CHILDREN REFERRED FOR SPECIALTY CARE: PARENTAL PERSPECTIVES AND PREFERENCES ON REFERRAL, FOLLOW UP AND PRIMARY CARE

ABSTRACT

AIMS: Over the last decade, there has been a dramatic increase in the number of referrals for paediatric subspecialty care and in overall appointments (new and review) to these doctors. We sought to determine the perspective of parents regarding their role in the initiation of referrals, their preferences for follow-up and the role of GPs in care coordination.

METHODS: Self-completed survey in outpatient paediatric clinics (general paediatrics and four subspecialties) at 2 children's hospitals in Victoria. Recruitment targets were 100 parents in each of the general paediatrics clinics and 50 parents in each subspecialty clinic, equally divided between new and review visits (Total N= 600).

RESULTS: A total of 606 parents provided responses, with a decline rate of 9%. Many (52%) new patients were referred by a GP with the remainder from a variety of other sources. With specific regard to providing general care to their child, only 45% were completely confident in a GP. Most (76%) agreed with the statement that a GP would give their child a referral to see a paediatrician whenever they ask. Approximately a third of parents reported that a GP rarely or never coordinates the care of their child with other doctors.

CONCLUSIONS: Parents play an important role in both the initiation of paediatric specialty referrals and the patterns of follow-up care provided. Parent perspectives, preferences and motivations on both the referral process and the patterns for ongoing care are essential to develop policies that provide the best and most efficient care for children.

Keywords: Parents, paediatric, referral, primary care, specialists

INTRODUCTION

In the Australian healthcare system, general practitioners (GPs) provide primary care to patients of all ages, including children. Specialty care from a general paediatrician or paediatric subspecialist requires a referral, usually from a GP. Most general paediatric care is provided in private rooms and is based on a fee for service model. By law in Australia there is no private insurance for outpatient care, but the Medicare Benefits Schedule provides a set rebate for a portion of private patient charges. In contrast, paediatric subspecialty care is almost exclusively provided in public hospital-based clinics.

Over the last decade, there has been a dramatic increase in the number of referrals for paediatric subspecialty care. For example, at the Royal Children's

Hospital in Melbourne, the number of visits to paediatric specialists increased 45% in the 5 year period from 2008 to 2013. The increase in referrals has led to long waiting times for paediatric subspecialty care.

Reasons for the increases in new referrals and overall visits to paediatric subspecialists are unknown. Some have hypothesised that GPs may be becoming less comfortable in the care of children due to an increased focus on chronic disease management in the ageing population in Australia. Indeed, recent research has shown that visits to GPs by children constitute a diminishing proportion of their patient care experiences. (1) Additionally, both the proportion and actual number of extended consultations for children by GPs has fallen over the past decade despite an increasing number of children in Australia and a growth in the number of children surviving with chronic illnesses. (2) The link between these changes in visits to GPs by children and increased referral to paediatric subspecialties has not yet been explored.

We suggest there are three primary parties involved in the paediatric referral process: (a) the parent of the patient, (b) the referring doctor, and (c) the specialist. All three play a role in both the initial referral and follow-up care. No information currently exists in Australia on the perspective of parents regarding their role in the initiation of referrals, their preferences for follow-up and the role of GPs in care coordination. To better understand this perspective we conducted this study of parents of children referred for general and subspecialty paediatric care.

MATERIALS AND METHODS

Sample and recruitment

The sample consisted of parents presenting with their child to one of five specialist paediatric outpatient clinics at two public hospitals in metropolitan Melbourne. The five specialties were: general paediatrics, respiratory medicine, developmental medicine/community child health, neurology, and endocrinology. These five specialties were chosen as they have the highest volume of medical (non-surgical) patients excluding haematology/oncology (which has defined protocols for care) and cardiology (which has a large proportion of post-surgical patients). Recruitment targets at each hospital were 100 parents in each of the general paediatrics clinics and 50 parents in each of the subspecialty clinics, equally divided between new and review visits (Total N= 600). Parents in the waiting room/area of these specialist clinics were recruited by trained research assistants from December 2014 to July 2015.

Potential respondents were given an information sheet about the study and asked to sign a consent form if they agreed to participate. The questionnaire was administered on iPads. The data were collected and managed using REDCap electronic data capture tools hosted at The University of Melbourne. (3) Respondents were offered a \$10 gift card on completion of the questionnaire. Parents with limited English proficiency were excluded. Responses were voluntary and anonymous.

