not surprising: family violence, parental addiction and substance abuse in patients were named most difficult (COAF Survey, 1994).

Although these issues may be sensitive, it behooves child and adolescent health care providers to identify these and other family problems because of the tremendous impact they can have on the well-being of patients. The first, and perhaps most important, step in this process is communication between clinicians and patients and their families. Gone are the days when intuition would point the way toward simple inquiries and easy answers. Faced with complicated medical and ethical issues, clinicians need to work with each family to assess the possibility of family problems, and address these problems when necessary. Screening today requires skill, interest and a deliberate effort.

Despite the importance of communication skills, only in the last ten to twenty years has explicit instruction in the clinician/patient/family relationship become a formalized part of academic training. Even now, it is given only limited attention in medical schools and professional training courses because of the competing attentions of other more biomedical topics.

Audience for this Manual

This manual is intended for a wide variety of child health

Chapter I

- ***Pediatric health problems are often the result of the stress and chaos of family problems.***

1994 survey of AAP members found the most difficult issues for clinicians to discuss with patients include:

- ***parental addiction***
- ***family violence***
- ***substance abuse by patients***

care providers - pediatricians, family practitioners, nurse practitioners, physician assistants, pediatric nurses, school and parish nurses - all in an ideal position to identify problems, offer support and refer patients to appropriate services. Through basic screenings, these professionals can help identify family problems and direct patients towards helpful resources. For many of the sensitive issues covered in this manual, clinicians can also dispel common myths, and encourage patients and their families to get the help they need.

Three functions of medical interview:

- ***collect information***
- ***respond to emotions***
- ***educate patient and influence behavior***

Functions of the Medical Interview

In order to foster a strong, supportive relationship with a family, the clinician needs to be aware of the three basic functions of the medical interview: collect information about a potential problem, respond to the patient's and family's emotions, and educate both the patient and the family and influence behavior (Cohen-Cole, 1991).

As part of the information gathering process, the clinician needs to screen for both physical and emotional problems. Children, adolescents and parents need to be encouraged to talk about their concerns and tell the story in their own words. To organize the flow of information, the clinician may have to carefully manage the interview process by using appropriate open- and close-ended questions, asking for clarification when information is unclear, monitoring non-verbal cues and showing support and reassurance (Lazare, 1995).

The second function of the interview, responding to emotions without judgment, is vital for building rapport and contributes to the relief of physical and psychological distress. A patient or parent who is able to express negative emotions in the presence of someone who is not frightened by them will generally find this process in itself therapeutic (Werner, 1997). In fact, communication free of fear and anxiety has been found to be related to adherence and satisfaction (Hall, 1981).

The final function of the interview - to educate the patient and family and influence behavior - builds on the success of the other two activities. To successfully guide a patient toward a new, healthier behavior or to promote adherence to therapeutic recommendations, the clinician must first take steps to ensure that the patient and the family fully understand the problem and its influence on the child and

on the family. Once basic comprehension is achieved, the clinician can make plans for additional assessments or treatment of both the child's and the family's physical and emotional conditions.

Why Discuss Sensitive Issues

There are several important reasons clinicians working with children and adolescents need to discuss sensitive issues with patients and their families. From the public health perspective, these kinds of family problems are prevalent, and are central to pediatric morbidity and mortality. From the perspective of the individual patient, clinicians must discuss sensitive topics: (1) to collect information vital to forming an accurate diagnosis or assessment of biological and psychological health, (2) to collect information that may affect the ability of the patient and family to adhere to a prescribed treatment plan, and (3) to establish and maintain an effective clinician/patient/family relationship.

Sensitive issues are not just difficult for clinicians to discuss, they are also difficult for patients and their families. In fact, many concerns that are considered sensitive are family problems heavily shrouded in secrecy and denial, such as parental substance abuse, domestic violence, child abuse and neglect and incest. As a result, few patients or parents will volunteer information about such problems unless the right questions are asked in the right way by a trusted professional.

