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### Pediatric Asthma Telemonitoring: Literature, Theory, and Application to Practice

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**Pediatric Asthma Telemonitoring: Literature, Theory, and Application to Practice**

Erin Christine Shankel

Scholarly Project

Prepared as partial fulfillment of the requirements for

Doctor of Nursing Practice degree

Belmont University

College of Health Sciences and Nursing

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### **Scholarly Project Introduction**

Asthma is one of the most prevalent and costly chronic diseases faced by Americans today. It is marked by inflammation and hyperresponsiveness of the airways which fluctuates, often unpredictably, in response to triggers. As such, it causes particular challenges symptom management, especially on the part of the patient who is tasked with dealing with these frequent fluctuations for months at a time between regularly scheduled health care appointments. This is further complicated when the patient is a child, and symptoms must be interpreted and managed second-hand by a caregiver. Uncertainty about how to manage symptoms, as well as minimization of symptoms, contributes to delays in seeking treatment, leading to higher acuity visits, increased costs, and poorer outcomes.

Meanwhile the field of telemonitoring is evolving. New technologies offer patients and providers novel ways of communicating between visits. This is supported by telemonitoring literature and theoretical frameworks, which will be addressed in this manuscript. It is the assertion of this project that asthma symptom telemonitoring holds promise as a way for patients to conveniently and more adequately manage symptom fluctuations from home.

The first paper in this manuscript surveys the existing literature on asthma telemonitoring modalities. The second paper examines the problem of symptom minimization and uncertainty through the framework of Symptom Management Theory. Finally, the third paper is a technical report describing a pilot study that used the AsthmaChecker app among children with asthma and their caregivers to assess linkages to Symptom Management Theory and Diffusion of Innovation Theory. This project and these writings offer new insights into the emerging field of telemedicine and its potential usefulness in the context of pediatric asthma management.

**Synthesis of Literature: Related to Asthma Telemonitoring**

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### ABSTRACT

**Background:** Asthma is a chronic disease characterized by fluctuating symptoms and sporadic exacerbations. National guidelines emphasize the importance of patient self-monitoring of asthma symptoms in conjunction with a written asthma action plan, but barriers continue to prevent compliance. Telemonitoring is an evolving field that may improve compliance with symptom self-monitoring and asthma control.

**Aims:** We sought to review the literature for ways that telemonitoring has been used to facilitate asthma self-monitoring and the outcomes that have been identified.

**Methods:** A focused review of the literature was conducted. Qualitative and quantitative studies were included. The evidence related to various asthma telemonitoring methodologies was reviewed and synthesized.

**Results:** Telephone interviews, Short Message Service messaging, mobile phone applications, electronic asthma action plans, handheld spirometers and exhaled nitric oxide monitors, and Personal Digital Assistants have been used to evaluate asthma symptoms remotely. These methods have been well-received by patients but have shown mixed outcomes on asthma control.

**Implications for Practice:** Close asthma monitoring is required in order to provide adequate treatment for the fluctuations in severity that are characteristic to this disease. Telemonitoring strategies show great promise in improving the way patients and providers identify exacerbations and interact to control them, but more research is needed.

**KEYWORDS** asthma, telemonitoring, telemedicine, telehealth, symptoms, self-management, action plan, monitoring

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**BACKGROUND**

25.9 million Americans were afflicted with asthma in 2011, and that number appears to be rising [American Lung Association, 2012]. People with asthma experience continuous underlying lung inflammation and may remain asymptomatic for varying stretches of time. This inflammation, coupled with characteristic airway hyperresponsiveness to triggers, causes sporadic exacerbations. The management of these exacerbations depends upon patients' self-monitoring and initiative to seek help, which can be problematic because many wait until their exacerbations are severe before contacting a clinician.

Exacerbations can quickly progress and often lead to emergency room visits, hospitalizations, and even death. 2.1 million emergency room visits were directly related to asthma in 2009 [Centers for Disease Control and Prevention, National Center for Health Statistics (CDC-NCHS) 2011)], and subsequent mortality rates were roughly 1.1 in 100,000 [ (CDC-NCHS), 2012].

Asthma exacerbations account for the consumption of disproportionately large amounts of health care resources [Gibson, 2000], costing approximately 56 billion dollars each year [CDC, 2011]. Furthermore, asthma accounts for at least 14.4 million annual lost school days [Moonie et al., 2008] and 14.2 million lost work days [Barnett and Nurmagambetov, 2011] per year.

Exacerbations managed in the primary care setting are more difficult to quantify, but are estimated to occur at a rate of 16,400 per 100,000 population per year [Gibson, 2000]. Because asthma is characterized by frequent fluctuations in symptoms and severity, effective monitoring of asthma control must happen at home as well as in the clinic. Home monitoring of asthma has the potential to drastically reduce exacerbations and adverse outcomes. Guidelines from organizations such as the Global Initiative for Asthma (GINA) and the National Asthma Education and Prevention Program's Third Expert Panel Report (EPR-3) agree that home

monitoring is a critical piece of asthma management, but adherence to these guidelines is weak, and agreement on how this monitoring should take place is a subject of great debate.

According to Healthy People 2020, only 68.4% of patients with asthma received any education about symptom recognition and management during an exacerbation [U.S. Department of Health and Human Services, 2012]. One tool that guidelines recommend to assist with home monitoring is the asthma action plan. These written instructions help guide patients through the appropriate steps for managing their asthma, based either on peak flow readings or interpretation of symptoms. Only 33.4% of all Americans with asthma received a written asthma action plan in 2008 [U.S. Department of Health and Human Services, 2012].

Great debate surrounds the issue of whether objective peak flow readings or subjective symptoms should be utilized in conjunction with asthma action plans for home monitoring.

While the idea of using an objective measurement is appealing, peak flow readings are notoriously effort- and technique-dependent, making them especially problematic for use in children. Additionally, multiple studies have found that the peak flow monitoring does not add appreciable benefits over symptom monitoring [Kotses et al., 2006]. Symptom monitoring is less labor-intensive, and a statistically significant preference for symptom monitoring among patients has been observed [Harver et al., 2009]. What is known is that using either method, symptom monitoring or peak flow monitoring, is better than no monitoring at all.

Nevertheless, patients and caregivers do not tend to systematically monitor symptoms until they become severe, and each individual has a different threshold at which he or she decides to call upon his or her provider for guidance [Fowler et al., 2007]. This threshold could theoretically be standardized by the implementation of asthma action plans, but as previously stated, provider adherence is lacking.

Because patients or caregivers may wait too long to enlist the help of clinicians, exacerbations intensify and become acutely unmanageable. This is the point at which many asthmatics seek treatment. Their asthma status may have reached a very high acuity level, and the likelihood of higher costs and poorer outcomes has unnecessarily increased. Even if the patient is able to be managed on an outpatient basis, they often require oral steroids when, if treated earlier in the course of the exacerbation, they may have been adequately treated with an inhaled steroid with less systemic absorption.

Barriers to patient and provider adherence to asthma action plans have been identified. One of the largest barriers is the general lack of enthusiasm toward guided self-management plans that is frequently expressed by patients and providers. Also, attempts to implement action plans that do not incorporate the patient's individual goals are met with limited success. Patients and providers report a common attitude that following asthma action plans requires too much time and effort and are unnecessarily bothersome [Jones et al., 2000].

Meanwhile, technology is constantly evolving and creating new avenues for patient-provider interactions. "Telemonitoring", a term that refers to the use of remote communication between providers and their patients, is an evolving method of caring for patients remotely. Telephone calls, SMS (text) messaging, and email are just a few of the tools being utilized in the management of chronic disease. The aim of this literature review is to ascertain which telemonitoring methods have been used specifically in the care of patients with asthma, and whether it has been effective in improving patient and provider adherence to home monitoring of symptoms.

## **FRAMEWORK**

The threshold of severity at which patients decide to contact their health care providers during an asthma exacerbation varies from one patient to the next, and several theories have been used to explain this phenomenon. Symptom Management Theory, proposed by University of California San Francisco nursing faculty, looks at the interaction between person, health, and environment with specific emphasis on the way individuals experience, perceive and respond to symptoms [Dodd et. al, 2001; Newcomb, 2010]. Leventhal's Common Sense Model of Illness Representation (CSM) has been used to investigate how patients recognize worsening symptoms, assign meaning to them, and then take action [Fowler et al., 2007]. Both models can help providers understand why and how different patients seek care for asthma exacerbations. The variability in patients' response to worsening symptoms can be problematic, often resulting in high-acuity exacerbations. Most asthma guidelines, including GINA and EPR-3, recommend the use of written asthma action plans to help standardize the self-management of asthma. However, these tools still depend on the initiation of the patient to make contact with the provider. It is yet to be discovered whether telemonitoring, in conjunction with written asthma action plans, helps aid in the appropriate utilization of healthcare resources during times of symptom exacerbation.

## **METHODS**

We searched the following electronic databases from 2009 to 2013: CINAHL, Cochrane Library, MEDLINE, and Science Direct. Search terms included: asthma, symptoms, monitoring, internet, telemonitoring, telehealth, telemedicine, peak expiratory flow rate, asthma action plan, adherence, telephone, electronic, and exacerbation. We excluded articles which were published in languages other than English and were not peer reviewed.

*Types of studies.* We included qualitative, quantitative, and descriptive studies for consideration. We included articles in which telemonitoring was used to interact with asthmatic patients while eliminating those which focused primarily on monitoring conditions other than asthma.

*Participants.* Study participants were asthmatics five and older. When reviewing the ten articles as a group, there was a total of at least 241 children and 1764 adults. An additional 288 adolescents and adults age 12 and older, with a mean age of 49.0, participated in one study [Ryan et al., 2012] that did not specify how many of the participants were adults and how many were children. Most had mild to moderate asthma. Articles referenced various types of health care professionals and settings and took place in several different countries.

## **RESULTS**

*Details of the Included Studies.* A total of ten studies involving 2,293 asthmatic patients were included. Six were randomized controlled trials [deJongste et al., 2009; Deschildre et al., 2012] Møldrup et al., 2012; Prabhakaran et al., 2010; Ryan et al., 2012; van Gaalen et al., 2013], one was a descriptive study (Holtz and Whitten, 2009), one was a randomized crossover design, (Kosinski et al., 2009), and two were prospective observational studies (Bynum et al., 2011; Jiang et al., 2009). When reviewing the ten studies as a whole, patients were age 5 through adulthood (several studies did not specify an uppermost age) and included more than 241 children and 1764 adults. Asthma severity ranged from mild to severe, and patients were without significant pulmonary comorbidities. All reviewed articles are summarized in Table 1.

*Types of Interventions.* The studies reviewed used several different telemonitoring modalities in the context of asthma. These included interactive video technology, internet sites, mobile phone applications, short message service (SMS) communications, personal digital assistants (PDAs), electronic spirometers, and telephone interviews.

deJongste et al. [2009] used electronic measurement and communication of fractional exhaled nitric oxide (FENO<sub>0.05</sub>), a marker of eosinophilic airway inflammation. They also used a PDA to record and transmit symptoms. Similarly, Jiang et al. [2009], Bynum et al. [2011], and Deschildre et al. [2011] used electronic spirometers to monitoring lung function. Bynum et al. [2011] additionally provided interactive video teleconferencing to the participants. Two studies used the Asthma Control Test (ACT), a validated 5-item symptom questionnaire, in a novel way: via the telephone. Kosinski et al. [2009] administered the ACT via direct telephone interviewing while Prabhakaran et al. [2010] used SMS messaging. Holtz and Whitten [2009] also used SMS messaging, but monitored objective peak expiratory flow rates (PEFR) rather than subjective symptoms. SMS messaging was used by Møldrup, Stein, and Søndergaard [2012] to collect symptom monitoring data and provide participants with medication reminders. Ryan et al. [2012] similarly used mobile phones to transmit data on symptoms, drug use, and peak expiratory flow, and to respond with feedback to the participants. Finally, van Gaalen et al. [2013] used an internet-based symptom monitoring program that provided interactive advice and patient education.

*Effects of Interventions.* In the study by deJongste et al. [2009], daily telemonitoring of FENO<sub>0.05</sub> was compared with telemonitoring of symptoms alone. 147 children aged 6-18 with mild to moderate asthma were enrolled from 5 academic centers and 12 hospitals. They were randomized into 2 groups: those recording FENO<sub>0.05</sub> and symptoms and those recording symptoms alone. FENO<sub>0.05</sub> was measured using an electronic airway inflammation monitor (NIOX MINO; Aerocrine, Solna, Sweden) and symptoms were communicated using a PalmOne Tungsten W PDA with TrialMax software (CRF Inc.; Helsinki, Finland). After 30 weeks of telemonitoring, both groups experienced symptom improvement and steroid reduction over

baseline. While there was no additional benefit to monitoring FENO<sub>0.05</sub>, the findings suggest that frequent telemonitoring plays a role in improving asthma control. Additionally, the study demonstrated that 30 weeks of telemonitoring was feasible and well-accepted in children.

Bynum et al. [2011] found that, by using interactive video teleconferencing within the school health setting, children with asthma were able to achieve better outcomes. In particular, hospital admissions decreased during the time span from baseline (mean= 0.20) to 12-month follow-up (mean= 0.00) ( $p=1.00$ ) while reducing Medicaid costs by an average of \$168.40 per child.

School absences decreased from a mean of 4.33 to 2.87 days ( $p= .50$ ) and asthma-symptom days decreased from a mean of 3.26 to 1.33 days. In addition, participants' inhaler technique showed demonstrable improvement ( $p<.01$ ). While outcomes improved in each of these areas, enhanced inhaler technique was the only change over baseline that was statistically significant.

Kosinski et al. [2009] observed 1,181 adults with asthma in a randomized crossover study. ACT symptoms scores were self-administered on paper and via telephone interviews. Subjects were randomized into four groups: phone-phone, phone-paper, paper-paper, and paper-phone for comparability and reliability testing. Test-retest reliabilities ranged from 0.87 to 0.91. Internal consistency for paper testing was 0.81 and for phone interviewing was 0.83. Hence, the authors found that ACT scores derived from a telephone interview are reliable and comparable to ACT scores from the traditional paper and pencil format.

Telephone symptom monitoring was further studied by Prabhakaran et al. [2010]. This time, 120 adult participants communicated ACT scores through SMS messaging rather than verbal interviewing. Again, phone monitoring was well-accepted by patients. Overall, ACT scores improved, ER visits were reduced, and need for nebulization was reduced. However these findings were not statistically significant.



