AJRH The Australian Journal of Rural Health

Aust. J. Rural Health (2016) **24**, 170–175

Original Research

Carers' perspectives on an effective Indigenous health model for childhood asthma in the Torres Strait

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Abstract

***Objective*:** *To describe parents'/carers' views of the characteristics of a clinical service model shown to improve asthma outcomes.*

***Design*:** *A randomised controlled study on education intervention for childhood asthma by Indigenous health care workers.*

***Setting*:** *Thursday Island, Horn Island and Bamaga.*

***Participants*:** *Thirty-five children received the intervention and 53 were in the control group. At the last study visit 12 months after enrolment, carers were asked to give feedback about the clinical service delivered by paediatric respiratory physicians and the asthma education intervention.*

***Intervention*:** *Additional asthma education.*

***Main outcome measures*:** *Carers' responses to the open-ended questions were analysed separately by three Indigenous investigators who assigned codes and developed the themes. These were then cross-checked and combined to develop an overall interpretation of the data.*

***Results*:** *The carers (*n *= 81) of 88 children in the Torres Strait region of North Queensland reported positively to the clinical service delivery. Service was rated as excellent = 26.8%, very good = 51.2%, good = 19.5% and poor = 2.4%. Parents'/carers' views about the clinical service model were grouped into seven themes: clear communication by health professionals, service delivery, professional approach, clear transfer of knowledge and education/clinical knowledge of asthma, established rapport/caregiver satisfaction, importance of coming into the local community, and areas of concern for the carers/parents.*

***Conclusion*:** *Community-based perspectives of an effective health service model include empowered Indigenous health care workers currently attached to the medical specialist service with elements of high expertise and appropriate cultural awareness that enabled clear communication and transfer of knowledge.*

KEY WORDS: *children, education, Indigenous, respiratory, Torres Strait.*

Introduction

In nationwide data for Aboriginal and Torres Strait Islanders (referred to as Indigenous), respiratory disorders are the most common reason for general practice encounters, the second most prevalent self-reported chronic condition and the second most common cause for hospitalisation.[1] Overall, 27% of Indigenous people report some form of respiratory disease.[1] Yet respiratory health receives much less attention nationally compared with other diseases.[2] Asthma is the most common of these chronic respiratory illnesses.

Asthma is one of the most common chronic respiratory illness in Indigenous children worldwide, with prevalence rates of 14.3% for Canadian Indigenous children aged 6–14 years,[3] 14.8% for New Zealand Māori and Pacific children aged 2–14,[4] 12–23% for Australian Indigenous children (0–17 years),[5] and 13% for US American Indian/Alaska Native children.[6] While the prevalence of asthma in Indigenous children is similar to that of non-Indigenous children in Australia and elsewhere, the associated chronic morbidity of asthma is higher in Indigenous children compared with their non-Indigenous counterparts. For example, the hospitalisation and mortality rate for asthma is two to three times higher in Indigenous Australians.[7] These adverse clinical outcomes have also been documented in

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Accepted for publication 18 September 2015.

doi: 10.1111/ajr.12257

***What is already known on this subject*:**
- *Asthma education for patients is essential for improving asthma outcomes.*
- *The proportion children with persistent asthma living in the Torres Strait region of North Queensland is higher than that reported in children living in urban areas of Australia.*
- *Asthma education with an adjunct community-based education program by trained Indigenous health care workers improves some outcomes in Indigenous children with asthma.*

***What this study adds*:**
- *The parents'/carers' responses strongly indicated their satisfaction with an Indigenous health model of education for childhood asthma.*
- *Community-based perspectives of an effective health service model include empowering and resourcing Indigenous health care workers in parallel with a medical specialist service with elements of high expertise and cultural appropriateness.*

Indigenous children of New Zealand, Canada and USA, as well as other minority groups globally.[4]

To address this disparity of asthma outcomes, we used an Indigenous health model in partnership with local health workers over the last 15 years.[8] Prior to our study, there has been a paucity of data of such a model from the Indigenous community perspective subject to scientific rigour (at a randomised control trial level, RCT).[9] We undertook a National Health and Medical Research Council-funded RCT in the Torres Strait region to assess the outcomes of an education intervention for childhood asthma conducted by Indigenous health care workers (IHCWs).[10] While we saw improvements in some important asthma outcomes in those randomised to the asthma education model (e.g. children missed fewer school days due to wheezing, improvement of carers' knowledge of asthma medication), the benefits of the model and specific roles of IHCWs were not described or further explored. Here we describe the feedback received from carers about the asthma education intervention and the model used. Obtaining views of the parents/carers would characterise the aspects of a clinical service model that leads to improved health outcomes from a community perspective (as opposed to medical or administrators' perspective). Thus, in this study, we aimed to develop themes that characterise the clinical model from the parents'/carers' perspective.

