



MiPSAC

Newsletter of the Michigan Professional Society on the Abuse of Children, Inc., the Michigan Chapter of APSAC.

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PRESIDENT'S CORNER

By Patricia Siegel, PhD, Children's Hospital of Michigan

Fall is in the air and soon the Michigan landscape will be a blaze with brilliant colors. Hopefully most of you will find the time in your busy schedules to enjoy it. In this work we often forget to meet our own needs and since this issue is devoted to NEGLECT, I thought it was fitting to remind you to take care of yourselves too!

MiPSAC's collaboration efforts are steadily moving forward. Last month, Nannette Bowler, Director of the FIA, met with the FIA Medical Advisory Committee and me to discuss ways that we could work together. I am pleased to report that Ms. Bowler was very receptive to the idea of developing multidisciplinary regional assessment centers throughout Michigan to improve the response to child maltreatment. Since eleven such centers currently exist through the Michigan Chapter of the National Children's Alliance, there was some discussion of meeting with Susan Heartwell, Director of the Michigan Chapter, to begin to collaborate with the group.

Speaking of Susan Heartwell, she plans to attend the 7th MiPSAC Annual Meeting scheduled for Monday, October 20, 2003 at five o'clock, following the first day of the Child Abuse and Neglect Conference in Ypsilanti. She will discuss the mission of the Child Advocacy Centers and provide an overview of the ones in Michigan that are currently operational. Please mark your calendars and plan to join us. This meeting is also a good opportunity to learn more about MiPSAC, meet the board and relax after the conference.

The Munchausen by Proxy (MBP) document is now in print and available to interested professionals. You can obtain a copy by emailing Henry Hofstra at the Family Independence Agency (FIA). Henry's email address is hofstra@michigan.gov. Several MiPSAC members made valuable contributions to this document and both Don Duquette and I are very appreciative of your help. We would welcome your feedback and comments after reviewing the document. The next task of the MBP Committee is to set up training workshops throughout Michigan so that MBP cases can be managed in a standardized manner. Our goal is to have the first workshop in the spring of 2004 target attorneys, judges, FIA workers, psychologists, and social workers in a designated FIA zone.

Under Charlie Enright's direction, the MiPSAC board has identified a primary mission and focus for the next five years. Specifically, the MiPSAC board plans *to educate / train professionals who work in Michigan to know how to prevent, identify, and treat victims of maltreatment*. A preliminary brainstorming discussion began at our last meeting and will continue at the December meeting. My personal goal is to have a draft of a training proposal to give to next year's MiPSAC President, Elaine Pomeranz, M.D. MiPSAC membership has a great deal of talent and expertise and the Board plans to involve as many of you as possible in this effort. Finally, I want to thank Kim Aiken for editing this edition of the MiPSAC Newsletter. The articles written in this issue are an excellent overview of the often neglected topic of medical neglect and will be a valuable resource for all of us.

In this special issue on Medical Neglect (Guest Editor: Kimberly Aiken, MD PhD).....

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MiPSAC ANNOUNCEMENTS AND UPCOMING MEETINGS



7th MiPSAC Annual Meeting

Monday, October 20, 2003, 5-6:30 P.M.

Ypsilanti Marriott / 1275 Huron Street South

Ypsilanti, MI 48197 Info: (734) 487-2000

1. Election of 2004 Officers & Board of Directors
2. Presentation of 2003 MiPSAC Child Advocate Award

22st Annual Michigan Statewide Conference on Abuse and Neglect

October 20-21, 2003, Ypsilanti, MI

University of Michigan (734) 763-0215 sasmi@umich.edu

5th Annual Midwest Regional Children's Advocacy Center Conference on Child Abuse

November 4-6, 2003, Bloomington, MN

Kim at (888) 422-2955

APSAC First Annual Trauma Treatment Clinic

December 1-5, 2003 Lahaina, Maui, Hawaii

Tricia-Williams@ouhsc.edu

San Diego Child Maltreatment Conference

January 26-30, 2004, San Diego Children's Hospital

APSAC Pre-conference Institutes, January 26, 2004

www.chadwickcenter.org

APSAC 12th Annual National Colloquium

August 4-7, 2004 Hollywood, FL.

