Homicides and maltreatment-related deaths of disabled children: A systematic review

Abstract

This article aims to systematically review the empirical literature in relation to the homicides and maltreatment-related deaths of disabled children [PUBLISHER – THE PRECEDING UNDERLINED TEXT IS FOR THE MARGIN] to better understand risk factors and to assess support for the explanatory theories posited. These theories include: 1) the stress of caregiving; 2) altruistic intent; 3) lack of bonding with the child; 4) the challenging behaviours of a child; 5) cultural beliefs about disability; and, 6) evolutionary imperatives. Systematic searching techniques were used to retrieve relevant research articles in six electronic databases: AMED, CINAHL, Criminal Justice Abstracts, Medline (PubMed), PsycINFO and SCOPUS. The issue of a child being disabled was identified as a risk factor in most articles reviewed, however the definition of the term 'disability' was not consistent nor was there a consistent approach to recording children's disability. A range of potential risk factors were found, related to the child, the perpetrator and the environment, with the pathway to harming the child involving an interactive process between each of these. The stress of caregiving and altruistic theories were the two most common explanations, although a combination of theories may provide a more comprehensive explanation of these complex events.

Key Practitioner Messages

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- Coordination of clear care pathways for families with disabled children, including provision of support and counselling.
- Improved professional awareness of the needs of disabled children and understanding that these needs may not coincide with those of their parents or carers.
- Provision of opportunities for respite to enable parents of disabled children to continue their task of caring.
- Need for consistent data on disabled children to be collected through existing child death review processes and the criminal justice system.

Key words

child death; filicide; fatal abuse; disabled children; systematic review

Introduction

This article seeks to review the empirical literature regarding the homicides and maltreatment-related deaths of disabled children in three particular circumstances: (a) intentional filicides; (b) deaths directly caused by abuse or neglect (either one-off incidents, or the culmination of chronic maltreatment); or (c) deaths where abuse and neglect may have contributed but were not the primary cause of death.

In conducting this review, we wish, firstly, to better understand risk factors related to the deaths of these children and, secondly, to assess the empirical support for six proposed explanatory theories. To our knowledge, there has been no other systematic review of research regarding the deaths of disabled children in the aforementioned circumstances.

In this paper we have chosen to use the term disabled children rather than children with disabilities. This reflects the social model of disability, seeing individuals as having impairments, but being disabled by social factors. Disability is thus not just a health problem (United Nations Convention on the Rights of People with Disabilities, 2007).

Greater vulnerability of disabled children to abuse

Research has shown that, compared to non-disabled children, disabled children are three to four times more likely to be treated violently (Jones *et al.*, 2012). Taylor *et al.* (2016) have summarised a range of factors identified as explaining the increased vulnerability to abuse for disabled children: disabled children may be seen by possible offenders as less knowledgeable or aware of inappropriate behaviour than a non-disabled child; impairments in

their ability to communicate may reduce the capacity for a disabled child to disclose abuse; mobility difficulties may limit a disabled child's capacity to avoid an abuser; and, a disabled child's need for personal care may create opportunities for others to abuse them. Furthermore, factors within their family may include: stressful demands associated with the care of a disabled child; negative feelings about having a disabled child; and, behaviour management methods used by parents which may be inappropriate. Other vulnerability factors include disabled children's voices being unheard, both due to lack of engagement by professionals, and to a focus by professionals on the needs of parents, as though their needs were synonymous with their children's, resulting in professionals not looking for signs of abuse or hearing disclosures from children (Jones *et al.*, 2017; Stalker *et al.*, 2015; Taylor *et al.*, 2015).

Within the literature on the homicides and maltreatment-related deaths of children, disabled children have been identified as likely to experience a greater risk [PUBLISHER – THE PRECEDING UNDERLINED TEXT IS FOR THE MARGIN] (Chance and Scannapieco, 2002; Jonson-Reid *et al.*, 2007; Koenen and Thompson, 2008). The main theories proposed to explain this increased risk relate to:

1. The stress of caregiving
2. Altruistic intent
3. Lack of bonding with the child
4. The challenging behaviours of a child
5. Cultural beliefs about disability
6. Evolutionary imperatives

Each of these theories is summarised below.