Mobile phone applications expand the realm of possibilities for phone telemonitoring. Holtz and Whitten [2009] looked at the feasibility of a mobile phone application for tracking daily peak flow readings. Although this study only consisted of 4 participants over one month, the results showed that they were highly satisfied and found the application useful and effective. The application also interfaced with a website where patients could view their past entries and see graphs charting their entered data. While all of the participants were aware of the website, none utilized it.

Møldrup et al. [2012] used mobile phones to send SMS messages to participants. The authors state that the group receiving this intervention did not show significant changes in health care utilization, asthma control, or use of medication compared to the control group. However, the telemonitoring group did demonstrate improved prescribed medication compliance compared to the control group ( $p= 0.039$ ). A post-trial usability and satisfaction survey showed that participants thought the telemonitoring intervention was easy, not annoying, helped them to feel better overall, and should be subsidized by the (French) government.

In a study by van Gaalen et al. [2013], participants in the intervention group used an internet-based system to report FEV1 and symptoms daily, and to complete weekly Asthma Control Questionnaires. The system provided patient education and interactive treatment advice based on collected data. As planned, the internet intervention lasted for 12 months, while outcomes were measured for an additional 15 months to determine whether any long-term benefits were achieved. After 12 months, changes in Asthma Quality of Life Questionnaire scores differed in favor of the intervention group both at 12 months by 0.37, and also at 30 months- 15 months after cessation of the intervention- by 0.29 ( $p= 0.03$ ). Similarly, asthma control showed significant differences between groups at 12 months (-0.57) and 30 months (-0.33) ( $p= 0.03$ ) in

favor of the intervention group. No such differences were observed in FEV1 or inhaled corticosteroid dose. A post-hoc study showed that the greatest benefits were obtained by participants who had poorly controlled asthma. This study is significant in that it demonstrates sustained improvement in patients who use internet-based symptom monitoring, even after discontinuation of the program. It adds an important assertion to the existing knowledge: that telemonitoring interventions may be most effective amongst patients who are the least well controlled.

Operating from the theory that convenience plays a major role in compliance with home PEFr monitoring, Jiang et al. [2009] compared electronic readings of PEFr to paper peak flow diaries. The study included asthmatics living in China and ranging from 16 to 70 years of age. Patients were asked to record peak flows three times daily: in the morning, afternoon, and evening. Compliance was slightly improved with electronic monitoring at 81% compliance compared to 71.7% with paper diaries ( $p < .0001$ ). Deschildre et al. [2011] also studied home telemonitoring of spirometric data, however they found no significant difference between the telemonitoring group and the paper diary group in terms of exacerbations ( $p = 0.38$ ), unscheduled medical visits ( $p = 0.30$ ), FEV1 ( $p = 0.13$ ), quality of life ( $p = 0.61$ ), or dose of inhaled steroid ( $p = 0.86$ ). Ryan et al. [2012] also used mobile phones to transmit communication with asthma patients. Twice a day, participants sent information about symptoms and medication use as well as peak flow data to the telemonitoring system. A physician reviewed the information and intervened when appropriate. The same data was recorded in a paper diary by participants in the control group. There were no statistically significant differences between the groups in asthma control (as measured by the Asthma Control Questionnaire), self-efficacy (as measured by the Knowledge, Attitude, and Self Efficacy Asthma Questionnaire), or quality of life (as measured by the Mini-

Asthma Quality of Life Questionnaire). However, both groups improved by more than the minimum important difference in asthma control, and more people in the mobile phone group showed a greater-than-minimally-important improved quality of life than the in the paper group. However, at an additional cost of approximately \$108 per patient for the mobile phone telemonitoring system, the authors found that the intervention was not cost effective. They asserted that increased monitoring is likely to be the cause of improved outcomes in many telemonitoring studies, but the method by which the increased monitoring is achieved (paper or electronic) is not significant. Taken together, the findings from Jiang et al., 2009; Deschildre, et al., 2011; and Ryan, et al. 2012 may indicate that close self-monitoring is the key to better outcomes (whether that monitoring occurs electronically or on paper), yet compliance with this monitoring may be better among those who use a telemonitoring approach.

Even when looking at only ten studies, conflicting reports concerning the efficacy of asthma telemonitoring interventions exist. Inherent differences in telemonitoring methodologies, age and acuity of participants, study methodology, and care of those in comparison groups make the studies difficult to directly compare. Even in cases where clinical outcomes have improved, questions remain about feasibility and cost-effectiveness. More research is clearly needed in this emerging field.

**Table 1.**

TELEMONITORING INTERVENTIONS			
Authors Journal and Year	Sample	Method	Findings
Bynum A.B., Irwin, C.A., Burke B.L., Hadley M.V., Vogel R, Evans P., Ragland D., & Johnson T. <i>Journal of Education Research,</i> 2011.	56 minority, low-income rural children and adolescents in the Arkansas Delta region, aged 5- 18. Children were referred to the Telehealth KIDS project by a physician and had physician- diagnosed diabetes (N=6) or asthma (N=40), or another acute pediatric condition.	One-group pretest; 3-month, 6- month, and 12-month follow-up design, during which video telehealth consultations were used within a school setting to provide medical management and patient education for asthma, diabetes, and acute pediatric conditions. Telemonitoring transmitted peak expiratory flow, forced	Children with asthma had decreased hospital admissions, fewer school absences, more symptom-free days, reduced Medicaid reimbursement costs, and improved inhaler technique compared to baseline.

TELEMONITORING INTERVENTIONS			
Authors Journal and Year	Sample	Method	Findings
		expiratory volume, pulse oximetry, blood glucose, blood pressure, heart rate, and symptoms.	
de Jongste J.C., Carraro S., Hop W.C. & Baraldi E. <i>American Journal of Respiratory and Critical Care Medicine</i> , 2009.	151 children, aged 6-18, with mild to moderate atopic asthma who had been using a daily inhaled corticosteroid.	Children were randomized into two groups: one which reported daily asthma symptoms and one which reported both symptoms and exhaled nitric oxide levels. Reporting consisted of daily telemonitoring using a PDA. Researchers compared percentage of symptom-free	Both groups experienced tighter control of asthma as a result of daily symptom monitoring. Daily monitoring of exhaled nitric oxide produced no significant added benefit.

TELEMONITORING INTERVENTIONS			
Authors Journal and Year	Sample	Method	Findings
		days between groups over 30 weeks.	
Deschildre A., Beghin L., Salleron J., Iliescu C., Thumerelle C., Santos C., Hoorelbeke A., Scalbert M., Poussel G., Gnansounou M., Edme J-L., & Matran R. <i>European Respiratory Journal</i> , 2011	50 children aged 6-16 years with uncontrolled asthma (frequent severe exacerbations requiring oral corticosteroids and reversibility in FEV1) were included. Exclusion criteria were other congenital or acquired chronic illnesses. This study was conducted in Lille, France.	This was a 12-month, prospective, randomized controlled study. One group used an electronic handheld spirometer and modem to perform daily home monitoring of spirometry (n=21). Spirometric data included forced vital capacity, FEV1, peak expiratory flow, and FEF 25-75%. These data were	There was no significant difference between the two groups in exacerbations, unscheduled visits, FEV1, PAQLQ scores, and median daily dose of inhaled corticosteroids.

TELEMONITORING INTERVENTIONS			
Authors Journal and Year	Sample	Method	Findings
		<p>reviewed by a physician, and when necessary, the patient's parents were contacted by the physician to discuss clinical interventions. The other group (n=23) received usual care. Both groups recorded symptoms, use of rescue treatments, and unscheduled health care visits in a paper diary. All participants performed pulmonary function tests at the beginning and end of the study and had received</p>	

TELEMONTORING INTERVENTIONS			
Authors Journal and Year	Sample	Method	Findings
		follow up visits at 4 months. All participants completed a Paediatric Asthma Quality of Life Questionnaire (PAQLQ) at the beginning and end of the study.	
Holtz B. & Whitten P. <i>Telemedicine &amp; e-Health</i> , 2009.	The sample size was very small (n=4), and was convenience sampled from within one physician's practice. The researchers defend the sample size by stating that pilot studies in telemedicine feasibility are	Utilized SMS messaging (text messaging) to monitor asthma, using patients' preexisting mobile phones and network providers. They looked at participants' perception of phone-based asthma monitoring	On the questionnaire, subjects agreed that the SMS asthma management application was useful and effective for managing asthma, expressed satisfaction with this method of monitoring peak flow and



TELEMONTORING INTERVENTIONS			
Authors Journal and Year	Sample	Method	Findings
	usually quite small. Other inclusion criteria were a diagnosis of mild to moderate asthma and willingness to participate in a month-long study. The ages ranged from 18 to 32. Each subject had already been trained how to use a peak flow meter and had an asthma action plan. Exercise-induced asthma patients were excluded.	as well as utilization.	symptoms, and that it was easy to use. During the open-ended interviews concluding the study, subjects said they liked the daily reminder feature and felt more knowledgeable about their disease.
Jiang H., Han J., Zhu Z., Xu W.,	106 asthmatic patients were recruited from Peking Union	Patients were asked to assess their asthma three times daily	Monitoring with the electronic diary showed statistically

TELEMONITORING INTERVENTIONS			
Authors Journal and Year	Sample	Method	Findings
Zheng J. & Zhu Y.  <i>Journal of Asthma</i> , 2009.	Medical College Hospital.  Inclusion criteria were age of 16 to 70, history of asthma for at least 6 months, and at least 12% airway reversibility post-bronchodilator or 15% PEF variability during 14 days.	for two weeks. Symptoms and medications were charted on paper and peak flows were recorded by an electronic handheld spirometer (“electronic diary”). Compliance with each measure was assessed.	significantly higher compliance than the paper diary (80.0% vs. 71.7%, $p < 0.0001$ ). The study reports that “good patient compliance and acceptability can be achieved when a study takes into account patient convenience, uses user friendly electronic devices, and is less disruptive to patients’ daily life.”
Kosinski M., Kite A., Yang M.,  Rosenzweig J.C. & Williams A.	1090 asthma respondents age 18 or older, with asthma and	All completed ACT questionnaires. The respondents	ACT scores from a telephone interview are reliable and

TELEMONTORING INTERVENTIONS			
Authors Journal and Year	Sample	Method	Findings
<i>Current Medical Research &amp; Opinion</i> , 2009.	having received treatment in the past year.	were randomized into two groups: one group used paper and pencil questionnaires (n=579) and the other group utilized a telephone interview questionnaire (n=511).	comparable to the traditional paper and pencil ACT questionnaire.
Møldrup C., Stein J., Søndergaard B. <i>Journal of Pharmaceutical Negative Results</i> , 2012.	244 asthma patients aged 18-45 were recruited via an online invitation that was sent to an internet asthma interest group. Exclusion criteria included not having a mobile phone and not using the prescribed asthma	Prospective controlled randomized trial. A sequence of SMS messages were sent to the intervention group. The messages contained two or three monitoring questions as well as a reminder to take the daily	SMS messaging is reliable, convenient, affordable, secure, and feasible. However, the intervention yielded no improvement in asthma control, no decrease in health care service utilization, and no

TELEMONTORING INTERVENTIONS			
Authors Journal and Year	Sample	Method	Findings
	inhalation medication.	medication. Both groups completed questionnaires on days 0, 45, and 90. Outcome measures included a 5-question asthma control test, use of health services, and compliance with daily preventive medications.	change in use of medication.
Prabhakaran L., Chee W.Y., Chua K.C., Abisheganaden J. & Wong W.M. <i>Journal of Telemedicine and Telecare</i> , 2010.	497 Chinese asthmatic patients were considered and 120 were recruited by a trained asthma nurse educator and were subsequently randomized into	This randomized controlled trial compared patients who received SMS messaging to assist in their asthma self-monitoring to those who were left to monitor their	Response rate to text messages was 82%. The intervention group experienced statistically insignificant improvements in ACT scores, reductions in

TELEMONTORING INTERVENTIONS			
Authors Journal and Year	Sample	Method	Findings
	control and intervention groups. They were 21 and older, had persistent asthma, and were without significant comorbidities.	asthma on their own over a period of three months.	nebulizations, and reduction in emergency department visits compared to the control group.
Ryan D., Price D., Musgrave S.D., Malhotra S., Lee A.J., Ayansina D., Sheikh A., Tarassenko L., Pagliari C. & Pinnock H. <i>BMJ</i> , 2012	288 adolescents and adults aged 12 and older from 32 practices in the United Kingdom. The participants had to have access to a compatible mobile phone and network as well as poorly controlled asthma, as defined by an asthma control questionnaire	Investigator blinded randomized controlled trial. One group performed twice daily mobile phone transmission of symptoms, drug use, and peak flow and received immediate feedback that prompted them to take appropriate action when	There was no significant difference between the mobile phone monitoring group and the paper diary group in terms of asthma control, self-efficacy, acute exacerbations, steroid courses, unscheduled consultations, or healthcare

TELEMONTORING INTERVENTIONS			
Authors Journal and Year	Sample	Method	Findings
	(ACQ) score of $\geq 1.5$ . Exclusion criteria included people with other lung disease, inability to communicate in English, those receiving specialist care for severe or difficult asthma, and those whose provider recommended against inclusion due to other social or clinical problems.	necessary. The other group monitored the same data twice daily, but they recorded it in a paper diary and did not receive immediate feedback. Data was collected after 6 months.	costs. The mobile phone intervention was more expensive due to telemonitoring costs, and was therefore determined to not be cost effective in this study. The authors suggest that this supports the idea that telemonitoring benefits found in other studies may be related to enhanced clinical care, and are not inherent to telemonitoring interventions themselves.

TELEMONTORING INTERVENTIONS			
Authors	Sample	Method	Findings
Journal and Year			
van Gaalen J.L., Beerthuisen T., van der Meer V., van Reisen P., Redelijkheid G.W., Snoeck- Stroband J.B., Sont J.K. <i>Journal of Medical Internet            Research</i> , 2013.	200 adults with an asthma diagnosis who were taking 3 or more months of inhaled corticosteroids within the past year. They were recruited from 37 general practices and 1 academic outpatient center.	Randomized controlled parallel trial. The intervention group received 12 months of internet- based self-management support and the control group received usual care. The internet support included weekly asthma control monitoring, treatment advice, online education (individual and group), and online and offline communication with a respiratory nurse. Follow-up was conducted at 30 months	This study found significant improvement in asthma-related quality of life and asthma control among those who received internet support. No difference between groups was found in lung function or inhaled corticosteroid dosage. The difference in quality of life and asthma control was sustained, even at 1.5 years after termination of the intervention.