Questionnaire

The questionnaire was developed by the research team in consultation with department heads in each specialty at both paediatric specialty hospitals. Items developed were based on a supplementary literature review regarding paediatric referrals from primary to specialty care. A plain language advisor provided input about questionnaire readability. Comprehension was assessed with a convenience sample of three parents. Two general practitioners and paediatricians from all specialty focus areas provided feedback on survey content. Minor changes to survey wording were made following feedback. Answers were provided on Likert scales, or as single/multiple choice responses.

Different versions of the questionnaire were produced: one for new patients and one for review patients. The new patient questionnaire consisted of four sections: (1) making an appointment; (2) care from a GP; (3) follow-up care; (4) participant characteristics/demographics. The review patient questionnaire contained the same four sections with one additional section about care from the specialist paediatrician they had seen previously.

The questionnaire was pilot tested with 39 parents across both hospitals and all specialty clinics. Responses collected during the pilot testing were not used in analyses.

Data Analysis

Data were analysed using STATA 13.0 (StataCorp College Station, TX). Analyses initially involved frequency distributions and descriptive statistics, followed by bivariate analyses using chi-square statistics to determine the differences, if any, among respondents based on whether the patient was attending a visit with a general paediatrician or a paediatric subspecialist, and whether the visit was classified as new or review.

The project was approved by the Ethics Committees at the University of Melbourne and the two hospitals.

RESULTS

A total of 666 parents were approached to participate in the study. Of these, 606 parents provided responses, with a decline rate of 9%. There were approximately equal numbers of new patients (N=283; 47%) and review patients (N=323; 53%). The majority consulted with subspecialist paediatricians (N=395; 65%) and the remainder with general paediatricians (N=211; 35%).

Demographic Information

Most children (78%) were brought to the consultation by their mother. Approximately one-third (38%) had health insurance and 39% had household incomes less than \$50,000 per annum. Few differences were seen among

children presenting for new or review, or general vs. subspecialty, appointments. (Table 1).

Approximately two-thirds of children (65%) did not have an appointment to see an additional specialist regarding the same health concern. There was no meaningful difference among new or review, or general vs. subspecialty, patients.

Most children (91%) in the study affirmed they have a regular GP, and approximately a third (35%) reported having visited any GP >5 times in the past 12 months. Only 5% report not having seen a GP in the past year. There was no meaningful difference among new or review, or general vs. subspecialty, patients.

Parental Confidence in GPs

Table 2 provides information regarding parental confidence in GPs across a variety of issues. With specific regard to providing general care to their child, 45% of respondents were completely confident in a GP while 47% were fairly confident. Smaller proportions of parents were completely or fairly confident in their GP to treat the condition for which they were referred to specialty care, to provide follow-up care for that condition, or to share care with a paediatrician in follow-up.

Parental Perceptions of GP Care and the Referral Process

Most parents (79%) whose child was referred by a GP affirmed their GP explained to them why their child needed to see a paediatrician. The majority (61%) reported that at least sometimes a GP helps them to understand recommendations given by a paediatrician about their child's care. Approximately a third of parents reported that a GP rarely or never coordinates the care of their child with other doctors. (Table 3)

Approximately 40% of parents agreed or strongly agreed that they would prefer a paediatrician rather than a GP for any health issue for their child while 26% only take their child to see a GP when they need a referral. Most (76%) agreed a GP would give their child a referral whenever they ask. (Table 3)

Follow-up Care

There was significant variation among parents with regard to their preferences for follow-up care. More parents (78%) preferred follow-up with a paediatrician (general or subspecialist) than any other type of provider. However, there were significant differences among new and review patients and those who had seen either a general paediatrician or a subspecialist. There was a high preference for parents to be able to see a paediatrician of their choice with 82% stating this as important or extremely important. Of those referred by a GP for specialty care, only 25% responded they believed that the referring GP expected them to return to their clinic. (Table 4)

Specific Questions for New Patients

Most (52%) new patients were referred by a GP. Parents commonly reported that their GP was the first to suggest a referral (31%) relative to another specialist doctor (26%) or to the parent themselves (18%). The most important reason for referrals by GPs was their child's GP wanted to make sure that a serious condition was not being overlooked (39%). The same was true for referrals from paediatricians (45%). (Table 5)

Specific Questions for Review Patients

Many parents of review patients reported that the treating specialist (70%) was the first to suggest their child return to see a paediatrician. More than half of children (51%) had seen a paediatrician ≥ 3 times in the last 12 months for the same health concern. (Table 6)

DISCUSSION

Among the most important findings from our study was that only half of the new patients seen in these paediatric specialty clinics were referred by GPs. The remainder were referred from general paediatricians or EDs, or were referred as inpatient follow-up appointments. This is important as the number of referrals to paediatric specialty clinics has increased markedly over the past decade. Understanding the source of these referrals is necessary to determine the reasons for this increase and potential strategies to determine their appropriateness.