Theory relating to stress

While most parents of disabled children provide caring and safe homes for their children (Taylor *et al.*, 2016), many disabled children require a greater amount of care than their non-disabled peers. They can require a considerable amount of personal care and supervision and place significant practical and emotional demands on their parents (Peer and Hillman, 2014; Sidebotham *et al.*, 2016). This can involve direct care such as feeding and toileting beyond a child's younger years; increased need for supervision; attendance to care and medical needs at regular intervals throughout the day and night; and frequent appointments at health services, with little prospect of improvements in the child's well-being, or respite from the task of caring. Parents can be subject to exhaustion from 'round-the-clock care' (Nowak, 2015, p. 296) and have described,

'being 'stressed out', 'exhausted', 'burned out' or at their 'wits end'. Caregiving is experienced as a '24 hrs a day 365 days a year' job, something arduous and 'constant – it never stops'.' (Doig *et al.*, 2009, p. 236)

Families must also balance the requirements of other members of the family, cover the costs required when bringing up a disabled child, and frequently report isolation and social difficulties (Findler *et al.*, 2016).

Whereas parents of disabled children in general experience high degrees of stress (Davis and Carter, 2008; Peer and Hillman, 2014), mothers are typically the main caregivers for children, and as such they can be especially prone to stress when raising a disabled child (Findler *et al.*, 2016; Nes *et al.*, 2014). This can affect their mental health, with mothers of disabled children found to experience greater psychological distress and to have an elevated risk for clinical depression [PUBLISHER – THE PRECEDING UNDERLINED TEXT IS FOR THE MARGIN, i.e. ‘Mothers of disabled children [have been] found to experience greater psychological distress and to have an elevated risk for clinical depression’] compared to mothers of children with no disability (Nes *et al.*, 2014). Mothers caring for children with autism, in particular, have been found to have high levels of mental health problems (Fairthorne *et al.*, 2016; Sawyer *et al.*, 2010). In fact, higher levels of stress and indicators of emotional difficulties have been reported for parents of children with autism than for either parents of children with other disabilities or parents of non-disabled children (Davis and Carter, 2008). This theory proposes that the stresses experienced by these parents lead to parental behaviours (such as violent outbursts) which can result in the death of the child.

Theory relating to altruistic intent

The second theory focuses on altruistic intent. In his seminal paper proposing a typology of filicide Resnick (1969, p. 329) proposes two forms of altruistic filicide: Firstly, ‘filicide associated with suicide’ committed by parents who claimed that they ‘could not abandon their children’ when they sought to die by suicide; and, secondly, ‘filicide to relieve

suffering' where the parent's aim was to alleviate the victim's suffering, which may have been real or imagined. Friedman *et al.* (2005) found that parents who killed their children and then died by suicide had a high incidence of mental illness, and although some cases involved a psychotic delusion that the child was suffering, others included children with genuinely serious medical conditions.

Theory relating to lack of bond with child

According to Nowak (2015), parent-child bonding is vital in preventing child abuse, however in the case of disabled children it is frequently weakened because of the need for intensive care for the children as neonates or due to repeated stays in hospital. Parents may also experience grief reactions due to the 'loss of the expected child' (Nowak, 2015, p. 296).

It is recognised that the birth of a disabled child can affect parental psychological wellbeing and life satisfaction (Nes *et al.*, 2014; Fairthorne *et al.*, 2015). In such circumstances, the bonding between a disabled child with either or both parents can be compromised (Palermo, 2003), particularly for children who find it difficult to express certain emotional responses, such as children with autism (Coorg and Tournay, 2012; Palermo, 2003). Barone *et al.* (2014) have also reported that problematic attachment relationships were overrepresented among a group of filicidal mothers.

Theory relating to children with challenging behaviours

While younger children are more likely to be victims of homicide, murders also occur among older children (UNICEF, 2003). Parents may become frustrated with lack of response to conventional disciplinary methods and progressively turn to harsher punishments (Nowak, 2015). In instances where parents may be challenged by the behaviour of their child, some parents may use excessive force, resulting in the child's death [PUBLISHER – THE PRECEDING UNDERLINED TEXT IS FOR THE MARGIN]. As well as adolescents who are testing boundaries, children with autism are seen as part of this higher risk group due to the nature of their behaviour and a parent's sense of frustration at being unable to care for and control their child (Coorg and Tournay, 2012).