TELEMONITORING INTERVENTIONS			
Authors	Sample	Method	Findings
Journal and Year			
		after baseline (1.5 years after termination of the internet support).	



## DISCUSSION

Effective methods of home monitoring of symptoms is an enduring problem in the management of asthma. These articles each used the evolving technological approach of telemonitoring to attempt to improve this process. However, gaps in the literature exist.

First, only three studies focused exclusively on children, and none included children younger than 5 [Bynum et al., 2011; deJongste, 2009; Deschildre et al., 2011]. Each of these studies looked primarily at transmitting objective data, with little emphasis on helping children understand and communicate variations in their symptoms. In general, very little has been studied regarding the efficacy or importance of symptom telemonitoring in asthmatic children.

Two pilot studies examined feasibility of asthma telemonitoring [Holtz and Whitten, 2009; Prabhakaran et al., 2010]. One looked at SMS messaging and one used a mobile phone application. Both showed promising initial results in terms of patient satisfaction and compliance, however much more information on specific uses and outcomes is needed. The Holtz and Whitten [2009] study was the only one of the reviewed articles to mention the use of phone applications, which is another area for further research.

Cost effectiveness is always a valid concern when implementing new technologies. In the articles reviewed here, there is mixed data on cost effectiveness. Bynum et al. [2011] found that their video telemonitoring system was responsible for notable Medicaid savings, but Ryan et al. [2012] could not justify the additional cost of their mobile phone telemonitoring intervention, especially since it did not show any important outcome improvements. There is clearly a need for additional cost effectiveness studies for varying types of telemonitoring interventions.

The article by Kosinski et al. [2009] is of particular importance to the further development of asthma telemonitoring. It demonstrated that telephone administration of the ACT is

psychometrically sound and comparable with the more traditional paper-and-pencil testing. This finding supports the further development of remote methods of ACT scoring and tracking.

Van Gaalen et al. [2013] found an important correlation between telemonitoring efficacy and asthma severity. The other studies reviewed here did not specifically analyze data with an eye toward participants' asthma severity. Future telemonitoring studies should further investigate this proposed correlation.

Barriers to home monitoring of asthma have long been known to exist, especially with regard to compliance. Only one study specifically compared compliance rates with telemonitoring and traditional methods of symptom monitoring. Jiang et al. [2009] demonstrated statistically significant superiority of telemonitoring compared to paper monitoring in terms of patient compliance. This finding points to need for further study and implementation of telemonitoring for asthma patients.

## **CONCLUSION**

Current literature is mixed in its supportiveness of the efficacy of asthma symptom telemonitoring. Preliminary studies suggest that telmonitoring may improve patient compliance with self-monitoring, asthma symptoms, quality of life, and lung function, especially in those whose asthma is the most poorly controlled. This is a relatively new and evolving field of study, and there are numerous opportunities for further studies, especially in the areas of pediatric asthma, compliance, cost effectiveness, and efficacy among participants with varying levels of asthma severity. Technology is changing rapidly, and the research must struggle to keep up. The full extent of the benefits of telemonitoring is yet to be seen.

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DECLARATION OF CONFLICTING INTERESTS

The Authors declare that there is no conflict of interest.

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**Symptom Management Theory:**

**Application to Symptom Telemonitoring of Chronic Disease**

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### Abstract

Symptom Management Theory, developed by faculty at the University of California, San Francisco, is a model which explains the interaction between symptom experience, symptom management strategies, and outcomes. Successful integration of the model into the emerging field of telemedicine has the potential to improve outcomes and lower costs associated with the management of chronic diseases. Modifications to the model related to communication, feedback, and adherence may make it more suitable for this application.

**KEYWORDS:** telemedicine, symptom management theory, symptom assessment, chronic disease, nursing theory

## Symptom Management Theory as a Clinical Practice Model for Symptom Telemonitoring in Chronic Disease

As chronic disease and life expectancy continue to simultaneously increase, management of chronic conditions will become increasingly burdensome in terms of both manpower and financial costs. Now more than ever, creative strategies for the management of chronic diseases are needed. The field of telemedicine is growing rapidly, and clinical practice models must evolve to guide and support this field. The aim of this article is to discuss the potential of Symptom Management Theory to meet this need.

### **Burden of Chronic Disease**

The prevalence of chronic diseases such as asthma, chronic obstructive pulmonary disease [COPD], heart disease, hypertension, depression, and diabetes is on the rise. Approximately 133 million Americans had been diagnosed with at least one chronic disease in 2005, and that number is expected to grow to 157 million by 2020 (Bodenheimer, Chen, & Bennett, 2009). The reason for this rapid increase is multifactorial. On one hand, poor lifestyle choices abound. On the other hand, advances in medicine are contributing to greater life expectancies, giving genetic predispositions for disease more time to come to fruition.

The financial burden of chronic disease is staggering. Currently, 75% of U.S. dollars can be attributed to chronic conditions (Bodenheimer et al., 2009). By 2040, the number of Americans over 65 is expected to double, which will result in an estimated 25% increase in healthcare spending (CDC and The Merck Company Foundation, 2007).

Not only is the United States ill-equipped to handle the financial burden of increasing medical costs, but also the healthcare field lacks the manpower. Lower-cost methods of preventing and managing chronic conditions can be found in lower-acuity settings, such as

primary care. However, fewer and fewer physicians are choosing to go into primary care, and even increasing numbers of other clinicians (such as nurse practitioners [NPs] and physician assistants [PAs]) cannot make up the gap. In the United States only 35% of physicians are primary care providers (PCPs), compared to 50% in other industrialized countries (Bodenheimer, Chen, & Bennett, 2009). Of note, most of these countries with higher percentages of PCPs also have better outcomes, lower costs, and better access to care than what is seen in the U.S.

Bodenheimer et. al (2009) suggest that there are three ways that the increased demand for low cost, low-acuity management of chronic diseases can be met: specialty care, primary care, or multidisciplinary teams. First, if numbers of primary care providers continue to dwindle, many patients may be forced to receive care in specialty settings. This may provide better care of individual conditions, but would promote a steeper increase in medical expenditures and would also lack the coordination of care more typically found in primary care. The second scenario, in which primary care fills the gap, is more ideal but, as previously mentioned, current trends do not suggest this will be feasible. The third scenario would use a multidisciplinary team- made up of physicians, NPs, PAs, registered nurses, pharmacists, and community health workers- to address the needs of patients with chronic conditions. According to Bodenheimer et al. (2009), many studies suggest that this option has potential to ease disease burden, improve outcomes, and reduce costs.

A fourth option may exist. Telemedicine, a field in which technology is used to provide remote health care, could allow specialists, primary care providers, and multidisciplinary teams to more efficiently manage symptoms of chronic disease. Because the management of chronic diseases requires that much of the onus is placed on patients to perform adequate self-care between visits, remote communication with providers is sometimes necessary. Telemedicine can

provide a method by which patients' self-care strategies are guided by interactive communication with providers. The field is relatively new and much has yet to be discovered, but emerging research shows great potential. A 2012 literature review by Wootton examined 141 randomized control trials which included a cumulative 37,695 participants, each of which provided a telemedicine intervention for at least one of five common chronic conditions (diabetes, asthma, hypertension, heart failure, and COPD). Of these studies, 108 showed positive results and only 2 showed negative results. The remaining 31 studies were inconclusive. It is important, however, to note that cost-effectiveness was not examined. Costs and cost-effectiveness of any telemedicine intervention are necessarily dependent upon the type of technology being used, and as such, cost-effectiveness studies may not be generalizable.

Telemonitoring, as a subset of telemedicine, refers to the active monitoring of data, such as symptoms or disease processes via technology. Since symptoms are the most common reason patients seek healthcare (Lee & Miaskowski, n.d.), an acceptable alternative for symptom management might eliminate the need for some of these costly visits. Telemonitoring could potentially provide guided self-management of symptoms, thereby reducing unnecessary resource utilization. The full implications of symptom telemonitoring are not yet known, but so far it appears that "remote patient monitoring that tracks vital signs of patients with chronic diseases is offering more-frequent contact between the patient and the primary care provider, providing earlier detection of potential problems, and allowing real-time alerts, resulting in a proactive, affordable option for best-practice health care" (Schwartz & Britton, 2011, p. 216).

### **Overview of the Symptom Management Theory**

While many articles cite change theories that can be helpful in the diffusion and adoption of telemedicine, clinical practice models and other theoretical frameworks are lacking. How does

telemonitoring fit with what is already known about the interaction between self-care, symptom management, and outcomes? Symptom Management Theory may be useful in filling this gap.

Symptom Management Theory was originally introduced by the nursing faculty at University of California, San Francisco in 1994 and was updated in 2001 and again in 2008. The model development was a collaborative effort, incorporating the experience of faculty with diverse experience in managing symptoms of chronic diseases such as heart disease, diabetes, cancer, COPD, and chronic pain. It is a deductive, middle range theory describing three simultaneously interactive factors within the domain of nursing care (Humphreys et al., 2008). These three main factors are Symptom Experience, Symptom Management Strategies, and Symptom Status Outcomes, each connected to the others by bidirectional arrows. These arrows symbolize the mutual interaction of each factor with both of the other factors. Additionally, a broken bidirectional arrow between Symptom Management Strategies and Outcomes labeled “Adherence” exists to show the risk of nonadherence that occurs at this stage. The model has been described extensively elsewhere (Humphreys et al., 2014), but this article will briefly summarize the essential points.

The commonly acknowledged starting point of the model is the Symptom Experience component. Here the patient perceives, evaluates, and responds to symptoms. Bidirectional arrows indicate that these activities may occur repeatedly or simultaneously. While patients’ perceptions are valuable, it is important to realize that sometimes patients do not assign meanings to their symptoms that are evidence based or consistent. For instance, Janson and Becker (1998) found that among patients with asthma, two of the most common reasons that patients delay seeking care during an exacerbation are the concepts of “minimization” and “uncertainty”.

Minimization refers to under-recognition of the severity of the asthma episode, while uncertainty refers to a patient's ambiguity about how to interpret a symptom's meaning or what to do about it. Because patients suffering from chronic condition often deal with waxing and waning symptoms for long stretches of time between health care visits, patients are left to interpret their own symptoms through the lens of their own lay knowledge and past experience. Not surprisingly, this interpretation affects how and when they progress to the next phase of the model, Symptom Management.

It is at this second stage of Symptom Management that an intervention may be performed. According to Humphreys et. al (2014), the goal of symptom management is to “avert, delay, or minimize the symptom experience” (p. 144). However, since patients may delay seeking advice and treatment due to issues like minimization or uncertainty, the invasiveness, risk, cost, and potential success of the symptom management strategy varies accordingly. Using the example of asthma, if a patient delays seeking treatment for early signs of an exacerbation, what could have been managed conservatively through increased inhaled corticosteroid doses often progresses to a need for oral corticosteroids, emergency room visits, and hospitalizations. Authors of the model agree that more research is needed regarding how to deal with the issue of timeliness of patient-initiated strategies (Dodd et al., 2001). They also assert that the type of intervention should be specific to the symptom and should be guided by current evidence from within the field (Dodd et al., 2001). This is problematic in patients who have chronic diseases because, once again, they may be using symptom management strategies that are not evidence based. Patients rely not only on information from their health care providers, but also from family, friends, media, and the Internet (Humphreys et al., 2014), especially when communication with providers between visits is lacking. There is increasing emphasis placed on

shifting the responsibility for chronic disease symptom management to the individual patient (Humphreys et al., 2014), and this rightly affirms the value of the patient's own lived experience and self-knowledge. However, aligning the patient's experience and self-awareness with the provider's evidence-based knowledge can only strengthen the accuracy of the patient's interpretation of his Symptom Experience, and subsequently improves the efficacy of Symptom Management Strategies. Multiple studies have shown that this type of collaboration, known as "informed self-monitoring", does, in fact, improve outcomes (Janson & Becker, 1998; Janson et al. 2003, 2010, 2009).

Finally, in stage three of the model, the Symptom Experience and/or Symptom Management Strategies lead to Symptom Status Outcomes, which can then go on to subsequently impact Symptom Experience and Symptom Management in turn. Outcomes can include quality of life, self-care, morbidity and comorbidity, mortality, functional status, emotional status, and direct and indirect costs (Dodd et al., 2001). For patients with chronic diseases, Symptom Experiences and evidence based Symptom Management Strategies may not immediately or obviously result in improved Symptom Status Outcomes. For example, it may not be obvious to the hypertensive patient that daily adherence to a prescribed medication is correlated to a gradual improvement in blood-pressure related symptoms like headaches or blurred vision. Some telemonitoring technologies are able to store and graphically display symptom information over time (Janson et al., 2010), helping patients to appreciate subtle or gradual changes that otherwise might go unnoticed.

### **Modifications to the Model for Applications to Telemonitoring**

In 2010, Patricia Newcomb suggested an alteration to the SMT model in which Communication and Feedback were explicitly described as conceptual links between the model



components Symptom Experience, Symptom Management Strategies, and Symptom Status Outcomes (See Figure 1). Communication emphasizes the exchange between a patient's symptom experience and his attempts at symptom management. Newcomb (2010) used this communication concept to explain the unique ways children and parents collaborate to first perceive and interpret symptoms and then to respond. Newcomb's communication concept can also be used to explain the remote interactivity of patients and providers through telemonitoring. The UCSF faculty who developed the model agree that "providers must establish and maintain good patient-provider communication if they are to understand their patient's symptom perception, accept symptom experience, and implement management strategies" (Humphreys et al., 2014, p. 155). Newcomb's modified model simply makes this communication concept more explicit.

The second added concept, Feedback, explains how patients evaluate the efficacy of their symptom management strategies in terms of their resulting outcomes (Newcomb, 2010). When self-management strategies result in improved symptom status outcomes, those successful strategies are likely to be repeated. As already discussed, some outcomes may not be immediately noticeable to patients with chronic diseases, which causes a breakdown in the model at the point of Feedback. Because some telemonitoring technologies have the ability to store and display symptom data over time, a further modified model supports the theoretical usefulness of telemedicine as a solution to this potential breakdown.