Methods

Data for this study were embedded within our RCT on education intervention for childhood asthma by IHCWs. The details of the RCT have been described elsewhere.[9] Briefly, specialist asthma clinics were held on Thursday Island, Horn Island and Bamaga by two paediatric respiratory specialist doctors, a registered nurse and an IHCW who was based at the Primary Health Care Centre on Thursday Island. Children (<18 years) who had a diagnosis of asthma were eligible to take part. Before enrolment, all children had an asthma education session with a trained IHCW using the adapted asthma booklets. After informed consent, children were randomly allocated into two groups: (i) three additional asthma education sessions with a trained IHCW (at 1, 3 and 6 months after the baseline visit), or (ii) no additional asthma education. Both groups were followed for 12 months.

Specifically designed training for 67 IHCWs was undertaken through seven 3-day asthma education workshops on Thursday Island. IHCWs attended the specialist clinics where their asthma management knowledge and skills were reinforced by providing education to children and carers. The study protocol (including data collection forms and interview technique) was discussed in detail with IHCWs selected to work on this study. Existing paediatric asthma and respiratory education resources were used but adapted to the Torres Strait culture and language by our team in collaboration with local IHCWs, introducing child-friendly and age-specific booklets. Eighty-eight children (81 parents) completed follow-up: 35 were randomly allocated to receive three additional asthma education sessions with a trained IHCW and 53 were in the control group. At the last study visit (12 months after enrolment), carers provided feedback about the intervention based on face-to-face interviews with a trained IHCW at the clinic. The health worker conducting the 12-month follow-up interview was not the same IHCW who provided the additional education sessions, and the doctors were not present when the interview took place. Results for the intervention study have been described elsewhere.[10]

Standardised forms were used to collect information about the child's/children's schooling, their parents' level of education, the child's/children's respiratory symptoms (structured questions), and their evaluation

of the specialist asthma clinic and additional education sessions (four open-ended questions). Carers were asked to rate (6-point scale) the quality of the specialist clinic services provided by the doctors ('How would you rate the quality of the specialist clinical service provided by Drs AC and BM?') and the health worker ('How would you rate the quality of the education service provided the Health Workers?'). Two open-ended questions related to their satisfaction of the service provided by IHCWs ('What did you like about it?' and 'What didn't you like about it?'), and similarly two open-ended questions were regarding the clinical service provided by the doctors. Carers in the intervention group were asked to rate (6-point scale) 'the quality of the extra asthma education provided the Health Workers' and were asked 'Would you like to have the extra asthma education to be part of the usual service provided by Health Workers?'. Carers in the control group were asked slightly different questions: 'Do you think extra asthma education provided the Health Workers would help you better manage your child's asthma?' and 'Would you like to have the extra asthma education as part of the usual service provided Health Workers?'

Responses to the open-ended questions were analysed separately by three Indigenous authors (L.J.W., G.G. and N.M.-D.) to assign codes and develop themes. These were then cross-checked and combined to develop an overall interpretation of the data. Quantitative data were analysed using the Statistical Package for the Social Sciences (Statistical Package for the Social Science version 20, IBM). Baseline characteristics are presented as means and standard deviation and proportions.

We received support from the Torres Strait Regional Health Council and the Torres Strait and Northern Peninsula Area Health Service District to conduct this study. Ethics approval was given by the Queensland Institute of Medical Research Human Research Ethics Committee and the Royal Children's Hospital and Health Services District Ethics Committee.

Results

Overall, most parents in the intervention group rated the quality of extra asthma education by the IHCW as good (19.5%), very good (51.2%) or excellent (26.8%), with the exception of one parent who rated it as poor (2.4%). The majority of the intervention group parents indicated they would like to have extra asthma education be part of the usual service (95.1%). Those parents in the control group believed that extra education by IHCWs would help them better manage their child's asthma (93.8%) and would like the extra asthma education to be part of the usual service (91.8%).

Seven themes stemmed from the open-ended questions (Table 1): clear communication by health professional, service delivery quality, professional approach, clear transfer of knowledge and education/clinical knowledge of asthma, established rapport/caregiver satisfaction, importance of coming into the local community, and areas of concern for the carers/parents.

Health professional communication

Most parents'/carers' indicated a high level of satisfaction with the way health professionals communicated. Participants commonly reported clear communication by the health professional staff in regard to assisting the parent/carer understanding of asthma and instructions regarding treatment and asthma management plans.