Theory relating to disabled children and cultural beliefs

There has been a growing awareness of the death of children due to cultural beliefs about disabled children. For example, in the African context, Assouan *et al.* (2014) report that there is stigma surrounding facial clefts, often leading to rejection or infanticide of the affected newborn. Similarly, Denham *et al.* (2010) report that in the Kassena-Nankana District of Ghana, investigators have described situations whereby some children die by infanticide as they are considered 'spirit children' sent 'from the bush' to cause calamity to the family. Some disabled children are seen as such spirit children, thus increasing their risk of being killed.

Theory relating to evolutionary imperatives

Seminal research by Daly and Wilson (1988), proposes that specific patterns of parental inclination have evolved in mothers that lead them to commit infanticide, as the child would have been 'unlikely to survive during human evolutionary history' (p. 522). In such situations, mothers are typically relatively young and have considerable continued capacity for reproduction, but rearing a child with difficulties, such as a disabled child, could jeopardise their own survival and future opportunities to have further children. According to this theory, in a similar way to other mammals, the forces of evolution in distant eras have formed mothers' emotional responses, behaviours and motivations to be 'disinclined to raise (such) a child' (Daly and Wilson, 1988, p. 521).

In order to, firstly, develop greater knowledge of risk factors related to the homicides and maltreatment-related deaths of disabled children and, secondly, evaluate the support for the explanatory theories posited, the aim of this article is to systematically review the empirical literature relating to the deaths of disabled children intentionally (homicide), or through maltreatment. In doing so we intend to add to the understanding of this phenomenon and to support policy and practice responses.

Methods

Retrieval and selection of articles

Within a larger systematic search of literature regarding child homicide, the current review is focused on the deaths of disabled children through either (a) intentional filicides; (b) deaths directly caused by abuse or neglect (either one-off incidents, or the culmination of chronic maltreatment); or (c) deaths where abuse and neglect may have contributed but were not the primary cause of death. We identified relevant articles in peer-reviewed journals through systematic searches in six electronic databases: AMED, CINAHL, Criminal Justice Abstracts, Medline (PubMed), PsycINFO and SCOPUS. We used the following search terms to retrieve relevant articles: (homicide OR murder OR manslaughter OR filicide OR infanticide OR neonaticide OR filicide-suicide OR familicide OR fatal child abuse OR fatal child maltreatment OR death OR kill OR fatality) AND (victim OR child OR infant OR baby OR toddler OR pre-schooler OR adolescent OR teenager) AND (perpetrator OR parent OR mother OR father OR step-parent OR biological parent OR carer OR guardian OR foster-parent OR partner OR de facto OR paramour OR boyfriend OR girlfriend OR baby-sitter OR child-minder OR spouse OR friend OR stranger OR murderer OR killer). Additionally, we checked references in related review articles. We confined our searches to peer-reviewed articles published in English between January 1st, 1990 and December 31st, 2017 [PUBLISHER – THE PRECEDING UNDERLINED TEXT IS FOR THE MARGIN].

To assess the evidence base for the theories described in the introduction, we aimed to review empirical work only rather than opinion pieces or other reviews. Therefore, articles were included in our final selection only if they involved: (a) the collection of empirical data regarding (b) homicide or maltreatment-related deaths of (c) one or more people younger

than 18 years old, of whom (d) at least one was described as disabled, or where the article explicitly considered disabled children in its assessment.

Figure 1 shows the screening and selection flowchart. JF and JD carried out screening and selection by consensus, with EA screening a subset of the papers as an additional check (no discrepancies found).

- Please insert Figure 1 about here –

Coding and analysis

We identified and recorded information obtained in a standardised form. Initial coding was undertaken by JF and JD. Discussion regarding this coding then took place among all three authors until consensus was reached. We extracted information in three domains. Firstly, the design and methods were recorded. We included a brief description of the design and any standardised definitions and measures that were used. Secondly, we summarised the sample in relation to demographics, location and size of the sample. Thirdly, all information for the sample in relation to disabled children and whether this was thought to be relevant to the reason for their death was noted. As the number of relevant articles was so small and the approaches so diverse, we opted to describe all relevant information. As a consequence, our findings are tentative, given the small number and wide variation of the included articles.

Findings

Our initial search resulted in 535 potentially eligible articles, of which 25 met our criteria. The included articles described 5150 child homicides and maltreatment-related deaths [PUBLISHER – THE PRECEDING UNDERLINED TEXT IS FOR THE MARGIN], ranging from an article describing a single case to much larger samples of over 2000 cases (see Table 1 for an overview). Most (n=10) of the included articles drew upon data from the USA; four from the UK; two each from Australia, Italy, and Sweden, and single papers with data from Belgium, Canada, China, Finland, France and Turkey. The designs varied significantly, with 21 being case series, one a single case and three epidemiological studies. The vast majority (23) did not have specific hypotheses regarding disability.