Tricia-Williams@ouhsc.edu

15th ISPCAN International Congress on Child Abuse and Neglect

September 19-22, 2004 Brisbane, Australia

ISPCAN2004@icms.com.au

Michigan Professional Society on the Abuse of Children, Inc. **2003 MiPSAC Board of Directors**

President: Patricia Siegel, PhD, Children's Hospital of Michigan, 3901 Beaubien, Detroit MI 48201 (313) 745-4883
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Guest Editor: Kimberly Aiken, MD PhD

MiPSAC was founded in 1995 and incorporated in 1996 as the Michigan non-profit 501(C)3 state chapter of APSAC.

The comments expressed in this newsletter reflect the views of the author(s) and do not necessarily represent the views of MiPSAC or the American Professional Association on the Abuse of Children (APAC).

MiPSAC's Goals

- To bring together professionals working in the area of child maltreatment
- To foster networking
- To be an information resource
- To sponsor quality training

Brief Overview of Medical Neglect

Kimberly Aiken, MD, PhD
University of Michigan Child Protection Team Physician

Neglect is the most common form of child maltreatment. In Michigan during the year 2001, there were 19,571 substantiated child victims of neglect, or 68.8% of all substantiated cases. There were 703 victims of medical neglect (2.5% of all substantiated maltreatment cases) (U.S. Department of Health and Human Services, Administration on Children, Youth and Families, Child Maltreatment 2001 (Washington, DC: U.S. Government Printing Office, 2003)).

Physicians and other health care providers have many opportunities to identify different types of child neglect, including medical neglect. The most common forms of medical neglect seen by health care providers include noncompliance (nonadherence) with health care recommendations, delay or failure in getting health care, and refusal of medical treatment. Parental refusal of medical treatment is often based on religious views, and is discussed in detail by Dr. Howard Fischer in another article in this newsletter.

Noncompliance (nonadherence) with health care recommendations occurs when health-care recommendations are not implemented, resulting in actual or potential significant harm to the child. It is important that the health care provider determines that the child's condition is clearly due to lack of care, and not due to inherently severe disease or other factors.

Delay or failure in getting health care that results in actual or probable significant harm is another form of medical neglect seen by physicians. Typically, neglect is considered when the child has a health problem that a reasonable layperson would recognize but fails to do so, or fails to seek care in a timely manner. Both reasonableness and significance of delay are important considerations.

Except in life-threatening situations, medical neglect is usually a pattern of behavior by the parents or caretakers, rather than a single event. When a health care provider begins to suspect that a child may be medically neglected, he or she usually will take steps to intervene and stop the pattern of neglect before the child is at risk of significant harm. The health care provider may assess possible barriers to care, such as lack of health insurance, lack of transportation, inability to afford medication, poor skills to implement treatment, or a difficult treatment regimen. Equally important is evaluation of the physician-family relationship and communication, especially in cases with cultural or language differences.

The response of the health care provider can be guided by understanding the underlying cause, the degree of severity, and the availability of different response options. Awareness of public insurance programs and other community resources, and means to access them, can be very valuable information for a health care provider to pass on to his or her patients. When the underlying cause is lack of communication between the provider and the family, the provider can address the family's concerns and questions, and reach agreement with the family on a treatment strategy. Simplifying treatment as much as possible, setting priorities for treatment, giving written instructions and communicating clearly the importance of treatment can help improve compliance. Additional time spent in teaching the family the needed skills may improve treatment. Close follow-up can help ensure treatment is implemented.

