Medical Neglect and Pediatric Obesity: Insights from Tertiary Care Obesity Treatment Programs

Jane Gray, Adelle Cadieux, Brooke Sweeney, Amy R. Beck, Susan Edgar, Ihuoma Eneli, Elizabeth Getzoff Testa, Kristi Paguio, Melissa Santos & Wendy L. Ward Ph.D., ABPP

To cite this article: Jane Gray, Adelle Cadieux, Brooke Sweeney, Amy R. Beck, Susan Edgar, Ihuoma Eneli, Elizabeth Getzoff Testa, Kristi Paguio, Melissa Santos & Wendy L. Ward Ph.D., ABPP (2016): Medical Neglect and Pediatric Obesity: Insights from Tertiary Care Obesity Treatment Programs, Children's Health Care, DOI: 10.1080/02739615.2016.1163488

To link to this article: http://dx.doi.org/10.1080/02739615.2016.1163488

Accepted author version posted online: 17 Mar 2016.
Medical Neglect and Pediatric Obesity: Insights from Tertiary Care Obesity Treatment Programs

Jane Gray
Dell Children’s Medical Center/Texas Center for the Prevention and Treatment of Childhood Obesity

Adelle Cadieux
Helen DeVos Children’s Hospital

Brooke Sweeney and Amy R. Beck
Children’s Mercy Hospital and Clinics

Susan Edgar and Ihuoma Eneli
Nationwide Children’s Hospital/Center for Healthy Weight and Nutrition

Elizabeth Getzoff Testa
Mt. Washington Pediatric Hospital/Weigh Smart Program

Kristi Paguio
Helen DeVos Children’s Hospital/Spectrum Health Medical Group

Melissa Santos
Connecticut Children’s Medical Center, Hartford Hospital/The Institute of Living

Wendy L. Ward, Ph.D., ABPP
University of Arkansas for Medical Sciences College of Medicine/Arkansas Children’s Hospital

Abstract

Interprofessional pediatric obesity treatment teams may consider filing a report for medical neglect with their state child protection agency when a child’s family is consistently non-adherent to treatment recommendations and the child is medically at risk. The multifactorial
nature of the etiology and treatment of obesity makes this a challenging issue to navigate with families and child protection agencies. The aims of this paper are to 1) highlight common challenges faced by teams when addressing medical neglect, and 2) offer insights on navigating the medical protection of children with obesity and associated medical conditions in a way that minimizes adverse outcomes.

**Keywords:** pediatric obesity, medical neglect, interprofessional team, Introduction

Healthcare providers are mandated to report medical neglect when a child’s health and safety is at risk due to failure or refusal on the family’s part to provide treatment or provide access to treatment. Medical neglect is defined as failure to meet the healthcare needs of a child, resulting in harm to the child’s health, and represents a serious adverse experience in childhood with immediate and long lasting sequelae into adulthood (Dubowitz, & Black, 2002). In cases where the predominant concern for neglect is the child’s excess weight, the problem is often complicated by the presence of multiple family members and health providers, the social and medical complexity of obesity, spectrum of severity, and the prevailing societal bias that attributes severe obesity primarily to personal responsibility.

**Treatment of Pediatric Obesity**

Treatment of pediatric obesity is addressed using a staged approach (Spear et al, 2007). Initially, primary care providers offer prevention (Stage I). At Stage II, providers give basic counseling on healthy lifestyle changes including increasing healthy foods, physical activity and decreasing screen time. When the child continues to gain weight despite these efforts, the family is then
referred to a Stage III pediatric weight management clinic. These clinics typically offer medical evaluation, dietary counseling, exercise instruction, and behavioral counseling with a psychologist or other behavioral health specialist. This interprofessional approach has been found to be effective in improving weight-related health outcomes in children and adolescents (Whitlock et al., 2010). Initial signs of success may include modified behaviors that promote slowing of the rate of weight gain, stabilization of weight, stabilization of body mass index (BMI), and eventually decrease in BMI. These behavioral changes can also improve comorbidities associated with obesity, including high blood pressure (Shi, Krupp, & Remer, 2014). If families regularly attend and actively participate in appointments and implement recommended changes, they are more likely to experience positive outcomes. As utilized in primary care settings, weight management teams typically try to use a strengths-based approach to assist families in recognizing their strengths and resources, identify barriers and realistic solutions, and provide connection to additional resources in order to enhance engagement and adherence (American Academy of Pediatrics, 2013; Flaherty, Stirling & The Committee on Child Abuse and Neglect 2010).

