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Maternal help-seeking for child developmental concerns: associations with sociodemographic factors

Original Article

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Maternal help-seeking for child developmental concerns: associations with sociodemographic factors

Abstract

Aim: To examine sociodemographic factors associated with maternal help-seeking for child developmental concerns in a longitudinal birth cohort study. An understanding of these factors is critical to improving uptake of services to maximise early identification and intervention for developmental concerns. **Methods:** A birth cohort was recruited from the postnatal wards of two teaching hospitals and through community nurses in South Western Sydney, Australia, between November 2011 and April 2013. Of the 4047 mothers approached, 2025 consented to participate (response rate = 50%). Sociodemographic and service use information was collected after the child's birth and when the child was 18 months of age. Sources of help were divided into three categories (formal health services, other formal services, informal supports) and compound variables were created by summing the number of different sources identified by mothers. **Results:** Significantly more sources of help were intended to be used and/or actually accessed by mothers born in Australia, whose primary language was English, with higher levels of education and annual household income, and among mothers of first-born children. **Conclusions:** Developmental concerns are known to increase with increased psychosocial adversity. Our findings of reduced intent to access and use of services by socioeconomically disadvantaged families and those from culturally and linguistically diverse backgrounds suggests that an inverse care effect is in operation whereby those children with the greatest health needs may have the least access to services. Possible explanations for this, and recommendations for improving service accessibility for these populations through targeted and culturally-appropriate services, are discussed.

Key words: help-seeking behaviour; developmental disabilities; child development; developmental surveillance; early diagnosis; early intervention

What is already known on this topic:

- Early intervention is beneficial for children with developmental disorders but early detection remains a challenge.
- Children from disadvantaged backgrounds, who often have higher developmental risk, also have less access to surveillance and healthcare.

What this paper adds:

- In a large birth cohort from South Western Sydney, there is reduced intent to access and use of services among socioeconomically disadvantaged families and those of culturally and linguistically diverse backgrounds.
- Policy development and service delivery efforts should include a framework of proportionate universalism to ensure equitable access to and uptake of child health services for all parents.

Introduction

Developmental disorders are a major cause of global disease burden^{1,2}. Early detection and intervention for developmental disorders remains a challenge, despite research showing superior outcomes for children accessing intervention at the earliest possible age^{3,4}. In Australia, nearly one quarter of children start primary school with developmental vulnerabilities, but most have had no intervention⁵. Identifying at-risk children is particularly challenging, with research suggesting an inverse care effect such that children from disadvantaged backgrounds, who have a heightened risk for developmental disorders, also have lower attendance at surveillance programs and less access to preventative and comprehensive healthcare^{6,7}.

Research suggests that families experiencing disadvantage tend to seek less help for developmental concerns than other families. Parents of low socioeconomic status (SES) are less likely to attend universally-offered parenting classes⁸, to seek help for concerns about their child's communication⁹, and to access allied health services for their child's developmental and behavioural disorders¹⁰⁻¹² than those of higher SES, although these associations may be attenuated in countries with universal healthcare systems such as Australia¹³. Parents' ethnicity and language may also influence help-seeking for developmental concerns. In the United States, African-American parents expressed more negative expectations about treatment than Caucasian parents when seeking professional help for their children with behavioural issues¹⁴. In Australia, infants from indigenous and culturally and linguistically diverse (CALD) backgrounds have higher parent-reported unmet needs than infants from non-indigenous and English-speaking backgrounds¹⁵.

It is important to understand factors that are associated with the likelihood of parents seeking help for concerns regarding their child's development in order to improve uptake of available services and ensure that all children receive timely diagnosis and intervention for developmental concerns. An awareness of factors that may be associated with reduced service uptake is necessary in order to identify population groups that may be at risk of not accessing services and to inform research into targeted engagement efforts for these groups, such as trials comparing different methods of engaging at-risk populations. The aim of the current study was to examine sociodemographic factors associated with maternal help-seeking patterns – both intended and accessed sources of support – for concerns about their child's development during the first 18 months of their child's life.

Materials and Methods

Ethical approval

The study was approved by the Human Research Ethics Committees of the University of New South Wales and South Western Sydney Local Health District, and conformed to the standards of the Declaration of Helsinki. All families recruited to the study provided informed consent to participate.

Participants

A longitudinal birth cohort was recruited from the postnatal wards of two teaching hospitals and through community nurses in South Western Sydney, Australia, between November 2011 and April 2013 for the ‘Watch Me Grow’ (WMG) study. The WMG study was designed to evaluate the feasibility of current developmental surveillance systems in NSW and their accuracy in identifying children with or at risk of developmental disorders. Of the 4047 mothers approached, 2025 (50%) consented to participate. Further information on recruitment and methodology is presented elsewhere by Eapen, Woolfenden, Williams *et al.*¹⁶.

