

The use of a collaborative structured methodology for the development of a multifaceted intervention programme for the management of asthma (the MIA project), tailored to the needs of children and families of South Asian origin: a community-based, participatory study

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Scientific summary

The MIA project

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Scientific summary

Background

The outcomes for children with chronic disease in the UK are among some of the worst in Europe. Notably, minority ethnic groups are frequently having poorer outcomes for long-term conditions, and experiencing higher morbidity and mortality rates than majority populations. In the UK, people of South Asian origin with asthma experience excess morbidity, with hospitalisation rates three times those of the majority White population. Asthma places a substantial burden of care on families, communities and the health services, with a disproportionate impact on minority ethnic children. This inequality urgently needs to be addressed. As such, finding effective interventions to address these health disparities is important. Despite recommendations that tailored interventions are more successful than generic ones, many health promotion programmes often fail due to their lack of cultural sensitivity. This problem is particularly prevalent in the field of asthma. Most interventions to improve asthma care are directed at majority populations with few having been developed using a participatory approach. This potentially widens health inequalities. Tailoring interventions to specific population needs is an increasingly popular approach to intervention design, with success increased if collaborations with children, families, communities and healthcare professionals (HCPs) occur. To develop an effective intervention, it is important to, first, understand how patients and families experience the condition and, second, assess the barriers and facilitators to optimal management.

Project aims

The overall aim for the Management and Interventions for Asthma (MIA) research study was to use a collaborative method of designing healthcare interventions to develop an intervention planning framework for South Asian children with asthma. Asthma in South Asian children was chosen as an exemplar to demonstrate the structured processes involved in collaboratively developing a realistic and achievable tailored intervention programme within minority ethnic communities. The South Asian community was chosen because of the inequality in asthma outcomes in these children. This includes under-recognition of symptoms and increased attendance at the emergency department.

The MIA research study was thus designed to enable collaboration between South Asian children, families, communities and HCPs to produce a health intervention planning framework for asthma management tailored to the needs of South Asian children and an exemplar intervention programme addressing one key issue along the asthma pathway. The four main objectives of MIA were:

- to test a participatory model of healthcare intervention development
- to provide evidence-based understanding of asthma and its management in South Asian children
- to provide a comparative analysis of understandings of asthma and its management in White British and South Asian children to account for geographical and sociocultural context; and
- to produce a realistic and achievable intervention planning framework to address the pathway to optimise asthma management.

Methods

The MIA project followed a multiphase, iterative, participatory research approach, underpinned by the socioecological model of health and drawn on principles of intervention mapping. The project used a collaborative model of research by engaging with South Asian community members, South Asian parents

and children living with asthma, and HCPs providing asthma services to provide multiple perspectives on barriers and facilitators to optimal asthma management. The MIA study was formed of four linked phases. This iterative and structured approach provided an evidence-based framework to allow the research team to make effective decisions at each step of the intervention development process.

Phase 1, funded by Asthma UK (see *Appendix 1*) was carried out in separation from the subsequent phases and did not contribute to the National Institute for Health Research (NIHR) report. It consisted of an initial systematic evidence synthesis that highlighted the extent and nature of ethnic-specific cultural attitudes, beliefs and care experiences relating to asthma and the level of organisational discrimination and barriers to optimal provision of care. Examples include poor physician knowledge, subconscious bias and stereotyping. This, together with input from a broad based project advisory group, informed the initial question schedules for the subsequent study phase. Phase 2 utilised qualitative methods, including focus groups and interviews with members of South Asian communities to assess lay perceptions of asthma and the impact of cultural, religious and wider socioenvironmental influences on children's health and asthma in particular. Phase 3 involved a series of in-depth qualitative interviews with parents/carers and children from South Asian and White British families, and interviews with HCPs. This was designed to explore perceptions of asthma among South Asian families and a smaller, comparative group of White British families, and to understand how HCPs perceive asthma and its management in South Asian children. A White British sample was included in this phase of the study to identify whether or not the management of asthma was subject to variation between communities. Phase 4 brought together the qualitative findings from the first three phases, the information from the systematic evidence synthesis in phase 1, and a scoping intervention review of literature on existing asthma interventions conducted as part of phase 4. Collaboration between families, community members and HCPs was facilitated to discuss key issues encountered across the management of childhood asthma pathway and to prioritise one issue to take forward for the initial development and subsequent refinement of a multifaceted intervention programme, 'Awareness, Context (cultural and organisational) and Training (ACT) on Asthma', to demonstrate the process that could be adopted and applied for other key issues identified.

Results

Findings from the review of barriers and facilitators to asthma management in phase 1 (see *Appendix 1*) highlighted the need for research to shift from merely identifying barriers towards developing interventions to address them. The evidence synthesis highlighted a number of key concepts that needed to be sensitively explored in subsequent qualitative phases of the MIA project. The findings from the review were used as the basis for the project structure and initial question guides for the focus groups and interviews in phase 2.

