MEDICATIONS IN DRUG TREATMENT: TACKLING THE RISKS TO CHILDREN

Executive Summary

Adfam

Families, drugs and alcohol

Foreword

This report examines cases where children have died or come to harm from ingesting Opioid Substitution Treatment (OST) medicines prescribed to help people overcome drug addiction. There have been 17 Serious Case Reviews involving the ingestion of OST drugs by children in the last five years alone, plus potentially more incidents that don't reach that level of inquiry. The information we present in this report highlights that not only are such events not isolated, but that they have happened with quite depressing regularity. Each one of these incidents is a tragedy, but with so many, it could start to look like something even more worrisome: a pattern. We need to stop the continuing occurrence of these cases and make sustainable changes to practice on a national scale to make children safer.

OST is an extremely valuable tool in the fight against drug addiction, and we are clear that the evidence base supports its part in our treatment system. The overwhelming majority of the people who need and use OST do so safely. However, we also must recognise that the drugs used – especially methadone – are toxic, powerful and a clear danger to children when stored or used incorrectly by their parents and carers. Although the risks are minimal when taken in the context of drug treatment overall, just one of these cases is one case too many. Incidents where children accidentally ingest these drugs – or worse, are actively given them by their parents – appear to be both frequent and similar enough to merit a more open and honest debate about the risks, particularly amongst frontline professionals. It's clear that more could be done on a national level to share the learning from each local case and take coordinated action to minimise risks.

Tragedies occur, and we can never eliminate risks completely. But in conducting this research our thinking has always been: on a systemic level, are we doing all that we can to make sure these incidents don't keep happening? And based on our findings, the answer, so far, is no. Whilst this is a very complex area of practice, our central conclusion is extremely simple: these incidents are happening too often. Not enough is being done on a practical level to make sure that children are protected, and parents and the professionals working with them are sometimes taking insufficient safeguards. We can't just accept that 'these things happen' and we must be louder and more challenging.

We think it is possible to make these incidents less likely. What learning there has been from these cases has been isolated and localised, so we've gathered together the best and broadest evidence we can to improve practice on a national level. By doing this, we hope to stimulate debate around the issue and consequently encourage positive changes in practice.

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Adfam is the national umbrella organisation working to improve the quality of life for families affected by drugs and alcohol.

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Background

The impact of parental substance use on children has been a developing theme in policy and practice since the publication of Hidden Harm by the Advisory Council on the Misuse of Drugs in 2003. There have been significant improvements in the recognition of children whose parents use drugs, and a much greater focus on the need to support and safeguard them effectively. The last decade has also seen significant growth in the number of people accessing drug treatment to support them in recovering from addiction.

But whilst the need to support the children of drug users is quite widely recognised in general terms, gaps in knowledge and learning remain regarding the specific risks posed by the use and storage of Opioid Substitution Treatment (OST) medicines in the home. A number of cases where children have ingested such drugs have been reported in the media, examined in research and analysed in Serious Case Reviews (SCR). Although such incidents are extremely rare in the context of the widespread use of OST as a valuable and evidence-based way of treating drug addiction, the number is significant enough to merit further investigation of how these events happened, and what can be done to prevent similar tragedies in the future.

Aims

This review aims to assess how dangers to children can be minimised during the provision of Opioid Substitution Treatment (OST) to their parents, carers or other family members. This is undertaken through analysis of available literature, study of known cases where children have died or been harmed through ingesting OST drugs, and interviews and focus groups with a number of practitioners, clinicians and sector experts.

This review does not seek to comment on the efficacy of OST as an intervention in the treatment of addiction. Whilst we are aware that OST drugs are not the only substance which can cause harm to children if stored insecurely or used inappropriately, other medicines are outside the scope of this report.

Methodology

This research involved a number of different strands:

- A literature review, looking at existing guidance documents and research from the UK and abroad
- Analysis of media coverage of cases where children ingested OST drugs
- Examination of Serious Case Reviews involving the ingestion of OST drugs by children during the period 2003-13
- Interviews and focus groups with practitioners and experts on the key issues for practice.

