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To cite this article: Pamela Srour-Alphonse, Biljana Cvetkovski, Cynthia S. Rand, Elizabeth Azzi, Rachel Tan, Vicky Kritikos, Lynn H. M. Cheong & Sinthia Bosnic-Anticevich (2019): It takes a village - asthma networks utilized by parents when managing childhood asthma medications, Journal of Asthma, DOI: [10.1080/02770903.2019.1568456](https://doi.org/10.1080/02770903.2019.1568456)

To link to this article: <https://doi.org/10.1080/02770903.2019.1568456>



Published online: 22 Jan 2019.



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It takes a village - asthma networks utilized by parents when managing childhood asthma medications

Pamela Srour-Alphonse, BPharm^{a,b}, Biljana Cvetkovski, MPharm^{a,b}, Cynthia S. Rand, PhD^c, Elizabeth Azzi, BPharm^{a,b}, Rachel Tan, BS (Hons)^{a,b}, Vicky Kritikos, PhD^{a,b,d}, Lynn H. M. Cheong, PhD^e, and Sinthia Bosnic-Anticevich, PhD^{a,b,f}

^aSydney Medical School, Faculty of Medicine and Health, The University of Sydney, Sydney, Australia; ^bWoolcock Institute of Medical Research, The University of Sydney, Sydney, Australia; ^cPulmonary and Critical Care Medicine Department, John Hopkins University, Baltimore, MD, USA; ^dDepartment of Respiratory Medicine, Royal Prince Alfred Hospital, Sydney, New South Wales, Australia; ^eFaculty of Health, University of Canberra, Canberra, Australia; ^fCentral Sydney Local Area Health District, Sydney, Australia

ABSTRACT

Objective: We are yet to understand how widely parents seek asthma medication management information for their children, how they are used for health information, how parents engage with them and their influence on parent's decision-making. This study aimed to gauge the current level of asthma knowledge and skills of parents of children with asthma and gain insight into who and what influences their child's asthma medication management decisions. **Method:** Social network theory was used to map parents' asthma networks and identify the level of influence of each individual/resource nominated. Parents of children with asthma (aged 4–18 years) were interviewed, completed an asthma network map, questionnaires and an inhaler technique assessment. **Results:** Twenty-six parents participated and had significant gaps in asthma knowledge and inhaler technique skills. The asthma networks of participants ranged from two to ten individuals/resources, with an average number of five. The most commonly nominated individual/resource was general practitioners followed by family members and the internet. Professional connections represented 44% of individuals/resources in networks, personal connections 42% and impersonal connections 14%. When parents were asked about how influential individuals/resources were, professional connections represented 53% of parents influences, personal connections 36% and impersonal connections 11%. **Conclusion:** This study highlights the priority and co-influence of non-medical sources of information/support on parent's behaviors and decision-making with regards to their child's asthma medicine taking. In further understanding the complexities surrounding these connections and relationships, HCPs are better positioned to assist parents in addressing their needs and better supporting them in the management of their child's asthma.

ARTICLE HISTORY

Received 19 October 2018
Accepted 6 January 2019

KEYWORDS

Pediatrics; management/
control; quality of life

Introduction

Asthma is one of the most common chronic diseases of childhood, affecting one in 10 children in Australia and associated with many challenges for parents, families and healthcare systems [1,2]. Despite the availability of evidence-based guidelines, management practices are poor and asthma care is often suboptimal [3–7]. Research continuously shows that many children with asthma have high rates of unscheduled emergency department visits and hospitalizations, with more than one third of children with asthma reporting sleep disturbances and 60% reporting absenteeism from school, study or other activities [8]. The impact of asthma on normal daily

activities and education can result in a considerable burden for the whole family of an asthmatic child [8].

When it comes to the management of pediatric asthma, parents play a key role in their children's asthma care. In order to provide optimal care for their children with asthma, parents must be able to access and engage with quality health care resources and be able to implement the asthma management information provided. Past studies have shown that higher asthma knowledge and fewer parental fears regarding care lead to improved asthma control [9–11]. This highlights the importance of parental attitudes and knowledge in asthma management [4–7,12,13].

CONTACT Pamela Srour-Alphonse, BPharm  psro4130@uni.sydney.edu.au  Woolcock Institute of Medical Research, 431 Glebe Point Rd, Glebe NSW 2037, Australia.

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When it comes to the provision of education to parents, research indicates that parents feel they are not receiving enough [14]. Despite all available resources [15], parents still identify a need for education and information about medications use from professionals [4,14], demonstrating significant gaps in medication knowledge and their management [3,12,16] and skills in terms of adherence [17–19] and inhaler technique [20–22]. It is known that parent's need for information persists for years from a child's diagnosis [11]. This has shaped asthma management decisions and information seeking behaviors of parents as well as their interactions with health care providers [10,23].

