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Sudden Unexpected Death in Childhood in Greater Manchester (United Kingdom): A Five-Year Review (2015–2020)

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ABSTRACT

The sudden, unexpected death of a child (SUDC) is a devastating experience. It is vital that supportive and investigative services are effective and promote the best outcomes for families. Analysis of 5 years of data from 309 SUDC cases in Greater Manchester, United Kingdom (UK) shows how a number of key service outcomes can be measured and achieved through a raft of actions which are commensurate with and exceed the service level recommended by the UK Government. Annual reports covering the work of the Greater Manchester SUDC team are compiled from audit forms completed by the attending SUDC pediatrician for each case. Data from these reports from April 1, 2015 to March 31, 2020 were analyzed. Most cases happened out of normal working hours, predominantly on Sundays. This supports the need for a 24-hour, 7 days per week SUDC service to enable early investigation and timely support for families. The review demonstrated that the Greater Manchester model is able to deliver this in a rapid response with early attendance in emergency departments and early home visits; effective joint agency working with police, children's social services, and other agencies; and provision of support to families. The proposed instigation of a key worker role in the SUDC team is a welcome development. This is central to ameliorating the experience for parents by providing bereavement support separate from the investigative role of the SUDC team. Research is needed into the role of the key worker, potentially as a dedicated bereavement nurse, and understanding of families' experiences to ensure that support is optimal.

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Death; child; sudden unexpected death in childhood (SUDC); medico-legal; bereavement; support

Introduction

Sudden unexpected death in childhood (SUDC)

As of mid-2020 the population of the United Kingdom (UK) was estimated to be 67.1 million, with 14.2 million of these people being aged under 18 years old (and therefore children). Greater Manchester is a metropolitan county and combined local authority area in the Northwest of England, UK. It has an estimated population of just under three million people (just over 4% of the estimated UK population). There are 648,590 children estimated

to be living in Greater Manchester (4.6% of the estimated children living in the UK; Office for National Statistics (ONS), 2021). Greater Manchester comprises 10 metropolitan boroughs: Bolton, Bury, Oldham, Rochdale, Stockport, Tameside, Trafford, and Wigan; and the cities of Manchester and Salford (the Greater Manchester Combined Authority "GMCA").

Between April 1, 2019 and December 31, 2019, a total of 2498 childhood deaths were reported to the National Child Mortality Database (NCMD) in England; compared with a total of 2264 in the same period of 2020 (Odd et al., 2021). The sudden death of a young relative has significant and long-term emotional implications for the family, particularly for the child's mother (Yeates et al., 2013). Bereaved parents report more depressive symptoms, poorer well-being, and more health problems and were more likely to have experienced a depressive episode and marital disruption than were comparison parents (Rogers et al., 2008).

Greater Manchester's SUDC Rapid Response started in January 2009, investigating the deaths of children aged 0-18 years. There is a full-time SUDC on-call rota staffed by consultant pediatricians across Greater Manchester: which benefits from being a relatively small but population-dense geographical area. This enables pooling of resources to provide a regional service 24 hours per day, 365 days per year. These consultants respond immediately to the death of a child, joining with a senior police officer (detective inspector rank or above) to examine the child who has died, take a history from the parents/carers, visit the scene where the child died, and work closely with children's services and other agencies. The aim of the SUDC investigation process is to come to an understanding of why the child died and what had increased their vulnerability to dying that day, to co-ordinate bereavement support for the family, to assist coroners in their legal duties (Courts and Tribunals Judiciary, n.d.), and to consider what lessons could be learned to reduce future child deaths. This means that families receive the same level of support and care no matter where a child dies in the Greater Manchester area. This model also enables support for the team itself and learning among the SUDC pediatricians, as cases are reviewed at monthly meetings where experience and knowledge can be shared, and expertise developed.

Working Together to Safeguard Children: A guide to interagency working to safeguard and promote the welfare of children (HM Government, 2018a) and Child Death Review: Statutory and Operational Guidance October 2018 (HM Government, 2018b) included a revision from a "rapid response team" to a "Joint Agency Response" team (JAR) with the aim of reflecting the ongoing nature of the investigation of the child's death and the support required by the family. These policy documents also placed much greater emphasis on bereavement support, and this has resulted in improved support of families as the new guidance strengthens the role of the key worker, whose primary responsibility is to support the family.

A further change was in the suggested criteria that should trigger a JAR response. Before 2018, the SUDC team in Greater Manchester had investigated deaths that were not anticipated as a significant possibility 24 hours prior to the death, or when the collapse that precipitated death was similarly unexpected. This was in accordance with the definition of cases requiring a rapid response set out in *Working Together to Safeguard Children 2015* (HM Government, 2015). The new 2018 Working Together to Safeguard Children statutory guidance includes a number of situations that would trigger a JAR but implies that deaths



should be investigated only if there is no immediately apparent cause of death, if external causes are suspected, if a child is stillborn and that birth is not attended by a health-care professional, or if a child's death occurs in custody.