This breakdown illustrates a problem with adherence that occurs between the domains of Symptom Management Strategies and Outcomes. This is illustrated in Figure 2 by the broken arrows between these two domains and labeled "Adherence". However, the paper authors suggest that, when applied to telemedicine, adherence can also break down between Symptom

Experience and Symptom Management Strategies, as part of Newcomb's Communication modification. In essence, the telemonitoring intervention is a communication tool that links Symptom Experience and Symptom Management Strategies, and at the same time telemonitoring is a Symptom Management Strategy itself. As such, patient (or provider) nonadherence with the telemonitoring system is a risk. The proposed model suggests adding a second area for adherence by adding a broken bidirectional arrow between Symptom Experience and Symptom Management Strategies. The paper authors have taken the Newcomb's concepts of Communication and Feedback and superimposed them on the original model, and then nested the second Adherence linkage within Newcomb's Communication domain (See Figure 2).

### **Literature Support**

Chronic disease telemonitoring, guided by Symptom Management Theory, must be explored one study at a time. The model has gained particular acceptance in a few pockets of clinical practice such as oncology (Baggott, Cooper, Marina, Matthay, & Miaskowski, 2012; Cherwin, 2012; Steel et al., 2010) and cardiology (DeVon, Ryan, Rankin, & Cooper, 2010; Hwang, Ahn, & Jeong, 2012; Jurgens et al., 2009; McSweeney, Cleves, Zhao, Lefler, & Yang, 2010; Riegel et al., 2010). Therefore, those within that discipline have gradually become familiar with the theory through reading current literature relevant to their specialty. Likewise, those blazing trails in the field of telemedicine must be exposed to Symptom Management Theory through reading about successful applications to practice within that particular area.

Usefulness of Symptom Management Theory in the emerging field of telemedicine has only been overtly addressed in one article. In 2009, Barnason, Zimmerman, and Schulz used Symptom Management Theory as the framework for a study on the effect of a telehealth intervention on physical activity and functioning in patients who had recently undergone

coronary artery bypass surgery. The intervention was a 6-week symptom management tool that was connected to the participants' telephones. Participants were asked to respond to assessment questions, and then provided with management strategy suggestions based on the reported symptoms. In this way, the symptom perceptions (from the patient) were immediately addressed by electronic symptom management strategies (from the telemonitoring device), with an expectation of improving outcomes (activity and functioning). When comparing the telemonitoring group with the usual care group, there was a significant main effect by group ( $F[1,209]=4.66, p<.05$ ). In the study, the telemonitoring intervention used in conjunction with Symptom Management Theory led to improvements in physical activity and functioning.

The SMT model is relatively new and, while gaining popularity, is still not commonly known. As clinicians seek to find innovative ways to meet the challenges of healthcare in the twenty-first century, however, chronic disease management must change. When it does change, technology is likely to play a role. Theoretical frameworks suited to these questions will come to light, and Symptom Management Theory is in prime position to meet the task. Successful implementation of the model through telemonitoring would be evidenced by more timely and personalized responses to symptoms, thereby improving patient self-care and self-efficacy, reducing health care utilization and decreasing overall costs, all while achieving better outcomes.

More research is needed to test the applicability of the model to telemonitoring interventions. It is the suggestion of the paper's authors that such studies use Newcomb's Communication and Feedback modifications and recognize the potential for nonadherence at any point within the model as illustrated in Figure 2.

## **Conclusion**

Telemonitoring and telemedicine in general are areas in which frameworks are not yet well-established. While Symptom Management Theory holds promise for many areas within healthcare, telemonitoring is an emerging field for which it is a perfect match. Increasing chronic disease burden, fiscal strain, and technological advances are rendering older methods of healthcare inadequate. Chronic disease telemonitoring can fill a needed gap, but it will do so most efficaciously if it is grounded in theory. Symptom Management Theory incorporates many of the concepts of interest to telemonitoring: recognizing symptom experiences, implementing timely and cost-effective management strategies, and working toward improved outcomes. Chronic diseases that might benefit most from telemonitoring of symptoms are those with frequent fluctuations and necessary dose adjustments, symptom intervention, or social support, such as asthma, diabetes, substance dependencies, pain, and heart failure. It is the assertion of this article that the greatest benefit will be derived from Symptom Management Theory if the suggested adjustments related to communication, feedback, and adherence are employed.

It is important to recognize that certain geographical or socioeconomic barriers may prevent the implementation of telemonitoring in some populations. Access to technological equipment (such as mobile phones and computers) can be limited among many people in lower socioeconomic groups, and certain geographic regions are unable to receive reliable internet service. These are barriers that must be addressed.

The United States healthcare system is ready for a change. The burden of chronic disease is rising and costs are exceeding the country's ability to pay. Innovation in the management of chronic disease is essential, and telemedicine is poised to change the way patients with chronic diseases are managed. At the heart of any attempt at remote monitoring of disease is the question of how to monitor symptoms effectively. A very slight adaptation to Symptom Management

Theory can ease the transition to new ways of meeting patients' needs in timely, cost-effective ways, ensuring that the process is responsibly grounded in a strong theoretical framework.

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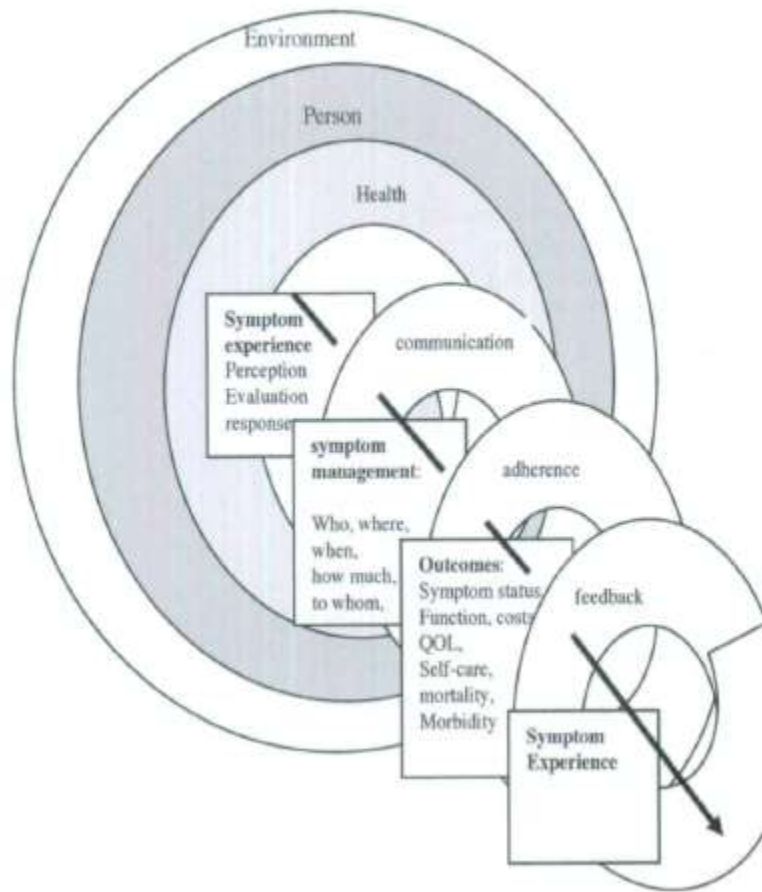
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Figure 1.

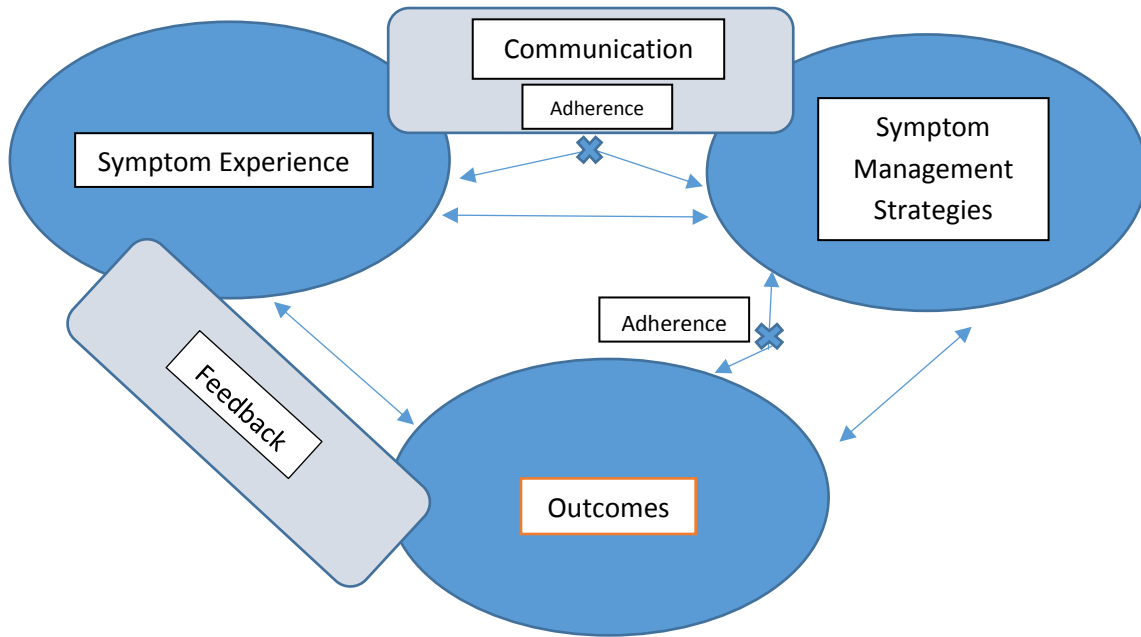


Newcomb's Spiral Symptom Management Model

Newcomb, P. (2010). Using symptom management theory to explain how nurse practitioners care for children with asthma. *Journal of Theory Construction & Testing*, 14(2), 40-44.

Figure 2.

Symptom Management Model for Telemonitoring Applications



**Scholarly Project Technical Report: Applications of Symptom Management Theory and  
Diffusion of Innovation Theory to Collaborative Pediatric Asthma Telemonitoring**

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### Abstract

**Background:** National asthma guidelines encourage patient self-monitoring of symptoms in order to allow for prompt management of early exacerbations. Symptom Management Theory provides a framework for understanding the particular barriers to this process, especially among children with asthma. Symptom telemonitoring may be helpful in overcoming these barriers, and Diffusion of Innovations theory might help predict the rate of diffusion of such interventions within a given patient population. In this project, the AsthmaChecker iPhone application was developed and analyzed in light of Symptom Management Theory and Diffusion of Innovations Theory. **Purpose:** The purpose of this project is threefold: (1) to examine the potential usefulness of the Asthma Checker app in addressing symptom management challenges in children with asthma, (2) to use tenets from the Diffusion of Innovations theory to predict the diffusibility of the app among a particular patient population, and (3) to determine the extent of the relationship between children's age and usability of the app. **Methods:** A 30-item questionnaire was designed and administered to children and caregivers in a private allergy and asthma practice. From those items, constructs were formulated to address the research questions related to symptom management, diffusion, and age-related usability. **Results:** Analysis of the Symptom Management construct items revealed that caregivers, children, and caregiver-child dyads scored means near the middle of the possible range of scores, indicating moderate uncertainty about asthma symptom management. There were no significant differences between the scores of caregivers and children, nor were there significant differences between caregiver-child dyads in which the child had intermittent asthma and dyads in which the child had persistent asthma. The Diffusion construct item means, completed by caregivers of children with asthma, also fell toward the middle of the possible range, indicating that the app is likely to

diffuse at a moderate rate within the patient population. Analysis of the Literacy and Development construct items showed that younger children have significantly more difficulty using the app independently ( $M= 6.08$ ,  $SD= 1.55$ ) than older children ( $M= 4.79$ ,  $SD= 1.36$ ),  $t(30)= 2.49$ ,  $p=.019$ ,  $d= 0.88$ . **Discussion:** The AsthmaChecker app may be helpful in addressing caregiver and child uncertainty related to asthma symptom management and is likely to diffuse at a moderate rate. It is important to consider that younger children might be unable to use the app independently, which could adversely impact adherence. The three constructs developed in this project require further testing and validation, but hold promise for use in other studies. In particular, the Diffusion construct could fill an important gap in the literature for evaluating emerging telehealth technologies.



The AsthmaChecker App: Applications of Symptom Management Theory and Diffusion of Innovation Theory to Collaborative Pediatric Asthma Telemonitoring

The Third Expert Panel on the Diagnosis and Management of Asthma (EPR-3) recommends that “every patient who has asthma should be taught to recognize symptom patterns that indicate inadequate asthma control” (EPR-3, 2007). Patients with asthma require vigilant self-management to control of symptoms, prevent exacerbations, preserve lung function, and enhance quality of life (Kotses & Creer, 2010). In fact, multiple studies have found that symptom monitoring produces equally beneficial outcomes compared to peak flow monitoring (Kotses, Harver, & Humphries, 2006). Symptom monitoring is less labor-intensive, and a statistically significant patient preference for symptom monitoring (Harver, Humphries, and Kotses, 2009).

Unfortunately, patients and caregivers do not tend to monitor symptoms until they become severe, and each individual has a different threshold at which they decide to call upon his or her provider for guidance (Fowler, Kirschner, Van Kuiken, & Baas, 2007). Barriers to home monitoring of symptoms include lack of social support and a perception of providers’ disinterest in patients’ unique symptom profile. These barriers underscore the need for improved communication and shared decision-making between clinicians and patients (Andrews, Jones, & Mullan, 2012).

Ralph Waldo Emerson is commonly credited with having said, “If you build a better mousetrap, the world will beat a path to your door.” The world of asthma management is in need of a better “mousetrap” for monitoring symptoms. Innovative strategies must be investigated to determine ways to increase self-monitoring of symptoms among patients with asthma. As the field of telehealth evolves, telemonitoring may open the way for new possibilities in home

symptom monitoring that may address the barriers of lack of social support, communication, and provider involvement. The EPR-3 supports the idea that information technologies are potentially useful for providing patients with skills to control their asthma symptoms and improve outcomes (EPR-3, 2007).