Research has explored parents' information needs and the resources used by parents to obtain health information. Our current knowledge indicates that parent's information needs are complex and shifting, with parents seeking information from multiple sources [10,11,15,23,24]. And while it is known that parents source health information from more than just health care providers [9,11,15,23,24], it is not known how and why these resources are used, how parents engage with them and the degree of influence these interactions have on parents' decisions in their children's asthma management. In adults, research has identified that many different sources of health information influence adults' decisions with regards to their asthma medication management [15,25–28] and have been shown to be an indicator of adults' confidence in managing their asthma [28]. It is therefore important to explore whether the same is the case in pediatric asthma. By identifying the key influences within parents' asthma networks, we can better understand both the challenges and opportunities for parents, health care providers and the health care system to effectively develop joint educational interventions to facilitate evidence uptake in decision-making and to improve asthma outcomes in children. Therefore, this study aimed to gauge the current level of asthma knowledge and skills of parents of children with asthma and gain insight into who and what influences their decisions with regards to their child's asthma medication management. We hypothesize that parent's asthma knowledge and skills are varied as are their networks of influence. The specific objectives were to i) assess the asthma knowledge and skills in inhaler device use of parents of children with asthma, ii) identify the individuals and resources involved in parent's decision-making and their level of influence in helping parents manage their children's asthma medications.

Methods

Study design

This study took the form of a cross-sectional survey which included an interview.

This study was based on the theoretical and analytical framework of social network theory [29] which focuses on relationships between people, groups or organizations. Social network approaches investigate the properties of relationships (ties) between individuals (alters) in a network. These connections can include anything from the physical contact between individuals to the exchange of information or the presence of feelings towards individuals. By mapping these relationships and connections, social network analysis (SNA) describes the unique patterns, structures and compositions of networks, and how they influence individual's behavior [29]. There are several different forms of SNA and in this study the egocentric social network theory was used. Egocentric social network theory focuses on the network of an individual/'ego' (the participant) and the relationships/'ties' with individuals or resources/'alters' within that network [29].

Setting and sampling frame

Purposive sampling was employed to enroll participants into this study between March and December 2016. Parents with a child aged between 4 and 18 years, with a diagnosis of asthma (self-reported) were eligible for enrollment into this study. Parents not fluent in English, and if their child had any other comorbid chronic illness along with asthma (with the exclusion of allergic rhinitis, eczema, and generalized allergic disorder) or if the child had not used an asthma preventer medication (oral and inhaled medication) for at least 3 months in the past 12 months, were ineligible to participate in this study. Purposive sampling was used to identify and select information-rich cases for the most proper utilization of available resources. In this study, it helped focus on particular characteristics of the population of interest, that is, parents of children with asthma, to better answer the research question. Advertisements were displayed in specialist asthma clinics, general practice clinics and community pharmacies. Parents of children with asthma who contacted the research team and expressed interest in participating were screened for eligibility by researcher (PSA). Written consent was obtained from participants prior to commencement.

This project was approved by The University of Sydney Human Research Ethics Committee (Project No: 2015/762).

Data collection:

The data was collected by one researcher (PSA). Interviews were conducted face-to-face in four parts:

i. Participant demographics and baseline data.

Participant demographic and baseline data were collected and included: participants age, gender, highest level of education and occupation. The participant's child's age, gender and asthma history were also collected. Participant's Asthma knowledge was assessed using the Newcastle asthma knowledge questionnaire (NAKQ) [13]. Participants were asked to demonstrate (with a placebo) how they use a metered dose inhaler (MDI) with spacer. Their inhalation technique was evaluated by a trained researcher (PSA) who recorded their findings on an inhaler technique error checklist (Table 3) [30]. The child's level of impairment due to asthma was assessed using the functional severity questionnaire (FSQ) [31].

ii. Identification of individuals/resources within the parent's asthma network. Utilizing the name generator technique [32–35], participants were asked questions (Table 1), designed to help them identify/generate a list of individuals or resources, which were named “alters,” whom they recognized to have influenced their decisions/actions about their child's asthma medication management. A predetermined list of potential “alters,” generated from evidence in the literature of people/resources that are commonly referred to, with regards to the management of asthma [4,25–27,36] and exploratory inquiry was used as secondary prompts in this process.

The interviews were recorded on digital media devices and transcribed verbatim.

iii. Mapping of participant personal asthma network diagrams. A personal network visualization approach in the form of a nested series of concentric circles

adapted from several social network studies [25,37] and previously applied [25], was used to represent the different levels of influence of “alters” in the management of participants' children's asthma medications [25]. Each participant (represented by a red dot) was asked to visually consider their relationship with each of their nominated “alters” with respect to their influence on their child's asthma medication management, by mapping them on a concentric circle diagram (Figure 1). Alters placed in Circle 1, had the highest level of influence. Alters placed on circles further away from the center (the ego) signified people/resources the participant identified as being less influential to the medication management of their child's asthma.

Data analysis:

Descriptive statistics were used to summarize participant demographic and baseline data. The NAKQ [13] contains 25 true/false questions and six open-ended questions. Correct answers were assigned 1 point and incorrect answers 0 points. Where specific answers were needed, the score given depended on the model answer and if correct scored 1 point. The maximum score which could be attained was 31. A higher score indicated a greater level of knowledge. The cutoff point of the instrument is ≥ 21 points for satisfactory levels (adequate) and less than 21 points for unsatisfactory levels (inadequate). The inhaler technique error checklist was based on a review of studies which