Identified comorbidities to pediatric obesity include diabetes, hypertension, sleep apnea, uncontrolled asthma, orthopedic concerns, and/or psychological comorbidities (Deckelbaum & Williams, 2001; Reilly et al., 2003). For those children already manifesting comorbid conditions related to their obesity, success in treatment is initially measured by the positive behavior changes needed to improve health and manage their comorbidities over time, and eventually lead to anthropometric changes. Typical treatment plans for children with severe obesity and associated medical and psychological comorbidities involve intensive behavioral changes in
nutrition and physical activity in addition to management of these medical comorbidities and mental health concerns (Spear et al., 2007). Common barriers to success include inadequate resources including transportation and lack of insurance coverage, implementation barriers such as the complexity of recommendations and difficulty managing child behaviors in response to change, and scheduling, expressed as a difficulty missing school or work (Hampel et al 2012). Thus, it is not surprising that the patients and caregivers often struggle with consistently attending appointments much less making the recommended changes. The intensity of treatment can create challenges related to communication, family engagement, attrition, and mutual understanding of the problem across parties.

It has been theorized in psychological literature that patient factors outside of the control of the treatment environment, such as lack of supportive family members or living in environments in frequent crisis, may have the most impact on overall outcomes when compared to factors that can be more directly impacted in a course of treatment (Thomas, 2006). In other words, the barriers commonly experienced by these families may predict poor response to treatment regardless of the interventions offered. From a cultural perspective, the culture of low socioeconomic status, or poverty, may also create a forced choice along a hierarchy of immediate needs that may minimize the opportunity for a patient and family to implement lifestyle change recommendations (Payne, 2005). Additionally, cultural differences and beliefs about weight can be barriers to change and treatment success. Specifically, prevalence rates of obesity are higher among racial/ethnic minorities. Aside from increased rates of obesity-related risk factors, such as greater consumption of fast food and sugar-sweetened beverages, as well as lower physical activity levels with fewer safely accessible environments in which to be physically active, beliefs
about obesity may vary by race/ethnicity. In some cultures, a healthy weight may be negatively construed as underweight, which may connote negative beliefs such as malnutrition. Further, cultural expectations about larger body shapes and heavier weights may promote lifestyle behaviors that lead to these outcomes (Peña, Dixon, & Taveras, 2012). Therefore, when unhealthy weights are normalized as healthy or unable to be changed, it can be challenging to help a patient and family find motivation to change.

**Pediatric Obesity and Determination of Medical Neglect**

Before a referral for neglect is made, health care providers must first assess for the presence of medical comorbidities, and the potential for those comorbidities to cause imminent harm (Varness, Allen, Carrel, & Fost, 2009). The severity of the child’s weight, and failure to reduce the weight, do not meet the threshold for neglect on their own. Rather, the essential factor for neglect is whether the risk of imminent harm from life-threatening medical conditions exists at the time of the report (Varness et al, 2009; Viner, Roche, Maguire, & Nicholls, 2010). Varness and colleagues (2009) identify four levels of risk, with higher levels indicating a stronger case for medical neglect. The first level is the presence of obesity without a comorbid condition, and the second level represents the presence of a comorbidity that has the potential to harm the child in the future, but is reversible. At the third level, the comorbidity has the potential to cause harm in the future and is not reversible, and at the fourth level, the child’s comorbidity has the potential to cause imminent, irreversible harm. In order to determine whether medical neglect is a potential concern, and the level of risk present, healthcare providers must evaluate several factors. The literature available provides some guidance for providers in terms of factors to
assess, including the presence and severity of medical comorbidities, the presence and reversibility of imminent harm, the nature and evidence base of the treatment and availability of alternatives, challenges with the family’s effort and engagement related to treatment, and the presence of parent behaviors that directly interfere with treatment (Varness et al., 2009; Viner et al., 2010). As these factors are increasingly present and pose a barrier to treatment, the probability that medical neglect is present increases; however, the literature lacks a well-developed tool or measure to evaluate for medical neglect in pediatric obesity.

