

ORIGINAL ARTICLE

Mexican-American caregivers' perceptions about asthma management: a photovoice studyJulie Marie Postma, PhD, RN¹, Robin Evans-Agnew, PhD, RN, AE-C², and Jared Capouya, MD³¹Washington State University College of Nursing, Washington State University Puyallup Research and Extension Center, Puyallup, WA, USA,²Nursing and Healthcare Leadership, University of Washington Tacoma, Tacoma, WA, USA, and ³Mary Bridge Children's Hospital, MultiCare Health System, Tacoma, WA, USA**Abstract**

Objective: The purpose of this study is to report how photovoice was used to (1) ascertain Mexican-American caregiver perspectives about asthma management, and (2) engage caregivers in dissemination. **Methods:** Eleven Mexican-American caregivers of children with asthma were recruited and given cameras to photograph what helped or hindered their ability to care for their child. Participants prioritized which images to share, discussed the images with the group, and wrote accompanying titles and captions in four photovoice sessions. Sessions were in Spanish and occurred in a community setting. Participants presented their work to peers and community members. Identified issues were subsequently categorized by investigators according to the four components of asthma care. **Results:** Participants prioritized 32 phototexts, the majority of which ($n=20$, 63%) reflected activities associated with environmental control. Caregivers highlighted asthma triggers, and suggested ways to maintain indoor air quality (IAQ) through home cleaning. The need for policies that enforce smoking bans in shared housing and public places was identified as an important strategy to improve outdoor air quality. "Education for a Partnership in Asthma Care" was represented in six (19%) phototexts. Five phototexts (16%) represented "Assessment and Monitoring". Only one phototext (3.13%) primarily represented "Medications". **Conclusions:** Results support the need for active partnerships between caregivers and providers. Photographs can serve as the basis for reciprocal education between patient and provider, especially in the area of environmental triggers. Provider visits should include assessment, strategies and resources to maximize IAQ. Photovoice facilitates caregivers' ability to advocate for improved asthma management and health equity.

Keywords

Community-based participatory research, Mexican Americans, pediatrics, perception, photography

History

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Introduction

Asthma is a chronic condition characterized by reversible airflow obstruction due to airway hyper-responsiveness and inflammation. Costs associated with asthma are substantial, with the most recent estimate totaling 56 billion dollars [1]. Asthma affects 7.1 million children aged 0–17 years and disproportionately affects racial and ethnic minorities and families living in poverty [2]. Hispanic populations are disproportionately affected by asthma with almost 3.6 million U.S. Hispanics (approximately 7%) reporting having asthma.

Asthma is a manageable disease. Suboptimal asthma management is burdensome to patients and their families in terms of human suffering, a decreased quality of life, lost school and work days, hospitalizations and death [3]. The burden of asthma is particularly heavy on Hispanic children [4,5]. Hispanic children are 70% more likely to visit the

emergency room for asthma and 40% more likely to die from asthma, as compared to Non-Hispanic whites [6]. Although the prevalence of asthma differs among Hispanics subgroups, with Puerto Ricans having the highest prevalence, evidence suggests that asthma is under-diagnosed among Mexican-Americans [4]. Hispanic children with asthma face many barriers often leading to inadequate diagnosis and treatment of the disease [5,7]. Poverty, lack of access to quality healthcare, language/cultural barriers, environmental factors, and possible genetic influences, are some of the many areas impacting the management and severity of asthma among Hispanic children [4,5,7].