The Working Together to Safeguard Children publication identifies statutory guidance for local authority chief executives, directors of children's services, safeguarding partners, teachers and education staff, social workers, health service professionals, adult services, police officers, and voluntary and community-sector workers in contact with children and families. It applies to local authorities and all schools. A version of the guidance for young people (Children's Commissioner for England, 2014) and a separate version suitable for younger children (Children's Commissioner for England, 2013) are also available for practitioners. Statutory guidance is issued by law - it must be followed unless there is a convincing reason not to do so (HM Government, 2018a, 2018b).

Given the experience of the Greater Manchester SUDC team over the last decade, it was felt that important information may be lost by the narrowing of the criteria for triggering a JAR response. The 2018 guidance was discussed with the commissioners for the Greater Manchester SUDC Rapid Response team who requested that the on-call team should continue to respond in the same manner at the point of a child's death to investigate jointly with the police. A request was made that there should not be a narrowing of the inclusion criteria for such a response and that the service specification should continue to be that the SUDC on-call team would respond to all deaths (under 18 years of age) that had not been a significant possibility 24 hours prior to the death, or when the collapse that precipitated death was similarly unexpected. In effect this represented maintenance of the pre-2018 arrangements.

For example, if a child died following an acute asthma attack, this is likely to be sudden and unexpected in the 24 hours prior to death, but with an identified medical cause of death a JAR would not be triggered. However, by maintaining the previous Greater Manchester criteria, this death would still be investigated. This could help to identify factors that may have contributed to the child's death, for example, poor compliance with preventer treatment, delays in acute management, or precipitating factors of the asthma attack in the community. This decision to retain the original investigation criteria was strongly approved by the regional SUDC steering group, the Greater Manchester Child Death Overview Panel chairs and by Her Majesty's Coroners in Greater Manchester. The Greater Manchester SUDC team has, therefore, continued to provide a "flying squad" approach with a 24-hour on-call service delivered by a consultant pediatrician. It was felt that this provided better care for families and enabled a more immediate and thorough investigation of factors that may have contributed to the child's death.

Since the introduction of a rapid response team in Greater Manchester to investigate SUDC cases an annual clinical audit has been undertaken to review the nature of the cases seen and the response provided by the team to these cases. In 2020, a retrospective review was undertaken of the previous 5 years of SUDC cases (309 cases) in Greater Manchester in order to gain a clear overview of the service currently provided, to shape future changes to the service, and to ensure that the SUDC team continued to provide the best possible response to families.

With effect from September 2019 additional audit data was collected to ascertain how many additional cases were being investigated by the JAR retaining the pre-2018 criteria, and to compare this with the number of cases that would be triggered if the new criteria were adopted. The aim of each annual audit (as well as collectively the five-year learning) was to ensure that the SUDC team was delivering the intended service, to inform further development of the service for the child in terms of robust investigation into the cause of death, to ensure that family distress is not heightened needlessly by the investigation, and to provide support as and when required. This paper reports the findings of the five-year review of SUDC cases in Greater Manchester from April 1, 2015 to March 31, 2020.

Context of the review

The imperative to act

The Department of Health and Social Care for England (DHSC) acknowledges the challenges that bereaved parents face and the potential results of not caring for them in an effective manner (HM Government, 2018a, 2018b). It acknowledges that parents "may be in state of extreme shock" and be unable to retain or process information. Although grief is a global phenomenon - and human beings grieve after any sort of loss - this is arguably most powerfully felt after the death of someone they love (Royal College of Psychiatrists, 2020). The death of a child or the unexpected death of a loved one are recognized risk factors for complicated grief (Shear & Solomon, 2015) a form of acute grief that is unusually prolonged, intense, and disabling. This can lead to adverse consequences for the bereaved, including increased mortality due to general medical conditions and suicide. Kurian et al. (2014) assert that failure to offer timely and appropriate support can lead to complicated, prolonged grief with longterm consequences of depression and premature death. These have implications for families, the NHS and the economy. During consultation with bereaved parents in preparation for a research grant application which this review supports, parents described a wide range of practical problems: changes in benefits, receiving the deceased child's bedding in black plastic bags, surprising funeral arrangements, and redoubling of pain when receiving the results of the inquest. Further afield, a Canadian review of the nursing role in coordinating care in primary care settings emphasized aspects of both families' and professionals' needs and activities, as well as the need to harmonize these (Karam et al., 2021).