Opioid Substitution Treatment (OST)

OST is a medical procedure whereby prescription drugs are used to support people trying to reduce or stop their use of opiods such as heroin. These medicines – usually methadone or buprenorphine – aim to manage withdrawal and reduce dependence over time so that people can overcome their addiction and pursue other life goals. They are powerful opiates in their own right, and illegal to possess without a prescription: methadone is a Class A drug, and buprenorphine Class C. Methadone usually comes as a liquid, whereas buprenorphine is a tablet placed under the tongue.

The National Institute for Health and Care Excellence (NICE) notes that there is a high mortality risk associated with methadone in 'opioid-naïve' people. Buprenorphine carries less risk of overdose, and is only partially absorbed when swallowed. NICE states that the decision on which medicine to use should 'take account of the person's lifestyle and family situation (for example whether they are considered chaotic and might put children and other opioid-naïve individuals living with them at risk)'.[1]

These medications can be prescribed for take-home use (for example on a daily or weekly basis), but users may also be required to take them in the presence of a health professional like a pharmacist – an arrangement known as 'supervised consumption'. NICE recommends that everyone begins their treatment journey under these conditions, which can then be relaxed by the prescriber after a period of time to recognise compliance with treatment.[2] Prescribing arrangements should aim to reduce risks to children, and these should be taken into account before any change in prescribing regime is made.[3]

Evidence shows OST can be an effective treatment for those with opioid addictions and can positively aid recovery.[4]

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1 *NICE (2007) Technology Appraisal 114: Methadone and buprenorphine for the management of opioid dependence*

2 *Ibid*

3 *Department of Health (2007) Drug misuse and dependence: UK guidelines on clinical management*

4 *National Treatment Agency (2012) Medications in recovery: Re-orientating drug dependence treatment*

Findings

Scale

It has been reported that 120,000 children live with a parent currently engaged in drug treatment.[5] It is also known that 60,596 adults in treatment in England in 2011–12 had parental responsibility, an opiate problem and were receiving a prescribing intervention. The parental status of a further 5,193 in treatment was not captured.[6]

Other, more specific statistics are not recorded, making a true estimation of the scale of the risks difficult. Figures on the number of children admitted to hospital with poisoning from OST drugs are not available. Although the total number of people receiving a prescribing intervention in drug treatment is known, how many of these are given take-home doses is not; this is important as the overwhelming majority of exposures occur within the child's own home, involving medication prescribed to one or both of their parents.

This research found 20 Serious Case Reviews in 2003-13 where OST drugs were ingested by a child. Whilst analysis of these cases provides a great deal of information, not all ingestions result in Serious Case Reviews, so there are an unknown number below this threshold.
Establishing the true scale of the problem is difficult due to two mutually reinforcing factors: firstly, a lack of reliable data; and secondly, a lack of awareness of the dangers of OST to children. Without robust data and the mechanisms to record it, highlighting risk is a challenge; but without greater awareness and the resulting emphasis in policy, there is limited drive to collect such data.

The numbers discussed in this research, and the seriousness of the incidents involved, mean that further investigation is merited on how the specific risks of OST can be minimised. However, it must be remembered throughout that these incidents represent a tiny fraction of child deaths overall: there were 3,857 Child Death Reviews in 2012-13.[7] Also, bearing in mind that over 60,000 people in treatment have parental responsibility and receive a prescribing intervention, it is also clear that OST presents a risk factor in very few families.

While SCRs can give some indication of how many children are exposed to OST, we must be mindful of the number of incidents which would not have met the requisite threshold for conducting a SCR, and the number of near misses of which we cannot know.

5 *NTA (2009): Moves to provide greater protection to children living with drug addicts (Media release)*

6 *House of Commons Debate 29 October 2013, vol 569, cols 439-477*

7 *Department for Education (2013) Child death reviews: Year ending 31 March 2013*

Serious Case Reviews

Serious Case Reviews (SCRs) are undertaken when a child dies or comes to harm, and abuse or neglect are suspected to be factors.