As with any other child who presents with protection concerns (e.g., physical abuse) two additional questions must be considered: is the child’s welfare at risk by staying in the home, and is there an alternative to removing the child from the home (Garrahan & Eichner, 2012; Varness et al., 2009)? In the case of obesity, answering the first question with certainty is a challenge due to several factors which are difficult to predict or ascertain. As is the case with other medical conditions, when families fail to participate in or access the healthcare necessary for their child’s condition, and/or fail to follow recommendations, it is difficult to disentangle factors inherent to illness management such as lack of resources, limited effectiveness of the intervention, or the etiology of the medical condition itself, from a refusal or inability to care for the child (Dubowitz, Giardino, & Gustavson, 2000, Fornari, Dancyger, Schneider, Fisher, Goodman, & McCall, A, 2001; Nejtek, Hardy, & Winter, 2010). With respect to the latter issue, while removal from the home is an intervention that is likely to immediately stop harm to a child who is being physically or sexually abused, this intervention may actually worsen a child’s obesity (Murtagh & Ludwig, 2011).
Need for Further Guidance for Healthcare Providers

Although the determination of medical neglect has been made more clear via the above recommendations, healthcare providers who take care of and advocate for children with severe obesity often find themselves struggling with how to navigate child neglect guidelines in a manner that offers the child the best outcome while maintaining a respectful and nurturing relationship between the healthcare team, the patient, and the family. Concern for the child’s safety rises when assessment indicates caregiver understanding of an evidence-based treatment plan while displaying behavior that prevents the child from getting such treatment (e.g. missing appointments, refusing to make changes, providing unhealthy foods, etc). Yet survey results suggest that, in general, physicians are hesitant to report abuse and neglect due to negative experiences such as ineffectiveness of state intervention and impact on relationship with the patient following a report (Flaherty, Sege, Binns, Mattson, & Christoffel, 2000; Vulliamy & Sullivan, 2000). Sustaining family’s engagement in weight management treatment can be particularly challenging due to multiple contributors such as frequency of and distance to appointments, satisfaction with treatment and providers as well as the cost of such services (Dhaliwal, Nosworthy, Holt, et al, 2014; Skelton & Beech, 2010). Attrition rates can be as high as 73 % (Skelton & Beech, 2010). It can also be challenging to tease treatment attrition from medical neglect. As such, the treatment of pediatric obesity brings even more complexity than most medical conditions, so teams may be especially hesitant to report medical neglect.
Case Series

The contributors to this paper represent an interprofessional group of pediatricians, psychologists, and social workers from 25 pediatric obesity centers participating in the National Association of Children’s Hospitals and Related Institutions (NACHRI, now known as the Children’s Hospital Association [CHA]) FOCUS on a Fitter Future (FFF) focus group from 2011 through 2013, an effort convened to improve care for children with obesity. Using several composite case examples drawn from clinical experiences, the objective of this paper is to provide insights on addressing several common challenges that may present when medical neglect is suspected and/or reported due to a child’s weight. These insights are aimed to reduce or eliminate the concern for medical neglect, increase family engagement and retention in treatment, minimize negative outcomes when a referral is made, and maximize support for the family to successfully improve their child’s health. In each clinical example, Body Mass Index (BMI) values are presented using recent guidelines for clinical tracking (Gulati, Kaplan, Daniels, 2012).

Case Example: Mario

Challenge: Insufficient Documentation to Support Report

Mario was a 12 year old boy with a BMI at 128% of the 95th percentile, insulin resistance, and elevated blood pressure. Mario had been seen at a Stage III intervention program, and over three years had continued to gain weight with an increase in his BMI up to 150% of the 95th percentile. Per his report, his family continued to provide him with access to fast food, calorie dense and
high sugar snacks, and large portion sizes, multiple opportunities for sedentary behaviors, and had limited compliance with physical activity recommendations. They repeatedly demonstrated verbal understanding of the new knowledge they gained, but failed to implement recommendations despite his increasing BMI. The interprofessional weight management team reviewed Mario’s case with the hospital child protection team to consider medical neglect. Due to the nature of the language used in the chart (e.g. use of word “recommendations”), the hospital’s child protection team felt there was insufficient documentation to support a concern about medical neglect and did not recommend a report to the state protection agency. The interprofessional team was advised to document the medical necessity of treatment, specific and measurable goals, and the specific level of compliance so documentation more clearly identified the level of risk to the patient.