- Please insert Table 1 about here –

The articles fell into three broad categories: firstly, those primarily focused on the perpetrators; secondly, those focusing mainly on the children; and thirdly, articles which explored the characteristics and circumstances of both perpetrators and victims (See Table 1).

Risk factors

The first aim of the review was to gain greater understanding of the risk factors regarding the homicides and maltreatment-related deaths of disabled children. Those found in these particular articles and described below included: parental failure to provide care/standard of care; parental lack of access to services; parental mental illness; and children with autism [PUBLISHER – THE PRECEDING UNDERLINED TEXT IS FOR THE

MARGIN, i.e. '[Risk factors] included: parental failure to provide care/standard of care; parental lack of access to services; parental mental illness; and children with autism'].

Parental failure to provide care

Sidebotham *et al.* (2011), in an analysis of reports into the death or serious injury of 276 children, identified five disabled children where natural causes had led to the child's death, but with a suggestion of parental failure to effectively deal with the child's illness and/or care needs. The article by Jonson-Reid *et al.* (2007) reported a link between health risks in infancy and future death, stating that there is a need to be clear about whether deaths of disabled children are more attributable to their disability/illness than to maltreatment, particularly when the cause of death may result from the standard of care provided (or not provided) by a parent or caregiver. In the article by Rougé-Maillart *et al.* (2005), a mother confined her disabled child in a room and deprived him of food and water until he died. Neglect by parents leading to death by starvation for a disabled child was also reported in the article by Sim (2015).

Parental lack of access to services

Palusci and Covington (2014), in an analysis of 49 947 child deaths in the USA identified 2285 cases where child abuse resulted in or was a contributing factor in the death. They identified that 341 (13.7%) of the children had a 'prior disability/chronic illness' recorded, of whom 223 suffered neglect, 121 suffered physical abuse and 10 suffered psychological maltreatment. They concluded that the high number of children with previous

disability or chronic illness emphasised the importance of parents having access to interventions and services for the additional needs of both carers and children in these situations.

Parental mental illness

Coorg and Tournay (2013) studied 22 children with developmental disabilities who were victims of filicide-suicide. There were 21 offenders of whom 10 were fathers, 10 were mothers, and one was a grandfather. Over a third (38%) of the offenders were reported as having a mental illness, which included depression, bipolar disorder and psychosis. Nordlund and Temrin (2007) found that three of five offenders died by suicide in connection with the homicides, of whom two had psychiatric illnesses. In Marleau *et al.* (1999), a 14-month-old child was killed by her father when he was experiencing a psychotic episode. The issue of a parent's or carer's poor mental health and the death of children, including disabled children, was also noted by McKee and Bramante (2010), who reported that children who were medically and mentally unwell were at greater risk of homicide when their mother had a mental illness.

Children with autism

A number of articles noted autism as a specific disability that appears to be associated with homicide in certain circumstances. Coorg and Tournay (2013) found that 55 per cent of the disabled child victims of filicide-suicide were diagnosed with autism spectrum disorder. The child in Declercq *et al.* (2017) also had autism, which was seen as a factor leading to him

being chosen as a victim. Sim (2015), too, in the case noted earlier, described a seven-year-old disabled girl with autism, who died from starvation and neglect on the part of her parents.

Definition of disability

An important factor pertinent to helping understand the homicides and maltreatment-related deaths of disabled children was the definition of disability employed. Most articles did not state how they defined disability [PUBLISHER – THE PRECEDING UNDERLINED TEXT IS FOR THE MARGIN]. Among those that did define it, the definitions varied from the very broad to the more specific. Coorg and Tournay (2013, p. 745) defined chronic disability as ‘any long term sensory, physical, or mental state that could interfere with self-care as a child ages’. Some articles framed disability in terms of medical diagnoses, for example, ‘trisomy 21’ (Rougé-Maillart *et al.*, 2005, p. 324). In most articles, disability involved the use of a wide range of terms and nomenclatures, for example, developmental delay/concerns/issues, learning difficulties, autism, mental illness, or behavioural disorders/disturbance/problems.