More research is needed to determine the effectiveness of these assumptions. In this pilot project, the author designed and tested AsthmaChecker, a pediatric asthma iPhone application (app), through the lens of two theoretical frameworks. In this way, the project simultaneously examines the potential benefits of the app itself, as well as novel applications of Symptom Management Theory and Diffusion of Innovations Theory. The findings of this study add breadth to existing knowledge about asthma telemonitoring and propose two new survey-based constructs for measuring Symptom Management and Diffusion.

### **Theoretical Frameworks**

This project is heavily informed by two theories: Symptom Management Theory and Diffusion of Innovations Theory. Symptom Management Theory, developed by nursing faculty at the University of California, San Francisco, is a model which explains the interaction between symptom experience, symptom management strategies, and outcomes (Humphreys et al., 2014). Diffusion of Innovations Theory, on the other hand, describes the predictable ways in which innovations spread through a population (Rogers, 2003). Symptom Management Theory can help determine the clinical benefit to the app in this project, while Diffusion of Innovations Theory gives a sense of how likely the app is to be accepted by the patient population.

### **Symptom Management Theory**

While many articles cite change theories that can be helpful in the diffusion and adoption of telemedicine, clinical practice models and other theoretical frameworks are lacking. How does

telemonitoring fit with what is already known about the interaction between self-care, symptom management, and outcomes? Symptom Management Theory may be useful in filling this gap.

Symptom Management Theory is a deductive, middle range theory describing three simultaneously interactive factors within the domain of nursing care (Humphreys et al., 2008). These three main factors are Symptom Experience, Symptom Management Strategies, and Symptom Status Outcomes, each connected to the others by bidirectional arrows (See Appendix A). These arrows symbolize the mutual interaction of each factor with both of the other factors. Additionally, a broken bidirectional arrow between Symptom Management Strategies and Outcomes labeled “Adherence” exists to show the risk of nonadherence that occurs at this stage. The model has been described extensively elsewhere (Humphreys et al., 2014).

In 2010, Patricia Newcomb suggested an alteration to the SMT model in which Communication and Feedback were explicitly described as conceptual links between the model components Symptom Experience, Symptom Management Strategies, and Symptom Status Outcomes. Communication emphasizes the exchange between a patient’s symptom experience and his attempts at symptom management. Newcomb (2010) used this communication concept to explain the unique ways children and parents collaborate to first perceive and interpret symptoms and then to respond.

Children are a notable exception to the traditional understanding of how patients typically manage symptoms. They generally depend in large part upon caregivers for symptom management and health care (Newcomb, 2010). Children have developmental and cognitive barriers to understanding and communicating their own symptoms, which impacts the way that parents, health care providers, and other caregivers interpret and respond to those symptoms (Newcomb, 2010).

Accurate and prompt communication of worsening asthma symptoms in children is essential in order to avoid unnecessary delays in treatment which can lead to poor outcomes. If a patient delays seeking treatment for early signs of an exacerbation, what could have been managed conservatively through increased inhaled corticosteroid doses, then the exacerbation often progresses to a point at which the patients need oral corticosteroids, emergency room visits, and hospitalizations.

Authors of the Symptom Management Theory agree that more research is needed regarding how to deal with the issue of timeliness of patient-initiated strategies (Dodd et al., 2001). They also assert that the type of intervention should be specific to the symptom and should be guided by current evidence from within the field (Dodd et al., 2001). This is problematic in patients who have chronic diseases because, once again, they may be using symptom management strategies that are not evidence based. Patients rely not only on information from their health care providers, but also on information from family, friends, media, and the Internet (Humphreys et al., 2014), especially when communication with providers between visits is lacking. Increasing emphasis on individual patient responsibility for chronic disease symptom management (Humphreys et al., 2014) rightly affirms the value of the patient's own lived experience and self-knowledge. However, aligning the patient's experience and self-awareness with the provider's evidence-based knowledge can only strengthen the accuracy of the patient's interpretation of his Symptom Experience, and subsequently improves the efficacy of Symptom Management Strategies. Multiple studies have shown that this type of collaboration, known as "informed self-monitoring", does, in fact, improve outcomes (Janson & Becker, 1998; Janson et al. 2003, 2010, 2009).

Among patients with asthma, two of the most common reasons that patients delay seeking care during an exacerbation are the concepts of “minimization” and “uncertainty” (Janson & Becker, 1998). Minimization refers to under-recognition of the severity of the asthma episode, while uncertainty refers to a patient’s ambiguity about how to interpret a symptom’s meaning or what to do about it. What caregivers of children with asthma may not know is that explicit guidelines exist which outline the characteristics of Well Controlled Asthma, Not Well Controlled Asthma, and Very Poorly Controlled Asthma (EPR-3, 2007). Providers often use these evidence-based guidelines to determine when to “step-up” or “step-down” on medications. However, if the providers only see patients at regularly-scheduled visits or when the caregiver subjectively deems the child’s asthma is severe enough to schedule an appointment, appropriate adjustments in therapy can be delayed. Making caregivers aware of these clear and objective definitions of asthma has the potential to improve informed self-monitoring while reducing minimization and uncertainty. The AsthmaChecker app was designed with this purpose in mind.

### **Diffusion of Innovation Theory**

Almost everything done in the field of healthcare involves asking the patient or organization to change in some way. For this reason, a consideration of appropriate change theories can be beneficial when approaching clinical questions. Roger’s Diffusion of Innovations Theory is one change theory that is particularly applicable to this study.

Everett Rogers first popularized and synthesized previous work by sociologist Gabriel Tarde (1903) and Ryan and Gross (1943) in the area of innovation diffusion in his 1960 book, *Diffusion of Innovations* (Surry, 1997). The original S-shaped diffusion curve illustrating the typical pattern for acceptance of innovations, plotted by Tarde, was then used by Ryan and Gross in 1943 to illustrate the rate of adoption of a new hybrid seed corn among Iowa farmers (See

Appendix B). Rogers then used this s-curve to describe the diffusion process, which he defines as “the process by which (1) an innovation (2) is communicated through certain channels (3) over time (4) among the members of a social system” (Rogers, 2003). See Appendix C. In this model, he shows that a small proportion of the population qualifies as “earlier adopters” who embrace innovations promptly. Shortly thereafter, there is a “take-off period” in which the innovation gains exposure and diffusion exponentially expands. As “later adopters” finally begin to accept the innovation, diffusion within the system approaches saturation and the rate decreases. Different innovations may follow slightly different slopes, as illustrated in the model by “Innovation I”, “Innovation II”, and “Innovation III”, but they all follow a roughly similar s-curve (Rogers, 2003). Of particular interest to this study are the five factors that can influence these slopes, or rates of diffusion.

Rogers (2003) points out 5 characteristics of the innovation that determine the rate of adoption: (1) relative advantage, (2) compatibility, (3) complexity, (4) trialability, and (5) observability. Relative advantage refers to the “degree to which an innovation is perceived as better than the idea it supersedes” (Rogers, 2003, p. 6). Mike Lee, a renowned computer programmer and app developer, is gaining notoriety for his three laws of app development, one of which is “New must be better than the old” (Brockheimer, 2011). This speaks to Rogers’ concept of relative advantage.

Compatibility is “the degree to which an innovation is perceived as consistent with existing values, past experiences, and needs of potential adopters” (Rogers, 2003, p. 6). If the innovation is compatible with the social system’s values, experiences, and needs, it will have a more rapid rate of diffusion. Therefore, Rogers (2003) suggests positioning the innovation relative to previous ideas and values.

Complexity refers to perceived difficulty in terms of use and understanding. Complexity is negatively related to diffusion rates. In order to be accepted within a social system, an innovation should not be overly complex.

Trialability refers to “the degree to which an innovation may be experimented with on a limited basis” (Rogers, 2003, p. 6). If a long-term commitment to the innovation is required, it will be less readily accepted, thereby negatively impacting diffusion.

Observability refers to the visibility of the results of the innovation, and is positively related to its diffusion rate (Rogers, 2003). For example, Diffusion Theory has its roots in agriculture, where an innovation’s success or failure can be easily seen within a community. Though Rogers had not yet identified the concept of observability, it almost certainly influenced the rate of adoption of hybrid seed corn in Ryan and Gross’s 1943 experiment. The hybrid seed corn in the experiment was more vigorous and drought-resistant than the traditional seed (Ryan & Gross, 1943), which would have been easily observable by other farmers.

Rogers further describes five categories of adopters- those within the social system who adopt the innovation. They include “innovators”, “early adopters”, “early majority”, “late majority”, and “laggards” (Rogers, 2003). The distribution of these categories follows a bell-shaped curve, as illustrated in Appendix D. He assigns a dominant attribute to each category as follows: “Innovators- venturesome; early adopters- respect; early majority- deliberate; late majority- skeptical; and laggards- traditional” (Rogers, 2003, p. 8). Those who are more likely to accept innovations sooner are people who live in cosmopolitan areas, are more highly educated, more literate, have a higher social status, and have a higher degree of upward-mobility. They also tend to be more empathetic, less dogmatic, are able to deal with abstraction, and have larger social networks. Interestingly, age does not play a role in propensity to adopt (Rogers, 2003).

Diffusion theory has been applied to many research endeavors, both in and outside the realm of healthcare. It has been used in studies of HIV prevention (Bowen et al., 2010) dental hygiene (Cobban, 2008), and nursing education (Gallos, Daskalakis, Katharaki, Liaskos, & Mantas, 2011). The theory has also been used to address the role for nurses as change agents as hospitals transition into using electronic clinical information systems (Hilz, 2000). Outside of healthcare it has been applied to instructional technology (Surry, 1997), accounting (Barney, 2010), advertising (Hui-Chih & Her-Sen, 2010), computer gaming (Egenfeldt-Nielsen, 2010), computer security (Smith & Rupp, 2004), online commerce (Barney, 2010; Mahmood, Siponen, Lopez, & Vance, 2010; Smith & Rupp, 2004), energy conservation (Völlink, Meertens, & Midden, 2002); global freedom of information laws (Relly, 2012), and social justice (Ratts & Wood, 2011). As might be expected, it has been used quite extensively in the field of agriculture, where it has its historical origins (Barney, 2010; Morrison, 2009); (Rebaudo & Dangles, 2011).

Articles about telehealth initiative implementations often cite the usefulness of diffusion theory (Brooks, Manson, Bair, Dailey, & Shore, 2012; Patel & Antonarakis, 2012; Peeters, Je, Lucas, & Francke, 2012; Sanders et al., 2012; Stronge, Nichols, Rogers, & Fisk, 2008; van der Linden, Waights, Rogers, & Taylor, 2012; Walker & Whetton, 2002), which is of particular interest to the proposed study. From this research there have been several practical recommendations to improve the diffusion of future telehealth interventions.

Walker and Whetton (2002) recommend that telehealth applications pay particular attention to the culture of the health service sector by minimizing complexity and maximizing compatibility. They encourage ensuring that future interventions are created through collaboration with team members so as not to be perceived as requiring drastic changes to daily roles and practice.



Peeters et al. (2012) give some specific recommendations for future telemonitoring interventions. In their study of chronically ill home care patients, the patients were more likely to adopt telemonitoring technology if they were already receiving long-term nursing care, living alone, or receiving fixed daily contacts initiated by a nurse. 61% of the variance of adoption could be attributed to relative advantage, complexity, compatibility, and observability, supporting Rogers' theory (Rogers, 2003). Based on their findings, they recommend that new telemonitoring strategies are easy to use, that nurses initiate daily "good morning messages" to the clients to encourage participation, and that benefits of telemonitoring be made more visible to the clients (Peeters et al., 2012).

While exploring barriers to adoption and adherence to telemonitoring, Sanders et al. (2012) found that frequently discontinuation occurred because of a misperception about the equipment or intimidation about the complexity of the device. Providers were also afraid of losing formerly utilized health services in exchange for the new method. These issues fall into Rogers' categories of complexity and compatibility (2003), and underscore the importance of keeping telemonitoring innovations simple and approachable, at least initially. They also hypothesize that providing clients more detailed introductions to technologies as well as time for discussion could prevent some of these issues in the future.

Any telemonitoring app is an innovation which must face the challenges of diffusing through a patient population. Considering the five characteristics which impact the rate of diffusion (relative advantage, compatibility, complexity, trialability, and observability) may be a helpful step toward predicting how well such innovations will diffuse in a clinical practice. It also may be beneficial in identifying particular aspects of the app that might promote or hinder

the rate of adoption. For this reason, this project critically appraised AsthmaChecker in light of each of these five areas.

### **Host Organization and AsthmaChecker**

This project was conducted in conjunction with The Allergy, Asthma, and Sinus Center (AASC), a private corporation of 28 specialty clinics across Tennessee, Georgia, and Kentucky. Providers in these clinics include 14 allergists, two sleep specialists, one dermatologist, one rheumatologist, 27 nurse practitioners (one of whom is the author/primary investigator of this project), and three physician assistants.

Traffic through each clinic on a given day is approximately 100 patients, the bulk of whom come to receive allergy immunotherapy injections (C. Wood, personal communication, March 21, 2013). Patients are treated for diagnoses including, but not limited to, allergic rhinitis, atopic dermatitis, COPD, chronic sinusitis, idiopathic urticaria, and, asthma. Many of the patients seen in this clinic are children, and it is common to see the atopic triad of allergic rhinitis, atopic dermatitis, and asthma in these children. Sometimes they have been referred to the specialty clinic by their pediatrician with the intent of receiving allergy shots, only to find that asthma is also playing a role in their constellation of symptoms. Other times, the pediatrician has identified the child's asthma and has referred the child in order to achieve better asthma control. In either case, AASC takes seriously their responsibility to provide superior management of the child's asthma, thereby improving patients' quality of life and preserving lung function, as well as strengthening relationships with referring providers within the community.

AASC is heavily invested in marketing and image. Websites, logos, brochures, and advertising are professionally designed, resulting in a polished product. The Knoxville, TN cluster of clinics, led by Dr. Robert Overholt, produces an educational television show which airs

twice weekly on the Knoxville PBS affiliate channel and has won 18 Telly Awards. The corporation also has an interactive iPhone app which provides clinic information, pollen tracking, and injection scheduling. All of these marketing initiatives are coordinated and developed by PME Communications, which maintains AASC as one of its primary clients. The two main contacts at PME, as it relates to this project, are Marcella Feathers, the creative director, and Ned DeLozier, the marketing and business development director.

Early conversations with PME Communications indicated mutual interest in pursuing an asthma telemonitoring app. AsthmaChecker was designed through collaboration between the author/primary investigator and Steve McManus, the app developer whom PME subsequently contracted, under the oversight of PME Communications.

