

Experiences of caregivers of asthmatic children regarding implementation of an asthma education programme at a community health centre in Cape Town

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Abstract

This study explored the experiences of caregivers of children with asthma regarding implementation of an asthma education programme at a community health centre in the Western Cape. The study explored the experiences of caregivers living with and helping the young asthmatic child when asthma symptoms first appear; their views and experiences on implementation of the asthma education programme; and their understanding of the expectations of them as caregivers, based on the guidelines provided to them. An exploratory, descriptive, contextual design was employed. Caregivers of children with asthma participated in semi-structured interviews which were guided by use of an interview schedule containing open-ended questions. The sample was derived through purposive sampling of caregivers who attended the health facility. Thematic analysis of the data was conducted. The results showed that caregivers found the education programme useful, and they reported that it was offered at a level that was easy for them to understand. Caregivers suggested that the programme should continue because they learned something new every time they attended the asthma clinic at the community health centre. Practical demonstrations were found to be particularly useful. It was clear that caregivers were aware of what was expected of them and that the education programme has assisted them in their caregiver role, despite the fact that they still experience moments of fear when the child has an asthma attack.

Keywords: Asthma, caregivers, children education programme.

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Introduction

Asthma is a chronic inflammatory lung disease which is associated with airway hyper-responsiveness and tissue remodelling of the airway structure, and physiological dysfunction of the lung characterised by breathlessness, wheezing and a variable airflow obstruction. The airways narrow and there is an increase in airways responsiveness to sensitisation due to a variety of stimuli. Asthma symptoms can, however, be controlled and can also be prevented (Murdoch & Lloyd, 2010). This means that the airflow limitation is reversible with the

appropriate asthma treatment. The burden of asthma affects the patient (the child), their families and the society in which they live, in terms of loss of work and school days, loss of income, impaired quality of life, hospitalisation, medical costs and mortality (Motala, Green, Manjra, Potter & Zar, 2009). Patient education has been described as an essential component of asthma management with clinical guidelines providing the basis for both clinical management and asthma education (Pinnock et al., 2010). The prevalence of asthma is high in Cape Town and childhood asthma is a common disease (Green, 2007). Despite the useful asthma therapies and management strategies which are available, asthma morbidity remains a problem (Green, 2007).

According to Braman (2006) there has been a sharp increase in the global prevalence, morbidity, mortality and economic burden associated with childhood asthma over the last 40 years. Approximately 300 million people worldwide currently have asthma, and its prevalence increases by 50% every decade. In 1989 the Global Initiative for Asthma (GINA) programme was initiated in an effort to raise awareness among public health and government officials, health care workers and the general public that the incidence of asthma was on the increase. GINA (2007) found that South Africa has the world's fourth highest asthma death rate among 5- to 35-year-olds. Almost three-quarters of all the deaths occurred away from hospitals. It is clear that a need exists to educate South Africans about the recognition, prevention and treatment of asthma (Zar, 2004).

The National Heart, Lung and Blood Institute (NHLBI) of the National Institutes of Health in the United States of America has established guidelines for the diagnosis and management of asthma (NHLBI, 1997). These guidelines include goals for asthma management as well as the following key components for achieving control of asthma: regular assessment and the monitoring of symptoms; appropriate pharmacological therapy; control of triggers and patient (asthma) education; and partnership with the families (NHLBI, 1997).

The South African Guidelines for the management of chronic asthma in children were updated in 2009 (Motala et al., 2009). The recommendations are that the practitioners (nurses and medical doctors) should strive to achieve the best possible therapy for each patient through the motivation and education of caregivers, and ensure that all patients have access to appropriate medication.

Barton, Sulaiman, Clarke and Abramson (2005) did a study of parent experiences of caring for their asthmatic child and concluded that caregivers had anxiety about their children's health, lack of knowledge about the asthma, fear of the child dying, uncertainty about management and prognosis, as well the physical and financial responsibility of caring for an asthmatic child.

Peterson-Sweetney and McMullen (2003) conducted a study to explore parental perceptions of their child's asthma. The findings were that caregivers acknowledged that they are learning to care for their asthmatic child and that they value knowledge about asthma, but did not acknowledge that there is a gap in their asthma knowledge.