**Insight: Clear Documentation in Medical Chart**

This example highlights the importance of clear documentation of the child’s medical chart. Even in cases of physical abuse, if medical documentation is inadequate it is difficult to substantiate the abuse (Jackson, Rucker, Hinds, & Wright, 2006). The importance of clear medical records including complete history, severity of the medical condition, and inconsistencies between the progression of the medical condition and parental report of behavior change has been discussed for some time (Solomons, 1980). Providers are encouraged to use direct language; use of the terms “rule out” and “alleged” may increase ambiguity in the medical record (Jackson et al., 2006). We recommend that healthcare providers document in the medical chart that weight stabilization is *medically necessary*, with the presence of imminent harm or
potential for harm of continued weight gain. To improve documentation records, a “structured”
documentation style is recommended (Newton, Zou, Hamm, Curran, Gupta, Dumonceaux, &
Lewis, 2010). This style includes noting who provided the information, whether information
provided by the family member or patient is a spontaneous statement or is in response to a
specific question, as well as any notable reactions to statements being made. Whenever possible,
verbatim statements of patient and/or caregivers are recommended (Dubowitz & Bennet, 2007).

Documentation should differentiate between medical neglect and other factors contributing to
lack of progress in treatment, and outline the barriers to compliance and how they were
addressed (Dubowitz & Black, 2002; Guenther, Olsen, Keenan, Newberry, Dean, & Olson,
2009; Robers, Wheeler, Tucker, Hackler, Young, Maples, & Darville, 2004). The chart should
also include specific evidence of noncompliance with treatment including missed appointments,
lack of follow through with nutritional recommendations, physical activity, medical monitoring,
and efforts the clinic has made to increase compliance (Sherman, Baumstein, & Hendeles, 2001).
Treatment teams will need to document how these behaviors negatively impact the child’s health
and place the child at imminent harm. Using a consistent style of documentation across the team
can decrease ambiguity, improve communication between the weight management team and the
family, and help the hospital child protection team and/or state agency better understand the level
of risk in order to make the appropriate determination in the best interest of the child.
Case Example: Joel

Challenge: Protection Agency’s Limited Understanding of Medical Risk Related to Obesity

Joel was a 14 year old boy who had a BMI at 167% of the 95th percentile with several medical and psychiatric comorbidities including severe obstructive sleep apnea requiring Continuous Positive Airway Pressure (CPAP) treatment, nonalcoholic fatty liver disease, and depression. Several members of the treatment team became concerned about Joel’s physical and emotional health due to frequent and unpredictable transitions between primary caregivers, failure for those caregivers to keep his medical appointments, and Joel’s worsening physical and emotional condition. The team made a report to the state child protection agency, providing education to the intake worker about the seriousness of Joel’s medical comorbidities and how parental behavior negatively impacted his health. The team explained potential immediate harm as well as long-term impact. The child protection agency investigated the report but did not provide more intensive services for the family or make changes to Joel’s living arrangements, and Joel continued to fail to attend appointments. He continued to gain weight and his psychiatric comorbidity worsened, requiring an inpatient psychiatric hospitalization for a suicide attempt.
Insight: Communicate with Agency Workers about Risk of Obesity and Comorbidities

This example demonstrates that protection agency workers may have limited understanding of the potential risk to the patient when obesity and related medical comorbidities are untreated. Often these medical risks do not fit within the existing parameters of harm and safety to which protection agencies must adhere. The imminent danger threshold is difficult to meet in pediatric obesity. Healthcare providers should provide the child protection agency with the rationale behind medical necessity of treatment and the severity of medical risk and harm to the child when treatment recommendations are not followed (Jenny, 2007). Secondly, emphasizing evidence of the treatment nonadherence and efforts to address barriers with the family and increase compliance offers a stronger case for the state protection worker to grasp the seriousness of the concern (Sherman et al., 2001; Viner et al., 2010). Finally, healthcare providers should consider the provision of clinically relevant information as their primary role and avoid any recommendations or opinions about the placement of the child or direction of the investigation (Bourne, 2000).

Joel’s case raises the issue of a need for additional education and training for both healthcare providers and state protection workers in order to fully appreciate the level of risk and harm medical neglect can bring to the child (Feng & Levine, 2005; Fraser, Mathews, Walsh, Chen, & Dunne, 2010; Geffken, Johnson, Silverstein, & Rosenbloom, 1992). Collaboration between obesity programs and their child abuse colleagues could lead to educational outreach efforts to state agencies and clinical teams in order to address the issue of more effective reporting on the
part of the healthcare provider, and more effective response on the part of the child protection agency.