The AsthmaChecker app consists of 5 questions which children (with the help of caregivers) are asked to answer daily. The first 4 questions come directly from the EPR-3 (2007), which defines whether or not asthma is “Well Controlled” (See Appendix E). The last question is included in order to serve as a reminder to adhere to prescribed medications. The questions include:

1. Have you had any asthma symptoms today, such as coughing, wheezing, chest tightness, or breathing harder or faster than usual?  
 Yes                       No
2. Last night, did you wake up because of coughing, wheezing, or chest tightness?  
 Yes                       No
3. Did your asthma keep you from doing anything you wanted to do today (such as playing, exercising, or participating in PE)?  
 Yes                       No

4. Did you need to use your rescue inhaler (e.g. albuterol, ProAir, Ventolin, Proventil, Xopenex) today to help control coughing, wheezing, or chest tightness? (Do not include times you used your inhaler before exercising to prevent exercise-induced asthma.)

Yes

No

5. Did you take your controller medication today (e.g. Advair [fluticasone/salmeterol], Symbicort [budesonide/formoterol], Pulmicort [budesonide], Alvesco [ciclesonide], Flovent (fluticasone), Asmanex [mometasone])

Yes

No

The app is designed to calculate the answers to the first four questions and give the caregiver and child one of two messages, based on the data collected. The calculations are running tabulations based on the preceding entries. If the parent/child dyad has entered data that correspond to the EPR-3 definitions for “Well Controlled”, they see the following message:

Your symptoms this week indicate that your asthma is WELL CONTROLLED. Keep taking your medicines and checking your symptoms daily because your asthma control can change quickly. If at any point you are in distress or have coughing, wheezing, or shortness of breath that does not stop after you use your inhaler, you should ASK YOUR PARENT TO TAKE YOU TO THE CLOSEST EMERGENCY ROOM or CALL 911.

If responses indicate that symptoms fall anywhere outside the EPR-3 definition for “Well Controlled”, they receive the following script:

Your symptoms this week indicate that your asthma is NOT WELL CONTROLLED. Your medications may need to be adjusted. [CLICK HERE](#) to schedule an appointment

with your doctor/nurse practitioner. If you are in distress or have coughing, wheezing, or shortness of breath that does not stop after you use your inhaler, you should ASK YOUR PARENT TO TAKE YOU TO THE CLOSEST EMERGENCY ROOM or CALL 911.

During this preliminary testing phase, the responses are not stored in a centralized database to be accessed by providers. However, the app has the capability to securely store this patient information so that clinicians can access the information at regularly scheduled or urgent appointments.

### **Purpose**

Given the waxing and waning of symptoms that is characteristic of asthma, careful monitoring is essential. Newcomb (2010) has proposed a mechanism by which communication barriers among children, caregivers, and health care providers adversely impacts the transition from Symptom Experience to Symptom Management Strategies. Minimization and uncertainty have been identified as major contributing factors to delays in seeking care among asthma patients of all ages (Janson & Becker, 1998), but these factors may play an even larger role among children with asthma and their parents. One goal of this project is to examine the potential usefulness of the AsthmaChecker app in bridging the communication gap among children with asthma, their caregivers, and their health care providers, with particular attention devoted to how the app impacts uncertainty.

A second goal of this project is to use tenets from the Diffusion of Innovations theory to predict the diffusibility of the AsthmaChecker app among AASC's patient population. This involves specifically quantifying the app's relative advantage, compatibility, complexity, trialability, and observability, since these five factors influence any innovation's rate of adoption (Rogers, 2003).

Finally, an unexpected third research question arose during the pilot of AsthmaChecker related to the impact of children's development and literacy skills on the usability of the app. The third goal of this project is to determine the extent of this relationship.

## **Methods**

### **Study Design and Sample**

This study used a cross-sectional survey design using four groups: caregivers of children with asthma, caregivers of children without asthma, children with asthma, and children without asthma. Children with asthma were further separated into those with intermittent and persistent asthma for some analyses. Some analyses grouped children and their caregivers into "families".

Potential participants were approached in the waiting rooms of five AASC clinics across Middle Tennessee. They each received a formal Letter of Invitation to Participate in Research, which served as implied consent. The study received authorized exemption from the Belmont University Institutional Review Board.

A convenience sample of 73 participants was obtained. These 73 participants included children ranging in age from 5-11 years old and their caregivers. Exclusion criteria included caregivers or children having an obvious mental impairment, not having full use of both hands, and the caregiver being unable to read. Children did not necessarily have to be diagnosed with asthma. Surveys were designed to be administered to caregiver/child dyads, with questions broken into four sections: questions for all caregivers, questions for caregivers of children with asthma, questions for all children, and questions for children with asthma.

Of the 73 participants, there were 23 children without asthma with 23 corresponding caregivers. There were 14 caregivers of children with asthma and 13 children with asthma (one caregiver volunteered to take the survey even though his child was not present). Of the children

with asthma, six were taking a prescribed daily inhaled medication and six were not. One respondent with asthma did not answer the question about whether he takes a daily medication. Because guidelines (EPR-3, 2007) recommend treating mild, moderate, or severe persistent asthma with long acting controller medications (typically an inhaled corticosteroid or inhaled corticosteroid/ long acting beta agonist combination) while mild intermittent asthma only requires symptomatic treatment, asthma severity of the sample can be inferred. By this standard, it can be assumed that six children had intermittent asthma, six had persistent asthma, and one had asthma of undetermined severity.

### **The Questionnaire**

A search of the literature in CINAHL, Medline, and Health and Psychosocial Instruments revealed a lack of validated tools for evaluating telemonitoring technologies. Additionally, this project sought to evaluate AsthmaChecker in light of Symptom Management Theory and Diffusion of Innovations Theory. For these reasons, a new four-point Likert survey was created, the full version of which can be found in Appendix F.

Questions were designed to assess the app's usefulness in improving child and caregiver uncertainty about asthma symptoms and likely rate of diffusion. Additional questions were designed to answer usability and satisfaction questions of interest to AASC and PME Communications. The usability and satisfaction findings are beyond the scope of this particular paper.

A Symptom Management Theory construct, consisting of five questions for caregivers of children with asthma and two questions for children with asthma, was developed. The caregiver items include:

- This app would be useful in assisting me to manage my child's health.

- I felt more involved in my child's care by using the app.
- Using this app would provide me with a sense of security and peace of mind.
- In the past, I have missed signs of worsening asthma symptoms in my child that have led to missed school days, ER visits, or hospitalizations.
- I always know when my child's asthma is bad enough to call the clinic.

Items for children include:

- Sometimes I forget to tell my parent my asthma is bothering me.
- This app helps me understand if my asthma is under control.

Each of these questions addresses a piece of the Symptom Management Theory, in which communication between the asthma dyad (caregiver and child), uncertainty, and minimization play a role in prompt management of worsening asthma symptoms. Answers indicating poorer communication and greater uncertainty and minimization may indicate greater usefulness of the app in filling a Symptom Management need.

A second construct was designed to evaluate each of the five factors identified in Diffusion of Innovations Theory which impact rates of diffusion: relative advantage, compatibility, complexity, trialability, and observability. Six items were presented to caregivers of children with asthma:

- I found the app unnecessarily complex. (*Complexity*)
- I found the app too complicated to use. (*Complexity*)
- If recommended by nurse practitioner or physician, I would be willing to use this app. (*Trialability*)
- I have heard that symptom monitoring works well for other people with asthma. (*Observability*)



- This app gives me a way to monitor my child's asthma that I have been wishing for. (*Compatibility*)
- Using this app to monitor my child's asthma is better than what I have already been doing. (*Relative advantage*)

The first two items both relate to undue complexity, but are asked in different ways.

These two items were designed to be collapsed into one item for statistical analysis. The third item speaks to trialability, in that the caregiver is essentially being asked whether he or she would be willing to try the app. Observability is assessed in the fourth item by ascertaining to what degree caregivers have already seen evidence of telemonitoring success diffusing through culture. The fifth item assesses how compatible the app is with the caregiver's preexisting values and wishes. Finally, the sixth item determines whether the caregiver believes that the app offers any relative advantage over existing asthma management strategies. It is hypothesized that measuring these five areas can give some indication of relative rates of diffusion as well as illuminate particular areas which may promote or inhibit diffusion.

Children were given only two Diffusion items, one related to complexity and one related to relative advantage. This was decided, in part, due to difficulty with communicating issues of trialability, observability, and compatibility in developmentally-appropriate language. The two items presented to children with asthma included:

- The app is easy to use. (*Complexity*)
- Using this app is better than what I am already doing to keep track of my asthma. (*Relative advantage*)

One final construct was created to answer a question that came to light during the surveying phase. Several caregivers approached the investigator and informally reported that the child would have answered several questions differently if they had been older or had been more proficient in reading. They wanted the investigator to understand that the app itself was not necessarily difficult to understand, but due to their child's developmental ability, they needed the help of an adult to use it effectively. The Literacy and Development construct, drawn from previously created questions, included three questions related to a child's ability to use the app somewhat independently. These items were offered to all children, regardless of whether they had asthma, and included:

- The app is easy to use.
- When I use this app, I need lots of help from my parent.
- I am able to understand all of the questions in the app.

### **Data Analysis**

For the entire survey, the four-point Likert responses were assigned values as follows: Strongly Agree= 1, Agree= 2, Disagree= 3, and Strongly Disagree= 4. Construct items were summed to create overall scores for each, as outlined below.

The caregiver Symptom Management Construct was summed to create a "Parent SMT Score". This required first recoding the item stating, "I always know when my child's asthma is bad enough to call the clinic", due to reverse wording compared to the other items. After this recoding, a lower summed score indicates greater caregiver uncertainty and less adequate communication concerning asthma symptoms. Conversely, a higher summed Parent SMT Score indicates less uncertainty and better communication. The possible range for summed Parent SMT Scores was 5-20. Descriptive statistics were analyzed.

“Child SMT Scores” were also summed. Similar to caregiver scores, lower Child SMT Scores indicate greater uncertainty while higher scores indicate less uncertainty. The possible range for Child SMT Scores was 2-8. Descriptive statistics were analyzed.

Family SMT Scores were subsequently calculated. Caregiver scores were summed with child scores to give an overall score for the caregiver/child symptom-managing dyad. The possible range for summed Family SMT Scores was 7-28. Descriptive statistics were analyzed.

These Parent, Child, and Family SMT Scores were used to answer research questions about the degree to which caregivers, children and families dealing with asthma experience uncertainty. The next calculation determined whether significant differences in uncertainty exist between asthma caregivers and children with asthma. In order to make Parent and Child SMT scores comparable, it was first necessary to convert each group of scores to a standard scale. Because caregivers answered five questions and children answered two, Parent SMT scores were multiplied by two and Child SMT Scores were multiplied by five. The new scores were used to run a paired sample t-test to look for differences between the groups. Finally, using demographic data about daily medication use to divide children with asthma into those with intermittent asthma versus those with persistent asthma, the investigator used a Mann-Whitney U test to look for differences in Family SMT Scores that might be dependent upon the child’s asthma severity. It was hypothesized that families with children who have persistent asthma would have higher levels of uncertainty due to greater severity of and fluctuations in the child’s asthma symptoms.

Diffusion scores were similarly summed for asthma caregivers and children with asthma. For the “Parent Diffusion Score”, both complexity items were recoded due to reverse wording. Then they were summed and multiplied by .05 in order to weight them such that complexity was measured evenly compared to the other four items. Finally, the new complexity score was

summed with the trialability, observability, compatibility, and relative advantage items to create the overall “Parent Diffusion Score”. The possible range was 5-20, with lower scores indicating a greater likelihood for rapid diffusion. Descriptive statistics were analyzed.

In an effort to roughly estimate whether any of the six ordinal diffusion items showed significant differences from the others, frequency distributions for each response were tabulated.

The “Two Item Child Diffusion Score” was calculated using their complexity and relative advantage items. The possible range was 2-8, with lower scores indicating a greater likelihood for rapid diffusion. Descriptive statistics were analyzed.

For the Literacy and Development construct, responses to “When I use this app, I need lots of help from my parent” were recoded due to reverse wording. The three items were then summed, giving a possible range of 3-12. Children were dichotomized into two groups, based on age, 5-7 years old and 8-11 years old, and an independent t-test was conducted in order to test for differences in scores between the two groups.

For all statistical tests, the alpha level for significance was set at .05.

## **Results**

### **Symptom Management Constructs**

Descriptive statistics for Parent, Child, and Family SMT Scores can be found in Table 1. Adjusted Parent and Child SMT Scores, which were standardized by multiplying by conversion factors of two and five, respectively, are also shown in Table 1. Each grouping of scores showed a Gaussian distribution, as evidenced by a Fisher Index of Skewness of  $\leq \pm 2.58$ .

Because Adjusted Parent SMT Scores and Adjusted Child SMT Scores were both normally distributed, a paired samples t-test was justified for comparing differences between the groups. The paired samples t-test failed to reveal a statistically significant difference between the

mean adjusted SMT scores of caregivers ( $M= 25.2$ ,  $SD= 3.86$ ) and children ( $M= 23.8$ ,  $SD= 3.11$ ),  $t(11)= 1.308$ ,  $p= .218$ ,  $\alpha= .05$ . See Table 2.

Family SMT Scores were used to look for differences between families with children with intermittent asthma and families with children with persistent asthma. Out of the 12 families studied, 6 families had children with intermittent asthma and 6 families had children with persistent asthma. Because of the small sample size in each group, a nonparametric test, the Mann-Whitney  $U$ , was conducted. See Tables 3 and 4. The two groups did not differ significantly,  $U(11)= 17.5$ ,  $Z= -0.83$ ,  $p= .937$ .