Studies have been done on the childhood asthma community and the findings are that childhood asthma management is substantial under treatment, but that there is a need to increase awareness of the chronic nature of asthma and the need to follow the treatment prescribed in asthma treatment guidelines (Maziak et al., 2002).

A Columbian researcher, Findley (2011), developed the Asthma Basic Care (ABC) Program, which provided multiple opportunities for caregivers to learn about asthma signs and triggers in the asthmatic child. This strategy strengthened the communication skills of caregivers and their asthmatic child's health, and suggests that the health care provider contributed to changes in the caregivers' asthma management behaviours through improved confidence and improved asthma control.

Warschburger et al. (2002) ran an educational programme with caregivers and found that the short-term patient-centred patient education programme increased knowledge and the health status of asthmatic children. A study was done in Norway to evaluate the effectiveness of various methods of asthma education for parents, and the results revealed three themes: sharing of experiences; accepting the illness; and partnership building. The importance of a partnership between the caregiver and the health care provider was identified (Trollvik & Severinsson, 2004). Valerio, Cabana, White, Heidmann, Brown and Bratton (2006) conducted a focus group study on Medical-Aid caregivers on their understanding of asthma. It was suggested that caregivers require on-going asthma education, with the emphasis on support and development of caregivers' confidence regarding their asthma self-management skills.

Watson et al. (2009) conducted a study on small-group interactive educational programmes for asthmatic children and their caregivers. The results were effective and showed a significantly reduced need for hospital-based emergency services. The quality of life of the asthmatic child and caregivers also improved.

Despite the availability of effective treatment, and although caregivers attend the clinic and are given education on preventative behaviour based on the education programme, children's asthma is not under control. The aim of this study was therefore to explore and describe the caregivers' experiences of managing their

asthmatic child, and to establish whether implementation of the asthma education programme assisted them in managing their child's asthma.

The aim of asthma education is to reduce the morbidity rate and to increase the caregivers' knowledge of asthma. Learning from caregivers about their experiences of implementation of the educational programme for prevention of an acute asthma attack in the young child is crucial for improving preventative strategies and education programme. The outcome of the research may contribute to the knowledgebase of the nursing profession in this field of practice.

Patient-centred theory was the conceptual framework for this study, but other related theories (self-determination; social cognitive; health belief model and family-centred theories) are inter-related with the patient-centred theory. Dexter and Walsh (1995) define the patient-centred approach as "based on the belief that the patient is the important person in the relationship and that he/she has the resources and ability to help him/herself given the opportunity to do so." Speechly, Rimver and Hodson (1992) outline a patient-centred model which stresses that a partnership needs to be created between patient and the health professional. The health professional brings an expert knowledge base and, hopefully, long-term support. The patient brings the experiences of the chronic disease (asthma) that is long term. Together these players can implement a plan of care and continue to evaluate it. One of the key features of the patient-centred model is that it suggests that the health care provider enter the patient's world and see the illness through the patient's eyes (Speechly et al., 1992).

Methodology

A descriptive, exploratory and contextual design was used to explore and describe the caregivers' experiences with implementing the asthma education programme from Red Cross Memorial War Children's Hospital, Rondebosch.

The setting for the study was Red Cross Memorial War Children's Hospital, a known children's hospital and a tertiary learning institution situated in Rondebosch, Cape Town. This hospital serves the entire Western Cape. The study population included all caregivers with asthmatic children younger than seven years of age who attended this hospital. Eighteen caregivers of asthmatic children younger than seven years of age who received education about the asthma guidelines of 2009 were selected for participation in the study through non-probability purposive sampling.

Ethical clearance was granted by the University of the Western Cape (Registration 11/5/10), and permission to conduct the study was sought from the management of the nursing division at the health care facility. Participants signed consent after they were briefed on the purpose of the study. Their rights to voluntary participation, confidentiality and anonymity were explained and upheld.