The gap in service provision

The DHSC has issued guidance for those involved in the care of bereaved families, highlighting the importance of a key worker to guide and support families. Across the UK, the response to SUDC is varied in nature and intensity. SUDC teams in England tend to include a health-care professional (either a pediatrician or a specialist nurse) and a police officer as well as, depending on the region, a police coroner's officer, a social worker, and/or a bereavement practitioner. Although the Greater Manchester team has 24-hour on-call access to a consultant pediatrician, this clinician is part of the investigatory team involved after SUDC and not there primarily to provide family bereavement support. Awareness of end-of-life care and bereavement care, especially in the North West of England and including the SWAN model of bereavement care, has recently been raised by NHS England (NHS England, 2021).



Most teams around England provide a 9 a.m.--5 p.m., Monday-Friday service. The lack of universal bereavement support in the NHS on a 24-hours, 7 days basis means that accessing effective support is either difficult or impossible. Most child deaths occur after hours and at weekends, and in Greater Manchester most sudden unexpected child deaths occur on Sunday. Nonspecialist health professionals involved in SUDC cases may lack confidence and skills to support families (Dent, 2002; MacConnell et al., 2012).

The Consultant Pediatrician involvement in the Greater Manchester SUDC team is a model that is not universally replicated elsewhere in England or internationally. For example, there are SUDC investigation teams outside Greater Manchester that do not involve 24-hour on-call access to a senior pediatrician. These teams may operate between 9 a.m. and 5 p.m. and/or may be nurse-led (Darlington Safeguarding Partnership, 2019; Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust, 2021; NHS England, 2019). Looking at models outside of the UK, for example, in the United States of America (USA), it is recognized that after the sudden and unexpected death of a child, there are a multitude of medical professionals who enter the families' lives including pediatricians and nurses (Bowen, 2020). The nursing involvement may take the form of specially trained forensic nurses to undertake death scene examination (Pasquale-Styles et al., 2007; Valentine, 2018).

There is no consensus on optimal bereavement support. Support for bereaved parents by professionals differs in quality and effectiveness (Stephen et al., 2006; Wilson et al., 2017). In the UK, the unexpected death of a child requires a detailed investigation to assist Her Majesty's Coroner ("HM Coroner") to identify the cause of death as well as to support bereaved families to cope with the death. This requires an effective multi-agency approach (HM Government, 2015). "Working Together to Safeguard Children" (HM Government, 2018a, 2018b) requires agencies involved in the SUDC process to balance support with investigation but is not explicit about the model of bereavement support to use, nor the underpinning evidence base.

Perceptions of support and care

Canadian parents found that keeping in touch with health practitioners after the death of their child minimized feelings of abandonment, and they felt less isolated (DeJong-Berg & deVlaming D, 2005), and such contact was supportive and prevented secondary loss (D'Agostino et al., 2008). In other research from the UK some parents reported feeling isolated, unsupported, and abandoned by community health professionals (Dent, 2002), though nurses were seen to be key players in the interdisciplinary effort to provide support (Price et al., 2011). In a Finnish evaluation of bereavement follow-up care addressed by a nursing program in association with peer supporters, parents described follow-up phone calls, mails and home visits as being useful (Aho et al., 2011a). A qualitative nursing study exploring bereavement support for Irish mothers after the death of their children showed that they relied on a combination of formal, informal, and self-support (Jennings & Nicholl, 2014). Formal support was gained from health practitioners and voluntary organizations. Some mothers felt supported particularly in a group with other bereaved parents. Bereaved fathers in Finland also have deep emotional needs (Aho et al., 2011b), but these needs are often ignored (Schott et al., 2007). A UK systematic review of the evidence on support for bereaved parents concluded that parents sought ongoing support from professionals after

their child's death but rarely experienced this (Garstang et al., 2014). In summary, a wider variety of interventions have been found to be of use to families as part of their bereavement care. In addition, practitioners providing bereavement care need to be aware that families may rely on different types of support – and for some family members their needs may have previously been under recognized. This needs to be accounted for in future service developments.

Improved coping

The pain of losing a child is almost unbearable and especially difficult to cope with (Hindmarch, 2009; Wilson et al., 2017). Wilson et al. added that the effects on Canadian parents can be lifelong with psychosocial and physiological consequences if not adequately addressed. Bereavement support and intervention in Australia were found to improve coping by bereaved families (Donovan et al., 2015). In a qualitative study, Reilly-Smorawski et al. (2002) noted that support groups for American parents following a neonatal death facilitated the expression of grief while reducing the pain of losing a child. In an Australian control group study, Murray et al. (2000) found that outcomes were improved mostly for those parents who were assessed to be at risk of developing complicated and unresolved grief. A controlled trial in Finland showed that fathers in a support intervention group demonstrated fewer grief reactions and better adaptation than those in a control group (Aho et al., 2011b). American siblings have developed coping mechanisms through attendance at bereavement camps and sharing experiences with other children (Creed et al., 2001). In summary, tailored bereavement care can result in better adaptation - especially important following the unexpected and sudden death of a child given bereavement grief is exaggerated in unexpected cases and may result in morbidity and mortality of the bereaved (Schott et al., 2007).

