Beliefs Regarding Asthma Management Relating to Asthma Action Plans (AAPs) of African American Caregivers Residing in Newark, New Jersey Public Housing Communities

Frank Wagner, DNP, RN a,1, Lorraine Steefel, DNP, RN, CTN-A b,*,2

a Rutgers University School of Nursing, Newark, NJ, USA
b Rutgers University Correctional Health Care, Trenton, NJ 08625, USA

Abstract

Purpose: The purpose of this study was to explore the beliefs regarding asthma management and Asthma Action Plans (AAPs) of African American caregivers residing in three New Jersey public housing communities in Newark, New Jersey.

Design: A qualitative methods design was accomplished using semi-structured interviews with a purposive sample of nine African American caregivers of children with asthma. Information was coded using NVIVO™, the textual analysis combined codes into categories, which were then assembled into themes.

Results: Self-determination was found to be a fundamental goal of asthma management; however, three themes emerged as barriers and facilitators to this goal: challenges in the urban environment, preference of familial methods, and access to medical care.

Conclusions: Findings from this study regarding minority caregivers’ beliefs regarding difficulty navigating the health care system coupled with insurance instability, leading to use of Emergency Departments, are consistent with past research. Although caregivers expressed belief in use of prescribed medications as indicated on AAPs, familial methods, found to provide a sense of control over asthma, were preferred.

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Introduction

Childhood asthma is a health condition that disproportionately affects New Jersey’s poor, particularly African American children residing in inner city housing communities. In New Jersey, in the lowest income households (less than $15,000 annually), where minorities reside, children’s lifetime asthma prevalence is highest at 14.4% (NJAAEP, 2012b; New Jersey Department of Health [NJDH], 2013). In Newark, the incidence is one-in-three children, twice the national average for non-Hispanic Black Children (New Jersey Department of Health [NJDH], 2014).

In addition to the environment, other social determinants of health, that is, nonmedical factors influence health including health-related knowledge, attributes, beliefs, or behaviors (Braveman, Egerter, & Williams, 2010). Low income African American caregivers rely on their own familial methods to manage asthma, which provide them some measure of control over the disease. They rely on the emergency department (ED) for asthma crises and substitute it for primary care, thus challenging education about asthma management and the opportunity to build a collaborative relationship with a health care provider (HCP).

If left unmanaged, asthma leads to poor quality of life; even death (American Lung Association, 2012). While there is no cure for asthma, well-established clinical guidelines exist, such as Asthma Action Plans (AAPs) for asthma management that provide important home-care information such as how to monitor air flow, administer maintenance and rescue medication, assess the severity of an episode, when to call the provider, and when to seek emergency care (National Institutes of Health [NIH], 2013). Optimal self-management that includes provision of a written action plan for self-management of exacerbations, self-monitoring, and regular medical review “…almost halves the risk of hospitalization, significantly reduces ED use and unscheduled consultations, and improves markers of asthma control and quality of life” (Pinnock, 2015, p. 99). According to Bhogal, ZeneK, and Ducharme (2006), the written AAP combined with patient instruction for self-management has been found to result in a 27% decrease in the relative risk of exacerbations (Bhogal et al., 2006); a 40% decrease in hospital visits; and a 40% decrease in use of Emergency Departments (Gibson & Powell, 2004; Schwartz, Rachelefsky, & Krishnan, 2009). When plans with guidelines similar to the 1997 National Heart, Lung, and...
Blood Institute recommendations (NHLIB) “Global Initiative for Asthma” are presented in written form, they consistently produce better results (Sawyer, 2002). According to Douglas et al. (2002), “asthma action plans are a protective factor against death from asthma” (p. 1).

Although in 2001 legislation in New Jersey mandated the maintenance of an AAP in schools for every child using asthma medication (Justicia US Law, 2013), only 34% reported receiving an AAP with specific instruction on how to change the amount or type of medicine taken, when to call a doctor, and when to go to the ED (Akinbami, Moorman, & Liu, 2011; NJAEEP, 2012a). Lack of awareness of AAPS and proper self-management of asthma (as written in AAPS) as well as lack of health care provider-caregiver communication on asthma management and of caregivers’ beliefs and preference for familial methods challenge asthma outcomes.

In 2003, the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) published Key Clinical Activity for Quality Asthma Care, one of the first to acknowledge that African American asthma management and use of AAPS may be shaped by cultural practices and beliefs (Williams, Schmidt, Redd, & Storms, 2003). Despite decades- old recommendations for implementing the collaboration and use of AAPS, there is a lack of studies on the perspectives of African American caregivers on asthma management and AAPS with children who have asthma.