But without information about these problems, clinicians may lack the facts they need to fully understand the patient and the problem, to form an accurate diagnosis or develop an appropriate treatment plan. This, in turn, might result in a progression of symptoms and frustration for the clinician and patient alike. Treating the symptom will not eliminate the underlying problem and the same problem that causes a child's symptoms may also compromise a parent's ability to carry out a prescribed treatment regimen. Emotions such as anxiety and fear may be left untouched, compromising patient satisfaction and adherence (Hall, 1981).

Because family difficulties are so frequently associated with physical and mental health problems, early identification of problems may help prevent some of the associated morbidity. Moreover, studies have found that patients want their health care providers to ask about issues such as family

Reasons to discuss sensitive issues:

- ***pediatric morbidity and mortality***
- ***prevalence***
- ***collect information to help formulate diagnosis and treatment plan***
- ***maintain effective relationship with patient and family***

Barriers to discussing sensitive issues:

- **lack of time**
- **lack of training**
- **clinician beliefs**
 - **intrusive to ask**
 - **parents will be angry, leave practice or even sue**
 - **family problems are not medical problems**
 - **too much to resolve alone**

alcoholism, because they believe their clinician will be able to help the family seek treatment and cope with the problem (Graham, 1994).

Barriers to Discussing Sensitive Topics

Despite the importance of discussing sensitive topics, many clinicians are still hesitant to initiate or follow-up on such discussions. Perhaps the most common reason for this reluctance is time. Health care providers are increasingly constricted in the amount of time they have to spend with each patient. Most clinicians are already struggling to cover a vast amount of territory in a short amount of time, and sensitive topics may require lengthier conversations than providers' schedules allow.

Other times, however, the reluctance to delve into these issues is lack of skill. Many clinicians feel that they are inadequately trained to interview patients and families or provide effective interventions for behavioral problems (Werner, 1997). They may also lack familiarity with treatment options and resources.

Another barrier to discussing sensitive issues is provider attitudes. Some clinicians believe that family difficulties are not medical problems. Others think that the only way to help a child in a troubled family is to get the parent into treatment, something best handled by a social service or mental health professional. And some clinicians believe that if they introduce a potential problem, they are being intrusive, or are responsible for ensuring a timely resolution of the problem without any outside assistance (COAF Survey, 1994).

Some practitioners have made attempts in the past to broach a sensitive topic with a patient or family and have been met with anger and resentment, and even the loss of the patient to another practice. These clinicians feel they have learned a lesson the hard way, and are reluctant to attempt the same again. Others worry there will be legal concerns or reprisals if they pursue sensitive topics.

What Should Be Accomplished

A health care provider who discusses sensitive issues with patients and their families is taking on an appropriate, and

not monumental, task. The first step, screening, is facilitated when there is a trusting, open relationship between clinician, patient and family. In general, there will be no indications of a problem and further screening will not be required.

But when a potential problem is identified, the clinician's responsibility is to acknowledge the problem, assess it, and provide some basic information to the patient and the family about the issue and their options, make a referral to other experts who specialize in the area of concern, and follow-up with the patient as appropriate.

However, health care providers should not feel compelled to handle psychosocial problems alone. Instead they can develop a team of specialists for referrals, including social workers, health educators and counselors to help share the work load and improve care for the entire family.

Purpose of this Manual

Pandora's Box is intended to provide child and adolescent health care providers with guidelines and techniques for discussing sensitive topics in the context of a regular pediatric interview.

Format

Chapter 2 explores the family, resiliency, and the use of a family genogram as a clinical tool. Chapter 3 details the screening interview and referral process. The Appendix contains background information on four topics commonly perceived as sensitive (parental substance abuse, child-witnessed domestic violence, child abuse and neglect, and adolescent substance abuse), an annotated bibliography, and a comprehensive list of resources for patients and their families.

Special Note

For some readers of this manual, some of the information and suggestions contained herein may be a review. However, because there are a wide variety of practical suggestions and tips, it is recommended that clinicians at least peruse the sidebar summaries to ensure that they are familiar with all the information before putting the guide aside.