Impact on health-care staff

Health-care staff in the USA also felt unsupported, neglected, and unprepared to deliver bereavement support, especially in situations of unexpected death (Contro & Sourkes, 2012). Lack of time and training made them ill-equipped to undertake such tasks and there was emotional impact on their own wellbeing (Contro & Sourkes, 2012). A study of Canadian nurses' experience of providing bereavement follow-up to families after the death of a child found that this care requires knowledge of beliefs, needs, and values about death and the reaction of the bereaved (MacConnell et al., 2012). Nurses described bereavement care as being intense, requiring emotional energy, time, and flexibility. They were frustrated by the invisible nature of bereavement care despite the intense emotional distress felt by them. Despite this, they found it extremely rewarding (MacConnell et al., 2012). Mothers in an Australian qualitative study exploring support services received indicated that communication was vital (Donovan et al., 2015). However, a doctoral study in Canada (McConnell et al., 2012) suggested that communicating with bereaved families can be anxiety-provoking and challenging for nurses, especially for those with limited knowledge. Nevertheless, in addition to parents benefitting from a parent-led support program in the USA, the involved health professionals also reported enhancement of their experience in supporting parents (Snaman et al., 2017).



Diverse approaches

There is no consensus on optimal approach to be reavement support services. Organizations adopt diverse approaches which vary in effectiveness (Jennings & Nicholl, 2014; Wilson et al., 2017). In Ireland, Jennings and Nicholl noted that support is circumstantial, accounting for the different approaches employed by different organizations. In a scoping review by Canadian nurses to identify types of bereavement services and their effectiveness, Wilson et al., 2017) concluded that of the varied services identified none was more efficient than any others. They deduced that success of bereavement support was locally contextual. The review noted the lack of robust evaluation of bereavement service. Providing bereavement support to families who lose a child unexpectedly is mandatory (HM Government, 2018b). Affected families are considered to be a group at risk of poor outcomes with the death of a child being one of the most stressful experiences in parents' lives that can have long-lasting effects (Aho et al., 2011a). Research from Canada and the USA suggests that this includes having an impact on the health of the parents and their social relationships and network; or contributing to a sense of isolation and lack of intimate social relationship (Kavanaugh et al., 2004; Malacrida, 1999; De Montigny et al., 1999); or reducing inter-partner communication and increasing relationship strain (Wing et al., 2001).

Method

Data from the annual reports covering the work of the Greater Manchester SUDC team between April 1, 2015 and March 31, 2020 were reviewed and analyzed. The consultant pediatricians participating in the SUDC on-call service were asked to commence a SUDC audit form with initial information immediately after each SUDC call-out, and to complete the final parts of the audit form on conclusion of the SUDC case. These audit forms were collated into an annual report, approved by the local safeguarding children board, and the data from these reports was transcribed into Microsoft Excel for analysis for this study. The data from each of the five annual reports covered here was extracted manually into Microsoft Excel for manual analysis.

Data collection

Data collection of the following occurred:

- Number of cases referred to the SUDC team in Greater Manchester during the fiveyear period
- Age of children referred to the SUDC team
- Site where the children were received
- Month and day of death
- Time from death to review by the SUDC pediatrician
- Length of time for the call out intervention by the SUDC pediatrician
- The circumstances of the history-taking and examination of the child after death
- Whether a home visit occurred and reasons if this did not take place
- The support offered to families
- The circumstances of the multi-agency meeting and final case discussion meeting

• Whether the case involved child protection concerns.

This data was extracted from each of the annual SUDC reports over the five-year period of this study.

Selection criteria

Inclusion criteria

- Case recorded between April 1, 2015 and March 31, 2020 (inclusive) in the Greater Manchester Combined Authority region (GMCA); AND
- Child aged 0–18 years who died, and who had an audit form completed by the attending SUDC pediatrician; AND
 - o Death was not thought likely 24 hours beforehand; OR
 - Still birth (a baby born dead after 24 weeks of pregnancy) where no health-care professional was present at the birth; OR
 - Died following an unexpected collapse.

Exclusion criteria

- Any child who died outside of the GMCA region, regardless of primary residence location; OR
- Any fetal loss before 24 completed weeks of pregnancy.

Ethics and governance

In the UK, clinical audit and service evaluation studies are not subject to review by a research ethics committee. Data were amalgamated when indicated to ensure that no individual child or family could be identified from this report.