**Case Example: Jessica**

**Challenge: Discordant Levels of Concern between the Team and the Family**

Jessica was a 7 year old female who was 175 % of the 95th percentile. Jessica had multiple medical comorbidities associated with her obesity, including non-alcoholic fatty liver disease, hypertension, and pulmonary hypertension. The weight management team repeatedly expressed concerns to her caregivers regarding her continued weight gain and its impact on her physical and emotional health, yet the family repeatedly failed to implement recommended changes. The team discussed these concerns with the family at individual visits and patient care conferences, and discussed the team’s obligation to make a report of medical neglect if the family did not make efforts to address Jessica’s continued weight gain and the medical complications of her obesity. The team worked to address barriers such as Jessica’s difficulties with food sneaking, and her parent’s physical disability which interfered with that parent’s ability to model an active lifestyle for Jessica and attend scheduled medical visits. The team worked with multiple caregivers (grandparents, school, and daycare) to provide consistent messages and layering of interventions and goals. Jessica’s family had also been having difficulty following medical treatment prescribed by her pulmonologist and nephrologist. The treatment team obtained written consent from Jessica’s caregivers to consult with her other medical providers. This
provided the treatment team the ability to coordinate Jessica’s overall medical treatment, develop a treatment plan that incorporated all of her medical needs, and establish strategies to implement all medical recommendations. The treatment team worked with the family and other medical providers on coordinating medical appointments to decrease interference in the family’s schedule and reduce transportation needs by scheduling appointments on the same day for providers in the same facility.

The team met with the entire family and communicated with outside caregivers (school and after school childcare) to provide education about Jessica’s medical risk, and set the following goals: 1) limit access to unhealthy foods, 2) use food and exercise logs, and 3) structure meal times and snacks across all settings. Telemedicine visits with the dietitian were added between medical visits to address identified barriers of difficulty attending face-to-face visits due to distance and disability of her parent. By mobilizing all involved systems (home, medical, school, and daycare) and setting specific goals, the family’s attendance and adherence improved considerably, Jessica’s weight decreased and her hypertension improved, the team’s concern about neglect dissipated, and the team did not have to file a report with the state child protection agency.

**Insight: Effective Communication and Collaboration with all Caregivers**

Early collaboration between providers across medical specialties and community settings that involve the child can be an effective first step in addressing behaviors and improving outcomes,
thereby eliminating the concern about medical neglect (Garrahan & Eichner, 2012). Strong provider-family relationships can have a positive impact on caregivers’ compliance (Dubowitz & Black, 2002; Nelson, Higman, Sia, McFarlane, Fuddy, & Duggan, 2005). Thus, specifically addressing any discordant levels of concern between healthcare teams and families, as a problem affecting the therapeutic relationship, may increase the family’s understanding of the medical condition and improve compliance. In the immunization compliance literature, it is recommended that healthcare providers elicit parental concerns in order to directly address these concerns and provide a rationale for the treatment (Diekema, 2005). This should include evoking all barriers to change and success, even those that patients or family members may be reticent to share, such as cultural beliefs, physical disability, or lack of resources, all of which may create a challenge for patients to attend medical visits and engage in behavior change at the intensity needed to attain a decrease in weight (Miller & Rollnick, 2013). Having a treatment plan that is clear and specific, includes all caregivers including childcare providers and schools, and demonstrates agreement from the health care providers and family is important in assuring that the family knows what is expected (Dubowitz & Black, 2002; Dubowitz et al. 2000; Jenny and the Committee on Child Abuse and Neglect, 2007). Telemedicine has been shown to be acceptable to providers and patients, and may increase access for families in both rural and urban settings, particularly low-income areas, when having difficulty adhering to recommended medical and weight management team visits (Davis 2011, Slusser 2015) Families need to have a good understanding of the rationale behind the goals and recommendations, the ability to follow through with the plan, and an understanding of the consequences if the plan is not followed (Dubowitz, et al., 2000; Johnson, 1993; Jenny et al., 2007). In Jessica’s case, multiple
discussions and care conferences with the family and other providers was effective in preventing the issue of noncompliance from becoming an issue of medical neglect.