The clinician's responsibilities are to:

- **acknowledge the problem**
 - **provide basic information about problem and options**
 - **make referrals as appropriate**
 - **follow-up**
-
- **Clinicians do not have to handle psychosocial problems alone - they should develop a team of specialists for referrals and sharing the load.**

THE FAMILY SYSTEM

Chapter 2

Traits of a healthy family:

- **can carry out basic functions**
- **provides emotional safety**
- **promotes individuality**
- **promotes continuity**
- **communicates effectively**
- **accesses support as necessary**

As every pediatric practitioner knows, a child's well-being is determined in part by the health of its family. As a system of mutually interdependent individuals, families are responsive to the needs and concerns of their individual members. What happens to one family member is likely to affect the rest of the family.

Healthy Families

Every family, even the most dysfunctional, has both strengths and weaknesses. One measure of a family's health is its ability to carry out its basic functions: provide shelter, food, clothing and safety for its members; encourage independence and uniqueness; promote a sense of connectedness within the family unit; foster self-esteem; and develop a sense of ethics and an interest in conforming to the basic values of society (Werner, 1997).

In addition to these core functions, healthy families exhibit other traits:

- **Emotional Safety** - Expectations are developmentally appropriate and responsive to the changing needs of family members. Safety is ensured through clear limits and appropriate physical, emotional and sexual boundaries. Through experience, children trust that parents will behave consistently, say what they mean, and do what is promised.
- **Promote Individuality** - Family members are encouraged to be themselves and their uniqueness is respected. Roles are flexible and relate to individual strengths rather than the survival needs of the family.
- **Continuity** - Structure and continuity are hallmarks of a healthy family. Traditions and "rituals" for holidays, vacations and other celebrations provide a sense of connection as they are passed down through the generations, linking the past with the future. They contribute to a sense of "family" by helping members to feel part of a larger ethnic, religious and social community. They also provide bonding experiences that have been shown to be critical to healthy psychosocial development.

- **Effective Communication** - Effective communication in healthy families is direct and open. What is said in words out loud is what is communicated non-verbally. Parents model their capacity to share deep feelings and children learn by example. All feelings are acceptable, and a distinction is made between feelings and behavior. Empathy is apparent in the way members communicate with one another and children feel understood. The family members listen and respond, rather than react to, what the person is saying. Responses are given to both the spoken word and nonverbal messages.
- **Accessing Support** - Healthy families recognize that everyone has problems from time to time. Consequently, they develop problem-solving techniques, and are not afraid to turn to sources of help when they think they need them.

Troubled Families

Troubled families, on the other hand, are characterized by a lack of safety, poor boundaries, ineffective communication, mistrust, and extremes. Consider the chart below comparing the ways healthy families and troubled families carry out core family functions (Cermak, 1990):

Troubled families are characterized by:

- **lack of safety**
- **poor boundaries**
- **ineffective communication**
- **mistrust**
- **extremes**

Healthy Families

- provide safety
- parent available
- model limits on behavior
- establish boundaries

Troubled Families

- safety jeopardized
- parent not available
- parental loss of control
- abuse

Self-care

- choices important
- responsibility for self
- everyone is important
- trust own judgment

CoDependency

- few or no choices
- others' needs come first
- some are more important
- rely on others' judgment

Open Communication

- share range of feelings
- direct communication
- judge behavior
- forgiveness

Closed Communication

- feelings hidden
- secrets to keep peace
- judge person
- shame

Individual Roles Valued

- flexible
- disciplined
- role chosen
- cooperation, respect
- respect for privacy
- uniqueness encouraged

Family Roles Dominate

- rigid roles and rules
- punishing or permissive
- role assigned
- unhealthy competition
- intrusive
- individuality a threat

Continuity

- consistent
- relationships steady
- natural consequences
- solution focused

Chaos

- arbitrary
- relationships unpredictable
- illogical consequences
- problems unresolved

Family Genograms

Prior to the development of family systems theory, clinicians targeted treatment to those family members that exhibited behavioral or psychosocial problems. With growing recognition of the intergenerational, systemic nature of many problems, clinicians began to see the importance of gathering family history for both physical and mental health problems.