Improved scientific understanding of the disease process has led to improvements in asthma care and development of evidence-based clinical practice guidelines. The core components of comprehensive asthma management within the "Guidelines for the Diagnosis and Management of Asthma", include: Assessing and monitoring; Education for a partnership in care; Control of environmental factors and co-morbid conditions; and Medications [3]. Previous studies provide evidence that achieving and maintaining asthma control via

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these four components of care is complicated by factors related to social determinants of health. For example, receipt of an asthma diagnosis is predicated on access to health care. Hispanic children are more than two times more likely to be uninsured than Non-Hispanic white children [8]. Language barriers, limited health literacy, and differences in parent and providers' communication styles are challenges to developing a partnership in care [9–13]. Controlling indoor environmental factors often assumes that families have the ability to make structural changes to their homes but renters do not have that privilege [14]. Further, Hispanics are more likely to live in areas that exceed federal standards for toxic pollutants than Non-Hispanic whites [15]. Finally, medication compliance requires that patients and caregivers believe medications will work and can afford the medicine. According to the CDC, one in five Hispanic adults cannot afford their asthma medications [16]. Cultural beliefs and the use of home remedies may affect medication management such as the daily use of inhaled corticosteroids among Hispanic families [12,17].

Clinical practice guidelines are helpful to clinicians practicing in primary care settings, but asthma disparities result from a complex interaction of factors on multiple ecological levels [12,18]. Integrating primary care and public health requires community participation in health care decision-making [19]. As causes of asthma are poorly understood, and there is no cure for asthma, a better understanding of asthma management among caregivers is an important step to developing a partnership in care and diminishing health disparities associated with this chronic disease. Asthma self-management should be tailored to patients and the communities in which they live.

Participatory approaches to research can help caregivers and patients address their own needs and participate in health care decisions. Photovoice is a participatory method that may be well-suited for engaging marginalized women in asthma management research through increased personal empowerment, improved understanding of community needs and assets, and enhanced community engagement in action and advocacy [20,21]. The purpose of this study is to report how photovoice was used to (1) ascertain Mexican-American caregiver perspectives about asthma management, and (2) engage caregivers in dissemination of their work.

Research design and methods

Photovoice is a participatory research process through which people can “identify, represent, and enhance their community” by taking photographs that record their everyday realities to foster social change through critical discussion [21]. Photovoice is based upon the theoretical literature on education for critical consciousness, feminist theory, and empowerment [21,22], and has been a successful strategy to engage Hispanic populations in the research process. For example, photovoice has been used to understand Hispanic perspectives on issues such as teen pregnancy [23], immigration [24], and environmental health risks [25]. As a participatory method, photovoice increases issue ownership and opportunities for capacity building at the community level [26,27].

Ten caregivers were recruited from a Hispanic parent advisory group to an asthma home visiting program to

participate in the study. Research suggests that a sample size of 10 is adequate in identifying a breadth of issues, prioritizing those issues, and following up on a subset of issues [20]. Inclusion criteria consisted of: (a) self-identifying as a Hispanic adult, (b) Spanish or English speaker, (c) caregiver of a child with asthma. To characterize the participants, two written questionnaires were administered at the first session in their preferred language (English or Spanish): (1) An 11 question demographic questionnaire, and (2) The 13 question Pediatric Asthma Caregiver Quality of Life (PACQOL) [28] (intraclass correlation = 0.84). The PACQOL has 13 questions related to two domains: emotional function and activity limitations. It uses a 7 point Likert scale, with one signifying severe impairment and seven signifying no impairment. Higher scores indicate better quality of life.

Four, 1.5–2 hour sessions were held two weeks apart at a school that hosts a family literacy program (through Head Start/Early Childhood Education and Assistance Program) where many participants were enrolled. The photovoice sessions were facilitated by a bilingual interpreter experienced in asthma outreach. Sessions were co-hosted by one member of the investigative team. Participants received grocery store gift cards (\$40 for each session) and a digital camera (\$85.00) for their participation in four sessions and two presentations, which occurred between February and May 2014. Childcare was provided on site. The research was approved by the MultiCare Healthcare System Institutional Review Board prior to the start of study activities.

