Opportunities for empathetic responses in field interview scenarios investigating home health routines

Introduction
This proposal describes a reflection at the midpoint of data collection in the first round of interviews for grant-funded research exploring medical reminder systems used by mothers of children with asthma. For several weeks, we have conducted interviews in participants’ homes. The semi-structured interview questions probe existing reminder and notification systems used to manage family life, including maintenance care for children with asthma.

The long term goal for this study is to bring mothers of children with a chronic condition together with healthcare providers to design better healthcare reminders. That goal involves some unique challenges in establishing an open and trusting environment in the interview and design processes. These interviews can be seen as the first step in understanding how to engage the mothers who will benefit from the reminders system, and for this reason we have chosen to reflect on interview transcripts to identify the most effective interview techniques for fostering trust with participants.

The area of clinical research has developed guidelines for effective use of empathy in patient interviews; in
the clinical context, empathy is used to elicit effective information about each patient’s state of mind and to influence outcomes in adherence to treatment regimens [4]. Furthermore, empathy in the clinical setting is operationalized as an “opportunity” for the clinician to respond to a patient, utilizing both body language and utterances for the purpose of gathering information that clarifies a patient’s mind set or life experience [1].

Although we are not working in a clinical context for the purpose of this study, we draw from the idea of gathering valuable contextual information from research participants to enrich our findings, as well as the notion of opportunities for empathy. In reviewing the first round of interview transcripts, we have found empathetic opportunities and responses on the part of the interviewer to be crucial in 1) establishing a connection with participants and 2) eliciting the most helpful information about the subject matter. We are interested in the Enabling Empathy in Health and Care workshop for the purpose of discussing our strategies in interviewing, and carrying out lessons learned from other research to improve data collection throughout the course of our study.

**Literature: Parental mediation in pediatric health care**

Parents are important decision makers and information mediators in child health care, and are often a crucial link to doctors in describing asthma symptoms and triggers to their pediatricians. As such, parents can be important participants in research related to health care outcomes for children, and the stresses on parents in caring for a child with a chronic illness encompass economic, emotional, and social realms [3]. Nursing literature has taken a holistic view of child health care, incorporating parental quality of life in its research. Pressures on parents with children of asthma include managing sick days taken from work to care for a sick child, as well as transporting a child with asthma to medical appointments [5]. Finally, patient education extends to the parents for the purpose of increasing adherence to medication schedules [2].

**Our experiences in interviews**

We have identified three themes in research interview transcripts so far related to opportunities for expressing empathy in the elicitation process. All three of these themes are important for conducting an empathetic interview. The goal of eliciting the best information by using empathetic listening and response methods enables us as researchers to respect the participant’s world view (primarily) and to generate authentic findings to best serve the population of interest (secondarily).

The first theme involves the participant state of mind – the extent to which the mother has accepted the asthma diagnosis. The second theme has emerged during narratives involving a perceived failure on the part of the caretaker in refilling medications, giving us important information about the pressures and constraints under which parents must make decisions about asthma maintenance routines. Finally, we have found that participants are taking care of their children in a complex family environment – their children are more than just a diagnosis, and listening carefully to the context of asthma maintenance routines is essential. We outline the three themes below.
Participant state of mind regarding asthma diagnosis
The first important factor in empathizing with participant mothers occurred during the recruitment phase. In certain cases, parents may not agree with the diagnosis of asthma from the child’s pediatrician. This could be due to a variety of reasons, as emerged in subsequent interviews; e.g., the child does not have frequent asthma attacks or the child’s symptoms appear to the parents to be bad allergies. For this reason, we found it helpful to recruit parents based on reported asthma maintenance routines and related behaviors, rather than focusing on a child’s diagnosis. This acknowledgement of the mother’s and parents’ state of mind regarding asthma diagnosis has been invaluable in gaining a range of participants for the study, as well as allaying participant concerns that a clinical diagnosis is central to the interview. In recruiting participants who followed an asthma maintenance regimen for their children, we were able to elicit responses that demonstrated the mental models the mothers applied to asthma as a disease:

“I’m not 100% convinced yet, that [child] is a full asthmatic, because even now – that’s something once again I’m discussing with the doctors.” [P03]

“My son has a form of asthma, but he doesn’t have the asthma attacks or anything to where it would be a red flag.” [P09]

For the purpose of eliciting information about medical notifications and reminders from the parents, we found that focusing on maintenance and inhaler use behavior removed controversy from the interview. That is, there was no need to focus on the asthma diagnosis, thereby possibly distressing or offending the mother, in order to gain valuable information for the exploratory stage of the study.

