

Review

Improving Pathways to Assessment and Care for Infants of Substance Abusing Mothers: Are We Getting It Right?

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Abstract: There is documented correlation between parental substance abuse, child maltreatment, and poor outcomes. In two health districts in Sydney, Australia (Site A and B), specialised clinics were established to provide comprehensive assessments for infants of substance abusing mothers (ISAM). We aimed to determine whether there was a difference in outcomes between infants who attended clinic *versus* those who did not; and to identify differences in the pathways to care between sites. We analysed child protection reports and available health markers of all ISAM referrals in 2011. We held stakeholder meetings with services involved with ISAM in both sites; to describe service components; strengths and weaknesses of pathways. Fifty-five per cent (11/20) attended clinic in Site A; 80% (25/31) in Site B. Three-quarters of ISAM had at least one referral to child welfare; child protection service involvement was more common in those who attended. Immunisation status was lower than the national Australian average; approximately half were seen by community nursing services. Gaps in services, lack of database, and differences in pathways between sites were identified. Attending clinics correlates with child protection service involvement and may afford health protection. Transparent communication, service integration, and shared learning can improve outcomes for this vulnerable group.

Keywords: infant of substance abusing mother; child maltreatment; child wellbeing; substance abuse; service integration; health services; child welfare

1. Introduction

There is an extensive body of literature worldwide confirming the strong correlation between substance abuse and child maltreatment [1–3]. In keeping with the international research, a recent Australian study reported that maternal disclosure of substance use is greatly associated with increased rates of involvement with statutory child protection services [4]. Infants of substance abusing mothers (ISAM) have poorer developmental, behavioural, and social outcomes [3]. A number of variables coexist and influence the environment of the child in this situation, including parental effectiveness in providing nurturing care [5–8]. Engagement with health services can be a protective factor in maintaining child safety and child wellbeing, suggesting that child health engagement decreases child protection risk [9].

In two metropolitan health regions in Sydney, Australia (Site A and Site B), there has been more than a decade long program to support mothers with substance abuse concerns through the pregnancy and early childhood period. A multi-disciplinary service with Drug Health, Community Health, Maternity services and Social Work involvement was set up and operated in these health districts from 2005 onwards. In 2007, a specialised multi-disciplinary paediatric clinic, was set up to provide comprehensive paediatric, developmental and psychosocial assessment and support for ISAM. Referral to the clinic was primarily through perinatal identification of at risk families, by antenatal health care workers (social workers, drug health workers, neonatologists) and also through identification of children with child protection concerns, usually referred by Community Services (CS), the statutory child protection service. A previous audit looking at the cohort of patients attending this clinic suggested that despite early identification, uptake of services was not occurring in the early years of life [10]. Anecdotal reports suggested that there was poor attendance at clinic, across both sites, in spite of many reminders by administrative staff and others. There were also concerns voiced by clinicians that ISAM were falling through gaps within the system, and that various components of the hospital and community services working with this client group were not communicating effectively. Poor clinic attendance and ongoing child safety and wellbeing concerns prompted a clinical service improvement project to improve the quality of service provided to ISAM. Our overall aim was to examine the quality of the Community Paediatric service provided with a view to improving the quality of the service. Specifically we wanted:

- (1) To determine if there was a difference in health and social outcomes, between those who attended clinic and those who did not;
- (2) To determine if existing pathways translate to proactive engagement with the health service;
- (3) To identify differences in robustness of pathways and functioning of services between the two sites;
- (4) To identify service improvement recommendations that are feasible, appropriate and relevant to ISAM, their families and the stakeholders who provide health services to this vulnerable group.

2. Methods

This quality improvement project was a mixed methods study utilising both quantitative and qualitative components.

2.1. Quantitative Component—Audit

A retrospective analysis of the electronic medical record was undertaken of all referrals to clinic between January and December 2011, for both Site A and B. Available data was collected for ISAM who attended clinic as well as for those who did not attend. Clinical measures including immunisation status, attendance at hospital emergency departments (ED) and engagement with the child and family health nurse (CFHN); and child protection reports to Community Services (Risk of Significant Harm over the statutory threshold) and child wellbeing referrals to the Child Wellbeing Unit (Risk of Harm under statutory threshold) were determined. Immunisation status was identified as an important measure of a good health outcome and was verified using the Australian Childhood Immunisation Register (ACIR). Health service encounters including ED visits and CFHN encounters were sought using information available on the electronic medical record (CERNER) for the two local health districts covered by site A and B. Both child protection reports and wellbeing referral data was drawn from the Child Wellbeing Unit database, “Well Net”, which contains information about children from across the state of NSW, enabling access to child protection reports even if the families have moved out of area. As this was an audit of the baby’s medical records, information about what services the mother received for her substance abuse or mental health issues was not available.