Results

Number of cases referred to the SUDC team

During the five-year review period, a SUDC rapid response occurred for 309 children with a median of 57 cases per year (range 55–79). In all years reviewed except 2015–2016, there was a slight male preponderance in SUDC cases with a median of 35 males (range 25–48) and 27 females (range 21–30) per year (Table 1).

Age of children referred to the SUDC team

In line with national data, and consistently across the 5 years, the majority of cases occurred in children under 1 year of age with a peak incidence between 1 and 6 months. There was a second peak in older teenagers who exhibited risk-taking behaviors. There was a rise in deaths in 16- and 17-year-old children, making up 20% of cases in 2019–20. This appears to coincide with an increase in the number of deaths by suicide, but the numbers were too small to support statistical analysis.

Year	Male [Median per year: 35]	Female [Median per year: 27]	Total cases [Median per year: 57]
2015–16	25 (45%)	30 (55%)	55
2016-17	35 (56%)	27 (44%)	62
2017-18	35 (63%)	21 (38%)	56
2018-19	48 (61%)	31 (39%)	79
2019–20	34 (60%)	23 (40%)	57

Sites where children were received

Greater Manchester has a mixture of district general hospitals together with a tertiary children's hospital (Royal Manchester Children's Hospital). Across the study period, the largest proportion of cases (n = 57, 18.5%) was received at one district general hospital. This was closely followed by the tertiary children's hospital (n = 52, 16.8%). Acute hospitals in the city of Manchester accounted for 107 cases; the remaining 202 cases being received at other sites in the wider Greater Manchester area. In a small number of cases (mean 4.2% across the 5 years), the specific hospital site was not recorded on the audit forms.

Month and day of death

Most commonly, deaths occurred at weekends, with a median of eight cases on Saturdays and nine on Sundays across the five-year period. The least deaths occurred on Thursdays, with a median of two cases (Table 2). There was a small peak in deaths in July and December, both with a median of six deaths per month (Table 3). The fewest deaths were recorded in June (median two deaths).

Time from death to referral to the SUDC pediatrician

This information was documented for only the last 3 years of data collection, where it was recorded whether the SUDC pediatrician was informed within 0-2 hours of the child's death. For the 3 years when this was recorded, the SUDC pediatrician was informed within 2 hours for 100%, 90%, and 100% of cases, respectively, giving a mean of 96.7% (median 100%) of cases.

Length of time for the initial call-out to a SUDC case

When a SUDC death occurred, the team managing the child (either the police or the hospital where the child was located) made a referral to the SUDC pediatrician oncall. The SUDC pediatrician was asked to make a note of the time they arrived on-

Table 2. Day of death.

	Monday	Tuesday		- !	Friday	6	Sunday
	(n)	(n)	Wednesday (n)	Thursday (n)	(n)	Saturday (n)	(n)
Year	Median = 5	Median = 5	Median = 6	Median = 2	Median = 6	Median = 8	Median = 9
2015-16	5	7	9	10	4	6	17
2016-17	3	6	2	2	1	5	9
2017-18	7	5	8	2	7	12	14
2018-19	5	5	6	2	6	8	8
2019-20	2	5	3	2	11	8	4

Table 3. SUDC deaths in Greater Manchester by month and year (April 1, 2015 to March 31, 2020).

			Year			
	2015–16	2016-17	2017–18	2018-19	2019–20	
Month	n (%)	n (%)	n (%)	n (%)	n (%)	Total
January [Median: 4]	2 (3.5)	4 (13.8)	5 (8.9)	8 (10.0)	2 (6.1)	21
February [Median: 4]	7 (12.3)	1 (3.4)	4 (7.1)	9 (11.3)	3 (9.1)	24
March [Median: 4]	6 (10.5)	0	4 (7.1)	4 (5.0)	2 (6.1)	16
April [Median: 3]	2 (3.5)	2 (6.9)	5 (8.9)	4 (5.0)	3 (9.1)	16
May [Median: 5]	5 (8.8)	1 (3.4)	5 (8.9)	9 (11.3)	4 (12.1)	24
June [Median: 2]	5 (8.8)	2 (6.9)	3 (5.4)	1 (1.3)	2 (6.1)	13
July [Median: 6]	6 (10.5)	2 (6.9)	10 (17.9)	8 (10.0)	4 (12.1)	30
August [median: 4]	4 (7.0)	0	5 (8.9)	5 (6.3)	2 (6.1)	16
September [Median: 4]	3 (3.5)	5 (17.2)	4 (7.1)	9 (11.3)	2 (6.1)	23
October [Median: 4]	5 (8.8)	3 (10.3)	4 (7.1)	9 (11.3)	2 (6.1)	23
November [Median: 4]	6 (10.5)	4 (13.8)	4 (7.1)	5 (6.3)	3 (9.1)	22
December [Median: 6]	6 (10.5)	5 (17.2)	3 (5.4)	9 (11.3)	6 (18.2)	29

site to begin their in-person duties following a call-out. A further note was also made of the time of conclusion of the initial work and the time taken for telephone discussions prior to arriving on site. From these entries in the audit forms, the median time spent by the SUDC pediatrician during the initial call out was 5 hours (range 5–25 hours). In addition, there was also travel time of up to 3 hours per case for the initial call out.