Support for theories for increased risk of homicide

The second aim of the review was to provide a reflection on the evidence to support any of the theories proposed to explain the increased risk of homicides and maltreatment-related deaths to disabled children.

Theory relating to stress

In Harper and Voigt (2007, p. 305), the authors described a case which appeared to explain the homicide as being motivated by the stress involved in caring for a disabled child. The mother killed her two children and then herself, leaving a series of notes saying, 'she is 'tired' and worn out by caring for her 8-year-old severely mentally handicapped daughter'. The article by Coorg and Tournay (2013) suggested that certain types of disabled children, such as children with autism, may place a greater stress on carers. Stress was also noted in the article by Miller *et al.* (2007) regarding the homicide of internationally adopted children. They observed that these children can have complex behavioural problems such as reactive attachment disorder, with reports also of violent outbursts on the part of the children. They highlighted the vigilance required by professionals in identifying parents or carers who may be showing signs of disappointment, stress, or depression when adopting children in these circumstances. Hegar *et al.* (2015) also noted a significant degree of stress among those parents with internationally adopted children.

Theory relating to altruistic intent

Rougé-Maillart *et al.* (2005) outlined two cases they described as altruistic homicides. In the first a mother killed her two-year-old son. When questioned, she said that life ‘would be too hard for him if he did not know how to speak’ (p. 324), even though he was just 18 months old. In the second case, a couple had decided to put their son into a centre for disabled children, although subsequently the boy's mother said she could not bear this idea. The child, who had Down Syndrome, was locked in a room by his mother and deliberately deprived of food and water until he died. Marleau *et al.* (1999) reported a case where the motivation appeared to be altruism. A father killed his youngest daughter to prevent her from becoming like her older sister, who was significantly disabled and who died after being in a coma for a long period. The killing occurred when the younger daughter was 14 months old and her father was experiencing a psychotic episode. The article was not clear whether the child who was murdered was actually disabled. Nordlund and Temrin (2007) reported that the deaths of five disabled children were seen as ‘acts of mercy’. The children were experiencing illness and the perpetrators were deemed to be ‘saving’ them from further suffering. Three of the five offenders died by suicide in connection with these homicides; none of the offenders killed any other family members; two of the perpetrators had psychiatric illnesses; and one had social difficulties. In Eriksson *et al.* (2016, p. 25), a mother killed her son who was chronically physically disabled because he had ‘been through enough, I saw him hurting so much’. Coorg and Tournay (2013) suggested that parents of autistic children, when feeling depressed and at risk for suicide, may consider filicide as altruistic. While the perceived intention may have appeared altruistic, these cases could also be seen as representing parents

with a mental illness [PUBLISHER – THE PRECEDING UNDERLINED TEXT IS FOR THE MARGIN].

Theory relating to children with challenging behaviours

Coorg and Tournay (2013) indicated that autistic children can be liable to volatile behaviour which may place them at risk for physical maltreatment, which could result in a fatality. Miller *et al.* (2007) referred to challenging behaviour in their article regarding internationally adopted children with complex behavioural problems. Hegar *et al.* (2015) also described acute special needs and challenging behaviours associated with internationally adopted children.

Theory relating to lack of bond with child

There was only one article which referred to the theory regarding the lack of bond with a disabled child. Difficulties in bonding with a child with autism were noted by Coorg and Tournay (2013).

Theories with no support

In this review, there was no support found for the theories relating to cultural beliefs or evolutionary imperatives [PUBLISHER – THE PRECEDING UNDERLINED TEXT IS FOR THE MARGIN] for the increased risk of homicides and maltreatment-related deaths for disabled children. This is not to say that these theories are baseless, rather that the currently available empirical research has not looked specifically at the deaths of disabled children

through such a lens, even though there is a literature on child homicide related to culture and evolutionary imperatives (e.g. Miller, 1987; Mathews *et al.*, 2013; Mishra *et al.*, 2014).

Discussion

As noted by Sidebotham *et al.* (2016) and Mathews and Abrahams (2018), the pathway to harming a child, by either action or omission, involves an interaction between the child and their vulnerabilities, the perpetrator and their situation, and the wider environmental context within which the human actors find themselves. The articles reviewed in the current paper show such a pathway, with reported risk factors related to the child (for example, type of disability, such as autism), risk factors associated with the perpetrator (for example, family stress, mental illness), and risks linked with the environment (for example, lack of services).