Phase 2 highlighted that community perceptions and understandings of asthma, its aetiology, treatment and outcomes often differed from biomedical understandings. Findings also revealed that community perceptions had an impact on parental management by setting social norms and expectations for children and parents.

In phase 3, the detailed interviews with parents/carers and children revealed that many of the problems facing families of a child with asthma are common to all communities, both minority and majority: lack of understanding and knowledge about the origins or triggers of asthma; poorly communicated information, inconsistent and/or unco-ordinated care and dissatisfaction with the healthcare system. Barriers related to information provision existed for both groups but were exacerbated in South Asian families owing to language barriers, translation issues or limited provision of information in formats other than the written form. Issues particularly relevant to South Asian families included the use of complementary therapies or dietary adjustments to manage their child's asthma. South Asian families were more likely to use the emergency services if they could not access their general practitioner (GP). One reason for this was the difficulty parents experienced in recognising the severity of symptoms and thereby delaying access to

treatment. Furthermore, some parents were not confident that GPs were adequately equipped to handle acutely unwell children and awareness of alternatives to emergency department (ED) presentation was limited. Children described fear of acute attacks, confusion around causes and triggers of asthma and a lack of engagement with school activities. Healthcare providers also identified several issues that led to poor asthma management for children: barriers that arose during consultations with South Asian families, such as time and communication; perceptions of barriers to asthma management for South Asian families; and professional and organisational barriers to asthma management. They acknowledged that their focus was on addressing medications required for treating asthma and admitted that less attention was given to the more holistic approach to asthma management that these families may have been seeking. Language barriers and time to deliver optimal care were also raised as major concerns. Additionally, HCPs demonstrated organisational discrimination and revealed the potential existence of problematic cultural stereotypes about South Asian families accessing health services.

Phase 4 was designed to develop a tailored asthma intervention-planning framework to identify key issues along the pathway and then to develop a focused exemplar intervention programme. The qualitative data from phases 2 and 3 identified 11 key problem areas within asthma management that were then developed into an intervention-planning framework. Adults, children and professionals in a series of collaborative workshops prioritised the 11 problem areas. The problem of 'getting a diagnosis' was ranked as the most significant problem by parents/carers and was approached from a socio-ecological and holistic perspective covering a number of steps required within the diagnostic process. These steps included; an awareness of asthma, recognition of symptoms, accessing health care and the investigative process to make the diagnosis of asthma and not solely the narrow steps of investigating the child to confirm or refute a diagnosis.

'Getting a diagnosis' was therefore chosen as an exemplar for the process by which a four-part multifaceted integrated intervention programme, 'ACT on Asthma', was developed using modified intervention mapping and underpinned by relevant behavioural and psychological theory. The four arms of the 'ACT on Asthma' programme represented key intervention strategies; community awareness, education and training; clinical support; and the provision of an advice centre. Each was underpinned by tailored strategies, integrated and centrally co-ordinated by a principal team. Finalisation and refinement workshops, taking into account the feasibility of the programme within the NHS, were carried out to allow participants to appraise and refine the programme. An economic evaluation was also undertaken to identify the key cost elements of the intervention and overall costing of the intervention programme to the NHS. Feedback from participants regarding their involvement in the overall project was gained to enable them to discuss participants' experiences of participating in the MIA research project.

Conclusions

The MIA project has demonstrated that the social patterning of perceptions of asthma, together with a lack of alignment between the priorities and competencies of British South Asian communities and families and the organisation of health services, conspire to create vulnerabilities and difficulties in effectively managing childhood asthma. The study has also shown that it is possible to work with minority ethnic communities and engage them throughout the process to collaboratively develop a multifaceted intervention to begin to address these issues. The MIA study showed that minority ethnic communities, even though considered to be 'hard to reach', can be successfully engaged in collaborative intervention development if careful planning and tailored techniques are used to encourage and sustain participation. The diverse perspectives gained from collaborative, participatory engagement with communities, children, parents and HCPs demonstrated the value of fully engaging with service users and the need for interventions to address issues at the level of the individual, the community and the organisation/system. The MIA project was able to develop an intervention for asthma management using a structured 'bottom-up' holistic approach, taking into account the perceptions, attitudes and opinions of families, communities and HCPs, to design an intervention for service improvement which takes seriously the

needs and perspectives of those most closely involved in living with and managing this common childhood condition. The participatory, collaborative approach can, and should, be considered when developing interventions to improve outcomes for other clinical problems and with other communities.

Following on from the MIA study, further research is required to explore the asthma management pathway further. Future research should seek to:

- assess the feasibility and effectiveness of the 'ACT on Asthma' intervention programme
- develop methods to increase the participation of children in research and service development
- explore techniques to further enhance public understandings of asthma in South Asian communities
- explore and identify effective means of engaging the wider family in optimising asthma management
- identify ways of improving understanding and management of acute attacks in children
- examine the effectiveness of a range of complementary therapies for asthma management
- explore the barriers to the implementation of asthma guidelines in the NHS.

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