An introductory session was held to consent and train participants in photovoice methods, including how photographs may be used, ensuring participants' safety, and subject privacy. Participants were given digital cameras and asked to take pictures of things that represent what helped or hindered their child's asthma management. In sessions two and three, participants selected some or all of photographs to share with the group. Photographs were digitally uploaded and images projected. Women told stories about the photographs, using the mnemonic SHOWeD: S: What do you See here?; H: What's really Happening here?; O: How does this relate to Our Lives?; W: Why does this problem, concern or strength exist?; D: What can we Do about it? [29,30]. In session four, participants each selected up to three of their own photographs and prepared a title and a caption to accompany the photographs, hereafter referred to as “phototexts”. Captions combined the participant's own writing and a transcribed quote made from a statement recorded by each participant about their select photographs. Captions were translated into English by the bilingual facilitator. Participants also disseminated their work at two community exhibitions, described in the results section.

As a participatory methodology, photovoice participants “drive the analysis” [30]. Analysis occurs in three stages: selecting, contextualizing, and codifying [21]. Participants self-selected the photographs most significant to them and contextualized the photographs by telling stories about the image to the other participants. They codified the photographs as a group by determining which issues, as represented in the photographs, should be highlighted for dissemination through the exhibitions.

Phototexts were used as the primary data for analysis. For the purposes of this paper, the investigative team

independently categorized the phototexts into each of the four activities of asthma management, per the Asthma Guidelines [31]. In addition, the team indicated whether this activity was primary or secondary in meaning within the phototext. Differences in categorization were reconciled through discussion among the investigators. Demographics were summarized using descriptive statistics. Participant scores from the PACQLQ scale were averaged across the entire scale and within each domain.

Results

Eleven female caregivers participated in the project and all were mothers to at least one child with asthma. All of the women were born in Mexico. The average age of the women was 35 (Range: 26–41). Nine (82%) reported Spanish as their preferred language, whereas two women had no preference between English or Spanish. On average, the highest level of education completed in school was 8.7 years (Range: 6–12). Using a dialogic interview technique, the women were also asked to reflect on which of their demographic characteristics (e.g. age, birthplace, education) were most valuable to them in caring for their child with asthma [32]. (Women could select more than one response option.) Education was most frequently selected ($n = 8$, 73%), followed by ethnicity ($n = 5$, 46%), age ($n = 4$, 36%), birthplace ($n = 4$, 36%), gender ($n = 3$, 27%) and preferred language ($n = 2$, 18%). On average, the women had “some” experience taking pictures (Average 2.6, Range 1–5, with 1 being no experience) although only two women owned a camera (18%). Ten women (91%) reported having participated in the asthma home visiting program through the local health department.

Ten women completed the Spanish version of the PACQLQ. The average score, on a scale from 1 to 7, was 4.9 (Range 3.3–6.4), reflecting a moderate degree of impairment. The average score for the activity limitation domain was 5 (Range 3.0–7.0) and the emotional function domain was 4.9 (Range 3.4–6.1).

Participants prioritized 32 phototexts for presentation and analysis (Table 1). Ten phototexts (31%) related to more than one component of care. The majority of phototexts reflected activities of environmental control either as primary ($n = 20$, 63%) or secondary ($n = 6$, 19%) subject matter. “Education for a Partnership in Asthma Care” was represented in six (19%) phototexts. Five phototexts (16%) represented “Assessment and Monitoring”. Only one phototext (3.13%) primarily represented “Medications”. However, medications were identified as secondary in an additional four phototexts.

Among the phototexts classified as representing “Control of Environmental Factors and Comorbid Conditions”, caregivers highlighted asthma triggers such as pollen, dander, dust, mold and mildew, cigarette smoke, and sawdust. They identified safe and unsafe cleaning products, and suggested ways to keep triggers out of the house by using doormats and changing out of work clothes. For example, in her phototext titled “Saw Dust at Home”, one participant suggested that “It is important for people who work at a sawmill to change clothes because their work clothes may bring saw dust residue”. Pictures also depicted the importance for caregivers of keeping the house ventilated using kitchen and bathroom

fans, and the need to regularly change furnace filters. Another participant was concerned about the actions families could take in environmental management. In her phototext, “Keeping the Air Clean in our House”, she stated, “I took this photo because it is very important to remove your shoes before entering a house, because shoes bring much dirt and debris from outside. And it is very important to keep the carpet clean especially if we have babies that crawl, because everything that they find, they put into their mouth”. Women identified strategies to monitor temperature and humidity in the house, and made suggestions as to how healthcare providers could assist in teaching parents how to use hygrometers. Caregivers also emphasized the need for policy change to promote clean air, such as banning smoking in parks, in cars, and enforcing no smoking in public places.