2.2. Qualitative Component—Stake Holder Engagement and Interviews

A meeting of key stakeholders from Site A and B was held prior to and after the quantitative component (audit) of the study. Stakeholder membership included representatives from Drug Health, Community Health, Maternity, Neonatal, Paediatric services and Social Work services. Both individual and group interviews were conducted. The purpose of the Stake holder meetings was to describe the service components of the perinatal drug health and maternity service through to Community Paediatric pathway, to identify strengths and weaknesses of the current processes, and to develop and enhance those pathways following the results of the audit.

2.3. Analysis

2.3.1. Quantitative

Data collected from CERNER, ACIR and Well Net was entered onto an EXCEL database. A Pearson chi-squared test for two independent samples was used to calculate the difference in proportions between the sites and between patients who attended and those that did not (p value = 2 sided significance).

2.3.2. Qualitative

Information was compiled from a series of stakeholder interviews held between March 2012 and August 2012. This included personnel from Site A (12 interviewees) and Site B (10 interviewees). The information from the key stakeholder interviews was analysed using thematic content analyses.

2.4. Ethics

A National Ethics Application proposal was developed describing both the quantitative and qualitative methodology of the project, which gained approval, by the lead Human Research Ethics Committee at Royal Prince Alfred Hospital.

3. Results

3.1. Quantitative Component—Audit

In Site A in 2011, a total number of 56 women were seen through the drugs in pregnancy coordinated care program (DAPCC); the women were being seen through three separate centres in the local health district. Similar data was not accessible for Site B. The last available database (2008) from Site B had 101 women identified through the Perinatal and Family Drug Health Service (PAFDHS); a significant majority of these were cannabis smokers. A total number of 51 ISAM were referred to ISAM clinic in the two sites. There were 20 appointments made for ISAM in Site A and 31 made for those in Site B. Of the appointments made 11 (11/20—55%) were attended at Site A, and 25 were attended at Site B (25/31—80%), significant difference between attendance at two sites ($p = 0.05$). Mother's ages ranged from 18 to 42 years at site A with a mean of 28 years and from 20 to 41 years at site B with a mean of 30 years.

The referrals to Site A were from a variety of sources, whereas referrals to the Site B clinic came entirely from the hospital neonatology team. Mothers of ISAM disclosed using a variety of substances in their antenatal visit, and approximately 30% of the infants referred to clinic had documented evidence of Neonatal Abstinence Syndrome (NAS) (Table 1). Three-quarters of ISAM had at least one child wellbeing unit referral at the time the study was being carried out (2012). Active involvement from Community Services was more common in those who attended clinics, at both sites (Table 2). Immunisation rates across both Sites were lower than the national Australian average, for those who did and those who did not attend clinic (Table 3). Half of ISAM, at both sites, had no documented electronic medical record evidence of a child and family health nurse visit. ISAM in Site A were more likely to be taken their local hospital emergency department (ED visits) for health related concerns, as compared to Site B (Table 4). The analysis of the data contained a count of less than five cases in various subgroups; therefore results of statistical significance were interpreted with caution. Table 5 shows demographic data across both sites.

Table 1. Drug use identified at Site A and B.

Drug Use		Site A <i>n</i> = 20 (%)	Site B <i>n</i> = 31 (%)
Drug	Methadone	8 (40)	9 (30)
	Illicit/Methadone/Poly drug use	7 (35)	8 (25)
	THC	3 (15)	4 (13)
	Alcohol	1 (5)	4 (13)
	Unknown	1 (5)	3 (9.5)
	Amphetamine	0	3 (9.5)
NAS		6 (30)	11 (35)

Table 2. Child protection concerns for clinic attendees *versus* non-attendees.

CP Concerns		Site A		Site B		<i>p</i> value
		Attended <i>n</i> = 11 (%)	DNA <i>n</i> = 9 (%)	Attended <i>n</i> = 25 (%)	DNA <i>n</i> = 6 (%)	
Risk of harm reports	0	3 (27)	2 (23)	6 (24)	2 (33)	0.8
	≥1	8 (73)	7 (77)	10 (40)	2 (33)	
	Unknown	0	0	9 (36)	2 (33)	
CS involvement	Active	6 (54)	4 (44)	15 (60)	0	0.02 *
	None	4 (37)	4 (44)	3 (16)	4 (67)	
	Unknown	1 (9)	1 (12)	7 (24)	2 (33)	
OOHC placement		4 (36)	1 (12)	8 (32)	0	0.05 *

Notes: * significant; CP: Child Protection; CS: Community Services; OOHC: out of home care.