As in all states, Michigan physicians are required by law to report child neglect to Child Protective Services. Because the majority of patients reported to CPS will not be removed from the home, efforts of the health care provider to work with the family and maintain a good relationship with them can be very important for the ongoing care of the child. Health care providers generally do not involve CPS unless the degree of risk or harm is serious, or when attempts to rectify the underlying cause have failed. Even after reporting to CPS, health care providers are usually available to provide support and follow-up to the child and family. Progress can be reviewed and the plan of treatment adjusted if needed.

Religion-based Medical Neglect

Howard Fischer, MD
Children's Hospital of Michigan
Child Protection Team Medical Director

In the 20-year period between 1975 and 1995, at least 172 children died in the United States because of their parents' religious opposition to medical care. All but 3 of the victims of this medical neglect would have been expected to survive with usual medical care. According to Rita Swan, Ph.D., president of CHILD (Children's Health Care is a Legal Duty) Inc., religious exemption laws are a result of lobbying by the Christian Science Church (CSC).

The following was placed in the Code of Federal Regulations by the U.S. Department of Health, Education and Welfare (HEW) in 1974 in response to CSC lobbying:

A parent or guardian legitimately practicing his religious beliefs who thereby does not provide specified medical treatment for a child, for that reason alone shall not be considered a negligent parent or guardian

All of the states had to pass a version of this in order to obtain federal money for their child protection programs. By 1984 all states and the District of Columbia had an exemption law either for religion or "nonmedical remedial care". The HEW mandate pertained only to civil child abuse and neglect laws, but some states added religious exemptions to their criminal laws after 1974. Depending on the state, there could be religious defense to manslaughter (Iowa and Ohio), capital murder (Arkansas), child murder (Delaware and West Virginia) or homicide by abuse (Oregon). Several dozen other states had exemptions to some criminal laws. These exemptions have discouraged reporting of religion-motivated medical neglect, even though children's lives may depend upon reporting. When state law indicates in advance that withholding medical care on religious grounds is not child abuse or neglect, potential reporters may be deterred from reporting.

In 1983, the Department of Health and Human Services removed the religious exemption from federal law and required states to include failure to provide medical care in their definition of child neglect. Most of these efforts have been defeated by lobbying of state legislatures by exemption advocates. Only 5 states (Massachusetts, Maryland, Nebraska, North Carolina and Hawaii) currently have no exemptions to either civil child abuse and neglect charges or criminal charges. In 1996 Congress once again reinstated a religious exemption in the Child Abuse Prevention and Treatment Act, stating that there was no requirement for a parent or legal guardian to provide a child with any medical treatment against that parent or guardian's religious beliefs.

What do we do?

Every state allows the court to offer needed medical care for children over the objections of their parents. This mechanism will only work, though, if health care providers or reporters (mandated or not) are aware of the child's condition and are convinced that medical care is needed. The American Academy of Pediatrics "calls for all those entrusted with the care of children to:

1. Show sensitivity to and flexibility toward the religious beliefs and practices of families;
2. support legislation that ensures that all parents who deny their children medical care likely to prevent death or substantial harm and suffering are held legally accountable;
3. support the repeal of religious exemption laws; and
4. work with other child advocacy organizations and agencies and religious institutions to develop coordinated and concerted public and professional action to educate state officials, health care professionals and the public about parent's legal obligations to obtain necessary medical care for their children."

References

Swan R. Children, medicine, religion, and the law. *Adv Pediatr*. 1997; 44:491-543.
Asser SM, Swan R. Child fatalities from religion-motivated medical neglect. *Pediatr* 1998; 101:625-629.
AAP. Religious objections to medical care. *Pediatr* 1997; 99:279-281.
Swan R. Religious-based medical neglect. *APSAC Advisor* 1998; 11:2-3.