Who took the history of the circumstances surrounding the child's death?

In most cases (Table 4) the history was taken jointly by the SUDC pediatrician and the police senior investigating officer (SIO). In some cases, the history had already been taken by the emergency department doctor (mean 13.4% of cases over the study period) or local hospital pediatrician (mean 38.2% of cases over the study period) prior to this. It is clear that in some cases more than one history was taken which can occur in clinical practice if relevant information is offered by parents or needs to be urgently gathered for acute treatment purposes.

Who examined the child after death?

As with history-taking, it was found that in most cases the child was examined jointly by the SUDC pediatrician and the police SIO (Table 4). In the annual reports it was commented that many cases documented as being examined solely by the SUDC pediatrician were actually

Table 4. Professional taking the history of the circumstances surrounding the child's death and examining the child.

Year	Professional taking the history					
	Emergency medicine doctor (%)	Hospital pediatrician (%)	Joint SUDC pediatrician/ PSIO [#] (%)	SUDC pediatrician (%)	Police PSIO (%)	
2015–16	7	66	71	25	0	
2016-17	29	36	71	32	0	
2017-18	26	22	41	37	22	
2018-19	18	33	70	18	4	
2019-20	17	34	80	6	11	

Year	Emergency medicine doctor (%)	Hospital pediatrician (%)	Joint SUDC pediatrician/ PSIO (%)	SUDC pediatrician (%) *	Police PSIO (%)
2015–16	7	66	71	25	0
2016-17	29	36	71	32	0
2017-18	26	22	41	37	22
2018-19	18	33	70	18	4
2019-20	17	34	80	6	11

^{*}PSIO = Police Senior Investigating Officer.

joint assessments done with the SIO. A peer review of the circumstances of this identified that some new doctors joining the on-call rota had inadvertently indicated a single examination by the SUDC pediatrician, when joint examinations had been conducted.

Support offered to families

UK guidance advises that every family should receive a copy of "When a Child Dies" (NHS England, 2018), and after September 2019 all families received this booklet: 82% across the whole year 2019 to 2020 (Table 5).

Timing of multi-agency meeting

A formal multi-agency meeting was held in the majority of cases, either by telephone or in person. Some cases (median 34%, mean 37%) underwent a multi-agency meeting on the same day of death, or the day immediately following death. However, more multi-agency meetings took place after this.

Table 5. Support and/or information offered to families after their child's death April 1, 2015–March 31, 2020.

			Year		
Support and information	2015–16	2016–17	2017–18	2018–19	2019–20
Allowed to hold their child (%)	94	89	89	85	88
Offered photographs and/or mementos (%)	72	96	93	83	80
Offered bereavement counseling and/or religious support (%)	88	86	89	78	97
Given information about the rapid response process (%)	94	96	89	88	94
Offered written information (%)	53	71	85	88	94
Given contact numbers (%)	91	100	81	73	97
Informed about the postmortem examination (%)	94	100	89	83	82
Given a copy of the "When a Child Dies" booklet (%)	0	0	0	0	82

^{*} Likely to be joint assessments with the PSIO.



Format and timing of home visit

A home visit should be considered in all cases, especially where the death is of a child aged under 2 years. If the police had already visited the place of death and photographed this location, a decision was taken between the SIO and SUDC pediatrician about whether there would be any benefit to a joint examination of the home and/or place of death. A home visit occurred in 74% to 84% of audited cases over the study period. For all cases in which the timing of the visit was recorded, this occurred on the day of the child's death.

Final case discussion meeting

A final case discussion meeting was held in 50% to 87% of cases over the study period (mean 64.4%), with 87% in the latest year of data available. There was usually a significant time-lapse until the final meeting; most occurring more than 4 months after the child's death. The final case discussion meetings preceded the coroner's inquest in 36% to 75% of recorded cases. Following the final case discussions, families were informed of the findings by letter, home visit, or telephone. In some cases, the offer of a face-to-face meeting was declined by families.

Child protection concerns

Whether or not child protection concerns were identified during the SUDC process was not recorded in all cases. For those years where data were available, between 16% and 22% of cases were recorded to involve some child protection concerns.

Limitations

General matters

In the annual reports it was commented that many cases documented as being examined solely by the SUDC pediatrician were actually joint assessments undertaken with the SIO. This is likely to have arisen as some new doctors joining the on-call rota, and using the audit forms for the first time, indicated during peer review an inadvertent audit form indication. This has been addressed through the induction process for new members of the team and this will be kept under review in future audits to see if any change to the data collection process is required.