Table 3. Immunisation status of clinic attendees *versus* non-attendees.

Immunisation		Site A		Site B		<i>p</i> value
		Attended <i>n</i> = 11 (%)	DNA <i>n</i> = 9 (%)	Attended <i>n</i> = 25 (%)	DNA <i>n</i> = 6 (%)	
Immunised	Fully	5 (45)	4 (44.5)	17 (68)	2 (33)	0.9
	Partially	5 (45)	3 (33.5)	6 (24)	3 (50)	
	Not	1 (10)	2 (22)	2 (8)	1 (17)	

Table 4. Health encounters of clinic attendees *versus* non-attendees.

Health Encounter		Site A		Site B	
		Attended <i>n</i> = 11 (%)	DNA <i>n</i> = 9 (%)	Attended <i>n</i> = 25 (%)	DNA <i>n</i> = 6 (%)
CFHN involvement	Any visit	4 (36.5)	6 (66)	15 (60)	2 (33.5)
	0 visits	7 (63.5)	3 (33.5)	10 (40)	4 (66.5)
	<10 visits	4 (36.5)	4 (44.5)	9 (36)	2 (33.5)
	>10 visits	0	2 (22)	6 (24)	0
ED visit	0	6 (54.5)	3 (33)	0	0
	≥1	5 (45.5)	6 (66)	0	1 (16)

CFHN: Child and Family Health Nurse.

Table 5. Demographic details of clients referred to clinic.

Demographics		Site A <i>n</i> = 20 (%)	Site B <i>n</i> = 31 (%)
Attendance		11 (52)	25 (80)
Cultural background	Anglo	12 (60)	
	Indigenous	5 (25)	
	Culturally/linguistically diverse	3 (15)	
Referral	Social Work	13 (65)	Neonatal team
	PAFDHS	4 (20)	
	CFHN	1 (5)	
	CS	1 (5)	
	Carer	1 (5)	

3.2. Qualitative—Information Gathered from Stakeholder Meetings

3.2.1. Barriers to Pathways to Care for ISAM

Issues Common to Both Sites

- Non-disclosure of substance use in pregnancy by mothers
- Substance abusing women reluctant to engage with services
- Lack of clear mechanism to monitor ISAM progress using current health records
- Overlap of risk categories such as mental health concerns, teen mother, intimate partner violence
- Lack of clarity of case management responsibility for the infant between health and statutory child protection services
- Children placed in foster care outside the health district are likely to be lost to follow up
- Work force issues including recruitment and retention of skilled staff

Site A

- Lack of designated senior medical clinician involvement and leadership (especially for obstetrics and neonatal services)
- Limited involvement of child protection services with families at significant risk
- Lack of health services engagement with Indigenous Medical Service in the antenatal and postnatal period
- Discontinuation of multidisciplinary health and support service involvement after delivery of baby
- Poor linkages within Community Health services

Site B

- Multiplicity of meetings with risk of multiple care plans
- Lack of use of a unified database by all teams involved with ISAM families. This makes it difficult to capture the true extent of substance abuse in pregnancy and to track ISAM progress through the health system
- Senior drug health nursing position vacant

3.2.2. Facilitators to Pathways to Care for ISAM

For both Sites

- A skilled and committed workforce with a multidisciplinary model for perinatal psychosocial assessment and care

Site A

- The presence of senior Drug Health Nurse with access to database on drug health attendees

Site B

- Engagement of and leadership from senior clinicians (e.g., Obstetric and Neonatal Services)
- Involvement of neonatal medical staff through antenatal, perinatal and postnatal periods
- Strong engagement with Indigenous Medical Service
- Ongoing connection between neonatal team and ISAM Clinic
- Perinatal Family Conferencing: an innovative program involving a multi-disciplinary health team with CS engagement for pregnant women with substance abuse who are at risk of losing their infants to alternative care

4. Discussion

Infants of substance using mothers are a particularly vulnerable group in our society [1]. Psychosocial factors surrounding mothers prior and throughout pregnancy, the intrauterine environment, the perinatal period and postnatal care are all times of potential risk of harm [8]. Targeted care and support for ISAM from conception into their first few years of life is required for this group to optimise health and well-being outcomes [10]. Our study focused on examining the quality of care provided by our health service to this vulnerable group given recent anecdotal reports of poor attendance to these clinics, with the aim of improving the quality of this service. We found that there were differences in pathways and a significant difference in engagement between sites for ISAM. Analysis of audit data suggested that child protection service involvement and being in out of home care (OOHC) appears to increase clinic attendance; we saw no evidence to suggest that attending clinic resulted in babies being placed in OOHC. Attending clinics may decrease hospital visits and provide some health protection. Importantly this project identified both facilitators and barriers to service delivery for ISAM, and also identified health indicators that can be improved for ISAM, such as immunisation status, community nurse engagement and acute hospital visits.