Medical Neglect: Definitional Problems and Professional Judgment

Frank E. Vandervort, JD, University of Michigan

Defining medical neglect is sometimes a difficult task that results from a combination of imprecise statutory language and agency policy, and the application of normative judgments. When deciding if a parent has been neglectful, we must carefully consider the right of parents to make medical decisions for their children. Consider the following scenarios:

1. An infant's parents, concerned about potential negative impact, refuse to permit the child to receive the typical childhood vaccinations.
2. Parents, based on religious objections, refuse to authorize a lifesaving blood transfusion for their child after an accident.
3. A parent does not seek medical treatment for an injured child but provides medical treatment himself and the child's condition worsens.
4. A parent needlessly takes a child to numerous doctors and repeatedly persuades these doctors to perform unnecessary, invasive medical procedures on the child.
5. A terminally-ill child's parents faced with different choices regarding the child's treatment reject the advice of doctors that they pursue one avenue and choose to follow a riskier course of treatment.

Any one of these scenarios could result in a report being made to Children's Protective Services (CPS). Which, if any, would constitute medical neglect under Michigan law and FIA's policy implementing that law? Should they? I think most people would agree that the fourth scenario constitutes neglect (or, more accurately, medical abuse). What about the last situation? Should we ever say a parent in such a position is neglectful? Should we do so only if the parents have failed to *consider* options? Is there a "correct" decision in such a situation? These situations and questions are intended to highlight the difficulty of defining medical neglect—and our reactions to it—in the real world of our day-to-day work.

Michigan's Child Protection Law (CPL) defines medical neglect as part of a broadly worded general definition. Neglect is "*harm or threatened harm to a child's health or welfare by a parent, legal guardian, or any other person responsible for the child's health or welfare that occurs through . . . negligent treatment, including the failure to provide adequate . . . medical care.*" This definition is certainly broad enough to cover each of the factual situations.

Do we like that answer? Does saying that each of these situations constitutes parental neglect fail to take account of other important considerations?

The legislature determined that it doesn't like that answer in the second scenario. It enacted a separate provision in the CPL to except from the definition of neglect religiously rooted refusal to provide medical care, although the law permits the family court to order necessary treatment. Clearly, defining medical neglect is a balancing act. The state's interest in child protection is weighed against the right of persons to freely practice their religion. The rights of children are balanced against the rights of parents.

Because of the breadth of the statutory definition of neglect, the FIA has sought to operationalize the term "medical neglect" in its policy, which defines the term as "*the failure to seek, obtain or follow through with medical care for the child, with the failure resulting in or presenting a substantial risk of death, disfigurement or bodily harm or with the failure resulting in an observable and material impairment to the growth, development or functioning of the child.*" (CFP 711-5 at p. 4)

Consider the first scenario. The facts do not seem to meet the definition in the first part of the policy, the failure to vaccinate a child is unlikely, at least in the short term, to result in "a substantial risk of death, disfigurement or bodily harm." Nor would it seem that the child's "growth, development or functioning" would be impaired in any "observable" way. In considering the longer term effects of a decision not to vaccinate, what of a parent's right to make medical decisions for her or his child? The law presumes not only that parents have the right to make decisions for their children

but that their decisions are in the child's best interests. Model parents may decide not to have their children immunized. Are they neglectful? What if their child contracts, say, pertussis?

If the parent in the third scenario honestly believed the child's injuries may be adequately treated at home, has that parent been neglectful? Parents make difficult—sometimes life altering—decisions on behalf of their children daily. As professionals we must endeavor to remember that this is true. Because a parent makes decisions that are different from what we would have made, or things turned out badly, does not necessarily mean a parent has been neglectful.

Medical Neglect from a CPS Worker's Viewpoint

Heather Giese

Prevention Worker and former CPS worker, Newaygo County

The Child Protection Law defines the more general term, Child Neglect as: *“harm or threatened harm to the child's health or welfare by a parent, legal guardian or any other person responsible or any other person responsible for the child's health or welfare.”* There are five types of neglect that Children's Protective Services (CPS) is responsible for investigating: physical neglect (failure to provide clothing, shelter, or food), medical neglect, improper supervision (putting a child at unreasonable risk given the age or developmental characteristics of a child) and failure to protect (having the knowledge that a certain situation has presented harm to a child or risk of harm, allowing that situation to continue, and the child is harmed again), and abandonment.