Measures

Sociodemographic and service use information was collected via surveys administered to mothers at two time points – shortly after birth (baseline survey) and when children were 18 months of age (18-month survey). Surveys were designed to assess variables known to be important for child health and development based on existing literature and questionnaires from other Australian cohort studies^{17,18}. Baseline survey data was available for 1763 (87%) participants while 18-month survey data was available for 482 (24%) participants.

Mothers were asked two questions to assess help-seeking intentions and actual service use: “Where would you get information about your child’s development if you needed it?” (baseline survey), and “Since your child was born, where have you tried to get information about your child’s development, if you needed it?” (18-month survey). Mothers were asked to select as many options as applied from a list (see Table 1) and to identify any additional services that were not on the list. Fathers’ responses to these questions were not collected, partly because they were usually not present when questionnaires were completed, with most baseline surveys administered on the postnatal wards. Further, due to the primary caregiving role generally being assumed by mothers (over 99% of mothers in the present sample identified themselves as the child’s primary caregiver), our study aimed to examine factors associated specifically with maternal help-seeking.

{Insert Table 1 here}

Statistical analysis

Sources of help were categorised into: 1. formal health services, 2. other formal services, and 3. informal supports (see Table 1). Literature on help-seeking typically distinguishes between two sources of help – informal and formal. Given that timely detection of and intervention for developmental concerns is best achieved through direct engagement with health services, it was considered important in the present study to further divide formal services into two categories – health services and other (non-health) services. Compound variables were created by summing the number of sources of help (total, formal health, other formal, informal) that mothers intended to use (baseline survey) and those that they had accessed in the 18 months following their child's birth (18-month survey), resulting in eight dependent variables. Sociodemographic variables were maternal marital status, country of birth, education and primary language, post-tax annual household income, and the child's birth order (see Table 2).

{Insert Table 2 here}

To account for possible overdispersion of each of the dependent variables, likelihood ratio tests were run to determine which of Poisson or negative binomial regression models were more appropriate for analyses in the univariate models. Starting with variables with $p < 0.2$ in univariate models, multivariable Poisson or negative binomial regression models were used to determine predictors of each outcome. Variables were removed in a backward stepwise method. A p -value < 0.05 was considered statistically significant.

Results

Commonly identified help sources

The mean number of help sources identified by mothers at both baseline (those that they intended to use) and 18-month surveys (those that they actually accessed) is shown in Table 3.

{Insert Table 3 here}

Formal health services were identified as intended sources of support and accessed more frequently than informal supports and other formal services. There was limited awareness or use of other

formal services in the current sample, with 62.7% of mothers not intending to use and 81.3% of mothers not having accessed these services at baseline and 18-month surveys respectively. GPs were the most frequently identified intended source of help at the child's birth (68.8% of mothers) and the most accessed help source at 18 months (64.1% of mothers). Other common intended and accessed sources of help included family and friends (59.2% and 42.3% of mothers at birth and 18 months of age respectively), the internet and books (50.8% and 57.1% of mothers), and CFHNs (31.6% and 25.3% of mothers).

Fisher's exact tests were run in order to examine whether there was an increased likelihood of mothers accessing a GP or CFHN by the 18-month survey – services that form part of routine developmental surveillance in NSW – if they had reported intention to use these at their child's birth. Thirty-six percent of mothers who had identified CFHNs as an intended source of help at their child's birth had accessed a CFHN by the 18-month survey, compared to only 18% of mothers who had not identified this at birth ($p < 0.001$). There was no significant difference, however, in the proportion of mothers who had attended a GP by the 18-month survey between those who had identified this as an intended source of support at their child's birth and those who had not.

Factors associated with help-seeking intentions and behaviours

Intended help sources identified at baseline

Significant associations were found between sociodemographic characteristics (mother's country of birth, primary language and education, annual household income, and the child's birth order) and the number of intended help sources identified by mothers following their child's birth (Table 4).

Mothers who were born in Australia identified on average 23% more total help sources ($p < 0.001$), 22% more formal health services ($p < 0.001$) and 24% more informal supports ($p < 0.001$) than mothers born overseas. Mothers whose primary language was English reported 13% more total help sources ($p < 0.001$), 11% more formal health services ($p = 0.04$) and 64% more other formal services ($p < 0.001$) than mothers with a different primary language. Mothers of first-born children reported 7% more total help sources ($p = 0.02$) and 22% more other formal services ($p = 0.01$) than mothers whose child was not their first. Further, there was an increase in the number of total help sources ($p < 0.001$) and informal supports ($p < 0.001$) identified by mothers as annual household income increased.