Table 1. Descriptive Statistics for Parent, Child, and Family SMT Scores

	<i>N</i> (valid)	<i>N</i> (missing)	<i>Possible</i> range	<i>Observed</i> range	<i>Mean</i>	<i>Standard</i> deviation	<i>Confidence</i> interval 95%	<i>Fisher</i> Index of Skewness
<i>Parent</i> <i>SMT</i> <i>Scores</i>	13	1	5-20	9-16	12.5	1.85	11.99, 13.01	0.562
<i>Child</i> <i>SMT</i> <i>Scores</i>	13	0	2-8	3-6	4.6	0.77	4.39, 4.81	-0.74
<i>Family</i> <i>SMT</i> <i>Scores</i>	12	2	7-28	14-22	17.3	2.27	16.64, 17.96	1.24
<i>Adjusted</i> <i>Parent</i> <i>SMT</i> <i>Scores</i>	13	1	10-40	18-32	25.2	3.86	24.09, 26.31	0.41
<i>Adjusted</i> <i>Child</i> <i>SMT</i>	12	2	10-40	20-30	23.8	3.11	22.90, 24.70	0.27

Scores

Table 2. Differences Between Adjusted Parent SMT Scores and Adjusted Child SMT Scores

**Paired Samples Test**

	Paired Differences						t	df	Sig. (2-tailed)
	Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference					
				Lower	Upper				
Pair 1 AdjParentSMT - AdjChildSMT	1.41667	3.75278	1.08333	-.96773	3.80107	1.308	11	.218	

Table 3. Descriptive Statistics and Ranks for Family SMT Scores for Families of Children with Intermittent vs. Persistent Asthma

**Ranks**

	FamilyAsthmaSeverity	N	Mean Rank	Sum of Ranks
FamilySMTScore	IntermittentAsthma	6	6.58	39.50

PersistentAsthma	6	6.42	38.50
Total	12		

Table 4. Mann-Whitney *U* Test for Differences Between Families of Children with Intermittent and Families of Children with Persistent Asthma

**Test Statistics<sup>a</sup>**

	FamilySMTScore
Mann-Whitney U	17.500
Wilcoxon W	38.500
Z	-.083
Asymp. Sig. (2-tailed)	.934
Exact Sig. [2*(1-tailed Sig.)]	.937 <sup>b</sup>

a. Grouping Variable: FamilyAsthmaSeverity

b. Not corrected for ties.

**Diffusion Constructs**

After summing the complexity, trialability, observability, compatibility, and relative advantage items, caregivers showed a mean Parent Diffusion Score of 12.6, with a possible range of 5-20. Six caregivers scored in the upper half of the range while six scored in the lower half. The scores were



normally distributed, with a Fisher Skewness Index of .013. Frequencies are shown in Table 5, descriptive statistics are shown in Table 6, and a simple number line plotting the mean within the possible range is shown in Table 7.

Frequency distributions for responses to each of the six caregiver Likert items are shown in Table 8. The item stating “I found the app unnecessarily complex” is labeled Complexity 1, and the item stating “I found the app too complicated to use” is labeled Complexity 2. The chart is organized to reflect the reverse wording of the complexity items, such that each column indicates a similarly positive or negative attitude toward diffusibility. Smaller numeric values for responses indicate more favorability toward rapid diffusion. No items stand out as receiving vastly different responses compared to the others.

Complexity and relative advantage items were summed to calculate the Two Item Child Diffusion Score. Children had a mean score of 3.92, with a possible range of 2-8. The scores were normally distributed (Fisher Skewness Index= .086). 11 children scored in the lower half of the range and two scored a 5, which was in the middle of the range. No children scored in the upper half of the range. Frequencies are shown in Table 9, descriptive statistics are shown in Table 10, and a number line plotting the mean within the possible range is shown in Table 11.

Table 5. Parent Diffusion Score Frequency Distribution

**Parent Diffusion Scores**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	9.00	1	1.4	8.3	8.3
	10.00	3	4.1	25.0	33.3
	11.50	1	1.4	8.3	41.7
	12.00	1	1.4	8.3	50.0
	13.50	1	1.4	8.3	58.3
	14.00	2	2.7	16.7	75.0
	15.00	1	1.4	8.3	83.3
	16.00	2	2.7	16.7	100.0
	Total	12	16.4	100.0	
Missing	System	61	83.6		
Total		73	100.0		

Table 6. Descriptive Statistics for Parent Diffusion Scores

**Statistics**

Parent Diffusion Scores

N	Valid	12
	Missing	2
Mean		12.5833
Median		12.7500
Mode		10.00
Std. Deviation		2.49393
Skewness		.008
Std. Error of Skewness		.637
Range		7.00
Minimum		9.00
Maximum		16.00
Percentiles	25	10.0000
	50	12.7500
	75	14.7500

Table 7. Mean Parent Diffusion Score

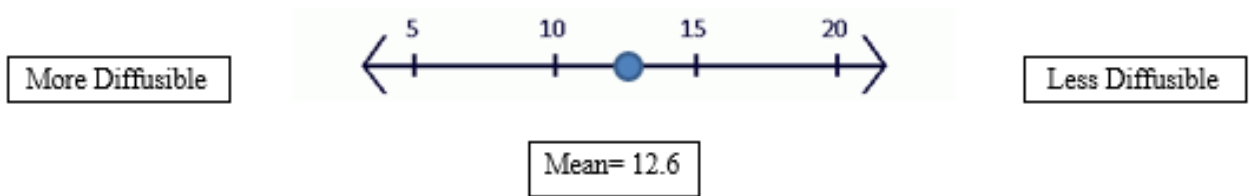


Table 8. Frequencies of Caregiver Responses to Diffusion Items

	1= Strongly Disagree	2= Disagree	3= Agree	4= Strongly Agree	Missing
Complexity 1	4	7	2	0	1
Complexity 2	7	7	0	0	0
	1= Strongly Agree	2= Agree	3= Disagree	4= Strongly Disagree	Missing
Trialability	1	10	1	1	1
Observability	1	8	4	0	1
Compatibility	0	6	7	0	1
Relative Advantage	1	7	4	0	2

Table 9. Two Item Child Diffusion Score Frequency Distribution

Two Item Child Diffusion Scores

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 3.00	3	23.1	23.1	23.1
4.00	8	61.5	61.5	84.6
5.00	2	15.4	15.4	100.0
Total	13	100.0	100.0	

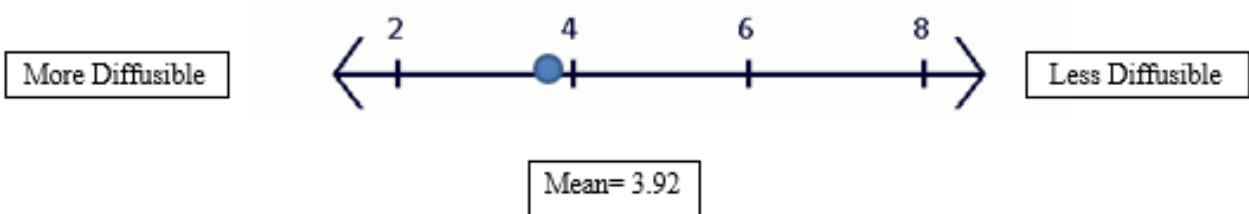
Table 10. Descriptive Statistics for Two Item Child Diffusion Scores

**Statistics**

Two Item Child Diffusion Scores

N	Valid	13
	Missing	0
Mean		3.9231
Median		4.0000
Mode		4.00
Std. Deviation		.64051
Skewness		.053
Std. Error of Skewness		.616
Range		2.00
Minimum		3.00
Maximum		5.00
Percentiles	25	3.5000
	50	4.0000
	75	4.0000

Table 11. Mean Two Item Child Diffusion Score



### Literacy and Development Construct

When comparing differences in usability for all children, regardless of asthma, based on age, children were dichotomized into two groups: those aged 5-7 and those aged 8-11. Levene's test for homogeneity of variance showed that equal variances could be assumed. An independent samples t-test indicated that literacy scores were significantly higher for younger children ( $M=6.08$ ,  $SD=1.55$ ) than for older children ( $M=4.79$ ,  $SD=1.36$ ),  $t(30)=2.49$ ,  $p=.019$ ,  $d=0.88$ . This suggests that younger children have significantly more difficulty using the app independently compared to older children (See Table 12). Descriptive statistics are shown in Table 13.

Table 12. Independent t-Test for Differences in Usability Based on Age

**Independent Samples Test**

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2- tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
LiteracyScore	Equal variances assumed	.096	.759	2.486	30	.019	1.28745	.51778	.23000	2.34490
	Equal variances not assumed			2.423	23.540	.023	1.28745	.53137	.18961	2.38528

Table 13. Descriptive Statistics for Literacy and Development Scores, Sorted by Age

**Group Statistics**

	LiteracyAge	N	Mean	Std. Deviation	Std. Error Mean
LiteracyScore	5-7	13	6.0769	1.55250	.43059
	8-11	19	4.7895	1.35724	.31137

**Discussion**

The findings of this study show that, in the area of Symptom Management, caregivers, children, and caregiver-child dyads express moderate amounts of uncertainty concerning asthma symptom management. Questions in the Symptom Management construct pertain to this uncertainty and the

respondant's perception of whether AsthmaChecker would be helpful in mitigating it. The fact that caregivers, children, and families each show moderate scores in this construct indicates that some amount of uncertainty about asthma symptoms exist, and that the app could offer an added therapeutic benefit to some patients.

The hypothesis that greater uncertainty exists in families with children with persistent asthma was unsupported. It would seem that patients who have more severe asthma would have more frequent symptom fluctuations and exacerbations and would therefore require more assistance in management than those who rarely have symptoms. However, it may be that children, caregivers, and dyads dealing with more severe asthma have more experience and expertise with asthma symptom management, and therefore feel less uncertain than the hypothesis assumed. Another reason for this finding could be that the author's inference of severity from medication use was faulty. It is possible that child participants who responded that they were not taking daily medications were either a) noncompliant with a prescribed medication, or b) under-medicated due to misdiagnosis. The author assumed that all providers in the practice were diagnosing and prescribing according to published guidelines, when this may not actually be the case.

Diffusion scores were also moderate, indicating that the rate of diffusion for AsthmaChecker will neither be extremely rapid nor extremely slow. No one diffusion item seemed to be of particular benefit or hindrance to diffusion. It must be noted, however, that different Diffusion scores would be likely in different clinic locations. Characteristics of each population can impact overall diffusion of innovations, and since each clinic has its own demographic and cultural distribution of patients, what may diffuse easily in one location might not be as successful in another. In this way, the Diffusion construct does not only measure an inherent quality of the app itself, but of the app within the context of a particular population. The Diffusion findings of this study will, therefore, be more generalizable within the five clinics where surveying occurred than in the other clinics within the corporation. Similarly, if



AsthmaChecker were to be released for public use, other clinics should be advised to test diffusion among their own patient population.

This study reveals a significant relationship between age-related literacy and development issues and app usability. This is not unexpected, but it does indicate that particular barriers may exist for patients younger than eight-years-old. These are the very patients for whom, according to Symptom Management Theory, communication and caregiver uncertainty already present a significant risk for treatment delay. Solutions to this problem should be explored through further research.

Limitations to this study include the small sample size and use of instruments and constructs that do not have established reliability or validity. Use of the instrument and constructs, as currently worded, may not be generalizable for other uses. However, with minor adjustments and further testing, the Symptom Management, Diffusion, and Literacy and Development constructs could be helpful tools for other studies.

The field of telemedicine has seen rapid advances in recent years, but there is a dearth of validated tools for the evaluation of emerging telemonitoring interventions. For this reason, the Diffusion construct holds great promise for predicting rates of diffusion of telemonitoring interventions in clinical practice. Construct validity and reliability testing is warranted.

Self-monitoring of asthma presents unique challenges to children and their caregivers. Emerging technologies, such as telemonitoring apps, should be further explored in order to offer patients a diversity of tools with which to aid their self-management. Telemonitoring interventions may promote better evidence-based informed self-monitoring, and it is likely that such interventions will become increasingly prevalent in the future. Research must strive to keep up with these advances.

