

Qualitative research in teens with asthma: Understanding patterns of symptoms and self-management

Jennifer R Mammen, MSN NP-C PhD Candidate, Hyekyun Rhee, PhD PNP, Sally Norton, PhD RN FNAP FPCN FAAN, Arlene Butz, ScD RN

Background

Self-management is central to controlling disease and preventing morbidity and mortality. Many teens have suboptimal asthma control, which is often attributed to poor self-management. Thus it is important to:

- Understand how teens self-manage their asthma
- Understand perceptions and rationales underlying behaviors

In this study we used interviews, self-management voice-diaries, and card sorting techniques to map teens' unique patterns of symptoms and responses and facilitate in-depth discussion of asthma self-management.

Study objectives: To explore teens' experiences of asthma self-management across life-contexts, and to describe how teens manage their asthma and what is important to them.

Methods

Design: Theoretically informed case-based qualitative description

Setting: Community, Emergency Department, Pediatric Pulmonary Department, Prior study subjects

Participants: Teen/parent dyads (N=30)

Data collection methods: (1) semi-structured first teen interview (1 hour); (2) semi-structured parent interview (1 hour); (3) 2-week self-management voice diary; (4) open ended second teen interview (1 hour); (5) symptom-response card sort to map self-management behaviors

Data Management: Interviews transcribed using modified Jefferson Transcription method and uploaded into ATLAS.ti

Data analysis: open, process, and pattern coding (Saldaña)

Results

1. Teens have unique treatment thresholds for responding to asthma symptoms.

- Treatment thresholds = the point at which asthma symptoms are considered important enough to require use of rescue medication
- Symptoms **less than** teen's threshold were usually considered low-level, unimportant, and not needing rescue medication
- Symptom thresholds were *individually* and *contextually* variable, and corresponded with the teens usual symptom pattern
- Teens with uncontrolled asthma had higher thresholds (i.e. delayed response) for reacting to symptoms than teens with controlled asthma
- The most common treatment threshold was the point at which asthma symptoms interfered with activities

2. Teens with asthma felt that not all asthma symptoms were important.

- Symptoms that occurred on a regular basis (i.e. daily) were not viewed as serious and were referred to as "**normal symptoms**"
- Normal symptoms mirrored teens usual symptom pattern (Ex. Poorly controlled teens considered wheezing "normal;" well-controlled teens did not)
- Normal symptoms were overlooked, ignored, forgotten, and were **not reported** to parents or healthcare providers

3. Clinical definitions of controlled asthma did not correspond well with teens' understandings of controlled asthma.

- Having "controlled" asthma meant not having symptoms of asthma that exceeded teens "**normal symptoms**"
- Teens felt asthma was controlled if they could get the symptoms to go away—either by waiting or by using an inhaler
- Teens with uncontrolled asthma accepted a higher symptom frequency within their paradigm of "controlled" than teens with well-controlled asthma

Case 01 Teen with Very Poorly Controlled Asthma						Treatment Threshold	
1. Coughing	2. Wheezing		3. Itchy eyes	4. Swollen eyes	5. Hard to breath		6. Can't breathe (and nothing else worked)
GET AWAY FROM WHAT'S CAUSING IT	SLOW DOWN	COLD AIR ON FACE	DRINK WATER	WASH FACE OFF	RAG OR COOL CLOTH	CALM DOWN	HOLD BREATH
							RESCUE INHALER
							REST

Case 06 Teen with Not Well Controlled Asthma				Treatment Threshold
1. Chest tightness	2. Short of breath	3. Wheezing	4. Coughing	
WAIT	SLOW DOWN	HIT CHEST	TAKE INHALER	DRINK WATER

Case 08 Teen with Well-Controlled Asthma					Treatment Threshold
1. Coughing	2. Chest tightness	3. Wheezing	4. Short of breath	5. Pain with cough	
WAIT	TAKE ALBUTEROL	REPEAT ALBUTEROL	BREATHING TREATMENT	GO TO EMERGENCY ROOM	

Teens with daily symptoms of asthma may report having no symptoms because they have not exceeded their threshold for perceived "normal" symptoms.

Discussion

Our data extend upon prior research, indicating teens underreport and ignore asthma symptoms, by suggesting:

Teens thresholds for reporting /responding to symptoms hinges on perception of seriousness of symptoms and understanding of "normal"

- Clinicians and researchers will need to carefully investigate teens' asthma symptoms to understand which are likely to be normalized and not reported

Identification of treatment thresholds can contribute to developing:

- Better understanding of patients' perspectives and experiences
- Targeted self-management interventions and improved health outcomes.

Symptom-response card sort data



UNIVERSITY of
ROCHESTER
MEDICAL CENTER

SCHOOL OF
NURSING