Semi-structured interviews were conducted face-to-face from July to October 2012 to obtain information on the caregivers' experiences with implementing the asthma education programme. Participants were asked specific questions and the interviewer probed for additional information to obtain the necessary depth of information (Brink, Van der Walt & Van Rensburg, 2006). Questions centred around the experiences and fears of caregivers regarding living with and helping the young asthmatic child when symptoms first appear, and their views on the user-friendliness of the education programme (how easy or difficult it was to implement) in helping the child.

The interviews were tape-recorded and played back to the participants, who confirmed that the interview had been recorded fully. The recorded interviews were transcribed verbatim by an independent transcriber, and some were later translated from Afrikaans into English by an independent language practitioner. Thereafter thematic analysis was done through the process of coding and generating categories from which the themes were derived.

Trustworthiness was ensured by employing strategies of credibility, dependability and conformability. Credibility was ensured by collecting data at a health care facility where the research was not known to the participants. Data were collected over a period of four months until data saturation was reached. Transferability was ensured by the presentation of a dense description of the participants in the study, the research context and setting. The researchers kept an audit trail of the research process to enhance dependability of the study. Independent verification of coding was also done to enhance dependability of the study.

Results and Discussion

Relevant demographics data were documented (Table 1), and represent a general profile of the study participants. This enabled the researcher to identify precipitating or contributing factors to problems that the caregivers may experience.

Table 1: Demographic information of the participants

| Characteristic variable | Number of participants (n = 18) |
|-----------------------------|---------------------------------|
| Age (years) | |
| 21-25 | 3 |
| 26-30 | 8 |
| 31-35 | 3 |
| 36-40 | 1 |
| 41-45 | 3 |
| Marital status | |
| Married | 5 |
| Single | 13 |
| Educational level | |
| Primary school | 3 |
| Incomplete secondary school | 12 |
| Matric completed | 3 |
| Occupation | |
| Housewife | 12 |
| Employed | 6 |

Almost all of the caregivers were the asthmatic children's biological mothers. The majority of the participants (8) were in the age group of 26-30 years. However, the age did not have a direct bearing on the analysis, but is an indication of the participants' level of maturity. Twelve of the participants were unemployed, single and had incomplete school education. This was significant as participants may experience financial difficulties and/or difficulty in understanding the asthma education programme due to their level of education or literacy, which may in turn have a negative impact on the management of the child's asthma.

Caregivers described their experience of implementation of the asthma education programme. Two major themes emerged from the data, with categories and subcategories. Appropriate quotes from the raw data and literature are used to substantiate the themes. The themes that emerged are the following: asthma education programme has a positive effect on asthma management and care; and overwhelming emotions interfered with performing the prescribed interventions.

Asthma education programme has a positive effect on asthma management and care

The value of the patient-centred approach is attested to by the participants' reports that they found the education programme interesting and useful. Some of them reported that "*It [asthma education] was very useful, and the nurse did elaborate why we must use the pumps*"; "*I did understand it and it was good*"; and "*The asthma education was useful for me, because the more I can learn about asthma the better it would be for me, I would say every time I learn more and more and he [the asthmatic child] got better and better.*"

Caregivers verbalised that they found the asthma education programme useful and noticed an improvement in their asthmatic child's condition: *"It was [asthma education] useful, and when I give him a pump as I was told, he gets better, and I know now what to do."* Another participant reported that she learnt new information from the asthma education: *"It was useful, because I learned stuff I never knew before; they showed me the right way how to use the pumps, and the preventer and so on."* Willingness to learn is one of the key elements of the self-determination theory, and the extent to which caregivers are open to new information is the extent to which they will become competent to manage the asthmatic child (Markland, Ryan, Tobin & Rollick, 2005).

One of the participants acknowledged that she was taught how to use asthma inhaler correctly and saw an improvement in her child's condition: *"I did understand it [how to use the asthma inhaler], but in the beginning it was a bit difficult and I did everything as I was told, like how to give the pumps and his treatments [medication]. And every time when I came it went better and better. I would say every month I learnt more and more."* The self-determination theory emphasises that the health care provider must ensure that caregivers know how to use the asthma inhaler device, and motivate them to comply/adhere to the prescribed medication (Deci & Ryan, 2002).