- In 2003-13, there were 20 Serious Case Reviews where OST drugs were ingested by a child
- These 20 cases involved 23 children, and there were 17 deaths
- Methadone was mentioned in 19 of the 20 reviews, and was the cause of 15 fatalities. Methadone was also responsible for all of the cases involving very young children, and all of those involving parental administration of drugs to a child. Buprenorphine was the cause of one death.
- Seventeen of the 20 reviews were conducted in the last five years (2008-2013)
- There was an obvious age bias towards very young children: 17 of the 23 children were aged three or younger, and the median age was two years old
- In five of the cases, the parents had deliberately administered the drug to their child. In six cases, the ingestion was accidental. In six of the cases it was unclear how the child came to ingest the drugs. In the other three cases, teenagers had taken the drug deliberately.

Recognising the dangers

This research demonstrates that people in drug treatment and the practitioners supporting them are not always sufficiently aware of how dangerous OST drugs (specifically methadone) can be if stored or used incorrectly. Service users may not take adequate precautions in their own homes to prevent children having access to dangerous substances, and professionals may not prioritise this issue in practice, in recognition that a tiny amount can be fatal to a child. Although NICE stipulates that the dangers to children should be taken into account when prescribing methadone or buprenorphine[8], this report shows that this is not always followed through into practice.

This review also highlights a lack of awareness and understanding amongst non-drug service professionals of the risks around OST. Several SCRs reported that professionals such as health visitors, social workers and police officers were not vigilant regarding the risks of OST medicines in family homes.

Several SCRs suggested that this lack of focus is linked to a more general lack of awareness around the risks presented by parental substance use, and a symptom of an ingrained focus on the parent rather than the child. Building a true family focus was seen as crucial in supporting the children of substance users in general, as well as safeguarding them from specific risks like OST medications in the home.

8 *NICE (2007) Technology Appraisal 114: Methadone and buprenorphine for the management of opioid dependence*

Professional awareness of the dangers of OST can be built by learning from past experience, and practitioners reported that new measures were often proposed or implemented following tragic incidents such as those covered in SCRs. However, any learning from these cases is often localised and there is no reliable mechanism to build awareness on a national level.

Safe Storage

A variety of unsafe storage practices were uncovered in the study of existing research and Serious Case Reviews, including people in drug treatment keeping methadone in children's beakers or on bedside tables, and not disposing of containers properly.

Many SCR recommendations therefore looked to the improvement of safe storage policies as a way of minimising risk: for example the provision of free, lockable boxes for parents in treatment. Some drug treatment organisations have made the provision of such boxes mandatory, but this is by no means a consistent practice. It was also evident that such policies should be accompanied by information and advice from professionals on an ongoing basis. In some areas, professionals were required to note the provision of information in their client database, and it was also proposed that service users agree and sign a safety to plan to confirm their understanding of risk.

Whilst the widespread introduction of more robust safe storage policies would be a positive step, practitioners were sceptical about the extent to which the provision of lockable boxes alone could eliminate risks to children. It was considered to be a simplistic answer to a complex and multi-layered problem, which could give practitioners a false sense of security and result in reliance on procedure over practice. This conclusion was supported by analysis of the Serious Case Reviews, which often considered cases where children had ingested methadone despite safe storage policies being in place locally. Home visits to check on compliance are important to embed these practices, and it is also clear that this should be a shared responsibility amongst different agencies involved with the family, rather than just drug treatment workers.

Prescribing and Dispensing Practices

In the majority of cases examined in this study, the child's exposure to OST medications occurred in the home; this mirrors the findings of previous research. Implementing restrictions on the availability of take-home medications for parents with young children was often discussed in Serious Case Reviews and amongst the practitioners involved in this research, and the idea of placing parents on mandatory supervised consumption regimes to eliminate the presence of OST drugs in the home was considered.