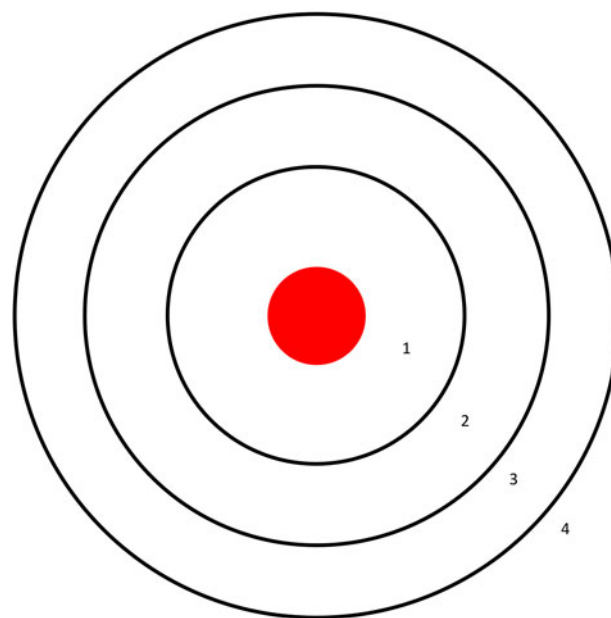


Figure 1. Nested concentric circles – personal asthma network diagram. Each ring represents a different level of contribution to participant's children's asthma management. From the inside first circle (labeled 1 – most contribution) to the outside circle (labeled 4 – least or no contribution).

Table 1. Interview guide: primary questions addressed.

Name generator questions

- Who are the people that you discuss your child's asthma medication-related matters with?
- Who have you either chatted with or visited in the previous 12 months in relation to your child's asthma medications?
- Did you use any resources in the previous 12 months in relation to your child's asthma medications?
- Have any of the following influenced your decisions in your child's asthma medication management over the past 12 months?
 - Doctors, pharmacists, family, friends, internet, books etc.

looked at critical inhaler errors in asthma [30,38–41]. The MDI with spacer checklist (Table 3) contained 12 critical errors which were considered to be associated with poor asthma outcomes and should be targeted in asthma management to ensure adequate drug delivery. The inhalation technique was considered correct when no critical errors were recorded. The FSQ [31] consists of six questions with five questions utilizing 5-point Likert scales and one question requiring a “yes/no” response where 4 points were given for yes and 0 points for no. The raw sum of the six question scores were then calculated and a severity score of low, mild, moderate or severe allocated. All statistical analyses were performed using SPSS 23.0 [42].

i. Identification of individuals/resources within the parents’ asthma network. A list of “alters” nominated by participants was created. If the interviewer noted an alter that had not previously been identified by any participant, that alter was then added to the predetermined list of “alters” to be mentioned to all future participants in the study. Recruitment continued until data saturation was reached, that is no new “alters” were identified. If there were any pre-scheduled interviews and data saturation was reached, these interviews were also included.

ii. Mapping of a personal asthma network diagram. The asthma network data was represented in two ways:

a) Asthma network maps. NetDraw [43] was used to visualize asthma network diagram data (RT) and to draw participant’s asthma networks. Based on participant positioning of alters across the concentric circles, collected network data was entered into a VNA file (format used by the NetDraw program to numerically represent “alters” and strength of connection “tie length”), with values assigned to each alter corresponding to the circle in which the alter was plotted. Collected network data included “alter” properties (different colors represent different alter categories) and “tie strength” among ego-alter pairs (length of line to represent personal network diagram rating). In the network diagrams, relationships between an ego and alter and is represented by a “tie.” The perceived level of influence by participants is represented by the “tie length”; the shorter the “tie length,” the stronger the influence; i.e. strongest “tie” is that between the “ego” and “alters” placed on Circle 1 and weakest in Circle 4.

An asthma network map collating all participants’ individual maps was drawn and was labeled as Group A. *Post hoc* representation of the health

network maps was conducted on two subsets of participants: those who placed their general practitioner (GP) in Circle 1 (labeled Group B) and those who placed their specialist in Circle 1 (labeled Group C). These were drawn to explore any differences in the distribution of the “alters.” All networks were visually inspected for trends and distributions.

b) Asthma network alter density graphs. In order to quantify the significance of the positing of “alters” (and the strength of ties), “network alter density” graphs were drawn [44].

In social network theory, *Network Density* measures the proportion of ties within a network out of all possible ties [29]. In an egocentric network, ties between alters are not measured and network density in its original definition is not applicable. In this study, we used the evolved term “network alter density” [44] to also consider the strength of ties (exemplified by the length of the tie i.e. the placing of the alter on Circle 1, 2, 3, or 4, where Circle 1 has the strongest tie length i.e. more influential, and Circle 4 has the weakest) as a pseudo-measure of the significance of “alters” within the egocentric network. This has enabled the determination of the participant’s perception of the influence of “alters” i.e. the influence of particular individuals or resources for parents in the management of their child’s asthma medications.

“Network alter density” graphs were determined for all participants. *Post hoc* analysis of “network alter density” data was then stratified into those who placed their general practitioner (GP) in Circle 1 (Group B) and those who placed their specialist in Circle 1 (Group C).

Results

i. Participant demographic and baseline data.

Participant demographic and baseline data are summarized in Table 2.

A total of 26 parents of children with asthma participated in this study and completed the interviews, with the majority recruited from a community pharmacy setting. Mothers represented 100% of participants ($n = 26$). The mean age of participants was 42 ± 7 (mean $\pm$ S.D) and 10 ± 4 (mean $\pm$ S.D) for the participant’s children (Table 2). In this study, 46% (12/26) participants had asthma themselves. Data saturation was achieved following the completion of the 20th interview as no new “alters” were nominated with the name generation technique by subsequent parent-participant. The average time for each interview was 20 min, ranging from 11 to 30 min.

Table 2. Participant demographics and baseline data ($n = 26$).