Another participant realised the importance of removing triggers at home: *"Yes, kind of like when they said I must remove things at home, which I didn't do before, e.g. vacuum the mattress."* These changes were also suggested by Bateman et al. (2008), because asthma exacerbations may be caused by a variety of factors, sometimes referred to as 'triggers', including allergens, viral infections, pollutants and drugs. Reducing an asthmatic child's exposure to some of these categories of risk factors (e.g. smoking cessation, reducing exposure to second-hand smoke, reducing or eliminating exposure to occupational agents known to cause symptoms and avoiding foods/additives/drugs known to cause symptoms) improves the control of asthma and reduces medication needs. Therefore medications to maintain asthma control have an important role because asthmatic children are often less sensitive to these risk factors when their asthma is under good control.

Overwhelming emotions interfered with performing the prescribed interventions

The participants verbalised that they become anxious while helping their asthmatic child when the child has asthma exacerbations. The following statements illustrate how the asthma exacerbations affected the caregivers emotionally: *"Well it is hard and for me I am giving the pumps and why doesn't it help him."* Other participants said that they would burst into tears: *"I wanted to burst into tears"; "I feel bad, and I cry"; "I just burst into tears."*

Some of the participants verbalised feelings of uncertainty: *“For me it was for how long he was going to have asthma as asthma is a very dangerous disease and you never know when it is going to happen again.”* The participant reported being extra cautious: *“I also walk around with his pumps for just in case. I feel bad, and I cry.”* This is in line with a study conducted by Barton et al. (2005) which confirms that the caregivers had little idea of coping strategies, and when the child presents with the first asthma symptom they felt overwhelmed by emotions and lost control of the management of their asthmatic child.

The participants reported that they experience anxieties when helping their asthmatic child at home: *“I’m nervous and I panic and I don’t know what is going to happen to him”*; *“My fears and I know it is fatal. I wouldn’t like it to get worse.”* This is in line with Juniper (2003) study which states that the primary caregivers of children with asthma are limited in daily normal daily activities and do experience anxieties and fears due to the child’s illness, but when feelings of guilt and uncertainty persist for a prolonged time the parents react to the child’s asthma situation in a destructive manner.

The participants verbalised that they were overwhelmed by their emotions, which made it difficult for them to help their asthmatic children, as illustrated by the following statements:

“It is actually sad; because it is like that I couldn’t take properly care of her.” This is in line with a study conducted by Sales, Fivush and Teague (2008) which found maternal coping plays an important role in the psychological well-being and quality of life of asthmatic children.

A study conducted by Trollvik and Severinsson (2004) described parents/caregivers’ experiences in four main themes: feelings of uncertainty, helplessness and guilt; the need for support and help from health care professionals; adaptations to everyday life; and development of coping strategies. Parents with subtle forms of guilt can be less open about their guilt because they are embarrassed about those feelings. Participants verbalised and reflected the point made in the literature in statements such as the following: *“I feel helpless and panic”*; *“I feel useless, and because you feel powerless and even if you try and you can see that things not working”*; *“I feel useless that moment and everybody is panicking and they didn’t what to do”*; *“I feel helpless, there’s nothing I can do for her”*; *“I’m nervous and I panic and I don’t know what going to happen to him. I cried and panic and didn’t know what to do.”*

Participants reported and confirmed these feelings as described in the literature – feelings of sadness, pain and nervousness – when they have to help their child

who is having an asthma exacerbation: “*Like I said it is not a nice feeling to see your child suffer and I would take his pain any time and he has a lot to live for*”; “*I am so nervous, and because I myself had bad asthma and I feel hurt when it happens to him*”; “*For me I’m not nervous, I just felt heartbroken and I’m stressing, and feel sad.*” A review of literature on the topic confirmed the prevalence of statements that the fear and anxiety become present, and it varies in degrees; from the first asthma attack on, even a single sneeze or runny nose can send the asthma caregiver into a panic.