Data is not collected on how many parents are in receipt of take-home prescriptions, and practice can vary considerably in the dose prescribed and

the frequency of dispensing (daily, weekly or in between, or for holidays or breaks). Whilst NICE states that supervision should only be relaxed when the client's compliance with treatment is assured, the SCRs showed that this is not always the case and highlighted some potentially concerning prescribing practices. The evidence presented shows that practitioners do not consistently recognise the possible risks to children posed by OST, despite NICE and the Department of Health stating this requirement explicitly.

As well as eliminating the presence of legally prescribed OST drugs in the home, some practitioners argued that mandatory supervised consumption could also lead to more opportunities to engage the client through more regular appointments, and thus help build a supportive relationship with treatment clients. However, a number of drawbacks to such policies were clearly identified by practitioners and researchers. The need to attend a pharmacy on a daily basis can be harmful to service users' ability to pursue other goals in their recovery, like job-hunting, and practitioners felt that there could be a 'disengaging effect' where people were unwilling to meet such conditions. Some practitioners thought the idea was a draconian and punitive response to those parents seeking to engage and progress in their recovery, and pointed to the wider consequence that parental disengagement would potentially increase risks for those children that the policy was originally designed to support.

Some SCRs recommended a more general review of prescribing practices for parents, apparently unaware that the possible dangers of OST drugs to children are already covered in clinical guidance from the Department of Health and a NICE Technology Appraisal. Professionals also expressed concern over a lack of clear guidance on what constitutes 'safe' prescribing for parents in OST, and indicated a lack of professional confidence in approaching the matter; this indicates that existing guidance is not sufficiently known or implemented. Inconsistencies in terms of the criteria which influence prescribing were also apparent, and a lack of clear guidance on accountability could leave workers confused over who is meant to act on what information and when.

Much like safe storage recommendations, the introduction of mandatory supervised consumption for parents was considered too simplistic a response in isolation, and professionals thought it likely to have a detrimental impact on the recovery of the parent. This corroborated findings from the literature, which showed that patient preferences strongly favour less frequent visits to the pharmacy. The issue is additionally complicated by consideration of family members other than the mother, to whom many discussions about safeguarding often revert. Fathers and mothers' partners are of particular note, as their contact can be more unpredictable and transient, and research has shown that practitioners are less likely to take child protection into account when working with men.

Intentional Administration

Five of the 20 Serious Case Reviews involved parents deliberately administering methadone to young children, apparently in misguided attempts to soothe or pacify them. In several more cases the practice was suspected, or how the child ingested the drugs is unclear.

It was clear from the Serious Case Reviews that professionals working with these families had not accounted for this possibility, and this was mirrored by the interviewees in this research. Even amongst experienced practitioners who recognise the dangers of children accessing OST drugs, the practice of administering drugs to children was difficult to accept or address. None of the practitioners spoken to considered this dangerous practice in assessments or discussions with clients, and it was not covered on information leaflets and posters. Many professionals found the very idea of intentional administration a difficult one to accept, and were reluctant to believe their clients would behave in such a way.

Practical recommendations like lockable boxes and safe storage advice are intended to prevent accidents, but cases of intentional administration present different challenges for practice. Focus inevitably falls on improving professional awareness and training staff to both account for the possibility and to effectively safeguard against it. Some SCRs examined the ability of practitioners to recognise the signs of methadone ingestion by children, or recommended research into how widespread the practice may be amongst the treatment population; there were also some calls for the drug testing of young children if they were considered to be at risk. This is an extremely challenging topic, and one which practitioners felt would require the utmost sensitivity in discussions with clients. Though controversial, and with significant risks of misrepresenting the vast majority of people in treatment, there is a need to highlight this practice as a rare but real possibility.

Professional Curiosity and Challenge

A common finding in the Serious Case Reviews was that practitioners missed or minimised risk factors during the family's contact with services. Professionals in these cases took an overly optimistic view of the parents' progress, and many involved 'disguised compliance' on the part of parents who were able to manipulate or deceive services into believing they were making positive changes. Practitioners and interviewees also highlighted the need for professionals to be more challenging and robust in work with families where the parents use substances. Although this was a more general point about working with challenging families, it was also specific to OST in cases which were described as an 'accident waiting to happen', where drug paraphernalia had been seen lying around the house, or where parents had to be given repeated reminders to observe safe storage advice.