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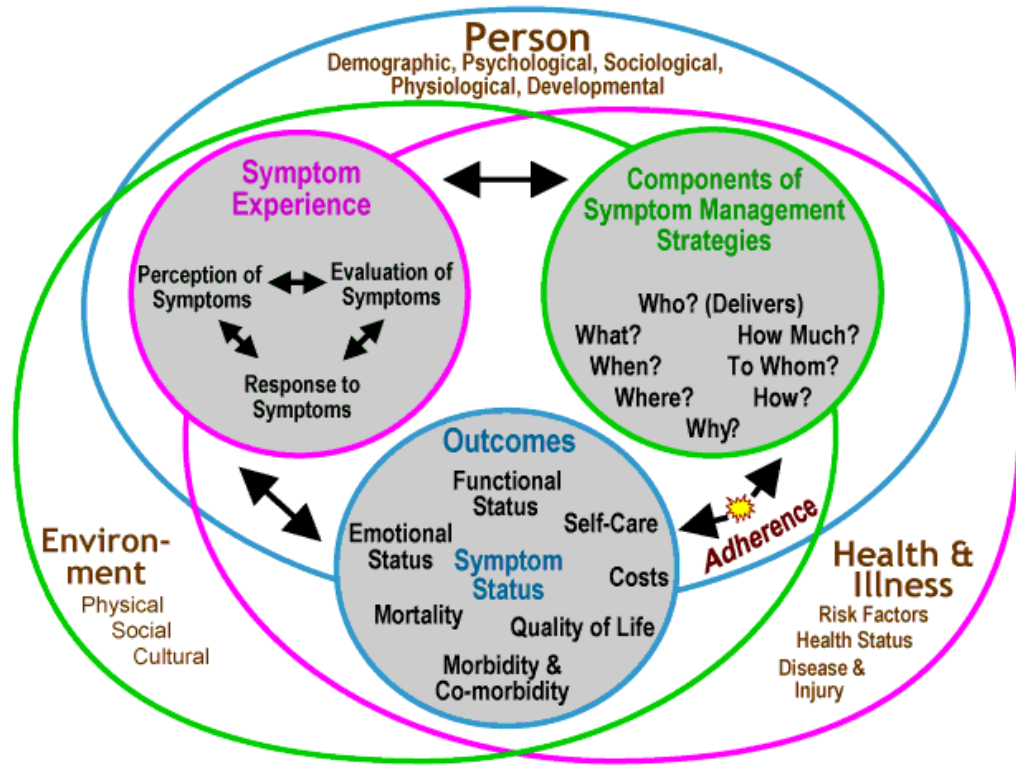
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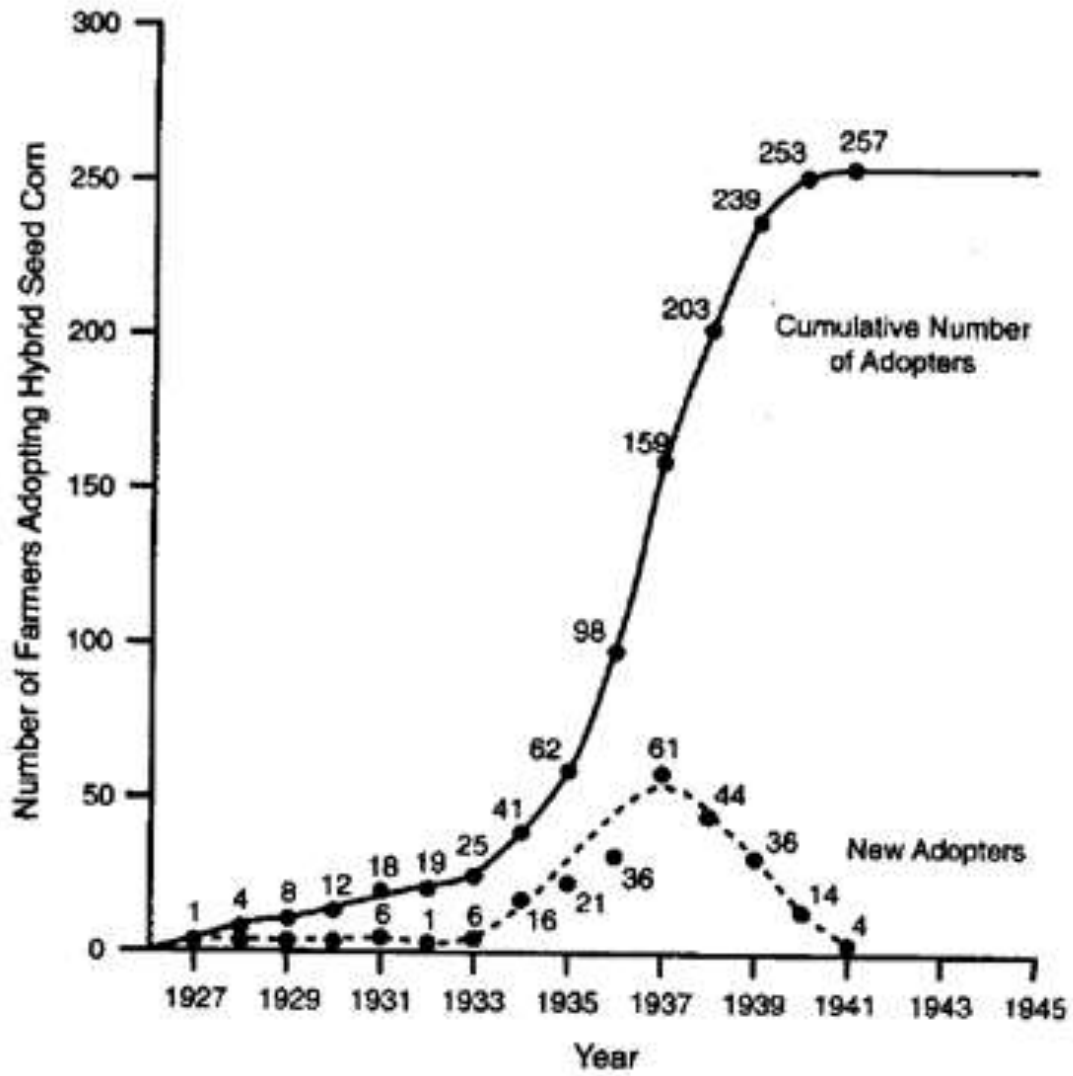
Appendix A

Symptom Management Theory



Appendix B

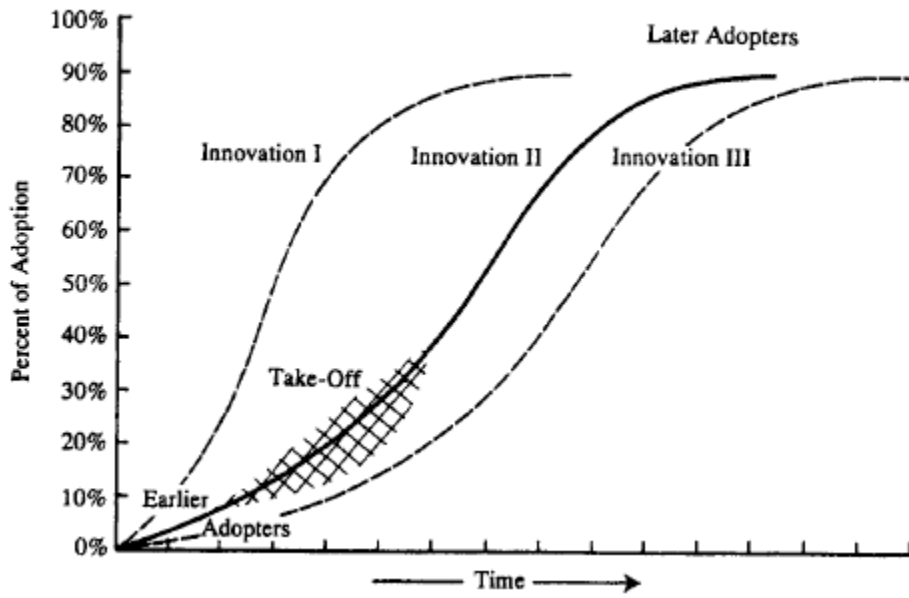
Diffusion S-curve





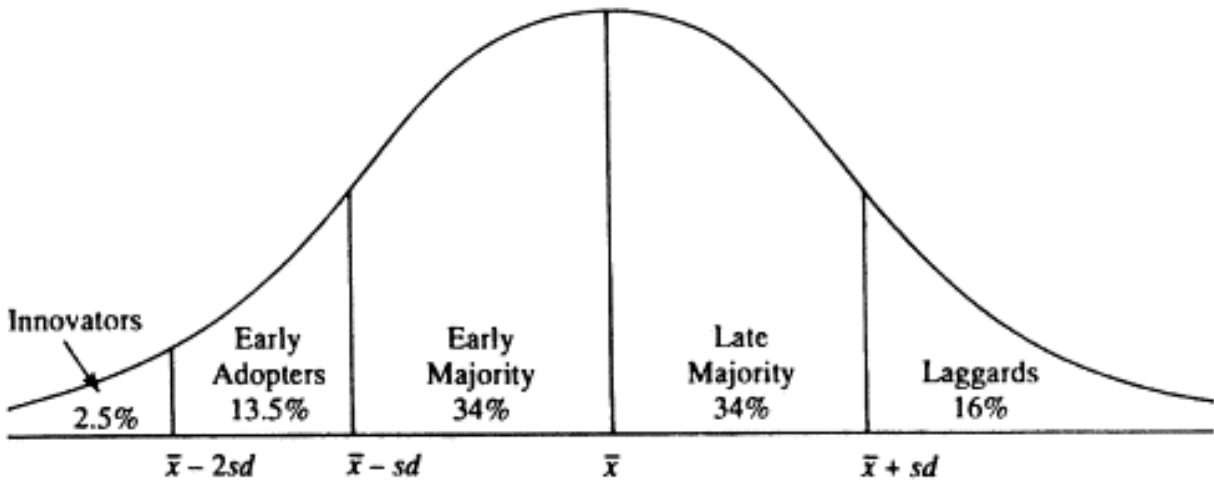
Appendix C

The Diffusion Process with Varying Rates of Diffusion



Appendix D

Categories of Adopters



Appendix E

EPR-3 Definitions for Asthma Control

Components of CONTROL	Age (Years)	Level of Asthma CONTROL			
		Well Controlled	Not Well Controlled	Very Poorly Controlled	
Impairment	Symptoms	0 – 4	≤ 2 days/week but ≤ 1x/day	> 2 days/week or multiple times on ≤ 2 days/week	Throughout the day
		5 – 11			
	Nighttime awakenings	≥ 12	≤ 2 days/week	> 2 days/week	
		0 – 4	≤ 1x/month	> 1x/month	> 1x/week
		5 – 11		≥ 2x/month	≥ 2x/week
	≥ 12	≤ 2x/month	1–3x/week	≥ 4x/week	
	Interference with normal activity	All	None	Some limitation	Extremely limited
	SABA use for symptoms	All	≤ 2 days/week	> 2 days/week	Several times per day
	Lung function				
	FEV <sub>1</sub> (predicted) or PEF (personal best)	≥ 5	> 80%	60-80%	< 60%
FEV <sub>1</sub> /FVC	5 – 11	> 80%	75-80%	< 75%	
Validated questionnaires					
ATAQ	≥ 12	0	1–2	3–4	
ACQ	≥ 12	≤ 0.75	≥ 1.5	n/a	
ACT	≥ 12	≥ 20	16–19	≤ 15	
Risk	Exacerbations requiring oral corticosteroids	0 – 4	≤ 1x/year	2-3x/year	> 3x/year
		5 – 11		≥ 2x/year	
		≥ 12		Consider severity and interval since last exacerbation	
	Reduction in lung growth	5 – 11	Evaluation requires long-term follow-up care		
Loss of lung function	≥ 12	Evaluation requires long-term follow-up care			
Treatment-related adverse effects	All	Medication side effects can vary in intensity from none to very troublesome and worrisome.			
Recommended treatment actions	All	Maintain current step, regular follow-up at every 1–6 months; consider stepping down if well controlled for ≥ 3 months	Step up 1 step	Step up 1–2 steps and consider short course of oral corticosteroids	
			Before stepping up, review adherence to medication, inhaler technique, environmental control, and comorbid conditions. If an alternative treatment option was used in a step, discontinue and use the preferred treatment for that step.		
			Reevaluate the level of asthma control in 2–6 weeks and adjust therapy accordingly		
			For side effects, consider alternative treatment options.		

ACQ, Asthma Control Questionnaire; ACT, Asthma Control Test; ATAQ, Asthma Therapy Assessment Questionnaire; FEV<sub>1</sub>, forced expiratory volume in 1 second; FVC, forced vital capacity; PEF, peak expiratory flow; SABA, short-acting beta<sub>2</sub> agonist

Appendix F

Asthma Symptom Monitoring App Survey

***Asthma Symptom Monitoring App Survey***  
 Erin Shankel, RN, MSN, FNP-BC  
 Allergy, Asthma, and Sinus Center  
 with  
 Belmont University  
 615-414-2861

<b>Parent's Name:</b>				
<b>Child's Name:</b>				
<b>Child's Age:</b>				
Has your child been diagnosed with asthma? YES <input type="checkbox"/> NO <input type="checkbox"/>				
Does your child take a daily medication for asthma? YES <input type="checkbox"/> NO <input type="checkbox"/>				
<b>PARENTS, please answer the following:</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
I would like to use this app frequently.				
I found the app unnecessarily complex.				
I thought the app was easy to use.				
I would imagine that most people would learn to use this app very quickly.				
I found the app too complicated to use.				
I felt very confident using the app.				
Information presented on screens was easy to comprehend quickly.				
Choices (yes and no) were clear and unambiguous.				
I was able to select the answer I wanted without pushing the wrong button.				
<b><i>If your child has asthma, please continue. If not, stop here and skip to the second page.</i></b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
This app would be useful in assisting me to manage my child's health.				
I felt more involved in my child's care by using the app.				
Using this app would provide me with a sense of security and peace of mind.				
I would be willing to use this app with my child on a daily basis.				
If recommended by my nurse practitioner or physician, I would be willing to use this app.				
I would recommend the use of this app to my family and friends.				
In the past, I have missed signs of worsening asthma symptoms in my child that have led to missed school days, ER visits, or hospitalizations.				
I always know when my child's asthma is bad enough to call the clinic.				
I have heard that symptom monitoring works well for other people with asthma.				
This app gives me a way to monitor my child's asthma that I have been wishing for.				
Using this app to monitor my child's asthma is better than what I have already been doing.				

CHILDREN, please answer the following:	Strongly Agree	Agree	Disagree	Strongly Disagree
I like using the app.				
The app is easy to use.				
I would be willing to use this app every day.				
When I use this app, I need lots of help from my parent.				
I am able to understand all of the questions in the app.				
It is easy for me to push the button I want to push for "yes" and "no" without making a mistake.				
Using this app takes too much time.				
<b><i>If you are a child who has asthma, please continue. If not, please stop here and skip to the end of the survey.</i></b>	Strongly Agree	Agree	Disagree	Strongly Disagree
Sometimes I forget to tell my parent my asthma is bothering me.				
Using this app is better than what I am already doing to keep track of my asthma.				
This app helps me understand if my asthma is under control.				

**Additional comments:**

**Thank you for your participation. Your input is valuable to us. Please return all forms to the researcher who approached you, and don't forget to pick up your gift card!**

### **Scholarly Project Conclusion**

Telemonitoring applications, such as the AsthmaChecker app, hold promise as a novel technique for managing chronic diseases. Pediatric asthma, in particular, presents unique challenges to patients, caregivers, and health care providers in terms of providing timely, effective, and evidence-based interventions. Improved collaboration among all those involved in managing a child's asthma is sure to improve costs, quality of care, and health outcomes. Apps provide an accessible and useful tool for facilitating this type of communication.

As discussed in the preceding chapters, existing literature suggests that telemonitoring may lead to improvements in improve patient compliance with self-monitoring, asthma symptoms, quality of life, and lung function, especially in those whose asthma is the most poorly controlled. However, the body of literature is still sparse. More research is needed, and this project helps expand current knowledge about telemonitoring of chronic disease, and of asthma in particular.

Furthermore, this project tests and applies the theories of Symptom Management and Diffusion of Innovations in the context of asthma telemonitoring. Minor adjustments to Symptom Management Theory have been proposed which may improve its applicability to pediatric populations and to clinical telemonitoring scenarios. Survey constructs for evaluating the AsthmaChecker app were developed to further apply these theories. Other studies may benefit from applying these constructs to emergent telemonitoring technologies.

Finally, a subset of this project involved developing and trialing the AsthmaChecker app. Survey responses indicate that children and parents see value in the app in terms of reducing symptom uncertainty and minimization. The app is likely to diffuse at a moderate rate within the

clinic population, and is able to be used independently by children age eight and older. For these reasons, work towards expanded development and implementation of the app is justified.

The work represented in this project is preliminary, but it does provide helpful insights into pediatric asthma telemonitoring, and it sets the stage for future research.