Our results demonstrated that one-third of children seen in paediatric specialty clinics have appointments to see at least one other specialist for the same condition. This outcome raises the importance of each child having a medical home for care coordination across multiple clinical settings. In Australia, the role of the GP in providing care coordination is considered essential. Our finding that 57% of parents reported GPs only sometimes, or never/rarely assist in coordinating care is deserving of future study and attention. Although not all patients in this study were referred by GPs, this does not diminish the need for care coordination. (4) Ultimately, improved communication from the treating specialist is essential for this coordination to occur. Although there are significant efforts to assist and promote GPs in the care coordination and management of chronic illness in adults, less emphasis has been placed on such activities with children. (5-9) Consistent with this finding is previous research that has shown over the past decade GPs are seeing fewer children for extended consultations, the type of visit where such care coordination may take place. (2) This is despite an increase in the number of children alive today with chronic illness.

Our finding that only 45% of respondents were "completely confident" in their GP to provide general care to their child is worthy of attention. A similar proportion (47%) was "fairly confident". There have been anecdotal reports of some parents losing confidence in GPs to provide care to children. While it should be noted that our respondents were a specific group of parents whose

children had appointments to see a specialist, the level of confidence in the provision of general care for any paediatric population is an important issue. Decreasing levels of parental confidence can impact the patterns of care for children and the choices parents make in seeking health care for either acute or chronic conditions. Reasons for this level of confidence are unknown, as is whether the experience of referral itself has an impact on parental perception. As such, additional work on this topic is warranted to determine the levels of parental confidence in a broader population.

Most parents who were referred by their GP for specialty care reported that their GPs explained to them why their child needed to see a paediatrician. Such information is important for all children so that specialists are clear regarding the reasons for referral given that referral notes have frequently been reported to be cryptic. (10,11) However, our finding that only 25% expect to return to a GP following referral is concerning and requires additional investigation.

The preference of 40% of parents to see a paediatrician rather than a GP for any health issue is noteworthy, given the central role GPs are meant to play in the Australian health care system. However, this finding may also be a function of the nature of the population in our sample. The parents of children who are referred for specialty care may have greater anxiety regarding their children. (12) A larger, more representative panel of parental preferences is needed to determine the prevalence of this view among the general population. However, our finding still has significant implications for the return of patients to their GP following referral. Parents who do not want to receive care from a GP will be less likely to do so. This may result in the inappropriate use of the scarce resource of paediatric specialty care providers and increase already lengthy waiting times for such care. Parental perceptions of GP expectations may also play into this scenario. Of those referred for specialty care by a GP, only 25% thought that the referring GP expected them to return to their clinic for follow-up. The role of specialists in encouraging families to return to primary care likely is also important in this process.

There are no data in Australia regarding the potential role of parents in contributing to the increase in paediatric referrals. Our finding that 25% of parents in our sample only take their children to the GP to get a referral and that 75% state that their GP gives them a referral whenever they ask is remarkable. Although we hypothesized parental pressure to play a role in the referral process, the prevalent parental notion of the ease with which referrals can be obtained from GPs also likely contributes. Further work must explore whether some of these referrals could have been more appropriately managed in primary care.

LIMITATIONS

The participants were parents of children presenting for specialty paediatric care and may not be representative of all parents. Further, the study was only conducted in Victoria. However, the participants were recruited from both of the

two paediatric specialty centres in the state, representing >90% of all paediatric specialty care provided in Victoria. The sampling was also conducted across general paediatrics and four subspecialties to ensure a broad spectrum of parental experiences and perspectives. Finally, the sample only included those who were able to complete the survey in English. Responses from parents of non-english speaking backgrounds may differ.

CONCLUSIONS

Parents play an important role in both the initiation of paediatric specialty referrals and patterns of follow-up care. Understanding parent perspectives, preferences and motivations can help to shed light on both the referral process and the patterns for ongoing care. There is a need for GPs and specialists to work together in the follow-up and coordination of care for children, regardless of where the initial consultation originates. Further efforts to both encourage better interaction between primary and secondary are essential. Finally, parental perspectives on specific components of GP care that may undermine the role of the GP in the Australian health care system should be noted and addressed by the GP community.

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Author/s:

Freed, GL;Turbitt, E;Kunin, M;Gafforini, S;Sanci, L;Spike, N

Title:

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