Potential comorbid conditions were addressed in three phototexts. The phototexts stressed the importance of exercise to prevent stress and cope with Attention Deficit Hyperactivity Disorder. One parent explained, in her phototext titled, “Physical Activity”: “As a mom concerned about the health of my child, I seek options for my child to be active. Physical activity for a child with asthma is very important; in this picture my son is taking swimming lessons. Swimming helps to strengthen his nervous system and have no stress this helps improve his asthma problem”.

Education at multiple points of care was highlighted in six phototexts, representing the core component, “Education for a Partnership in Care”. For example, in the phototext titled “Clean Air-The Heaters”, the local health department’s asthma home visiting program was mentioned as a way to learn about indoor air quality. The hospital’s interpreter program was highlighted by a caregiver as an important aspect of hospitalization. Two phototexts described the importance of parent and provider communication. For example, one participant stated, “It is very important that as a parent, you should let the doctor know that your child has asthma before surgery so that he or she can receive the treatment of asthma before surgery”.

The importance of “Assessment and Monitoring” was reflected in five phototexts, including one titled “Security”, which identified the role that parents play in monitoring their child’s health: “... as his parents we play a very important role. When he feels sick, being close to us makes him feel more comfortable than if he was with other people such as teachers or friends. He knows that anyone near can help him if he has an asthma attack but he knows his parents will act faster to help”. Another dimension discussed by caregivers was monitoring a child’s health during play and exercise.

Medication management was identified as a primary component of care in one phototext, and was identified as a secondary component in five phototexts. Caregivers discussed timing medication to prevent allergies, keeping medications in reach to “prevent more severe problems” and the challenges parents face administering a nebulizer to a small child. In the phototext titled “My Child Crying”, the participant stated “This is the problem with my child when it’s time to put on the nebulizer it’s hard for him because the medicine leaves a bad odor and flavor”. Another photograph depicted a rescue inhaler and an ICS inhaler side-by-side.

Table 1. Titles of photographs categorized by the core components of asthma management.*

Core components of asthma management			
I. Assessment and monitoring	II. Education	III. Control of environmental triggers and comorbid conditions	IV. Medications
Doing some exercise is good!		Grass Pollen	Doing some exercise is good!
		The dangers of mold!	
		Signs	
		Fan	
	The fan is very important	The fan is very important	
		Keep stuffed animals clean	
Medicine to reach			Medicine to reach
	Fresh air	Fresh Air	
		Our house	
		Cleaning	
Security		Exercise	
		Getting out of routine “the country”	
		Physical activity	
		Mold	
		Cleaning	
		Keeping the air clean in our house	My child crying
		Banning smoking in parks	
		No smoking inside the house or cars	
		No dogs on furniture	
	Hospital		Hospital
	Child in the hospital		Child in the hospital
	Worst stage for allergies		Worst stage for allergies
Fishtank		Saw dust at Home	
Plush toys		Black spot	
		Fishtank	
		Plush toys	
	Clean air – the heaters	Clean air – the heaters	
		Avoid harmful chemicals	
		The dangers of mold in the house	

*Bold text signifies the primary component of care in which the phototext was categorized.

Participants disseminated their work at two events. First, participants invited peers from the family literacy program to a facilitated session where all 32 of the phototexts were exhibited. Participants shared the stories represented in the photographs with the invitees in small groups. Invitees were then asked to share what helps or hinders their ability to care for their child with asthma based on what did or did not resonate in the phototexts they viewed. After a period of discussion, the small groups each shared two to three identified issues with the large group. Interpreters orally translated the group reports into English. Responses were recorded on a flip chart and will be the basis of future education and research initiatives for a local asthma coalition. For example, in the large group people expressed concern over indoor environmental triggers at child care settings and schools. The use of safe cleaning products and the lack of building maintenance in those environments were discussed as extensions of this work. An additional issue was the need to educate other parents to talk to their health care providers so they can understand what is going on with their children.