Jessica’s case also illustrates that increased collaboration can be achieved by being transparent with the family specifically about concerns related to medical neglect, including the obligation of health care providers to report these concerns to the state child protection agency (Jenny et al., 2007). When interprofessional team members are open with the family about these concerns, the family is provided with more opportunity to alter their behavior. If the desired changes do not occur, then the report to the child protection agency is an anticipated event and not a surprise to the family. If providers keep families informed, in a compassionate manner, about the rationale behind and progress of the report, it increases the likelihood that the family will remain in treatment even if the provider-patient relationship is strained (Dubowitz & Bennett, 2007). Given the sensitivity of the concern and the likelihood that the family may not be receptive, it is strongly recommended that these conversations with the family occur with at least two members of the treatment team. The following should be addressed during these conversations: 1) discuss the concern and frame in terms of the risk of imminent harm to the child 2) summarize what the team will report to the protection agency 3) succinctly outline areas the family’s inadequate adherence with the treatment plan and attempts by the health team to address barriers, 4) describe the resources the team is hoping to leverage via the protection agency, 5) acknowledge the family’s strengths, and 6) communicate the team’s commitment to provide health care for the child and support for the family through the process (Dubowitz & Black, 2002).

Case Example: Shane
Challenge: Lack of Progress despite Intensive Intervention

Shane was a 16 year old girl with a BMI at 170% of the 95th percentile and comorbid conditions including severe obstructive sleep apnea, hypertension and pseudotumor cerebri. As part of a bariatric surgery program, she was expected to work with the interprofessional weight management team to improve her diet, decrease sedentary behaviors and increase physical activity behaviors. Despite the family attending appointments and reporting improvements in her diet and activity, her weight increased steadily for three years. Concerns about the discordance between the family’s reported lifestyle behaviors and Shane’s increasing weight gain raised concern that Shane and her family were not accurately reporting behavior change. Given the increasing risk for imminent harm as her weight increased and OSA and pseudotumor cerebri worsened, the team became concerned about medical neglect. Following a hospitalization that successfully stabilized Shane’s weight, the team worked with the family to clarify goals and expectations using a collaboratively designed treatment agreement. The weight management team and the family designed an agreement that included goals and consequences of non-adherence with the contract, including a referral to the state’s protection agency if the family failed to follow through with their goals. The patient, family and treatment team signed the agreement. Goals and progress were reviewed at each subsequent visit, and barriers to progress were identified and resolved. Positive reinforcement from the team and tangible incentives e.g., gift cards, were provided as goals were accomplished. The treatment agreement was revised every two weeks, and after three months was no longer needed. Due to increased
engagement, significant behavior change, and dramatic weight loss, the team did not have cause to report neglect to the state protection agency.

**Insight: Continued Intensive Intervention and Development of a Written Patient-Provider Agreement**

In this case, as the team became concerned about non-adherence and began to consider whether the family was neglecting Shane’s medical care, they intensified the intervention (e.g. inpatient hospitalization) and collaboratively developed a treatment agreement with the patient and her family. Establishing a behavioral agreement can help maintain clear expectations and hold each party accountable (Jenny et al., 2007). These written agreements have been shown to improve adherence to treatment in other medical conditions (Carroll, DiMenglio, Stein, & Marrero, 2011). Goals and objectives should be collaboratively developed with the family that are clearly written and defined with a rationale that is well-understood by the family, realistic and attainable given the family’s resources, and specific enough to be measured so that both the family and the treatment team can observe progress (Bovend’Eerdt, Botell, & Wade, 2009; Dubowitz et al. 2000; Jenny et al., 2007; Johnson, 1993). Agreements need to have the expectations and roles outlined clearly for each member of the family as well as the treatment team, along with consequences if expectations are not met (e.g report of medical neglect to child protection agency). Role definition also allows for each interprofessional team member to clearly understand the responsibility of each discipline and provide an integrated treatment plan. This type of role definition has a positive impact on families’ engagement with care, and ultimately improvement in child’s weight status (McPherson, Headrick, & Moss, 2001; Vyt, 2008).
The agreement should be regularly reviewed with the family during appointments, by phone if appointments are missed, and with the team during team meetings, to address whether all parties are following the agreement, adjust goals as needed, and phase out the written agreement when appropriate (Dubowitz et al., 2000). It is imperative the team identify and address educational, physical or cognitive limitations in the caregiver and patient which may impair successful follow through with the plan. For instance, families with low health literacy levels will benefit from repeated review of the plan using their preferred style of learning. The patient and family should be praised and acknowledged for adhering to the plan either verbally or by using agreed upon incentives tied to accomplishment of the goals. It is recommended that teams consult with their institutions about the appropriate language for the agreement as its purpose is therapeutic rather than a legal binding document. In Shane’s case, the development of a formal written agreement helped improve her treatment outcomes, preventing a referral to the state protection agency. See appendix for a sample agreement.