The concepts of 'healthy scepticism' and 'respectful uncertainty' were seen as vital in cases where children come to harm from ingesting OST drugs. A focus on the child was found to be lacking in many of the cases, and a higher level of professional challenge in addressing the overall impact of parental substance use on children was a clear need.

Joint Working and Information-Sharing

Given that substance using families are often in contact with a range of local support services, collaboration and information-sharing between these agencies is vital to safeguard children. Breakdowns in communication were often found in cases where children had ingested OST drugs, for instance where a father had a history of 'hoarding' methadone, or where a mother's partner died of a methadone overdose weeks before a child also ingested the drug. In such cases, knowledge of risks was not shared between agencies and they did not feed into the prescriber's decision over the safest way to dispense medication. There were many more general examples of uncertainty over child protection procedures and a lack of joint work to safeguard children, and many SCRs identified a failure to share relevant information.

Although joint work between drug services and social work teams has improved since the publication of Hidden Harm in 2003[9], the research suggests there is still work to be done. Practitioners and interviewees verified a patchy depiction of inter-agency collaboration in reference to OST, including inconsistent attention by pharmacists to safeguarding concerns.

Learning and Development

This research identifies a number of similar incidents over a significant period of time; it also highlights a lack of coordination in how the learning from these individual incidents is applied to improve safety.

The frequency and similarity of Serious Case Review findings, piecemeal media coverage of individual events and professional uncertainty over learning processes are all evidence to support the conclusion that there is currently no reliable mechanism – either at local or national level – to improve practice when children ingest OST drugs. Practitioners expressed scepticism that an event in one area could be used to improve practice in another, and there were also doubts about how far SCR recommendations were really followed into practice at the local level. It was thought that a national overview of the situation would be valuable in minimising the risk of future incidents and highlighting the need to be proactive in improving safety measures.

9 *See Adfam (2013) Parental substance use: through the eyes of the worker; and Ofsted (2013) What about the children? Joint working between adult and children's services when parents or carers have mental ill health and/or drug and alcohol problems*

Conclusions & Recommendations

It is hoped that this report can stimulate productive debate about OST and its implications for safeguarding, and lead to meaningful improvements in practice. However, throughout these discussions we must not endanger the rightful place of medications in a recovery-orientated treatment system. The evidence is clear that OST is a valuable and effective tool in helping people overcome addiction.

It is evident from this research that the risks to children posed by OST medications are not being adequately managed in practice. This is particularly evidenced by the consistent stream of similar Serious Case Reviews, some of which recognised that they were not examining isolated incidents. Doubts are also raised about the extent to which these cases support national learning. Further research into these cases, including analysis of what was changed at the local level and how this was evaluated, is clearly merited.

Recommendation 1

The full overview reports of SCRs involving OST should be republished (in redacted forms where appropriate) or made available to government-appointed researchers.

Any further cases involving OST should be collected and analysed biennially to examine the key learning points for practitioners, the implementation of recommendations and lessons for good practice.

The Department for Education or Ofsted would be best placed to carry out this work.

As well as limited national learning, this research also brings into question the extent to which Serious Case Reviews result in sustainable local improvements in the area where the incident took place. Although OST is far from the only risk to children growing up in sometimes chaotic family environments, and it is valuable to look at a wide range of concerns, it is perverse that some SCRs do not prioritise learning on the specific cause of harm to the child in the incident at the centre of the Review.

Recommendation 2

A representative from a drug treatment agency should be present on all Local Safeguarding Children Boards, to ensure that lessons relating to parental substance use are properly prioritised locally. Drug treatment services should also be represented on the Review Panel for any Serious Case Reviews where the parents' drug or alcohol use is relevant.

The research also highlights a clear knowledge gap. The true number of incidents where children have ingested OST drugs is unknown, as not all will reach the threshold required for conducting a SCR and there is no mandatory mechanism for recording such incidents otherwise. The number

of parents in receipt of take-home doses of OST medication is also not known. This lack of data inevitably means that the picture of risk on a national scale is unclear.