The theory relating to stress and the theory relating to altruistic intent were the two most common explanations cited for the homicides and maltreatment-related deaths of disabled children in the articles reviewed [PUBLISHER – THE PRECEDING UNDERLINED TEXT IS FOR THE MARGIN, i.e. ‘Stress... and altruistic intent were the two most common explanations cited for the homicides and maltreatment-related deaths of disabled children in the articles reviewed’] . Both theories also have considerable support in the articles cited in the literature review in the introduction. Specifically, parents have more physical, economic and emotional demands upon them when their child is disabled. In turn this can increase the sense of being overwhelmed, stressed and isolated. In addition, this review lends support to the position by Camperio Ciani and Fontanesi (2012) that in instances

where children have significant disabilities, a parent may not be mentally ill when they seek to relieve the suffering of their child, and may be making a rational decision, albeit one that is unpalatable. However, the evidence we have found is limited, and more research is required to explore the interaction between altruistic intent and parental psychopathology.

There appeared to be some support for the theory relating to children with challenging behaviours and for the theory relating to lack of bond, but no evidence for the theory around cultural beliefs nor the evolutionary theory. Although there is a possibility that the deaths of internationally adopted children may have some explanation on the basis of evolutionary theory and parental disinclination to raise children with difficulties, including those not biologically related, we feel that the theories relating to stress and challenging behaviours, as suggested by Hegar *et al.* (2015) and Miller *et al.* (2007) provide more suitable explanations.

These theories should not necessarily be seen as discrete and disconnected, however. In the case described by Declercq *et al.* (2017, p. 45) a ‘critical interplay’ was seen to have occurred between the disability of the victim and the personality disorder of the offender. A number of theories, operating in combination, may provide a fuller explanation of these complex events. For example, Coorg and Tournay (2013) refer to four of the theoretical explanations in relation to children with particularly demanding care needs. Firstly, they propose that certain types of disabled children, such as those with autism, may place greater stress on carers. Next, they note the difficulty of bonding with a child with autism. They also indicate that autistic children can be liable to volatile behaviour which may put them at risk for physical maltreatment, with possible fatal outcomes. Finally, they suggest that carers may consider as altruistic the carrying out of filicide in such difficult circumstances.

Some of the articles reviewed have highlighted that while some disabled children have died as a result of violence directed at them, others have died either as a result of general neglect of their care and health needs (Sidebotham *et al.*, 2011), or neglect with the deliberate intention of causing death [PUBLISHER – THE PRECEDING UNDERLINED TEXT IS FOR THE MARGIN, i.e. ‘While some disabled children have died as a result of violence..., others have died either as a result of general neglect..., or neglect with the deliberate intention of causing death’] (Rougé-Maillart *et al.*, 2005). Golden *et al.* (2003, p. 105) have noted the issue of ‘deliberate or malicious failure to supply the needs of a child’ which they term as ‘deprivational abuse’. This intention may be a specific form of harm directed at and experienced by disabled children. Interventions to identify and meet the needs of children in such circumstances must be designed to differentiate between some parents' lack of understanding of, or inability to meet, or a combination of both, in relation to their child's needs, and other situations whereby carers are more intent on harming the child, even if the reason might be perceived as altruistic. This highlights the challenges for both practitioners involved in supporting a disabled child and their family, and also professionals involved in investigating a disabled child's death.

The issue of a child being disabled is recognised as a characteristic of a child and/or a factor worthy of note by some researchers looking at the homicides and maltreatment-related deaths of children. It is identified as a risk factor in most of the articles reviewed. However, the definition of the term 'disability' was not consistent, varying from the broad to the more specific. There was no single definition in use generally in the reviewed papers, which is also reflected within the relevant professional, scientific and academic communities. This

provides a significant barrier in seeking to quantify and understand the scale and nature of homicides and maltreatment-related deaths involving disabled children. At the most fundamental level it would appear necessary that the nature of any disability of a child at the time of their death is recorded consistently by child death review processes and review teams. As noted by Palusci and Covington (2014), some data are routinely recorded in certain countries or regions, but this is quite limited, and would benefit from a global approach given the relatively small numbers of disabled children killed. An example of an approach which could be taken is provided by Kelly and Dowling (2015), where they note that an agreed definition of disability is needed to address the issue of underreporting of disabled children in child protection statistics and to promote consistency in recording disability. They have outlined an operational definition of disability, based on the UK Disability Discrimination Act 1995 as ‘a physical or mental impairment that has substantial or long-term effect on a person's ability to carry out normal day-to-day activities’ (Kelly and Dowling, 2015, p. 8). They state that the UK Autism Act 2011 ‘further amended this definition of disability to include social and communication impairments related to autistic spectrum conditions’ (Kelly and Dowling, 2015, p. 4). They comment further that training for professionals could be made available to improve understanding of disability and emphasise the importance of information regarding disability being recorded to enable ‘assessment and monitoring of the population of disabled children in contact with the child protection system’ (Kelly and Dowling, 2015, p. 30).