Missing audit forms

One of the limiting factors in the data collection was that the audit forms were not completed for each SUDC case so there was missing data for each year. Audit forms are completed only once a case has concluded, and at the time of annual reports being prepared (July/August each year) a number of outstanding cases were still awaiting the results of postmortem examination at the time of analysis (usually cases from the first quarter of the year). These cases could not be included and could, potentially, have skewed the analysis. In the review of any one calendar year of cases, there will always be some cases that have occurred close to the deadline for inclusion in that year's data. As the audit



requires a PME examination to be completed ahead of completing the audit form, and it takes several months from PME to a copy of the final report becoming available, in any given year some cases will remain incomplete.

SARS-CoV-2

This review extends only to March 31, 2020. SARS-CoV-2 (COVID-19) was declared a global pandemic by the World Health Organization only on March 11, 2020. The intention of this study is therefore not to report on the impact, if any, of the virus on either the SUDC process or on childhood mortality. However, the authors wish to highlight that the arrival of the pandemic has had a significant impact on finding the balance between a humane approach for the families of children who have died and keeping those families and the professionals involved in the SUDC investigation process safe. The impacts of COVID-19 on the SUDC process, the health and social care system and, most importantly, the families of children who have died, will be the subject of a future review paper.

Discussion

This study identified that, where recorded, between 16% and 22% of the SUDC cases identified child protection concerns (for example, concerns about possible neglect; emotional abuse; sexual abuse or exploitation; and/or physical abuse). The cases where child protection concerns were recorded included cases that were suspicious from the start; cases where children's services (child protective services) were already involved and there were concerns regarding emotional abuse, physical abuse, sexual abuse, or neglect; cases where suspicions arose following PME; and cases where review of the child's home circumstances, once known, raised questions regarding their care.

In all cases, with or without child protection concerns, providing expert, timely and professional support to minimize adverse health consequences is paramount (Wilson et al., 2017). Currently, services are lacking. In Greater Manchester (UK), SUDC pediatricians meet regularly to provide peer review and support for those on the rota. These meetings provide opportunity to learn from good practice and share information from other agencies, Serious Case Reviews, and other sources of feedback. An annual study day is held to promote good practice, and this multi-agency meeting, open to those involved in the SUDC process - not just pediatricians, gives a chance to work and learn with other agencies. Future work will look to evaluate the impact of this educational program.

All doctors on the rota have confirmed that they have at least level three safeguarding vulnerable children training (Care Quality Commission (CQC), 2018), and that they have completed their trust's information governance training. All have been asked to confirm that they have appropriate equipment (e.g., work mobile telephone, and encrypted laptop for on-call duties) provided by their employing NHS organization.

Ideally, the history should be taken jointly by the SUDC pediatrician and the Senior Investigating Officer (SIO) in the presence of the Police Coroner's Officer (PCO) to minimize the number of times a grieving family has to recount their child's death. However, it is recognized that when resuscitation attempts are on-going it is necessary to take some history from those people accompanying the child in case this results in

information which could assist with the resuscitation attempts. In some cases, families or those accompanying the child want to tell their story. If such circumstances arise it seems the right thing to capture that story and to listen to the people giving it, rather than stopping them talking until the SUDC team, SIO, and PCO are available to take a single history jointly.

It is further recognized internationally that specially trained forensic nurses have a key role to play in the investigation of SUDC cases, and in various localities the clinician leading that team could be a registered nurse or a registered medical practitioner (Bowen, 2020; Darlington Safeguarding Partnership, 2019; Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust, 2021; NHS England, 2019; Pasquale-Styles et al., 2007). In the USA, forensic nurses may have a role when a child dies, including as a result of abuse or neglect, (Berishaj et al., 2020; Clements & O'Neal, 2020; O'Malley et al., 2014) and in New Zealand a review has found that a role for clinical forensic nurse specialists in Emergency Departments is clearly indicated (Donaldson, 2019). In the Netherlands, the forensic nurse curriculum includes sections on sexual assault examination, assessment of child abuse, and death investigation (De Vries et al., 2019).

Working together to Safeguard Children 2018 (HM Government, 2018a) identified that all families who have experienced the death of a child should have a "key worker" identified. This appeared to have a positive effect on the help and support offered to families in the most recent year of data collected. For jurisdictions without that recommendation in statutory guidance (or the international equivalent) the role of a "key worker" may merit serious consideration. The role of nurses in coordinating care within the interdisciplinary team has been well-established internationally for decades. It is likely that many of these key workers will be bereavement nurses.