Category	<i>n</i> (%)
Age range, years	
Participant	
18–29	1 (4)
30–49	21 (77)
50 or more	5 (19)
Participant's Children	
4–10	16 (62)
11–14	6 (23)
15–18	14 (54)
Gender	
Participant	
Female	26 (100)
Male	0 (0)
Participant's Children	
Female	10 (38)
Male	16 (62)
Asthma Status	
Asthmatic	12 (46)
Non-asthmatic	14 (54)
Highest level of education	
Year 11 or below (includes Certificate I/II)	1 (4)
Higher School Education	5 (19)
Certificate III/IVa	4 (15)
Diplomaa	4 (15)
Bachelor Degree	9 (35)
Postgraduate Degree	3 (12)
Asthma knowledge questionnaire	
Average total score answered correctly ($n = 31$ questions)	23 (73)
No. of participants with satisfactory levels (score ≥ 21 points)	12 (26)
No. of participants with un-satisfactory levels (score <21 points)	14 (26)
Sub-themes (number of participant's answering all questions correctly)	
General knowledge about asthma	2 (8)
Acute attacks: recognition, triggers and management	0 (0)
Knowledge regarding maintenance treatment	3 (12)
Knowledge regarding false myths about asthma	7 (27)
Children's Asthma Functional Severity	
Low (score 0–4)	6 (23)
Mild (score 5–8)	19 (73)
Moderate (score 9–14)	1 (4)
Severe (score 15–22)	1 (0)
Rate of children's hospitalization due to asthma	
Ever been hospitalized	26 (100)
Hospitalized in past 2 years	18 (69)
Hospitalized in past year	10 (38)
Missed school days due to asthma in past year	
0	11 (42)
>1	15 (58)
How often children had asthma symptoms in past year	
No symptoms	2 (8)
Less than monthly	17 (65)
At least monthly	7 (27)
Other family members with asthma	
Yes	7 (30)

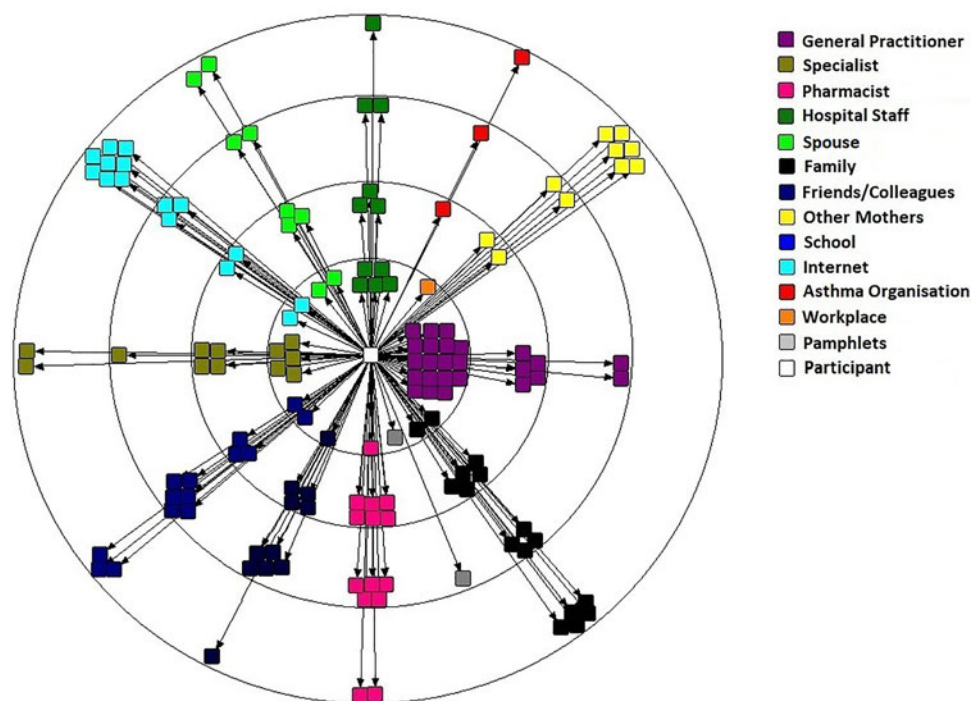
^aCertificate III/IV and diploma are vocational educational and training courses (VET) primarily taken by those aged over 18 years of age in Australia. VET courses are typically short, practical in nature and delivered by a Technical and Further Education (TAFE) college or Registered Training Organization at a certificate to diploma level.

Of the 26 participants assessed, only one participant (1/26, 4%) showed correct inhaler technique i.e. no critical errors were recorded. The number of critical errors made by participants ranged from zero to three, with an average of two. The most commonly reported critical error was related to “device knowledge (i.e. second dose, priming and empty device errors),” which was missed by 80% (20/26) of participants, followed by “Did not correctly assemble the spacer and MDI together, including shaking the MDI” (15/26, 58%).

The majority of children (19/26, 73%) were classified with mild asthma functional severity. Reporting of past experience with health care utilization indicated that all children (26/26, 100%) had been hospitalized at least once for their asthma in the past; 69% (18/26) in the last 2 years and 38% (10/26) in the previous 12 months. Overall 58% (15/26) of children had taken at least 1 day off from school due to asthma, 42% (11/26) had taken no days off due to asthma. Participants reported that over the previous 12 months, two children (2/26, 8%) had not experienced

Table 3. MDI with Spacer inhaler technique errors checklist.