Expressions of guilt
The second factor we encountered from reviewing the interview transcripts involved eliciting information about failures in the maintenance or inhaler routine. Mothers have expressed guilt about lagging on inhaler refills, citing hectic schedules or the cost of the medicine as barriers to reliably refilling a child’s medication:

“For [child’s] last inhaler, I gave it to him and it got to zero and we don’t know how long it was on zero because we just hadn’t been – since they started kindergarten, it’s been a crazy fall because it’s all these new routines.” [P01]

“Usually what happens is that he’ll be like ‘mom, I’m out,’ and I’m like, ‘oh no!’...I was thinking about doing the mail order, but buying two [refills] up front is harder, because I don’t have an income right now so usually I’m like, ‘can we do it this month?’” [P09]

When mothers have expressed embarrassment or guilt, we have found that reassurances are the most effective empathetic response. Statements from the interviewer acknowledging the frequency of failures from general experience in the study (“It’s okay, I’ve heard from other moms who forget sometimes”) or an empathetic interjection (“It sounds like certain times of the year are hectic!”) have been successful in putting mothers at ease when speaking about instances of shortcomings in their household or medications management.
Asthma maintenance care in the context of family life

Finally, we have faced participant narratives detailing failures in adhering to care plans or maintenance inhaler schedules. One mother stated that she did not adhere to the care plan set forth by her doctor for her asthmatic child due to a hectic child care schedule [P12]. In this case, the mother made the point that she relied upon unpaid child care help from family members, and felt uncomfortable insisting that family members learn the evening maintenance inhaler routine. At this point, the interviewer responded that it must be difficult to rely on family, and used body language (nodding, and an open, “listening” posture) to acknowledge the mother’s discomfort in revealing the noncompliant behavior. Often, body language was just as important to empathetic listening tactics as reassuring verbal responses.

In addition to noncompliance with maintenance inhaler use, the primary interviewer was surprised to find that many households visited in the asthma cohort had pets (including dogs, cats, and chickens). The mothers often introduced the interviewer to the pets, at which point the interviewer would talk about her cat at home. The small talk around pets worked as an “ice breaker” of sorts with the mothers, and even though it seemed a small gesture, that moment of empathy (and identifying with another pet owner) proved a good way to connect with participants. However, some participants did go on to comment during the interview on the presence of a pet in the household; some mothers acted more chagrined than others:

“We got a cat. Don’t tell her allergist. He’ll kill me.”
[P10]

In this case, the interviewer would bring the conversation back to family life, pointing out that family pets can be a lot of fun or foster a sense of responsibility for the child. In a situation where mothers are meeting with a researcher in their own home, we found this type of response put participants at ease and reassured them that they were not being judged for their family and home life.

Implications for research and design

The interview excerpts above are intended to give examples of opportunities for empathetic responses from field interviewers. We have found that we are better able to learn about the complex influences on family life that affect asthma maintenance routines and general adherence to care guidelines by demonstrating an empathetic position with participants. On the part of the interviewer, the act of listening, reacting appropriately to parental statements of guilt or failure, and otherwise exercising empathy is essential for eliciting good data for the research study and for respecting research participants.

Finally, as we move forward into the second stage of our project – one that will utilize a participatory design exercise to elicit further information from parents – it will be important to present design narratives and scenarios that parents are able to recognize from their own experience [6]. We will incorporate the findings from our exploratory interview phase to incorporate the pressures mothers with asthmatic children face in scheduling, maintaining routines, and caring for busy children and spouses.
References