The second exhibition was at a public event at a local university coordinated by an asthma coalition for World Asthma Day. After a welcome by the director of the local health department, and a short talk about local asthma prevalence, the audience was invited to view the phototext gallery and speak with the women about their work. One of

the photovoice participants then served on a panel, representing a parent perspective. The panel facilitator invited the audience to share what the photographs meant to them, generating conversation between the panel and the audience. For example, upon seeing “Security”, a woman discussed the challenges of caring for her child as he approaches his teenage years, given that he now has “a mind of his own”. This generated a discussion about asthma management over the lifespan and the importance of ongoing assessment and monitoring. Over 60 people attended the event, including faculty, providers, registered nurses, students, and community health workers. Representatives from the local public health department, housing and clean air agencies were also present.

Discussion

This photovoice project aimed to ascertain Mexican-American caregiver perspectives about asthma management and engage caregivers in disseminating their work. Both goals were met. Minimizing environmental triggers for asthma to optimize indoor air quality was the most prominent component of care identified in the phototexts. This may be because those triggers are modifiable [14], and/or because participants want to teach others the techniques they have learned through their participation in an asthma home visiting program. Parents reported that they were able to make adjustments at an

individual-level to their home environment, similar to another study of Hispanic caregivers with children who have asthma [33]. However, participants were still concerned about areas of environmental change that they perceived were beyond their powers and required protective policy changes, such as enforcing smoking bans in public spaces. While outside the immediate scope of the Guidelines, these issues speak to the importance of parents, providers, and public health practitioners working collectively to support legislation that protects public health [34,35].

Medication management was not a prominent theme, although managing asthma medications and associated devices (e.g. spacers, nebulizers) is known to challenge caregivers [36]. In contrast to other study findings, where Hispanic caregivers express high levels of concern about asthma medication use, our study participants described the preventive role that allergy and ICS medications play in controlling asthma [17]. Likewise, participants did not express confusion over contradictory recommendations from lay healers versus health care providers, as reported in other studies [33]. In fact, the main phototext concerning this issue depicted a corticosteroid inhaler commonly on the formulary for medicaid patients, perhaps indicating that corticosteroids are acceptable to this group of participants.

Implications

Clinical implications

Findings have important implications for providers, public health professionals, and researchers. Evidence from this study supports the development of active partnerships between clinicians and caregivers. This specifically means establishing open communication, identifying and addressing patient and family concerns about asthma and asthma treatment, identifying treatment preferences regarding treatment and barriers to its implementation, developing treatment goals together with patient and family, and encouraging active self-assessment and self-management of asthma [3]. This is especially important between providers and Spanish-speaking parents of children with asthma, as research shows a disparity in the receipt of quality asthma care between Spanish-speaking Hispanic parents and Non-Hispanic white parents [37].

This study also demonstrates that photographs provide a tangible link between the concerns and activities of caregivers and those who would want to assist them in managing asthma. Photography can be used as the basis of conversations between providers and their patients so that education is reciprocal. Pictures give voice to participants on multiple levels of concern and can be a starting point to work collaboratively toward family-tailored care. Providers can encourage patients to bring in photographs that depict their child, their home, or their neighborhood, such that barriers to asthma management can be identified and addressed. Photographs can also be used to promote wider discussions in the community concerning disease management. For example, during the World Asthma Day event, a nurse in the audience helped a mom strategize different inhaler options for her child after she saw a phototext of a child making a distasteful face due to the taste of the nebulizer. Asthma care can only be tailored to the family's

experience if the clinician is aware of their experience. Photographs can help build that awareness.