Mothers with TAFE/undergraduate university education identified 29% more total help sources than mothers with nil/primary education ($p = 0.02$), 16% more total help sources than mothers with Year 10 or 12 education ($p < 0.001$), and 12% more total help sources than mothers with postgraduate university education ($p = 0.02$). Mothers with TAFE/undergraduate university education also reported 20% more formal health services than postgraduate university graduates ($p = 0.01$) and 15% more formal health services than Year 10 or 12 graduates ($p < 0.001$). Mothers with tertiary qualifications (TAFE/undergraduate university or postgraduate university respectively) identified more informal supports than mothers without tertiary qualifications: 23% ($p < 0.001$) and 29% ($p = 0.002$) more than mothers with Year 10 or 12 education, and 77% ($p = 0.008$) and 86% ($p = 0.005$) more than those with primary school or less.

Help sources accessed by 18-month survey

Final multivariable Poisson regression models are shown in Table 5. The number of help sources accessed during the first 18 months of the child's life was significantly associated with maternal primary language and the child's birth order.

Mothers whose primary language was English reported accessing 21% more total help sources ($p = 0.004$), 169% more other formal services ($p < 0.001$) and 26% more informal supports ($p = 0.02$) than mothers with a different primary language. Mothers of first-born children accessed 35% more total help sources ($p < .0001$), 22% more formal health services ($p = 0.02$), 98% more other formal services ($p = 0.001$) and 37% more informal supports ($p = 0.002$) than mothers whose child was not their first.

{Insert Tables 4 and 5 here}

Discussion

The aim of this study was to examine sociodemographic factors associated with maternal help-seeking for child developmental concerns during the first 18 months of life. Results showed that mothers born in Australia and whose primary language was English intended to use more help sources following their child's birth than mothers born overseas or who spoke a different primary language. Mothers whose primary language was English also accessed help from more sources during the first 18 months of their child's life than mothers with another primary language. While language is likely to be a barrier to access, previous research has shown that infants from CALD backgrounds are less likely to receive services even if their mothers speak English proficiently¹⁹,

suggesting that differences in knowledge, cultural attitudes and/or beliefs about the role of healthcare services may also be contributing factors.

Birth order was associated with help-seeking intentions in the present study, with mothers of first-born children identifying and accessing more sources of help than mothers with later born children. There are several plausible explanations for this, including increased efforts by services to engage new mothers, higher anxiety about child development in first-time mothers resulting in increased service use, and practical difficulties in attending services when there are multiple children in the family.

Differences also emerged in the number of identified help sources between mothers from different educational and socio-economic backgrounds. Mothers with tertiary qualifications and higher annual household incomes intended to use more sources of help at their child's birth than those with primary or secondary qualifications and lower annual household incomes. This is partially consistent with findings from previous studies that parents from low SES backgrounds are less likely to seek help for their child's developmental disorders¹⁰⁻¹². However, there were no significant differences in the number of help sources accessed by mothers in the first 18 months of their child's development based on their education or income level. Previous research into the impact of maternal education on help-seeking behaviour has been inconsistent, with some studies finding increased service use among mothers with higher education levels¹⁹ and others suggesting the opposite pattern²⁰. One explanation for this discrepancy is that higher levels of education could plausibly be associated with increased service use due to awareness of available services and greater capacity to afford these, or with decreased service use due to time constraints as a result of differences in type of employment and working hours. It is important that future studies control for potential confounding variables, including SES and employment status, in order to clarify the relationship between education and help-seeking behaviour. Studies using qualitative approaches may also assist in disentangling motivations for different help-seeking patterns.

Previous research suggests that children from low SES and CALD backgrounds are more likely to be developmentally vulnerable and thus most in need of universal developmental surveillance and related services^{5,7}. Thus, the present study is strengthened by the recruitment of a birth cohort from a culturally and linguistically diverse area of Sydney, increasing sample representativeness. As with many other studies, mothers were the focus because of their availability and identified role as primary caregiver. Fathers will, however, influence help-seeking behaviour for child development concerns, and exploration of their help-seeking and how that interacts with mothers' help-seeking

could further assist service development. Our findings of reduced intent to access and use of services among socioeconomically disadvantaged families and those from CALD backgrounds support an inverse care effect where children with the greatest health needs have the least access to services⁶. Compounding this further, additional analysis showed that mothers from disadvantaged backgrounds – those who were born overseas and those with lower annual household incomes – were more likely to drop out of the study prior to and were therefore under-represented at the 18-month survey. Thus, in addition to the inverse care effect – mothers and children from disadvantaged backgrounds having reduced access to services, our findings suggest that these mothers and children may also be under-represented in research which aims to remediate this very effect.