Service delivery quality

Many parents' and carers' comments were positive in relation to the services provided by the specialists and the local IHCWs in their local community. They remarked they 'come to you' (community) and 'really thorough, especially with follow-ups'.

Professional approach

The approach by the specialists was described as being 'friendly' and 'hospitable', and that they showed a 'genuine interest'.

Transfer of knowledge and education

The majority of parents and carers commented that there was a clear transfer of knowledge and education. They 'teach kids how to take medication', give 'clear demonstrations on how to use puffer/spacer', and provide 'easy instructions very educational and informative'.

Rapport and parent/caregiver satisfaction

The specialists had a welcoming approach and were described as being 'helpful' and 'good with the kids' and 'help [ed] mum with the health of her children'.

Community clinics

The importance of the specialist coming to the local community and providing health worker education about asthma was greatly appreciated.

Parents'/carers' concerns

Some parents/carers also reported a few areas of concern that related to their accommodation to be able to attend the specialist clinics. Some parents and carers

TABLE 1: *Main themes emerging from the parents'/carers' responses to the open-ended questions*

Themes	Examples of responses from parents/carers
Communication	– *Helped parent/child to understand asthma*
	– *Clear, good explanations*
	– *Easy to talk to, approachable*
	– *Doctor spoke very well*
	– *Very polite and friendly*
Quality of service delivery	– *Good ethics/code of practice*
	– *Short waiting times*
	– *Come to you (community)*
	– *Continuity of service; same specialist visiting*
	– *Really thorough, especially with follow-ups*
	– *Very good checking children*
	– *They were on hand, available all the time when we needed assistance*
	– *Like everything about clinic, because it was very educational*
	– *It's good to have specialist clinical service*
	– *Good use of the local health workers for follow-ups and education*
Professional approach	– *In-depth investigations*
	– *Thorough results*
	– *Committed to kids*
	– *Experienced*
	– *Specialist knowledge*
	– *Good to get proper results from expert*
	– *Prompt responses with follow-up*
	– *Professional/code of ethics and practice, time management for sessions good*
Transfer of knowledge and education	– *Practical demonstrations 'they show you how to use spacer'*
	– *Family (mum/child) – help mum with the health of her children*
	– *Teach kids how to take medication*
	– *Health workers provided a good quality of education*
	– *Explanation of treatment plan*
	– *Good knowledge sharing*
	– *Giving out lots of information/reminder letter sent out/home visit and at work*
	– *Follow-up and using of devices properly*
	– *Good explanation and knowledge of asthma*
	– *Help to remind me about medicines*
	– *Thorough, good learning for parents, knew what to look for when child got sick*
Rapport and parent/caregiver satisfaction	– *Parent satisfied*
	– *Kids very relaxed and happy to see Dr*
	– *Patient knew the specialist (same Dr saw the kids at each clinic)*
	– *Very approachable*
	– *Interaction with kids, very thorough, caring, good with kids*
	– *Found health worker follow-up & education helpful*
	– *Workers are kind and help us a lot*
	– *Just help altogether/ good*
	– *Help mum well with health of her children*
Community clinics	– *Home visit*
	– *Good to have health worker education of the local people in the community*
	– *Able to come to remote areas*
	– *See specialist base in our own community*
	– *Come to you at the community/benefit for my children*
	– *Excellent that the specialists making time to come to district*
	– *Would see specialist regularly if seen on T.I. and not have to travel down south*
Parents'/carers' concerns	– *Need more notice for clinic*
	– *They didn't like the blow thing*
	– *Too short/not enough follow-up*
	– *No education at community level*
	– *Would like more education*
	– *Problem with travel & accommodation*

travelled from other islands with their children to attend the clinic, and at times it was 'short notice of clinic'.

Discussion

To our knowledge, this is the first study that has examined carers' view of a specialist service using an Indigenous model. We have shown that with additional training for IHCWs, improvement in chronic disease management can be made while empowering the role of the IHCW within the community.

The themes defined by most number of responses were 'service delivery quality' and 'clear transfer of knowledge and education/clinical knowledge of asthma'. They reiterate the importance of the health care worker in the remote setting and the value in providing education to the health care worker and local community. The parents'/carers' responses strongly indicated their satisfaction with the high level of communication, professional approach and rapport. Parents/carers also indicated their appreciation of access to a specialist in the community; the interaction experienced with the health professionals was positive and their sense of empowerment evident by learning how to manage their children's asthma. Some areas of concern reported by parents/carers related to their accommodation (some travelled from other islands to clinic location) and 'short notice of clinic'. Overall, these themes serve as a model to providing similar care in remote settings as they underpin the values of those in the community.