The genogram, a structured format for drawing a family tree, provides a graphic representation of relationships and their impact across generations. Genograms are useful to both clinicians and families because they clearly identify and delineate clusters of problems and family trends (McGoldrick, 1985).

genograms as a screening tool

Genograms that focus on genetics and physical health are regularly used by clinicians as part of the family medical history. However, genograms can also be used to identify family psychosocial patterns. Exploration of family history can begin during the initial interview, when information about the immediate family is gathered. Questions might be asked about the following themes (see pages 9 - 10 for an example):

- 1) family structure - occupation, roles, responsibilities, and any unusual family configurations
- 2) relationship issues - alliances and disconnections (“Who in the family does not get along well with each other?” or “Who is divorced or having marital problems?”)

In addition to biomedical information, genograms can also include information on strengths and weaknesses in:

- ***family structure***
- ***relationship issues***
- ***life events and family functioning***
- ***psychosocial patterns and trends***

The Story of J.

J. first came to Dr. Hamilton's office as a patient of the Adolescent Health Clinic at Springfield Community Health Center. J. explained that the reason for her visit was an increase in the number of headaches and stomach aches that she regularly experienced. Dr. Hamilton took a history and proceeded to examine J. but could find no physiological reason for her complaints. Before sending J. for a series of tests, Dr. Hamilton asked J. about what was going on in her life, to explore whether or not stress might have been the source of her suffering.

In the course of their brief discussion, Dr. Hamilton learned that J.'s mother, who was "never happy," had become increasingly stressed in recent months, and J. had taken over a lot of the basic household responsibilities. Moreover, J.'s brother, who was never an "achiever," had been using cocaine a lot recently, and had been arrested twice in the past two months for robbery.

Dr. Hamilton decided to construct a genogram (see page 9) at a follow-up visit in order to get a better sense of the different dynamics that might be causing J. to experience the headaches and stomach pains.

The genogram highlighted a number of stressors in J.'s life, including a live-in aunt dependent on Valium, an intergenerational pattern of substance abuse and family violence, and a conflictual relationship between J.'s brother and their step-father. Dr. Hamilton also learned that J. was the "hero" in her family, achieving both academic and athletic success. She had a close relationship with her uncle, a recently retired naval officer, who had provided her with structure, love and support.

Using the genogram, Dr. Hamilton was able to identify some of the protective factors available to J., and discussed with her some of the potential risks she faces as well as healthy ways to relieve stress. He also talked to J. about ways she could rely on her uncle when things got difficult at home.

A second follow-up visit six weeks later showed that both the stomach aches and headaches had subsided, and that J. was learning to use her inherent resiliency to maintain her own health.

- 3) life events and family functioning - tracking critical events, changes and coincidences, traumatic changes and the family's vulnerability to future stresses ("When did you all move in with your mother-in-law?")
- 4) patterns and trends - recognizing patterns across the generations, both strengths and weaknesses (such as supportive siblings or intergenerational substance abuse) (McGoldrick, 1985; Werner, 1997).

Questions should be asked matter-of-factly to minimize any discomfort for either the clinician or the patient/parent. In subsequent visits, additional information about others in the family, such as grandparents, uncles, cousins and aunts, can be collected.

Genograms used as clinical tools to assess family functioning are highly relevant to medical treatment. As Smilkstein (1984) notes, genograms help clinicians anticipate potential physical, emotional or behavioral problems and initiate preventive measures, such as referrals to other specialists. Genograms also help practitioners identify resources that might hinder or facilitate compliance and highlight potential stressors that might complicate treatment (Werner, 1997).