To establish preponderance of evidence CPS workers utilize the following definition of Medical Neglect as defined by the Child Protection Law: *The failure to seek, obtain, or follow through with medical care for the child, with the failure resulting in or presenting a substantial risk of death, disfigurement, or bodily harm or with the failure resulting in an observable and material impairment to growth, development or functioning of the child.*

Two factors lead CPS workers to perceive a medical neglect investigation as more difficult to handle than other types of investigations. The first is that CPS workers traditionally are not trained medical personnel. The second is the varying level of complexity that medical neglect investigations can entail.

In my experience as a CPS worker and a Prevention worker, I have had the opportunity to investigate and work with several cases of medical neglect. Two cases were particularly complex cases, one involved a little girl with a severe case of asthma, and the other involved a little girl with juvenile diabetes and epilepsy. Prior to working these two cases I would say that my knowledge and understanding of these medical conditions was, at best, very basic. I discovered that a side effect of working a medical neglect case is that, you as the CPS worker, become considerably educated on the particular medical issue or condition that is the subject of that investigation.

There are a number of steps that a CPS worker needs to pursue that are both helpful and necessary when investigating medical neglect allegations. One of the first steps is to request a copy of the child's medical records from the medical provider(s). Medical records, as is known in the medical community, contain a significant portion of the information that is necessary for a CPS worker to have in order to complete a thorough and accurate investigation. For example, copies of letters to the parents, medical treatment plans signed by a parent, or diagnostic reports showing medication levels are usually very relevant to a medical neglect case. Thus, it is really helpful and appreciated by CPS workers when requests for medical records are honored promptly. The Child Protection Law and the Public Health Code provide the legal authority and obligation for medical personnel to share their records with CPS, even without the client's consent. Although a written request for information is not required by law, a “Children's Protective Services Request for Medical Information” (FIA-1163-M) is available for CPS workers' use.

It is imperative for the investigation that the CPS worker is able to identify whom the contact person from the medical community will be for the case. In the case of the little girl with asthma, I had a wonderful experience working with the Nurse Practitioner. In the other case, I was graciously helped by two Medical Social Workers. I would have had a very

difficult time interpreting and deciphering the medical information and how it related to the condition of the child without them.

In those particular cases, as in other medical neglect cases, frequent and ongoing telephone calls, faxes, face to face meetings and an occasional case staffing with the child's team of medical providers were common. Of course, the frequency of contact between the CPS worker and the medical provider is dependent upon the complexity of the situation. The open line of communication between the CPS worker and the medical provider is important as the child is best served when the CPS worker has a clear understanding of the answers to questions such as the following: What is the diagnosis and current condition of the child? What treatment has been prescribed, provided or recommended? What treatment is still needed? What are the consequences to the child if treatment is not provided? What will we see in the condition of the child if they are not getting their medication? Have the parents been educated on the treatment? Do the parents understand what the treatment is? How do we know that a child has not been getting their medication? If the child was getting their medication as prescribed what would their condition be? It is in the process of analyzing the answers to questions like these that a CPS worker will develop an understanding of medical terms and issues such as peak flow meters, therapeutic levels, the differences between refrigerated and non-refrigerated insulin and A1C levels.

The other significant factor in these investigations is of course the interviews that the CPS worker must complete with the parents of the child. The primary focus of the interview is to determine the parents' understanding of the child's condition, assess their reasoning for the care that they are or are not providing to their child, and to assess for possible environmental or social barriers.

In summary, in cases of medical neglect, the best interests of children are served when CPS workers and the medical community combine their expertise and work together.

REMINDER!

Please renew your annual membership to APSAC.