To date, provision of health service models to remote communities has largely been based on viewpoints of few people from the hierarchy of health services. Rarely have the views of uses of the service been evaluated. Having documented the positive asthma outcomes of the education intervention program,[10] we sought to obtain parents'/carers' perspective of the service model used so as to characterise the aspects of a clinical service model that lead to improved health outcomes from a community perspective. The seven themes generated from the parents'/carers' perspective relate to the cultural aspects (established rapport/caregiver satisfaction, local-based approaches with involvement of HCW) and the high level of expertise in content and local issues (clear communication, quality service delivery, professional approach, clear transfer of education). These themes highlight the importance of the provision of education programs delivered locally to HCW complemented by experienced clinicians who are also familiar with cultural aspects so as to communicate effectively and have a good rapport with the local community. However, while cultural appropriateness is necessary, it alone is an insufficient aspect given the importance of 'content knowledge' expressed by the parents/carers. Our findings challenge current paradigms where education programs are usually delivered centrally and less experienced doctors often sent on outreach services. Our findings endorse our previous viewpoint on the model used in caring for Indigenous children with asthma.[11]

IHCWs can have a unique and undefined role in the primary health care setting. Despite being heavily depended on, particularly in remote community settings, the role of the IHCW is often blurred beyond clinical duties, being seen as an 'assistant' to other health professionals and the 'middleman' between client and health professionals.[12] An IHCW's approach to health and well-being encompasses a holistic framework and engagement of health determinants, socially, emotionally, spiritually, culturally and psychologically.[12–16] Some key factors identified in the carers' response are the importance of culturally appropriate respiratory practices and the process of developing rapport and establishing respectful approaches to practice, including respect for cultural ways, flexibility and understanding.

The health worker's local knowledge in conjunction with training sessions empowered and enabled them to be effective in their work. Having trained health workers in remote island communities can result in better health outcomes, less reason for patients to travel away from home. In addition, the provision of education and resources to the community is also beneficial to long-term health care and well-being. Further research is necessary to assess the cost-effectiveness of training IHCWs in other specialist areas.

One study limitation was that interviews were not recorded, and although the interviewers were instructed to take verbatim notes they might not have captured all that was said. However, the data were analysed by three Indigenous researchers, two with expertise in qualitative analyses (including one who originated from Torres Strait region). Given the scarcity of subspecialist services to families living in remote regions of Australia, the carers' positive responses in terms of the skills and expertise of the respiratory physicians can reflect the lack of quality of the ongoing service provision to remote regions rather than the specific quality of the service provided. It can also reflect the need and want from community for specialist services. Nevertheless, the responses from carers/parents clearly indicate participants' satisfaction with the services provided by the respiratory physicians, nurses and trained health workers. It brought to the forefront the need for more specialised health care training, education and appropriate respiratory services in remote communities. Furthermore, it highlighted the diverse areas of need and access to appropriate health care resources and education in remote and rural communities. The data complement

our RCT and potentially inform future health service delivery models to Indigenous remote and rural regions.

Conclusion

We conclude that community-based perspectives of the characteristics of a health service model that delivers improved health outcomes include[9,14,15] empowering and resourcing IHCWs concurrent with a specialist service with elements of high clinical expertise and cultural appropriateness. Whether this model can be used in other chronic diseases and other remote regions of Australia should be examined so as to narrow the health gap between Indigenous and non-Indigenous Australians.

Acknowledgements

Funding for the study came from a National Health and Medical Research Council (NHMRC) Project Grant (ID 389838), a Rural Health Support, Education and Training grant, the Telstra Foundation, and the Royal Children's Hospital Foundation. This work and NM-D was supported by an NHMRC Centre for Research Excellence for Lung Health in Aboriginal and Torres Strait Islanders grant (1040830). PCV was supported by the Australian National Health and Medical Research Council (Career Development Fellowship #1083090). LJW was supported by a Sidney Myer Health Scholarship and a Menzies Enhanced Living Scholarship funded by the Lowitja Institute. GG was supported by the Lowitja Institute. We thank Valerie Logan for technical support, and Janelle Stirling, Vanessa Clements, Brett Taylor, Helen Petsky, Justin Gaffney, Debra Nona, Saimo Gela, Yancy Laifoo, Kathy Cook, Veronica Harrhy and Torres Strait personnel for their help with the development of the culturally appropriate paediatric asthma education packages, running the workshops, data collection and clinics. We are grateful to the children and their families for participating in the study. We also acknowledge the support of the Torres Strait communities and the District Health Council – Torres Strait Health and Northern Peninsula Area, Queensland Health.

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