In conducting this project, we discovered that the true extent of substance abuse in pregnancy was not known, particularly in Site B. Data was available for the number of mothers in Site A in 2011 who attended the perinatal drug health service (total of 56), but similar data was not readily available for Site B. The Australian 2010 National Drug Strategy Household Survey found that 12.3% of females between 20–39 years of age, had used an illicit substance in the previous year [11]. Data from the United States suggest that illicit drug use is 7.4% among pregnant women aged 18–25 years [12]. When considering the birth rate at Site A for 2011 (approximately 2500 births), rate of substance abuse identified for our study would be placed at 0.2%, likely to be a gross underestimate of the actual burden of the problem, with concerns of non-disclosure of drug use by women presenting for antenatal care.

Attendance rates at ISAM clinic were significantly greater at Site B, proving that anecdotal reports were indeed true and that engagement with the clinic was better at this site. Identification of the facilitators and barriers to care between both sites highlighted the differences in pathways to care and may shed light on the possible reasoning behind the differing attendance rates. Typically this group is difficult to engage in post-natal care [7]. Nehra's study found that, in the general neonatal population, factors that significantly improved compliance included having patient contact after discharge, and also giving early intervention referral. In that study patients that were referred to follow up clinic and contacted by a fellow after discharge, were 85% more likely to attend follow up appointments [13]. The families at site B were engaged early, with all ISAM being followed up by the hospital neonatal team even if they did not develop NAS. ISAM were then referred by the neonatal fellow to ISAM clinic, where they were seen within a few weeks of discharge from the neonatal team. At Site A, following discharge from hospital, referral was made for an assessment at six months of age to the ISAM clinic. Although at Site A there was earlier engagement with nursing and general paediatric teams, communication between these teams and ISAM clinic was not integrated or structured as at Site B, where the community clinic occurred on site at the NICU within a few weeks of discharge from the NICU team.

Powell discusses the issue of "did not attend", reported as a marker of the quality of the interface between primary and secondary health care (in our case between hospital services and community health), an important issue when establishing engagement with health care services for families. She also discussed that patient explanation including forgetfulness, fear, anxiety and a misunderstanding of the system compound non-attendance. The issue of being "lost to follow up" as opposed to "did not attend", would also need consideration for our group, with the possibility of mothers having difficulty navigating the system, or ISAM being placed in foster care out of area. Reports from key stakeholders did suggest that families at Site A were less knowledgeable about the community paediatric service than at Site B which may have added to the lack of early post-natal engagement with this group. Interviewing the families to gauge their understanding for the need and purpose of ISAM clinic would further clarify this question. Overall non-attendance carries a significant cost in terms of health care expenditure, but more importantly can veil child maltreatment particularly in the form of neglect for vulnerable families [14].

Neonatal abstinence syndrome is a syndrome of drug withdrawal with nonspecific signs and symptoms that may appear in babies following in-utero drug exposure. The risk is greatest with opioids although other drugs such as methamphetamines have been implicated [15]. The prevalence ranges from 40%–60% and appears to be increasing [16–18]. Risk factors for developing NAS in ISAM include mothers with a previous mental health admission, low skill levels, Indigenous status or smoking during pregnancy [19]. Our cohort showed a prevalence of 30% for NAS, lower than reported prevalence in the literature, although our group across both sites included mothers who did not report use of opiates (37%). We are not able to account for this lower than expected rate by omitting mothers in the non-opioid group. Interestingly 9 of the 19 infants in our cohort who had documented NAS, had no documented evidence of opiate use by their mothers on electronic medical record (alcohol, cannabis and amphetamine use reported only), highlighting the issue of non-disclosure amongst this group, and/or the limitation in the use of the current electronic medical record to document drug use during pregnancy.