It is important to acknowledge the complex influences that may impact on service uptake. For example, even if parents are aware of services, a lack of understanding of their value or benefit or beliefs about developmental concerns' lack of response to treatment, could contribute to reduced help-seeking. Further, the cultural appropriateness of services is likely to influence families' willingness to seek support, and the question of how services can better engage and meet the needs of disadvantaged and culturally diverse families is important. Further, parents may vary in their knowledge of age-appropriate development and this can result in either service overuse or underutilisation. Increasing health literacy so that parents can identify whether their child is developing typically and are aware of available support services is important to ensure equitable access to health services. Initiatives such as the Raising Children website²¹, providing evidence-based information and resources for parents, are important in this regard. As such, one limitation of the present study is that mothers were asked to identify where they had sought help for child developmental concerns if they had needed it. It is therefore not possible to determine whether reduced service uptake was because mothers did not have concerns about their child's development (appropriate lack of help-seeking) or due to a lack of awareness or reluctance to access services even in the presence of concerns. Our findings of reduced service use among populations known to be at greater developmental risk, however, suggests that this result is unlikely to be solely attributable to a lack of developmental concern. Further, while it was not a focus of the present study, a previous publication from the WMG study examined the prevalence of parental concerns regarding development at 18 months within the same cohort. Of the 565 children for whom the Parents' Evaluation of Developmental Status (PEDS)²² had been completed at 18 months, 184 (32.6%) were identified as at high or moderate developmental risk²³.

The drop in response rate from 87% of participating mothers at baseline to 24% at the 18-month follow-up is a further limitation of the present study. While a small number of participants chose to withdraw from the study (4% of the overall sample of 2025), the drop in response rate is largely due to the research team being unable to contact participants at the 18-month follow-up. Several efforts were made to try to overcome this, including multiple methods of contact and multiple attempts at follow-up phone calls – at least three attempts were made to contact each participant – but the reduced response rate, particularly among more disadvantaged families, does highlight the additional efforts that may be needed to engage certain families in services. More effective methods of follow-up than phone calls are required to address the significant challenge of cohort retention. Adequate resources for a study director and ongoing participant engagement strategies, such as collaborative research planning, home visiting, study information days and community presentations, have been suggested as strategies that have been used with success in other Australian cohort studies²³.

Despite these limitations, the findings of the present study support the use of a framework of proportionate universalism, in which services are available to all children but the level of support is commensurate with the unique needs of individual children and their families²⁴, such that targeted and culturally-appropriate services are provided to meet the additional needs of those at increased biological or psychosocial risk. While such a framework is an integral part of current NSW Health policy, there are significant challenges in the resourcing of services to implement the policy given the finite health budget and competing priorities. However, since early identification of developmental concerns is the essential first step in ensuring that children receive timely intervention, no effort should be spared in promoting help-seeking by parents.

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Table 1: Sources of help included in baseline and 18-month surveys

Formal health services	Other formal services	Informal supports
Midwife	Australian Breastfeeding Association	Family or relatives or friends
Child and Family Health Nurse	Parent and/or family support groups	Charities (e.g., Salvation Army)
GP services	Migrant or ethnic resource services	Church or religious groups
Adult mental health services	Other counselling services	Internet/books
Other medical services	Parent line/help line	
<i>Personal health record/"blue book"</i>	<i>Preschool</i>	
<i>Paediatrician</i>		
<i>Hospital</i>		
<i>Tertiary Referral Centre</i>		

Italicised sources of help were those that were not on the printed list but were spontaneously identified by mothers.

Table 2: Baseline sociodemographic characteristics of the sample for participants by time point

Variable		Baseline survey (n = 1763)	18-month survey (n = 482)
Marital status	Married or engaged or de facto	89.8%	92.1%
	Single or separated or divorced	9.0%	6.5%
	In a relationship but not cohabiting	1.2%	1.5%
Country of birth	Australia	42.3%	48.8%
	Other	57.7%	51.3%
Primary language	English	52.1%	55.8%
	Other	47.9%	44.2%
Education	Postgraduate degree	11.7%	11.3%
	Undergraduate degree or TAFE	48.7%	53.8%
	Year 10 or 12	36.9%	31.8%
	Primary school or less	2.7%	3.1%
Post-tax annual household income	Under \$25,000	19.1%	12.6%
	\$25,001 - \$75,000	53.1%	53.2%
	\$75,001 - \$105,000	18.4%	22.8%
	Over \$105,001	9.4%	11.4%
Child's birth order	First-born	42.0%	42.3%
	Not first-born	58.0%	57.7%