Because caregivers do not fully know how to control or prevent symptoms, they feel frighteningly insecure. Besides fear and anxiety, the asthma caregiver may experience guilt. Thus well-managed asthma is the key to overcoming the fear and confusion that this illness causes the caregivers (Fleming-Carroll, 2004). Therefore, there is a need for healthcare professionals to emphasise the chronic nature of asthma, but also to negotiate strategies with caregivers to optimise the use of asthma medication, with due consideration being given to caregivers’ fears, frustrations and health beliefs (Barton et al., 2005).

Limitations

Limited literature was found on this research topic and none in the South African context. This meant the researcher had limited information with which to confirm the findings of the study. It is therefore important that the findings of this study be published in both national and international journals.

This study was done at a tertiary institution, which may not reflect the real difficulties at primary or secondary care levels. Lastly, the study focused on caregivers’ experiences around the implementation of the asthma education programme and did not include the health care provider’s experiences. In light of the understanding that education is a two-way process, this may be seen as a limitation of the study.

Recommendations

The results from this study also indicate that there is a need for comprehensive, continuous asthma education programme to ensure that caregivers understand, by offering the programme in simplified terms and in a language that the caregivers are able to understand; to exclude possible myths about asthma that may hamper the asthma management; to conduct regular checks of the asthma inhaler device technique through role-play and demonstrations of asthma management skills; to teach caregivers self-efficacy management and reduce asthma exacerbations; to give continuous asthma education at each follow-up visit and while caregivers sit in the waiting area, e.g. practical demonstration and

videos based on the premise that repetition serves as reinforcement; to ensure that the asthma education programme is more user-friendly for the caregivers, such as making it available in the patient's home language; and to make the asthma education pamphlets available in the languages of the caregivers, since language barriers may lead to misconceptions and poor adherence, thus increasing asthma morbidity.

There is also a need to provide a *social support group* to support caregivers who have emotional issues/difficulties around asthma management; assist caregivers with devising coping mechanisms and coping techniques; help dispel unwanted fears and guilt around asthma management from caregivers' minds; help caregivers deal with the process of change, adaptation and learning to cope with the asthmatic child's attacks; clarify misunderstandings/ misconceptions around asthma care and management; allow caregivers to meet each other and share their difficulties and experiences; facilitate the identification and referral of any caregiver who discloses feelings of depression; and give caregivers the opportunity to make suggestions on the asthma education programme.

In addition, *partnerships* should be established with the caregivers through the use of effective communication so as to overcome barriers of asthma education; and with educators at the day centres and schools so that the caregivers don't need to stay absent from work to take care of their asthmatic child, because absences from work have financial implication or could lead to job loss.

Conclusion

The caregivers found elements of the asthma education programme to be useful, even though it was not easy for them to implement it due to their emotional issues and their understanding of asthma education. This should be acknowledged by health care providers. It is expected that the asthma morbidity rate will decrease if the caregivers' knowledge of asthma care is improved, positive self-efficacy is developed, feelings of being overwhelmed are decreased, and emotional difficulties stabilised. Childhood asthma can be effectively managed through global asthma education, development of partnerships, and establishing social support groups for caregivers.

References

Barton, C., Sulaiman, N., Clarke, D. & Abramson, M. (2005). Experiences of Australian parents caring for children with asthma, it gets easier. *Chronic Illness*, 1(4), 303-314.

Bateman, E.D., Hurd, S.S., Barnes, P.J., Bousquet, J., Drazen, J., FitzGerald, M.P., Gibson, P., Ohta, K., O'Byrne, P., Pedersen, S.E., Pizzichini, E., Sullivan, D., Wenzel, E.H. & Zar, H.J. (2008). *Global Strategy for Asthma Management and Prevention, GINA Executive Summary*, 31(1), 143-178.

Braman, S. (2006). The global burden of asthma. *Chest*, 130(1), 4-12.

Brink, S., Van der Walt, C. & Van Rensburg, G. (2006). *Fundamental of Research Methodology for Health Care Professionals* (2nd ed.). Cape Town: Juta & Co.

Deci, E.L. & Ryan, R.M. (2002). *Handbook of Self-Determination Research*. Rochester: University of Rochester Press.

Dexter, G. & Walsh, M. (1995). *Psychiatric Skills A Patient-Centred Approach* (2nd ed.). London: Chapman & Hall.