With respect to child protection concerns, our study findings correlate with the existing literature as to the association of this group with child maltreatment. O'Donnell reported that NAS infants were at greater risk for having a substantiated child maltreatment allegation and entering foster care with increased risk for maltreatment associated with mothers aged <30 years, having socially disadvantaged backgrounds, Indigenous status, and mental health or assault related admission [19]. O'Donnell's study concluded that there was a need for well-supported programs as well as the need for sustained long-term support after birth for this vulnerable group. Three quarters of the children in our study group had at least one documented report below the statutory risk for harm, this included infants with no documented evidence of NAS, highlighting the need to not use NAS as a marker for referral to clinic. Dawe reported on the high rates of child maltreatment in families with substance abuse concerns, reiterating that drug use alone does not correlate with child maltreatment and that the adverse outcomes are intertwined with other associated socioeconomic factors. She presented an intensive home based intervention, which targets multiple domains of family functioning with results showing reduction in child abuse potential, highlighting the need for extensive ongoing intervention for this group [20]. A project along similar lines is the Perinatal Family Conferencing project, which commenced mid-March 2012 at Site B, using a strengths-based model of care servicing women at risk of their infant entering OOHC at birth. The intervention includes the integration of skills from health and community services, and is already showing positive engagement with this vulnerable group [21]. A similar service at Site A may benefit this population in their navigation of the health system.

Being involved with child protection services in our group could be seen as a protective factor with respect to health engagement, as those involved with child protection services and those in OOHC were more likely to attend clinic. However, being known to or involved with child protection services did not correlate with other health indices such as improved immunisation rates. Health outcomes for our cohort provided a mixed picture; immunisation rates were lower than national average for both attendees and non-attendees (*cf.* NSW children aged 12–17 months, 90% fully vaccinated: [22]. Niccol's *et al.*, carried out a systematic view of studies reporting on child outcomes for children with substance abusing parents in integrated health programs. They concluded that current evidence supports integrated programs as having benefits for the child with improvements in child development, growth, emotional and behavioural functioning. Integrated services were defined as caring, comprehensive, centralised services, which provided a “one stop shop”. This would include on site pregnancy, parenting, child related and addiction services that would offer long-term (to 18 months) treatment [23]. This is important information in moving forward to providing an improved service model for our group.

Among our group, half had no documented record on electronic medical records of a CFHN visit, indicating poor engagement with CFHN services. The importance of the role of the child and family health nurse in engaging this particular group has been well documented. CFHN staffs are in a unique position to be able to build trusting relationships, offer continuity of care and assist in accessing health care systems [7,24,25]. In relation to hospital visits, these were higher in Site A, where attendance at clinic was lower and communication between hospital and community services specific to this vulnerable group was less structured. Improving integration of services between hospital and community-based services may remove access difficulties regarding seeking of health care for this population. This may in turn result in the decreased use of the hospital emergency department in

seeking treatment of health care needs, although additional evidence would be required to substantiate this hypothesis.

Overall from the findings of our study and review of the literature, an integrated system with specific engagement of CFHN would be seen as critical in moving forward to providing improvement in the quality of service delivered to this population. Communication between all teams involved in the delivery of service including Child and Family Health Nurses, maternity, drug health, neonatology, paediatrics, and community health would assist in promoting service delivery. In addition this would allow for providing a service acceptable to mothers. There is evidence to suggest that longer-term multidisciplinary programs (beyond the first year of life), are of greater benefit for this group, although there is little in the way of documentation suggesting possible avenues to “track” these infants, or which of the many teams involved might be best placed to do this. A unified database with access to all teams involved in care for this group could allow for monitoring of progress. Longer term follow up of ISAM is required to determine how protective attending clinics are for these children, and in addition further evaluation of parental views of the current system would be highly beneficial in providing a user friendly service. These last two key components were seen as the main limitation of our study, and would be a direction for future research.

5. Conclusions

Key facilitators and barriers to care for ISAM were identified from this service improvement project. It was clearly noted that differences exist in pathways and engagement with health services for ISAM between sites; with child protection service involvement and being in foster care increasing clinic attendance. Overall transparent communication, service integration and shared learning can improve service provision for this population. Small service improvement strategies have already been put into place as a result of this project. Our fervent hope would be that this translates to positive and sustained health and social outcomes for this vulnerable group of infants and their families.

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Author Contributions

All authors contributed to the designing and implementing of this project. Writing up was principally done by first author, with support from other three authors.

Abbreviations

ISAM:	Infant of Substance Abusing Mother;
CS:	Community Services;
CFHN:	Child and Family Health Nurse;
ED:	Emergency Department;

ACIR:	Australian Immunisation Register;
DAPCC:	Drugs and Pregnancy Coordinated Care Program;
PAFDHS:	Perinatal and Family Drug Health Service;
NAS:	Neonatal Abstinence Syndrome;
OOHC:	Out of Home Care;
NICU:	Neonatal Intensive Care Unit.

Conflicts of Interest

The authors declare no conflict of interest.

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