Case Example: Jack

Challenge: Family Disengagement after a CPS Report

Jack was a five year old boy with severe obesity, developmental delays, and Blount’s disease. His family was of low socioeconomic status and struggled with food insecurity, significant financial difficulties, and lack of access to transportation. These barriers contributed to poor attendance to clinic appointments and adherence to treatment plan. Despite intensive case management support by multiple medical social workers on the treatment team, the family did
not make any lifestyle changes or follow through with repeated referrals to community resources, either of which might have reduced the need for a medical neglect report. Jack’s BMI continued to increase, worsening his Blount’s disease and further reducing mobility.

Team discussions over time reviewed the definition of medical neglect and assessed for supportive or discounting evidence of such neglect. Social work was included as a member of the team and consultation with Child Protective Services (using a “hypothetical” case and asking for whether sufficient evidence was present to suggest medical neglect and if so what services might be available) was helpful in making a determination. As evidence supportive of the presence of medical neglect was discovered over time, discussions about whether to and/or how to tell the family about the report ensued. At the time that the decision was made to report, the family was told about the report and framed in a discussion of the need for greater support in terms of financial aid, reducing food insecurity, and providing reliable transportation to appointments. It was emphasized that this was not a punitive measure for a way to obtain more services and out of concern for Jack’s wellbeing.

A report was made to the state child protection agency for medical neglect, and the case was investigated and substantiated. The case was followed in family court for several years. During this time, the family demonstrated increased engagement in treatment and benefited from resources provided by the state. Jack’s mother enrolled in a job training and placement program and Jack received early intervention and childcare. Transportation to appointments was provided by the state. With this support, the family improved attendance to subspecialist appointments and Jack’s BMI steadily dropped. Despite these improvements in engagement, the relationship
between the family and the weight management clinic was strained following the report of neglect. Further, once the child protection case was closed, the state could no longer offer extra community resources, and the family began to again miss weight management appointments and Jack’s BMI increased.

**Insight: Continued Engagement and Community Resources During and After Report**

This example demonstrates the likelihood of benefit when appropriate services are initiated as a result of a report to a child protection agency, and the need to continue to leverage community resources after the case is closed. The report to the state protection agency provided services that reduced barriers, provided an additional level of accountability, and supported the family to successfully initiate change, but the relationship between the family and weight management team was strained despite careful framing of the report as a supportive action made to protect Jack’s welfare and obtain services for the family. When the case was closed, resources were discontinued and the family began to struggle again with engagement. Ongoing engagement in community and medical programming is important for families to maintain success, but these resources are limited. If resources need to be discontinued, it may benefit families if services are gradually phased out, with an emphasis on helping families build the skill and/or alternative resources needed to maintain change.

The communication strategies outlined earlier in Jessica’s case are especially relevant when a report of medical neglect must be made, so that the family remains engaged in weight
management treatment. Careful framing of the report is key to minimize the potential negative impact on the therapeutic relationship. After a report is made, careful attention to relationship re-building can be helpful. Healthcare providers can employ cognitive behavioral strategies such as mindfulness, validation, and positive self-talk, while working with families, in order to enhance patient-provider interactions (Beach, Roter, Korthuis, Epstein, Sharp, Ratanawongsa, et al., 2013; Butalid, Verhaak, Boeije, & Bensing, 2012; Martin, Roter, Beach, Carson, & Cooper, 2013).

Conclusions and Implications for Practice

The determination of medical neglect includes consideration of the severity and risk of morbidity of the medical condition, whether the medical condition can be reversed, effectiveness of the intervention, the presence of an alternative treatment option that can successfully address the problem, and whether the caregiver treatment non-adherence exposes the child to imminent harm (Varness et al., 2009, Viner et al, 2010). However, as illustrated in the last case example, families often have a negative reaction to a report of medical neglect and may disengage from treatment with the interprofessional team. Thus, in addition to creating a collaborative treatment plan with clear roles for each individual on the family and treatment team and expectations related to adherence, it is critical that the team communicate the obligation to report medical neglect over successive visits using a strengths-based approach that affirms the caregiver and child. The team will also need to be responsive to the family’s needs and barriers to change, and demonstrate to the family that the team remains committed to provide optimal care for the child and support the family. Discussing the need to report must be approached thoughtfully and
carefully to minimize the damage to the therapeutic relationships. It is helpful if one or two members of the team take the lead on these difficult discussions. Assisting with leveraging resources for the family to address the child’s obesity as well as to overcome barriers to change, can help the family be more successful with initiating and maintaining progress. Finally, building a collaborative relationship with the state child protection agency and exploring reciprocal learning opportunities for child protection agency workers and the treatment team will help minimize negative outcomes.