	Device errors	Evident?
1	Did not correctly assemble the spacer and MDI together, including shaking the MDI	
2	Did not breathe out before inhalation	
3	Did not hold spacer with inhaler upright or did not actuate a dose into the spacer	
4	Did not put spacer in mouth and seal lips around mouth piece	
5	Did not have head tilted such that chin is slightly upwards	
6	Did not start to inhale through mouthpiece 2 seconds after actuating one dose	
7	Inspiratory effort (Did not inhale slowly, steady and deeply - defined as at least 3 seconds (may use tidal breathing, this should be slow and relaxed [not panting]), Aero chamber whistles during inhalation)	
8	Did not breath in through mouth, or coughs during the inhalation	
9	No breath-hold after inhalation (less than 3 seconds)	
10	Device knowledge (second dose, priming and empty device errors)	
11	Spacer has any faulty parts, valves, or cracks in the plastic	
12	Error made with washing the spacer	

**Figure 2.** Collated personal asthma network diagrams of Group A represented by the use of an egocentric social network map ($n = 26$).

symptoms, whereas 27% (7/26) had experienced symptoms more than once per month.

ii. Identification of individuals/resources within the parents' asthma network. A wide range of individuals and resources were identified by participants as being involved in discussions with the participants about their child's asthma medication management. This included HCPs (GPs, specialists (respiratory and pediatric), pharmacists and hospital staff), personal connections (school staff, friends, family, their spouse and their workplace colleagues), and impersonal connections/resources (pamphlets, the internet and asthma organizations).

iii. Participant asthma network diagrams. The collated overall personal asthma network diagrams of

participants are presented in Figure 2 (Group A). A total of 142 ties were identified by the 26 participants. The number of alters nominated by participants ranged from two to ten, with an average number of five. The most commonly nominated alter was the GP (25/142, 18%) followed by a family member and then the internet (both 15/142, 11%). HCPs represented 44% (62/143) of all ties, personal connections represented 42% (60/143) and impersonal connections represented 14% (20/143).

Among the HCPs identified in Group A, 96% of participants (25/26) mentioned the GP and predominantly placed them in Circle 1 (18/25, 72%). Specialists were less frequently mentioned by participants (12/26, 46%); however, when one was involved, they were placed a majority of the time in Circle 1 (5/12, 42%) or Circle 2 (4/12, 33%). Of these specialists, seven were respiratory specialists (7/26, 27%) and two were