**Purpose**

The purpose of this study was to investigate the beliefs regarding asthma management and AAPS of African American caregivers of children with asthma residing in three Newark, New Jersey housing communities.

**Review of Literature**

Health is influenced by living and working conditions in the home and overall community and the economic and social opportunities and resources that shape a person’s opportunities to live, learn, work, and play in health-promoting environments (Braveman, 2015). A large percentage of African Americans reside in urban neighborhoods where the social determinants of health burden asthma outcomes (Braveman et al., 2010; Rasrogi, Johnson, Hoeffel, & Drewery, 2011; Swartz, Banasiak, & Meadows-Oliver, 2005; Williams, Strenthal, & Wright, 2009). “Complex environments increase the challenges of symptom management, placing the child with asthma at risk for poor outcomes” (Dowell, 2015, p. 842).

For caregivers, cultural disparity includes health care providers’ lack of understanding of the complexity of symptoms management (Dowell, 2015). If beliefs and preferences are not identified and are not respected or included in care, asthma management is at risk and timely medical interventions may be delayed (George, 2012). Effective communication, necessary for providers to develop an accurate understanding of how patients’ beliefs and practices inform their health behaviors, is strained as caregivers substitute emergency care for primary care. Here cultural beliefs are not addressed and caregivers do not receive proper asthma education (Clement, Jones, & Cole, 2008). This impedes adherence to the development and use of asthma management, specifically with AAP creation, with “patients who are more likely to implement an integrated plan that accommodates their safe but unconventional beliefs and practices with standard biomedical approaches” (George, 2012, p.9). Hence, caregivers who leave the ED either without an AAP or without the complete understanding of that plan cannot be expected to properly manage asthma and will likely continue to use the ED (Clement et al., 2008).

Wilson et al. (2015) contend that lack of consistent health management at home remains an impediment to successful outcomes; “Caregivers must collaborate with health care providers in order to effectively manage pediatric asthma in the midst of stressful circumstances” (p. 19). An AAP partnering with a patient after a comprehensive review is an effective strategy that improves communication and resulting adherence to asthma medication (Howell, 2008).

**Methods**

This study utilized qualitative methods in order to capture and analyze the beliefs regarding asthma management and use of AAPS of low-income African American caregivers of children with asthma, having a household income of less than $35,000 annually and some high school education. To date, studies that have used qualitative methodology to gain insight into the use of AAPS have been conducted in the United Kingdom and Australia (Bhogal et al., 2006; Douglas et al., 2002; Gibson & Powell, 2004; Sawyer, 2002); more current studies need to be done.

This study was undertaken at a nurse-managed low-income housing development community health care center that provides comprehensive health services to specified families and residents. Study participants were referred to the study at the request of the interviewer research assistant, who had developed trusting relationships with select members of the community due to prolonged engagement at the center.

After obtaining IRB approval, interviews were conducted using a semi-structured guide composed of open-ended questions, sent for transcription, and reviewed by the study team that comprised the primary investigator (PI), co-investigator, study coordinator, and research assistant. Interviews were entered into the NVivo qualitative data management program and coded; whenever possible, the categories created to describe the codes reflected indigenous (emic) (Patton, 2002) concepts voiced by caregiver informants.

**Analysis of Data**

A research assistant interviewed three caregivers individually, recorded the interviews via iTunes®, and sent the group of three interviews for transcription. This process was repeated three times. Once the team members read the interview transcripts, each developed his own emerging codes and categories. The research team met for analysis to consider categories produced with codes of exact respondent words as in NVivo and Excel and to offer their own individual category selections for category development. After the third group of interview data were examined for any new categories, none were found; saturation was presumed and interviewing ceased (Ryan, Coughlin, & Cronin, 2007).

**Characteristics of Caregivers**

A purposive sample of nine African American caregivers of children with asthma from three housing communities in Newark, NJ comprised this study. Of this sample, the relationship of caregiver to child revealed that all nine caregivers were female heads of household; either mother (seven) or grandmother (two) to the child. Five participants had more than one child in their care. The children’s ages ranged from 3 to 15 years. The annual median incomes were: $22,000 for seven residents; $15,000 for two residents. Newark’s average median per capital income in 2015 dollars was $28,930 (U.S. Census Bureau, 2015). Each caregiver was a unique individual with singular reactions to circumstances that destined the choices and decisions they would make for the care of their child.

**Interview Guide**

A semi-structured interview guide was derived from potential barriers to using AAPS as identified in the literature and subsequent to each set of three interviews, to elicit participants’ perceptions of asthma management and AAPS. The interview questions were simplified to promote understanding for the caregivers. They were tailored to the caregivers with more exploration of a topic that they thought was
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