The issue of determining medical neglect is challenging for weight management teams, given the complexity of pediatric obesity and the nuances involved in defining imminent harm to the child. Drawing from the wealth of experiences of the Children’s Hospital Association’s FOCUS on a Fitter Future group of pediatric obesity centers, this paper provides insights for providers who may be faced with this challenging problem. There are substantial opportunities for further work in this area. Research and case study could provide more definitive guidelines with respect to variables such as the degree to which health worsens and the duration of non-compliance before neglect is present. A more structured protocol or measure to assess for medical neglect could assist providers in making more accurate, objective, and timely reports of medical neglect. Health care providers may also benefit from a professional forum to obtain consultation on navigating the issue of medical neglect in the case of obesity in a way maximizes the effectiveness of the interprofessional team and minimizes any negative impact on the child.
References


Table 1 Summary of Challenges, Potential Outcomes and Recommended Action

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Possible Outcome</th>
<th>Recommended Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insufficient documentation to support report</td>
<td>Report may be taken by agency, but may not be investigated, leaving child at continued medical risk</td>
<td>Clear documentation in medical chart</td>
</tr>
<tr>
<td>Protection agency’s limited understanding of medical risk related to obesity</td>
<td>Report may be taken by agency, but may not be investigated, leaving child at continued medical risk</td>
<td>Communicate with agency workers about risk of obesity and comorbidities. Build a collaborative partnership with local state agency</td>
</tr>
<tr>
<td>Family’s limited understanding of medical risk related to obesity</td>
<td>Limited awareness that behavior is neglectful may lead to continued behavior that puts child at medical risk</td>
<td>Effective communication with family about health risks and adherence to treatment plan. Identify preferred methods of learning for child and family.</td>
</tr>
<tr>
<td>Lack of progress despite</td>
<td>Missed opportunity for</td>
<td>Develop patient-provider</td>
</tr>
<tr>
<td>Intensive intervention team to intervene to address medical risk contracts with goals, acknowledgement’s and consequences. Explore reasons for resistance using motivational interviewing techniques. Define role for each member of interprofessional teams, map out an integrative plan across disciplines</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family disengagement after a report</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family may continue behavior that puts child at medical risk.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discuss concerns regarding neglect over successive visits prior to report. Use strength-based approach in treatment plan. Continue use of engagement techniques and link to community resources during and after report</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix

Sample Patient-Team Written Agreement

Date:

Plan for Shane’s Care

Weight Management Clinic will:

- Schedule follow up visit in the clinic
- Work with the family to develop and track use of meal plans (name of dietitian)
- Work with family to develop and track participation with exercise plan (name of physical activity expert)
- Work with family to develop individualized goals, and assist family in meeting those goals (name of psychologist)
- Make a home visit to identify additional needs to maximize success (name of social worker)
- Call the family 2 times a week to provide support, encouragement, and identify any needs (name of social worker)
- Provide resources to assist with transportation (name of social worker)

Shane will:
• Keep a food diary every day

• Follow meal plans developed with (name of dietitian)

• Follow exercise plans developed with (name of physical activity expert)

• Practice skills learned with (name of psychologist)

• Ask family for support in meeting goals

Ms. Smith will:

• Arrange for transportation for Shane to come to appointments

• Cancel an appointment only if necessary (illness, emergency) and call as far ahead of time as possible to cancel and reschedule

• Participate in physical activity with Shane at least twice a week

• Provide encouragement and praise to Shane for her efforts at least once a day

Whole family (grandparents, sister, stepfather) will:

• Work with dietitian to understand which foods to have in the home, and use label reading when grocery shopping.

• Eat at least one meal together as a family each week, with healthy food choices.

Everyone eats the same meal, at the table, with no televisions on.
• Get rid of secret stashes of treats.

• Do their best to encourage Shane by doing physical activity together instead of watching tv.

Note: If this plan is not followed, the team will need to reconsider whether the program is appropriate for Shane’s needs, and/or may need to involve other resources to protect Shane’s health and safety (e.g. hospital protection team and/or state child protection agency).