Recommendation 3

Data should be collected centrally on:

- *The number of parents prescribed different OST drugs, and on which supervision regimes*
- *The number of under-18s admitted to hospital after ingesting OST drugs*
- *The number of under-18s who have died after ingesting OST drugs.*

It would also be beneficial to analyse whether these cases involved accidental ingestion by the child or deliberate administration by the parent(s).

Collection of this data should be the responsibility of Public Health England (PHE) or the Department of Health

Professionals and service users can be insufficiently aware of the dangers that OST can present to children when not managed correctly. This is especially significant when considering cases where parents administer the drugs in attempts to pacify or soothe children: parents were evidently not aware of the real danger this posed, and it did not occur to practitioners that it might be happening. Professionals need greater support on assessing risks in families where the parent(s) use drugs, and priority should be given to developing the notions of healthy scepticism and professional challenge in practice.

Recommendation 4

Training for drug services, pharmacies and GPs must highlight the possible dangers of OST to children. Workers should also be able to address the deliberate administration of methadone and other drugs to children with service users and take an active role in promoting positive parenting practices. Other professionals working with vulnerable families, especially those undertaking home visits, also need to be alert and vigilant about the dangers of OST drugs.

OST medicines (particularly methadone) appear to present risks to children that other drugs do not. Toxicity in very small doses, possible attractiveness to children, the chance of unsafe storage in sometimes chaotic households and the rare but real use as a pacifier form a group of risks specific to methadone, and this must be recognised.

The vast majority of the cases studied – and all of those involving very young children or intentional administration – involved methadone rather than buprenorphine. NICE states that

risks to children should be considered when making prescribing decisions, and there is a legal obligation for this guidance to be followed at the local level. However, this research suggests that in reality, safeguarding considerations are not given adequate priority when making prescribing decisions. This applies both to the choice between methadone and buprenorphine, and decisions to allow take-home medication. Concerns for the safety of children should be at the top of the 'decision tree' in these cases, and local areas and service providers must be supported to implement this.

Recommendation 5

Guidance on the implementation of NICE, specifically Technology Appraisal 114, must reemphasise safeguarding children as a primary factor in making and reviewing decisions about OST, including which drug to prescribe and whether to permit take-home doses.

This would be the responsibility of PHE or the Department of Health. There is also a role for the Secretary of State for Health in ensuring that NICE is implemented at the local level.

Although risk cannot be entirely eliminated, safety measures should reflect the fact that a single ingestion of OST medication can be fatal.

Recommendation 6

Safe storage boxes should be provided to all drug treatment clients in receipt of OST, if they ever take any of their prescription home. This policy should be reinforced by consistent checks on storage arrangements and the ongoing provision of information about the dangers of drugs to children.

Systems should also be in place between different local agencies to distribute knowledge of, and responsibility for, monitoring and ensuring safe storage, including the sharing of safety plans agreed with the service user.

Such a policy does not eliminate all risk, and the Serious Case Reviews demonstrate that children have ingested OST drugs even in areas with safe storage policies in place. However, the implementation of a national policy would provide a valuable starting point and serve to highlight to professionals and service users the risks associated with OST.

Final Comments

Although this report discusses a limited number of cases, it also highlights an unacceptable number of child deaths which share a single, common risk factor.

It demonstrates that dangers to children are not sufficiently prioritised by practitioners working with people prescribed OST. Clear instructions from NICE are not sufficiently implemented at the local level or accessible enough to frontline practitioners, meaning that these incidents keep occurring.

It is also evident that the learning opportunities presented by each tragic case have not been used to make practice safer. The recommendations presented in this report therefore constitute a call for more coordinated, national action and awareness to stop more children from dying these unnecessary deaths.

This is an Executive Summary. The full report is available from www.adfam.org.uk.

Adfam is the national umbrella organisation working to improve the quality of life for families affected by drugs and alcohol.

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