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Medical neglect at a tertiary paediatric hospital

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ABSTRACT

Medical neglect is under-researched and the extent of the problem in Australia is unknown. We conducted a review of the referrals for medical neglect to the Child Protection Unit (CPU) at a tertiary children's hospital in Sydney over a 5 years period, from 2011 to 2016, to determine what medical conditions are being referred, the reason for the medical neglect concern and whether cases are managed in line with American Academy of Pediatrics (AAP) guideline on medical neglect.

61 cases of medical neglect were identified, constituting 4.1% of all referrals to the Child Protection Unit for physical abuse and neglect. There was a wide variety of medical conditions. Most were chronic medical conditions (87%). The top two medical conditions were chronic and complex multi-system disorders (37.7%) and endocrine disorders (18%). The majority of medical neglect were related to concerns that the caregivers were unwilling to follow medical advice (45.9%) or unable to provide necessary medical care (26.2%). In line with the AAP guideline on medical neglect, all cases were managed by addressing communication difficulties (100%) and resource issues were addressed in 80% of cases. A report to statutory child protection agencies was made in 50% of cases. Directly observed therapy and medical contracts were used in 30% and 26% of cases. We conclude that children with chronic medical conditions may be at risk of medical neglect. Communication difficulties were a factor in all cases. Statutory agency intervention is often required.

1. Introduction

Neglect is the commonest form of child abuse in developed countries (Dubowitz, 2009). Broadly, neglect is defined as an act of omission on the part of the caregiver that results in basic needs not being met, leading to actual or potential harm to a child (Dubowitz, 2009). Child neglect is often further categorised into different subtypes, for example, physical, emotional, supervisory, medical or educational neglect, with many variations of these categories in an effort to capture the varied types of neglect that can occur. Medical neglect is defined by the American Academy of Paediatrics (AAP) as a failure on the part of the parent or caregiver to recognize obvious signs of serious illness or a failure to follow physicians' instructions once medical advice has been sought, resulting in harm to the child (Jenny, 2007). Data from the US indicates that medical neglect occurs in 2.3% of all substantiated cases of child maltreatment reported to child protective services (U.S. DHHS, 2015). A review of child deaths from child maltreatment in the US showed that medical neglect, either alone or in combination, occurred in 8.9% of fatalities (Child Welfare Information Gateway, 2017). Neglect is the primary type of child maltreatment, occurring in 25% of substantiated child maltreatment cases, in Australia

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(AIHW, 2017). However, unlike U.S. child protection data, there is no separate data on medical neglect specifically in Australia and the extent of the problem is not known.

Medical neglect has different underpinnings compared to other forms of child neglect. Although some forms of medical neglect occur due to family dysfunction secondary to domestic violence, poverty, parental mental health problems or parental drug and alcohol abuse, in some instances, parents or caregivers actively refuse medical treatment on behalf of their children on the basis of firmly held cultural or religious beliefs, or belief in alternatives to mainstream medical therapies (Asser & Swan, 1998; Dubowitz, 1999, 2009; Jenny, 2007). Having a chronic and complex disease may also be associated with an increased risk of neglect (Nandyal et al., 2013). The impact of medical neglect can be severe with multiple examples of poor health outcomes for treatable medical conditions as well as child fatalities as a direct result of medical neglect (Asser & Swan, 1998; Azzopardi et al., 2014; Lawrence & Irvine, 2004; Sherman, Baumstein, & Hendeles, 2001; Welch & Bonner, 2013).

Studies relating to responses by medical practitioners to cases of medical neglect indicate medical professionals have difficulty identifying and responding to medical neglect (Merrick, Butt, & Jent, 2010). The AAP position statement on medical neglect provides a guideline for managing cases of medical neglect. The recommendations include a step-wise approach ensuring communication difficulties have been addressed, involving extended family members in the medical management and care of the child, ensuring appropriate resources have been allocated to help families manage the medical condition, using written contracts with the family, using directly observed therapy and if all else fails, referral to child protective services (Jenny, 2007). Cohort studies and case reports relating to medical neglect in children with chronic diseases such as asthma, obesity, perinatally-acquired HIV, have indicated that placement in foster care was the only successful intervention when all other interventions had failed (Alexander, Baur, Magnusson, & Tobin, 2009; Azzopardi et al., 2014; Roberts et al., 2004; Sherman et al., 2001; Williams, Bredow, Barton, Pryce, & Shield, 2014).

There are no studies of the Australian experience of medical neglect. There is a knowledge gap regarding prevalence, risk factors and how medical neglect is managed in Australia. The aim of the study is to examine the demographic and clinical characteristics of children referred to a child protection unit at a tertiary paediatric hospital with medical neglect, and to review the management of medical neglect cases in reference to the AAP guidelines.

2. Methods

We conducted a review of the medical records for referrals for medical neglect to the Child Protection Unit (CPU) at a tertiary children's hospital in New South Wales, over a 5 years period, from 2011 to 2016 to determine what medical conditions are being referred and whether these cases are being managed in line with AAP guideline on medical neglect.

2.1. Setting

The Child Protection Unit at a children's hospital in New South Wales. This unit is a tertiary referral child protection paediatric service. Referrals are accepted for any child aged 0–16 years with a child protection concern, including physical abuse, sexual abuse, domestic violence and neglect. Referrals can be made by health professionals (within the hospital or from other hospitals in NSW), general practitioners, police, child protective services and non-government organisations. Referrals are managed on a case by case basis by a multi-disciplinary team.

2.2. Participants

Participants were children aged 0–16 years who had been referred to the CPU who met the inclusion criteria for medical neglect, as outlined by the AAP position statement on medical neglect (Jenny, 2007). These are outlined in Appendix 1 and include failure to recognise signs of serious illness or failure to follow physician's instructions once medical advice had been sought. There also needed to be evidence that the child had been harmed or was at risk of harm from the medical neglect, the recommended treatment provided significant benefit which outweighed the morbidity of treatment, caregivers understood the medical advice and there was access to healthcare.

2.3. Exclusion criteria

Referrals were excluded from the study if they did not satisfy criteria for medical neglect as outlined above – either because the referral was regarding another form of neglect (for example, supervisory or environmental neglect), there was insufficient evidence to fulfil the criteria for medical neglect as outlined in Appendix 1, or insufficient information was recorded on the referral.

2.4. Data collection

The child protection database was searched for all referrals between 1 July 2011 and 30 June 2016. Any referrals relating to neglect were reviewed and screened for medical neglect. A referral was deemed to be relating to medical neglect if there was any indication that the neglect was associated with the medical care of the child. A checklist protocol derived from the AAP position statement was used to provide a standardised way of evaluating cases for medical neglect (Appendix 1).

Information from each child protection record was collected including the age of the child at the time of referral, gender, ethnic origin (if available), language spoken at home (if available), whether interpreters were required for communication, and source of