Findley, S.A. (2011). Asthma Basics for Children (ABC). Community-based strategy for improving asthma management and outcomes for preschoolers. *Journal of Urban Health*, 88(1), 85-99.

Fleming-Carroll, B. (2004). *Best Practice Guidelines for the Management of Asthma in Children*. Registered Nurses Association of Ontario, Toronto, Canada (online), at www.sickkids.ca. Retrieved 1 May 2011.

Global Initiative for Asthma. (2007). *GINA workshop report: global strategy for asthma management and prevention* (online), at www.ginasthma.org. Retrieved 22 October 2011.

Green, R.J. (2007). Understanding mild asthma/episodic asthma in children. *South African Family Practice*, 49(3), 36-38.

Juniper, E.F. (2003). The impact of patient compliance on effective asthma management. *Curr Opin Pulmonary Medicine*, 9(1), 8-10.

Markland, D., Ryan, R.M., Tobin, V. J. & Rollnick, S. (2005). Motivational interviewing and self-determination theory. *Journal of Social and Clinical Psychology*, 24(6), 811-831.

Maziak, W., Von Mutius, E., Beimfohr, C., Hirsch, T., Leupold, W., Keil, U. & Weiland, S.K. (2002). The management of childhood asthma in the community. *Europe Respiratory Journal*, 20(6), 1476-1482.

Motala, C., Green, J., Manjra, A.I., Potter, P.C. & Zar, H.J. (2009). Guidelines for Management of Chronic Asthma in Children; South Africa Asthma Working Group. *South African Medical Journal*, 99(12), 898-912.

Murdoch, J. & Lloyd, C.M. (2010). Chronic inflammation and asthma. *Mutation Research*, 690(1), 24-39.

National Heart, Lung, and Blood Institute (NHLBI) (1997). National Asthma Education and Prevention Program. *Expert Panel Report 2, Guidelines for the Diagnosis and Management of Asthma*. Bethesda, MD: US Department of Health and Human Services (online), at www.nhlbi.nih.gov/health/prof/lung/asthma. Retrieved 18 February 2012.

Peterson-Sweeney, K. & McMullen, A. (2003). Parental perception of their child's asthma and medication use. *Journal of Pediatric Health Care*, 17(3), 1-2.

Pinnock, H., Fletcher, M., Holmes, S., Keely, D., Leyson, J., Price, D., Russell, R., Versnel, J. & Wagstaff, B. (2010). Setting the standard routine asthma discussion of the aims, process and outcomes of reviewing people with primary care. *Primary Care Respiratory Journal*, 19(1), 75-83.

Sales, J., Fivush, R. & Teague, G.W. (2008). The role of parents coping with children with asthma's psychological well-being and asthma-related quality of life. *Journal Pediatric*, 33(2), 200-229.

Speechly, M.E., Rimver, S.J. & Hodson, M.E. (1992). Exacerbations of cystic fibrosis after holidays at high altitude-cautionary take. *Respiratory Medicine*, 86(1), 55-56.

Trollvik, A. & Severinsson, E. (2004). Parents' experiences of asthma: Process from chaos to coping. *Nursing and Health Sciences*, 6(2), 93-99.

Valerio, M., Cabana, M.D., White, D.F., Heidmann, D.M., Brown, R.W. & Bratton, S.L. (2006). Understanding of asthma management, Medicaid parents' perspectives. *Chest*, 129(3), 594-601.

Warschburger, P., Busch, S., Bauer, C.P., Kiosz, D., Stachow, R., Petermann, F. (2002). Health-related quality of life in children and adolescents with asthma: Results from the ESTAR study. *Journal Asthma*, 41(4), 463-470.

Watson, T.A., Gillespie, C., Thomas, N., Filuk, S.E., McColm, J., Piwniuk, M.P. & Becker, A.B. (2009). Small-group, interactive education and the effect on asthma control by children and their families. *CMAJ Journal*, 181(5), 257-263.

Zar, H. (2004). Fatal and near-fatal asthma in South Africa. *Current Allergy Clinical Immunology*, 17(2), 56-58.