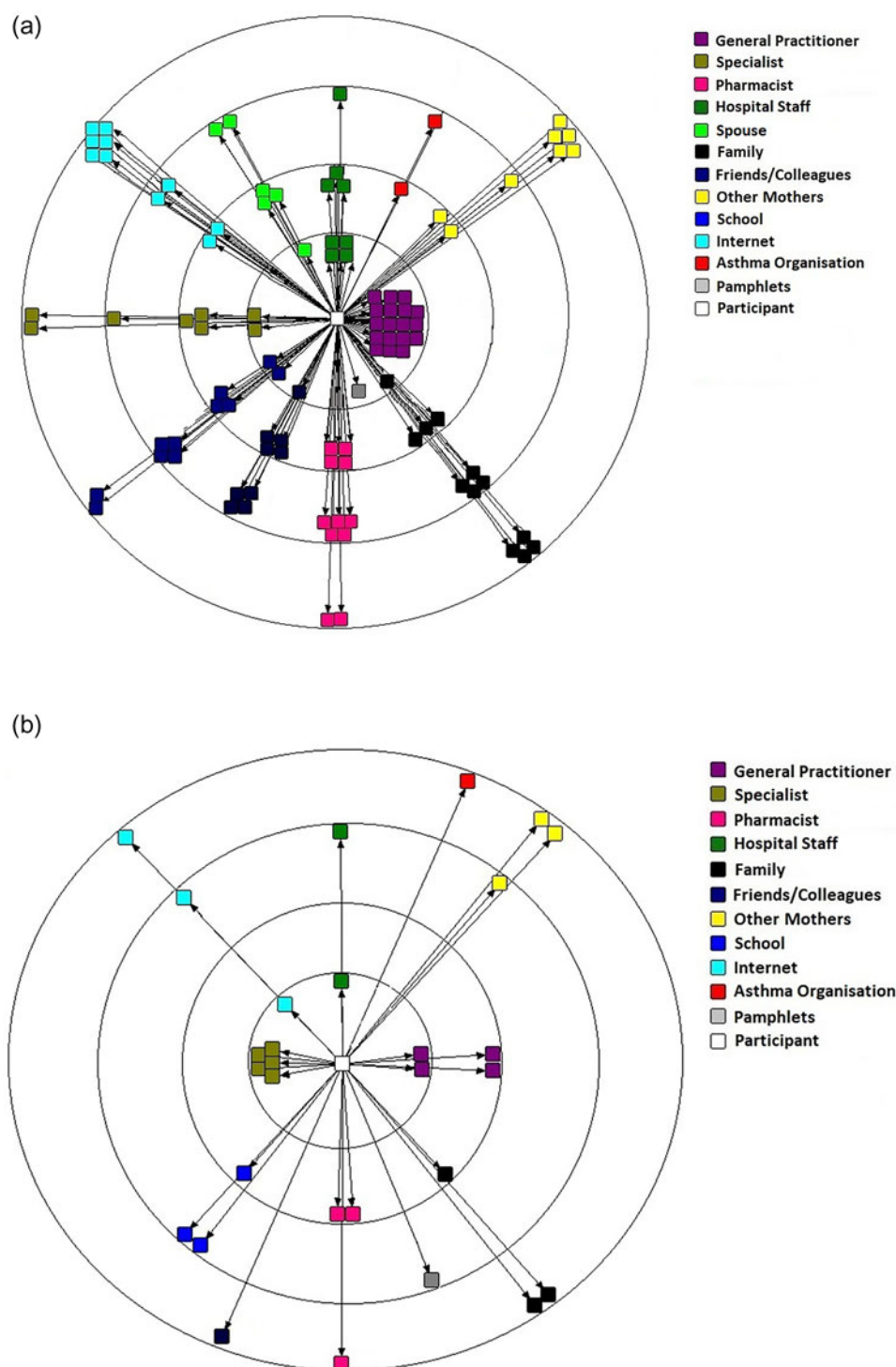


Figure 3. (a) Collated personal asthma network diagrams of participants who placed their GP as having one of the highest contributions to the management of their children's asthma medications (Group B) ($n = 18$). Personal connections (46/104, 44%) and HCPs (45/104, 43%) played a major role in their asthma networks. (b) Collated personal asthma network diagrams of participants who placed their Specialist as having one of the highest contributions to the management of their children's asthma medications (Group C) ($n = 5$). HCPs (14/29, 48%) played the largest role in their asthma networks. Personal connections represented 34% of the total network (10/29).

pediatricians (2/26, 8%). Community pharmacists were identified as being within the participant's network by 54% of participants (14/26). The majority were placed in Circles 2 (6/14, 43%) and 3 (5/14,

36%). A hospital staff member was mentioned by 42% of participants (11/26). In particular, the hospital staff considered influential by participants included both doctors and nurses. Hospital staff, without distinction,

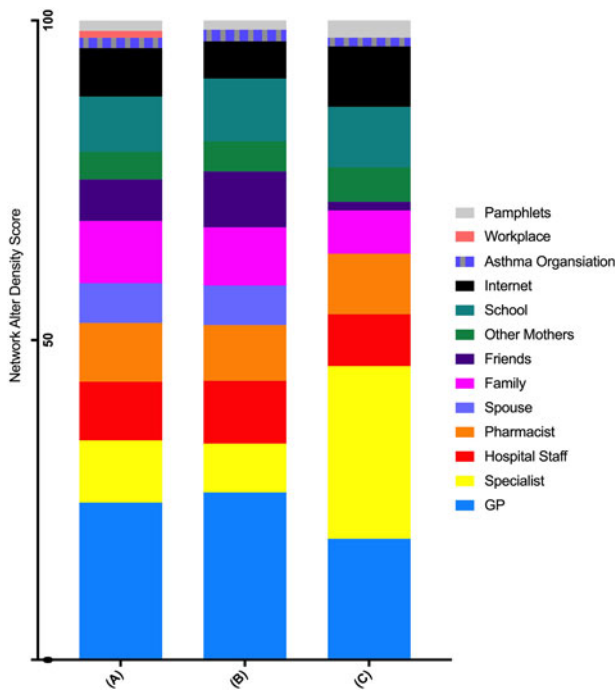


Figure 4. “Network alter density” score graph of the different “alters” for the: (A) total sample ($n = 26$); (B) participants who placed the GP in Circle 1 ($N = 18$); (C) participants who placed the specialist in Circle 1 ($N = 5$).

were most frequently mentioned in Circle 1 (5/11, 45%) and Circle 2 (3/11, 27%).

A large proportion of non-HCPs were also represented in Group A. Spouses (9/26, 35%) and other family members (16/26, 62%) were frequently mentioned. Spouses were evenly placed across all circles. Family members included participant’s parents, any extended family members, and their own children. Friends (10/26, 38%) and other mothers (10/26, 38%) were placed predominantly in Circles 2 to 4. “Friends” included neighbors, lifelong family friends and mothers from their child’s schools.

Impersonal connections were also common in participant’s asthma networks. The internet was mentioned by 15 participants (15/26, 58%) with the majority of these participants placing the internet in the outermost circle, Circle 4 (8/15, 53%). Asthma organizations were reported by 12% of participants (3/26) and pamphlets by 8% of participants (2/26).

Figure 3a and 3b further present the collated personal asthma network diagrams of Groups B (those who placed their GP in Circle 1) and C (those who placed their specialist in Circle 1). A total of 105 ties were identified for the 18 participants in Group B (subgroup of participants who placed their GP in Circle 1) and 29 ties for the five participants in Group C (subgroup of participants who placed their specialist in Circle 1). For Group B participants, the number of

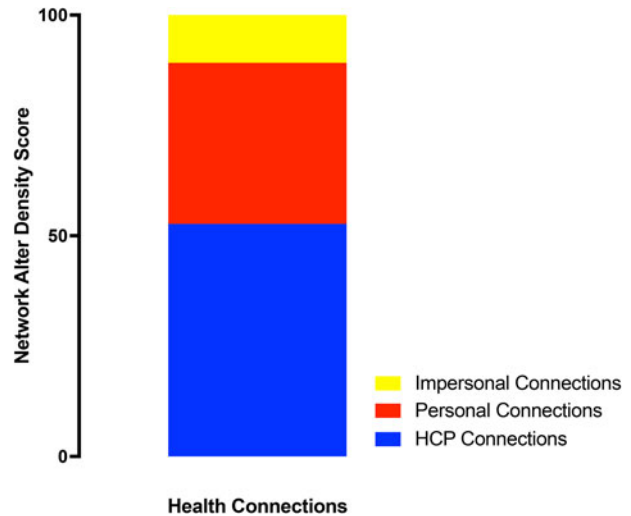


Figure 5. “Network alter density” graph of the different “alters” for the total sample (Group A) summarized into three subgroups: professional connections (53%), personal connections (36%) and impersonal connections (11%).

alters nominated ranged from two to ten, with an average of six health connections (alters) and a median of six. For Group C participants, the number of alters ranged from three to eight, with an average of six health connections.