You must have APSAC membership to be a member of MiPSAC.

Part of you dues to APSAC pays for MiPSAC membership automatically!

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Join the MiPSAC member email listserv (sponsored by Wayne State University)

by contacting Vince Palusci at

Vincent.Palusci@Spectrum-Health.org

or leave a message for MiPSAC at (616) 391-2297.

Website resources for information on child maltreatment, local and national organizations, statistics, legislative updates and prevention

by Rosalynn Bliss

www.apsac.org

www.childtrauma.org

www.preventchildabuse.org

www.michiganschildren.org

www.firststar.org

www.cwla.org

www.michigan.gov/fia

www.nationalcalltoaction.com

www.childrensdefense.org

Preventing Medical Neglect

Elizabeth Secord, MD

Department of Immunology, Children's Hospital of Michigan

Working as a Pediatric medical specialist and member of the Child Abuse and Neglect Prevention Team at Children's Hospital of Michigan, I sometimes find myself very discouraged at the enormity of the medical neglect problem.

A 13-year-old girl with HIV disease that has been untreated because the mother is concerned the neighbors may learn that she and the child have HIV, dies. She dies not of an acute infection, but because of disease related starvation that is unheard of in children in this country now that HIV treatment is available.

A 10-year-old boy with persistent asthma reveals that he missed over four months of school last year because of asthma symptoms. I am not surprised to learn that he has not used his preventative medication for over six months, because that is what would have allowed him to control his symptoms and attend school everyday. Why do his parents not administer the medication? They feel he is old enough to be completely responsible for his own medication.

Twin girls with primary immune deficiency miss more than half their medical appointments, and have been taken off their medications by their mother, a full-time college student, because she does not want to ask the father, from whom she is divorced, for financial assistance or help with transport for doctor visits.

These are all cases similar to those of real children seen in our clinics. Unfortunately the case scenarios of children with chronic diseases not receiving medical attention are very common. The solutions are not as plentiful. About half the children I see in the hospital for asthma attacks are "off of medication" or have "run out" for "the last few months." Poor adherence with medication sometimes leads to death, but more frequently to sub-standard health and unnecessary restriction of normal activities.

I believe that most of us could imagine interventions that would be useful, but most are difficult to implement in this time of financial recession. Educational interventions focused on parenting skills, developmentally appropriate expectations for children, and disease specific treatments would be useful. Psychological support and intervention for stress reduction and behavioral modification and social work intervention for assistance with accessing community services could be useful.

Access to all of these at one sight between communicating individuals would be ideal. That is why the Pediatric HIV team at Children's Hospital of Michigan developed, in cooperation with the Family Independence Agency, a multidisciplinary treatment team with Physicians, Nurses, Social Workers, Psychologists, Case managers, Community agency representatives, and representatives from FIA. The team has worked very cooperatively and effectively to develop and implement educational and adherence interventions for families affected by HIV.

Because of the success of this model in reducing morbidity and mortality, we have recently moved the model, with some modifications, to our high-risk asthma clinic. Currently our multi-disciplinary asthma clinic is held weekly, and the treatment team meets twice monthly to discuss high-risk cases where some form of intervention may be warranted. Family Independence Agency representation on this team has been critical in obtaining resources and in intervening in cases where the child is at risk. Having one individual to cover the clinic is time efficient, energy efficient, and financially efficient. The clinic staff and the FIA representative are in frequent contact, and can work as a real team.

The FIA supervisor, who is assigned to both the HIV and the asthma units has become very familiar with the medical needs and risks of the two diseases, and can accept new cases without starting a new educational process each time. He is also able to offer education about these specific diseases and the stresses and needs they place on the families affected to other FIA workers.

Working in these cooperative units removes many communication barriers and allows all of us to work in the best interest of the children. I am hopeful that we can, over time, reduce the long-term effects of asthma and other chronic diseases of childhood by cooperative teamwork between hospital staff and FIA.