TAFE = Technical and further education

Table 3: Mean number of help sources identified by mothers

Variable	Mean	SD	Range	% identifying 1 or more
<i>Baseline survey (intended), n = 1741</i>				
Total help sources	3.3	2.0	0 – 14	99.4%
Formal health services	1.6	1.0	0 – 5	88.1%
Informal supports	1.2	0.8	0 – 4	75.3%
Other formal services	0.6	0.9	0 – 5	37.3%
<i>18-month survey (accessed), n = 482</i>				
Total help sources	2.3	1.4	0 – 9	97.3%
Formal health services	1.1	0.8	0 – 4	75.9%
Other formal services	0.2	0.5	0 – 3	18.7%
Informal supports	1.0	0.7	0 – 3	73.0%

Table 4: Final multivariable models of number of intended help sources (baseline survey)

	Total help sources [‡]			Formal health services [†]			Informal supports [†]			Other formal health services [‡]		
	RR	95% CI	p-value	RR	95% CI	p-value	RR	95% CI	p-value	RR	95% CI	p-value
Mother's Country of Birth												
Australia	1.23	(1.15, 1.32)	<0.001	1.22	(1.10, 1.34)	<0.001	1.24	(1.12, 1.37)	<0.001			
Other		Reference			Reference			Reference				
Mother's Education			<0.001			0.005			<0.001			
Postgrad university	1.15	(0.92, 1.45)	0.23	1.01	(0.74, 1.38)	0.95	1.86	(1.2, 2.9)	0.006			
TAFE or undergrad university	1.29	(1.04, 1.60)	0.02	1.21	(0.91, 1.62)	0.19	1.77	(1.16, 2.72)	0.008			
Year 10 or 12	1.11	(0.9, 1.38)	0.34	1.06	(0.79, 1.42)	0.71	1.45	(0.94, 2.22)	0.09			
Primary school or less		Reference			Reference			Reference				
Primary Language												
English Only	1.13	(1.06, 1.22)	<0.001	1.11	(1.00, 1.22)	0.04				1.64	(1.40, 1.93)	<0.001
Others Spoken		Reference			Reference						Reference	
Income (After Tax)			<0.001						<0.001			
<\$25,000	0.76	(0.68, 0.86)	<0.001				0.69	(0.56, 0.84)	<0.001			
\$25,000 - \$75,000	0.90	(0.82, 0.99)	0.03				0.90	(0.77, 1.06)	0.20			
\$75,000 - \$105,000	0.97	(0.87, 1.07)	0.53				1.00	(0.84, 1.19)	0.98			
>\$105,000		Reference						Reference				
Birth Order												
First-born child	1.07	(1.01, 1.13)	0.02							1.22	(1.05, 1.42)	0.01
Not first-born		Reference									Reference	

[‡] Results based on negative binomial regression. [†] Results based on Poisson regression. TAFE = Technical and further education. RR = Relative Risk. 95% CI = 95% Confidence Interval. Formal health services refers to GP, other medical service, midwife, child and family health nurse, blue book, adult mental health service, hospital, tertiary referral centre and paediatrician. Other formal health services refers to Australian Breastfeeding Association, parent help line, parent/family support group, migrant/ethnic services, counselling service and preschool. Informal supports refers to family/friends, charities, church/religious groups and internet/books. Total help sources refers to all help sources described.

Table 5: Final multivariable models of number of accessed help sources (18-month survey)

	Total help sources			Formal health services			Informal supports			Other formal health services		
	RR	95% CI	p-value	RR	95% CI	p-value	RR	95% CI	p-value	RR	95% CI	p-value
Primary Language												
English Only	1.21	(1.06, 1.38)	0.003				1.26	(1.04, 1.54)	0.02	2.69	(1.62, 4.46)	<0.001
Others Spoken		Reference						Reference			Reference	
Birth Order												
First born child	1.35	(1.19, 1.54)	<0.001	1.22	(1.02, 1.45)	0.03	1.37	(1.13, 1.65)	0.002	1.98	(1.3, 3)	0.001
Not first born		Reference			Reference			Reference			Reference	

Results based on Poisson regression. RR = Relative Risk. Formal health services refers to GP, other medical service, midwife, child and family health nurse, blue book, adult mental health service, hospital, tertiary referral centre and paediatrician. Other formal health services refers to Australian Breastfeeding Association, parent help line, parent/family support group, migrant/ethnic services, counselling service and preschool. Informal supports refers to family/friends, charities, church/religious groups and internet/books. Total help sources refers to all help sources described.