Figure 4 represents the “network alter density” graphs for the total sample of participants (Group A), as well as the subgroups (Groups B and C) and Figure 5 represents the “network alter density graph” per “alter” category for Group A. Professional connections represented 53% of network influences, personal connections 36% and impersonal connections 11%.

Discussion

This study, to our knowledge, is the first to employ the use of network diagrams to determine the level of influence of individuals and resources on parents’ decisions about the medication management of their children’s asthma. This study has also reconfirmed that parents have significant gaps in asthma management knowledge and skills in terms of inhaler technique. The study builds on previous research by confirming that when it comes to managing their child’s asthma medications, parents actively seek advice and support from a wide range of individuals and resources. By utilizing a social network theory approach, this study provides new insight in our understanding about parent’s sources of health information by identifying not only the specific professional, personal and impersonal health connections and resources that parents deem as influential, but also the relative level of influence of these connections

and resources on parent's decisions about the medication management of their children's asthma. Network patterns clearly show that the influence of non-HCPs is just as important to parents as the influence of HCPs. While parents' health networks were shown to be large, complex and variable, significant gaps still remain in parents' knowledge and skills regarding the medication management of their children's asthma.

In addressing the aim of this study, a methodology embedded with social network theory was utilized [29]. The reasons for utilizing a patient-centric social network approach was based on this approach being successfully used to identify key influences within the networks of adults with asthma [25–27]. This method, for the first time has allowed us to gain insights into the individuals and resources influencing parents and through the application of the “network alter density” principle [44], a quantification of their potential relative level of influence. This added a deeper level of understanding to the relative importance of the different influences and adds novelty to this established method of patient-centric data collection. However, it should be acknowledged that in interpreting the results of this study, it must be considered that this is a health network of who/what the parent identifies to be influencing their child's asthma management and not who/what actually has the greatest clinical impact and why, i.e. it is based on the parents' perspective and perceptions of influence.

Despite the frequent regular nomination of HCPs by a vast majority of parents, HCPs only represent just over a third of all connections that were noted. When the level of influence is considered in the “network alter density” graph, HCPs influence is just over a half of the total influence on parent's decision-making about asthma medicines. While this study was not able to ascertain the exact way this influenced parents, this result was unexpected in the context of pediatric asthma and the interpretation of this finding is an important consideration for future health care delivery. It is surprising as it would be expected that HCPs have a significant influence and frequent input in aiding parents to manage their child's asthma, not only due to their expert advice and knowledge but also due to the child's vulnerability at this stage of life [45]. However, this result also raises the possibility that parents are more likely to talk to a family member on a day to day basis then they would need to talk with a HCP as medication management is a daily routine. This finding needs to be considered in light of their child's ability to manage and cope with

their asthma needs as they transition to autonomous management in the future.

It is important to consider why there is a great number of influences for parents and why the non-HCPs are equally influential as HCPs. It is hypothesized that there are several possible reasons for this. On one hand, for some parents, their child having a chronic condition may be a new phenomenon and turning to multiple resources may provide much needed emotional or social support at the early stages of living with an asthma diagnosis. On the other hand, it could suggest that parents' needs are not being met by HCPs, the nature and frequency of interactions is suboptimal (e.g. in parents' lack of utilization of pharmacist expertise and knowledge) or the parents themselves have barriers which are not addressed by HCPs such as health literacy, parental fears, stress and anxiety in dealing with a chronic condition [14]. While it can be argued that perhaps seeking and finding support through non-HCPs networks may fulfill particular non-medical-related needs of the parents, an issue arises when we reflect on the level of understanding these parents have of asthma. That is, despite the wide and varied network, the parents' knowledge and understanding of asthma was not optimal. The significance of this finding cannot be ignored and will be discussed further below.

When considering the asthma networks of parents placing a GP in Circle 1 versus those who placed a specialist in Circle 1, a shift in the influence of HCPs was observed. The decision to examine the influence of these two groups of parents separately was based on the hypothesis that parents would have had a heavy reliance on a HCP when learning to manage their child's asthma and may establish different asthma networks. In this study, parents who consulted primarily with a GP rated their HCPs as less influential when compared to personal health connections such as family and friends. In contrast, those who consulted primarily with a specialist, held HCP in a more prominent influential position. Further, these parents overall also had smaller asthma networks, utilizing less non-HCP individuals and resources, compared to parents who placed a GP in Circle 1. The reasons behind the higher level of influence of specialist care experience, smaller network sizes and the possible impact of this on their other relationships/health networks cannot be determined, however should be explored in the future. There appears to be a trend towards parents' preference of secondary care.