Prior to 2018, Working Together to Safeguard Children referred to a "Key Worker" who would support a family after the death of their child. However, there was no detail as to who this person should be, or what their role or responsibilities should be. It was unclear who had the responsibility to identify a Key Worker for the family. Support for families has always been looked at to some degree in the data collected prior to 2019. For example, asking if families were allowed to hold their child after death; whether families were offered religious support; whether mementos of their child were offered; whether written advice was provided; and whether contact details for the SUDC team were given to families.

Since 2018, there has been a much more formalized process as every family now receives a copy of "When a Child Dies" (NHS England, 2018). This contains details of the family's key worker, and the pediatrician leading the SUDC investigation, as well as contact details for both.

Guidance from HM Government (HM Government, 2018a, 2018b) requires agencies involved in the SUDC process to balance support with investigation but is not explicit about the model of bereavement support to use, nor the underpinning evidence base. To achieve this aim, the Greater Manchester SUDC team has identified the need to include, in the future, a bereavement professional in the acute on-call team to focus on practical matters, predicting distressing events, signposting to additional services, and responding to unforeseen emotional and physical needs with expert, empathetic, timely care. A study to investigate the effectiveness of an experienced bereavement nurse in this role is planned.



New guidance now requires that those who cared for a child in life should complete an analysis form for that child's death at a Child Death Review Meeting. This will require that all deaths will need a final meeting (although in some cases an initial and final meeting may be a single event).

Conclusion

This report is an important contribution to the literature as it provides the first five-year review of SUDC cases in Greater Manchester, UK - and is therefore important for service development, including considering the workforce necessary to deliver a SUDC service. Providing a 24-hours per day, 7 days per week SUDC service is meeting an important need as the majority of SUDC cases in Greater Manchester occur out of hours and take a significant amount of time to deal with. The dedicated consultant-delivered SUDC service allows for more timely investigation, support for families, support for local clinicians, and clinical care efficiencies by freeing up local teams to continue with their other acute workload. Maintaining previous inclusion criteria has not resulted in additional cases being investigated than would have been triggered by the new JAR criteria. The addition of the key worker role is welcomed, and the impact of a dedicated bereavement nurse in fulfilling this role needs to be established in further research. As part of this, the optimal bereavement support for families' needs to be determined (separately from the investigatory function). The findings of this study will be of international interest, especially in jurisdictions with a different model of delivering clinical input into the sudden and unexpected death of a child.

There are four key messages from this work, supported by the international literature. The evidence from anglophone countries is that families are in desperate need of wider support immediately and for months after the death, and this review offers deeper insight into the nature of the problems encountered. This was the case in Europe, North America, and Australia. Sustained, targeted means of support discrete from investigatory functions are required, addressing social, financial, legal, and psychological issues.

Health professionals also need help to address families' needs, often feeling inadequate and under-prepared for the encounter. Training and support (in the UK, in the form of clinical supervision) are vital for the wellbeing of professionals and for effective intervention.

Part of the burden for families is the disjointed nature of supportive services. Efficient interagency and inter-professional working is central to the minimization of additional burden for families. The review has demonstrated that when this is in place outcomes are improved. The precise processes and structures will vary between countries, but the principle of coordination in both investigation and support should be common to all.

In a study to follow this review, the impact of a specialist bereavement nurse in fulfilling the key worker role will be investigated. There are many reasons to believe that this will be most appropriate, not least the historical and continuing nursing role of coordination in the health-care team, and the focus on supportive intervention for children and families. This will be a different role to that of forensic nurses in the USA, although the caring and supportive features brought to that sphere by the application of nursing skills is acknowledged.



What research already tells us about this subject

- The sudden death of a young relative has significant and long-term emotional implications for the family, particularly for the child's mother.
- Between April 1, 2019 and December 31, 2019, there were a total of 2498 childhood deaths reported to the National Child Mortality Database (NCMD) in England; compared with a total of 2264 in the same period of 2020.
- Since 2018, statutory guidance underpinning the interagency response to the death of a child has placed greater emphasis on bereavement support for the family.

What this paper adds

- The addition of a "key worker" role into statutory guidance, and particularly the potential for this to be a dedicated bereavement nurse, needs to be investigated further to determine the impact on families.
- The optimal bereavement support to families following the sudden and unexpected death of a child needs to be investigated.
- Most sudden and unexpected deaths of children in Greater Manchester, United Kingdom, take place outside of Monday to Friday, 9 a.m. to 5 p.m.

Postscript

Those who experience distress associated with the death of a child can find support from Child Bereavement UK, the Lullaby Trust, or the Samaritans:

https://www.childbereavementuk.org/ https://www.lullabytrust.org.uk/ https://www.samaritans.org/

Authors contributions

ED: Collated the data and is the guarantor

SQ: Analyzed the data and produced the first draft of the manuscript

All authors: Contributed to the drafting of the manuscript and approved the final manuscript prior to submission.

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