Resiliency and Protective Factors

While many children grow up in troubled families, not all face a lifetime of trouble and unhappiness. Many go on to lead productive and satisfying lives. Much recent research has been devoted to better understanding the concept of resiliency, an individual's "capacity for, or the outcome of successful adaptation despite challenging or threatening circumstances" (Masten, 1990).

Because the field is still in its infancy, resiliency researchers have yet to come up with a single definition for the concept. But most scientists agree that resiliency is the result of both internal and external factors. Moreover, because resiliency results from the interaction of personality with environmental factors (which are dynamic), resiliency can be developed at any time, and there are many routes for achieving it (Butler, 1997).

Some children demonstrate resiliency right from the start. As infants, they are described as active, flexible, and adaptive. They are outgoing and engaging (Werner, 1986). As these children mature, the personality profile continues to be

- ***Resiliency is an individual's "capacity for, or the outcome of, successful adaptation despite challenging or threatening circumstances."***
- ***Resiliency is the result of internal and external factors. Some children demonstrate resiliency in infancy, others develop it later on.***

PANDORA'S BOX

Types of resiliency in children from troubled families:

- **insight**
- **independence**
- **relationships**
- **initiative**
- **morality**
- **creativity**
- **humor**

Protective factors, which support a resilient personality, include:

- **supportive family environment (can also be surrogate family)**
 - **strong family ties**
 - **consistent behavioral limits**
 - **praise, approval and encouragement**
 - **guidance**
 - **physical affection and companionship**
- **external support system**
 - **positive school experiences**
 - **religious affiliation**
 - **close relationships**
 - **group opportunities**
 - **consistent supervision**

positive. They are effective problem solvers, resourceful, and have higher than average levels of intelligence and social skills (Masten, 1990).

In examining resiliency in children from troubled families, Wolin and Wolin (1984) have identified seven key strengths:

- 1) **Insight** - the ability to ask tough questions and give honest answers
- 2) **Independence** - the ability to separate emotionally and physically from one's troubled environment
- 3) **Relationships** - the ability to develop fulfilling relationships with others to fulfill needs
- 4) **Initiative** - the ability to take charge of personal problems, set goals and be productive
- 5) **Morality** - the ability to seek a fulfilling personal life, demonstrate ethical conduct, and possess self-respect
- 6) **Creativity** - the ability to impose order and beauty on the chaos of troubling experiences and feelings
- 7) **Humor** - the ability to resolve conflict and heal pain through humor

Positive personality characteristics are strengthened by "protective" factors, or "traits, conditions, situations, and episodes that appear to alter - or even reverse - predictions of [negative outcome] and enable individuals to circumvent life stressors" (Benard, 1991). In addition to personality, a supportive family environment and external support system work together to promote resiliency.

Researchers have found that the concept "family" can take on very broad meanings. Although some families with problems can have supportive elements, many do not. However, the concept of family does not have to be limited to the "nuclear" version. Extended families, surrogate families, and even communities can become families for children from troubled homes. In fact, Dr. Emmy Werner (1986) found in her research that those who are most resilient are most adept at "recruiting surrogate caregivers and adult mentors" (Butler, 1997).

Important "family" factors include strong family ties, support, consistent behavioral limits, praise, encouragement, approval, guidance, physical affection and companionship (Needle, 1983). Environmental factors include positive school experiences, religious affiliation,

close relationships, group opportunities and consistent supervision.

The clinician's role in supporting resilience is to call a patient's or a family member's attention to a child's individual strengths, and to help parents recognize ways they might facilitate the development of a child's resiliency. With patients who are less adaptive, clinicians might begin the process of resiliency development by focusing on protective factors: which ones are available to the patient, and how they can be utilized.

Summary

As clinicians work with patients and their families, they need to recognize the inherent strengths and weaknesses that are part of any family. While health care providers are not responsible for solving family problems, they can play a significant role in recognizing intergenerational patterns, identifying family issues, and encouraging resilience in patients.

Clinician's role in promoting resiliency:

- ***identify patient's strengths***
- ***educate family about resiliency***
- ***identify and promote use of protective factors***