In considering the results of this study more broadly, an “alters” level of influence was not seen to be uniform by all parents in this study. When we look

at HCPs, it is established that GPs have a key role in asthma management, such as prescribing medications; discussing goals of management; reviewing treatment and providing information and skills required to manage asthma [2,46]. However, some parents placed the GP alter in the inner circle (less influential), whereas others noted their influence in the outer circles (more influential). This suggests that the level of influence is perhaps not about the role, but about other factors relating to possibly their level of satisfaction with the HCP; expectations of what the particular HCP was going to do for their child, whether this expectation was fulfilled or how far into the diagnosis the parent is (i.e., closer to diagnosis the HCP may have been more influential than down the track where parents had more experience in management). Understanding the roles of different HCPs as perceived by parents is critical to our understanding of the impact they have on the management of parents and their decisions about their children's asthma management.

The inclusion of a large number of non-HCPs in parent's asthma networks demonstrates that HCPs must be conscious that people who are not medically trained may be influencing parents. The role of non-HCPs in the management of adults with asthma has previously been identified by Cheong et al [25–27]; however, we are yet to understand the nature of their influence in children. From this research, it is difficult to determine the quality and accuracy of advice and information that these alters are providing parents. This is worrisome as accurate and relevant information can be beneficial, but inaccurate information can be harmful. HCPs need to support parents in seeking informed opinions.

In this study, a vast majority of parents were not able to demonstrate correct inhaler technique and reported low levels of asthma knowledge despite the wide range of individuals and resources noted within parent's asthma networks. This is consistent with current literature [7,17,18] and has been associated with worse care measures for children with asthma [12]. Despite HCPs having an influential role in asthma management, parents had poor knowledge and felt the need to source information from other avenues. This suggests 1. parents are not retaining critical asthma management information from the onset of their child's diagnosis, 2. they are initially not being provided with needed asthma information and training. The implications of this on children's future asthma management are unknown. Further, it is unknown whether parents are receiving conflicting advice from different sources, this need further investigation.

An observed disconnect was seen between parent reporting of their children's functional asthma severity, rate of hospitalization of children and absenteeism from school. Most children were reported by parents to experience mild asthma; however 69% of parents reported taking their child to the hospital for their asthma, reporting frequent exacerbations and multiple hospitalizations for asthma. This indicates a disconnect, as exacerbations and hospitalizations for asthma are continuously used as an indication of poor asthma control and certainly would not be expected to be associated with mild disease [2,47,48]. This suggests that either parents are underestimating their child's asthma severity or their children are sub-optimally managed, with a high risk of flare ups. This raises further questions about parent health beliefs, expectations and understanding about the condition and links into their asthma knowledge.

While this study has added valuable insight to our understanding of the key influences in parent's management of their children's asthma medications, further questions have been raised. Future research needs to explore the role of nominated “alters” within parents' asthma networks, what factors in their relationship are influencing their medication management decisions and how they are or are not fulfilling the needs of parents or in fact the children themselves. We must also investigate what factors determine perceived level of influence and how we can use this information to optimize asthma clinical outcomes in children.

These findings are based on a cross-sectional case study and parent relationships, which may change over time and under different circumstances, leading to different asthma networks. A longitudinal study should also be considered to examine parent's asthma networks at different times during childhood, which would allow us to gain further understanding.

Research constraints need to be considered. That is i) this study was conducted in only one particular Australian district, ii) the majority of children appeared to fall into the low to mild asthma severity category as classified by the functional severity questionnaire [30] and iii) all the parents interviewed were female, although the latest Census data shows that fewer than one in 20 families have a father who is the primary carer [1], iv) this study had a relatively modest sample size, which limits further exploration of the data.

Conclusion

In conclusion, this study adds to our depth of understanding relating to the sources of information/

support within which parents of children with asthma engage and for this first time, articulates the relative importance and influence that parents place on different sources. The asthma network identified professional, personal and impersonal connections and highlights the priority and co-influence of non-medical sources of information/support on parent's behaviors and decision-making with regards to their child's asthma medicine taking. While there are many individuals and/or resources within these networks, parents are still burdened by their children's asthma medication management, demonstrating poor skills in utilizing asthma medications, low asthma knowledge and using inhalers inaccurately. This emphasizes the major gap in our guidelines, which despite their evolution, continue to be framed in a biomedical model of health care and fail to address the needs of parents. This also raises further questions on the impact of this on children and their ability to self-manage as they transition to autonomous asthma management. We need to understand why HCPs are not optimizing children's asthma medication management and why non-HCP are so influential, within a network of a disease that can be optimally managed in primary care. It is only then that we can better aim to address the needs of parents, supporting them to deliver optimal medication management to their children with asthma.

Acknowledgements

The authors would like to thank all the participants that volunteered to be part of this study. The authors alone are responsible for the content and writing of the paper.

Disclosure statement

We wish to declare the following potential conflict of interest: PSA, EA, LC, BC, RT, and CR have no conflict of interest. SBA has received payment for lectures, expert advice and independent research from TEVA, AstraZenca, Boehringer Ingelheim, GlaxoSmithKline, Mundipharma, Mylan and Sanofi, outside the submitted work. VK has received honoraria from AstraZeneca, GlaxoSmithKline and Pfizer, outside the submitted work.

Contributions

PSA, LC, BC, and SBA are responsible for the study design. PSA and SBA are the guarantors for this work. PSA collected the data. RT drew network maps and compiled figures. PSA drew network map bar graphs. PSA, LC, BC, and SBA analyzed the data. PSA drafted the manuscript, which went through multiple rounds of discussion and feedback with SBA, EA, LC, VK, BC, CR, and RT. All authors have seen and approved the final version of this manuscript.

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