Policy implications

These findings also focus efforts on the importance of addressing social determinants of health in asthma management, such as improving housing quality. Asthma home visiting programs, which address environmental triggers in the home environment, have been shown to be effective in symptom management and decreasing urgent care visits [38,39]. One mechanism for these positive outcomes is caregiver education and active involvement decreasing environmental triggers [38]. The phototexts suggest that participants are poised to teach and demonstrate these approaches to others. Research demonstrates that volunteers can promote positive behavioral change through educating peers on ways to minimize indoor environmental triggers [40]. Despite these understandings, there remains a profound lack of resources to train volunteers and community health workers to conduct home visits. Access to home visiting programs on a nationwide scale, and reimbursement for home visits are barriers that clinicians, public health practitioners and the public need to address in order to optimize asthma management [41].

Advocacy training has been suggested as an important component to photovoice projects, given the expectation that projects promote capacity in the communities in which they take place [20,42]. While no advocacy training was offered in this study, there was evidence that personal empowerment and advocacy took place. Within the scope of the project, the women presented to their peers, to the public, and to leaders within important public health agencies. Women taught others what they know about living with a child with asthma and asthma management through disseminating their work at these public events. Women also used the phototexts for a presentation made in English as part of their literacy coursework, independent of the project. Thus, they were not only empowered through the photovoice study, but also through the medium of learning English.

Leveraging that personal empowerment could yield additional research opportunities, in terms of examining the most effective ways to involve caregivers in coalition efforts to collectively advocate for healthy housing through, for example, enhancement and enforcement of existing housing codes, and smoke-free multi-family unit housing [41]. Likewise, personal empowerment might give rise to efforts to address their concerns, for example by speaking at a local city council meeting regarding second-hand smoke exposure in local parks. Photovoice activities can give a collective voice to such strategies for addressing structural changes to improve asthma management activities and decrease inequities.

Limitations

Findings from this study were from a small group of Mexican-American caregivers and should not necessarily be generalized to caregivers living in other communities. That said, the findings resonated with themes identified in other photovoice studies focused on chronic diseases and/or children's environmental health. For example, reported factors that positively influenced students' health and asthma in one study included

social support (e.g. family, friends), neighborhood environment (e.g. clean air and homes), and lifestyle factors (e.g. physical activities) in addition to well-established factors such as medications and environmental triggers [27]. Women in this study reported similar factors. Latina women in another photovoice study on children's environmental health focused on the impact that housing has on health, identifying many of the same indoor air quality issues as identified in this study [25].

The women recruited for this study had all had previous contact with an asthma outreach worker. These experiences, in addition to receiving an incentive for participating, could have influenced their decisions on which photographs to take and discuss. In addition, the opportunities for being able to take photographs that typified encounters with medications (e.g. related to seasonal allergies) and clinicians might have been limited during the data collection period. It could also be argued that many of the direct experiences and frustrations participants have in managing asthma occur outside of the clinical encounter and inside the home environment.

This study was also limited by the depth into which specific discussions pertaining to empowerment, structural forces, and critical consciousness could be achieved. This was because of limitations in the experience of the translators and the English-speaking facilitators. It is possible that nuances in the Spanish texts pertaining to such oppressions might have been missed by the interpreter. That said, despite these limitations, this study generated findings that did address structural oppressions in the participants' environments, such as smoking in parks.

Conclusions

This study has provided important new knowledge on facilitators and barriers to asthma management experienced by a small group of Mexican-American caregivers of children with asthma in Washington State. While caregivers have been able to use their photographs to discuss their concerns about all four activities of asthma management, environmental control remains the concern they shared the most opinions about. Such discussions have yielded an array of important understandings concerning how these caregivers perceived such environmental threats, including individual, family, clinical, and community concerns. Furthermore, this study has demonstrated the utility of photovoice in describing chronic disease management and environmental concerns for marginalized groups, especially women. Photovoice not only is an adept engagement method, but it may also be a unique way to provide an important catalyst for the sharing of environmental health concerns between caregivers and health practitioners.

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Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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