Policy and practice implications

We could certainly do better in quantifying and understanding the homicides and maltreatment-related deaths of disabled children. There is a clear and pressing need for data on disabled children to be routinely collected and collated through existing child death review processes and the criminal justice system [PUBLISHER – THE PRECEDING UNDERLINED TEXT IS FOR THE MARGIN]. Not only would this help us to better understand this phenomenon, but it would also allow us to have fuller discussion about whether the deaths of disabled children are treated as seriously as the deaths of non-disabled children.

Sidebotham *et al.* (2016) and Mathews and Abrahams (2018) have commented that adopting a more ecological rather than pathological perspective holds out a greater prospect of intervening in ways that are likely to reduce the incidence of maltreatment deaths and ‘clear coordinated care pathways for families with particular vulnerabilities are needed to help ensure parents and children receive timely and accessible help’ (Sidebotham *et al.*, 2016, p. 17). Improved professional awareness of the needs of disabled children and understanding that these needs may not coincide with those of their parents or carers (Jones *et al.*, 2017; Stalker *et al.*, 2015; Taylor *et al.*, 2015), appears vital for the protection from harm of these vulnerable children.

There is a need for the incorporation into adult mental health professionals and services a consciousness of the needs of the children of their clients, especially of vulnerable disabled children. There were clear risks for children among some of the parents with mental illness in the articles reviewed, including suicidal behaviour and the inclusion of children in psychotic delusions (Coorg and Tournay, 2013; Marleau *et al.*, 1999; McKee and Bramante,

2010; Nordlund and Temrin, 2007). However, parents can sometimes be treated by adult mental health services without consideration of their family context and of the needs of their children (Brandon *et al.*, 2012).

Parents frequently experience stress during the assessment and diagnostic process involving their disabled child, with clear evidence that open, honest and positive experiences with health professionals at this crucial time, including the provision of support and counselling, can have important consequences for their ongoing coping capacity (The Royal Australasian College of Physicians - Paediatric and Child Health Division, 2013). The high care demands on parents of disabled children (Peer and Hillman, 2014; Sidebotham *et al.*, 2016), and consequent exhaustion (Doig *et al.*, 2009; Nowak, 2015), stress (Davis and Carter, 2008; Peer and Hillman, 2014) and isolation (Findler *et al.*, 2016) also mean that opportunities for respite or 'short breaks' can be vital in enabling parents continue their task of caring (Collins *et al.*, 2014, p. 1180).

Limitations

There are several limitations to this review. Firstly, our systematic search yielded only a small number of relevant articles. This suggests that there is a need for further research but also limits our current conclusions. In addition, the research designs varied considerably, and disability was often not central to the research questions; while providing some valuable insights, this diversity limits the potential for comparisons. Finally, any systematic review is

limited by decisions made regarding scope and design. For example, for feasibility reasons, we only included English language papers; it is possible that peer-reviewed work has been published in other languages.

Conclusion

In conclusion, in this review regarding homicides and maltreatment-related deaths of disabled children, a range of potential risk factors emerged, related to the child, the perpetrator and the environment, with the pathway to harming the child involving an interactive process between each of these. Type of disability, such as autism, family factors such as stress and mental illness, and risks associated with the environment, such as lack of services were evident. Theoretical explanations related to stress and altruistic intent were more commonly used and supported than explanations related to challenging behaviours, a lack of bonding, cultural beliefs and evolutionary imperatives, although a combination of theories may provide a more comprehensive explanation of these complex events. The overarching message is that we still have limited evidence about the specific risks involved in the homicides and maltreatment-related deaths of disabled children [PUBLISHER – THE PRECEDING UNDERLINED TEXT IS FOR THE MARGIN], and greater international co-operation about how we record such information would assist as we move forward.

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Figure 1

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