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Social Support and Empowerment Among Caregivers of Children with Asthma

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SOCIAL SUPPORT AND EMPOWERMENT AMONG CAREGIVERS OF CHILDREN WITH ASTHMA

by

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ABSTRACT

The purpose of this study was to better understand the concept of empowerment among caregivers of children with asthma. This study investigated what is already known about empowerment among caregivers and the instruments available to measure caregiver empowerment. This study then examined the relationship between social support and caregiver empowerment as well as income level and empowerment amongst caregivers of children with asthma. This study used the Federal Poverty Guidelines, Family Empowerment Scale and MOS Social Support Survey to measure these relationships. It was found that there was no relationship between income level and empowerment, but there was a significant correlation between social support and empowerment. The implications of this study are discussed as this study adds to the existing body of knowledge related to caregiver empowerment and establishes the foundation for further interventions to help increase empowerment among caregivers of children with asthma.

This work is dedicated to my husband and daughter, who have supported me through countless days of both good and bad, and whom I would not have been able to complete this work without. This work is also dedicated to my dad, who taught me to work hard, persevere through difficult times, and never give up.

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CHAPTER 1: INTRODUCTION

Asthma is a major chronic disease worldwide that affects both children and adults (World Health Organization, 2020). Children with asthma often miss days of school or have to visit the emergency department due to their disease (Zahran et al., 2018). Caregivers taking care of children with asthma can have decreased quality of life and increased stress (Ekim & Ocakci, 2016). Additionally, children living in families with a low socioeconomic status are more likely to be diagnosed with asthma (Zahran et al., 2018). Empowerment is a concept that has been studied in the caregiver population and has been shown to help improve caregiver burden by increasing knowledge and self-efficacy (Bickman et al, 1998), decreasing stress and anxiety (Etemadifar et al., 2018), and an increasing competence (Saeui et al., 2009).

Social support is an important predictor of empowerment (Peterson & Hughey, 2002) and of asthma control (Scheckner et al., 2015). However, there have not been any studies conducted that have examined the relationship between social support and empowerment among caregivers of children with asthma. The Caregiver Empowerment Model (Jones et al., 2011) establishes the relationship between social support and empowerment but it needs to be confirmed through research. Additionally, caregiving burden in caregivers of children with asthma can be influenced by low socioeconomic status, and low income can cause stress (Ekim & Ocakci, 2016). Research on the relationship between socioeconomic status and empowerment in this population can also help to better understand ways in which empowerment can be supported.

The goal of this study is to look further at the concept of empowerment related to caregivers of children with asthma. This study is divided into three articles: 1.) a literature review that looks at the existing literature on caregiver empowerment amongst caregivers with asthma, 2.) A descriptive study on the relationship between social support and empowerment and socioeconomic status and empowerment among caregivers of children with asthma, and 3.) A review on the available instruments in the literature to measure caregiver empowerment.

The first article is a literature review that was conducted in which 18 articles were selected either related to caregiver empowerment interventions or the concept of empowerment. The review found themes related to empowerment interventions including asthma management and quality of life as well as themes related to the concept of empowerment including facilitators for empowerment, consequences of empowerment, and the need for further development of empowerment methods.

The second article was a descriptive research study in which 58 participants were recruited from an asthma camp, online caregiver asthma support group and from an organization that supports asthma education and management. Participants were recruited to complete an online survey consisting of demographic information, the Family Empowerment Scale, and the MOS Social Support Survey. Results showed a correlation between all aspects of social support and overall empowerment, and all aspects of empowerment and overall social support. There was no significant relationship between income level and empowerment.

The third article was a review to compare measurement properties of instruments used to assess empowerment in caregivers. Twenty-one instruments to measure caregiver empowerment were identified and included in the review. The Family Empowerment Scale was the most widely used throughout the caregiver population. The instrument was adopted to different languages and to fit different populations. Other instruments used in multiple studies include the Generic Family Empowerment Scale, the Empowerment Questionnaire (EMPO) and the Genetic Counseling Outcome Scale (GCOS).

This research showed the importance of empowerment in the caregiver population, and that more research is needed, specifically to understand this concept in the population of caregivers of children with asthma. As the research showed a strong correlation between social support and empowerment, future research can focus on interventions to help increase social support among caregivers of children with asthma. Additionally, further research is needed on the relationship between socioeconomic status and empowerment as well as on the use and validation of more instruments to appropriately measure caregiver empowerment in this population.

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CHAPTER 2: LITERATURE REVIEW

Introduction

Asthma is a chronic health condition that affects both national and global populations and has a major impact on numerous communities. According to the World Health Organization (WHO), asthma is a major noncommunicable disease, and is the most common noncommunicable disease in children worldwide. Asthma is present in countries of all development levels. As of 2016, over 339 million people had an asthma diagnosis (World Health Organization [WHO], 2020). In that same year, in the United States alone, 8.3% of children aged 0-17 lived with asthma. Out of all children with asthma in the United States, 54% had an asthma attack, 49% of school-aged children were absent for at least one day of school and 16.7% visited the emergency department or urgent care due to an asthma attack. Additionally, asthma was more prevalent in children of families living at incomes below 100% Federal Poverty Level than in children of families living with incomes at 250% or more Federal Poverty Level (Zahran et al., 2018).

Childhood asthma can be difficult to diagnose and cannot be cured. While it cannot be cured, if it goes uncontrolled, it can lead to permanent lung damage (American Academy of Allergy Asthma & Immunology, 2020). Even though there is no cure for asthma, the burden of asthma can be reduced through disease management, including the use of medication. Appropriate disease management can lead to asthma control and high quality of life (WHO, 2020). Additionally, asthma contributes to the economic burden of disease. In 2012, $983 was the annual median cost for medical care for a child with asthma, and total costs for pediatric asthma ranged from $7.7 million to $488.1 million per state (Nurmagambetov et al., 2017).

Pediatric asthma not only impacts the lives of children with asthma, it also has an impact on the caregivers of these individuals. A systematic review on pediatric asthma and caregiving burden found that both decreased quality of life and stress can be present in caregivers of children with asthma. Sources of stress include the “caregiving activities...financial burden, parental responsibilities, and personal distress” (Ekim & Ocakci, 2016, p. 5). Higher caregiver stress is also associated with poorer asthma control (Sharp et al., 2009) and parental quality of life can be predictive of asthma control, with lower quality of life being associated with poor asthma control (Cano-Garcinuño et al., 2016). Management of caregiver burden is an important step in the mitigation of the adverse impact of pediatric asthma.

Empowerment is a concept that has been studied for many years throughout many disciplines including social work, psychology, sociology, management, education, and religion (Bartunek & Spreitzer, 2006). When relating empowerment to healthcare, it has been defined by the WHO as “a process through which people gain greater control over decisions and actions affecting their health” (WHO, 1998, p. 16). Empowerment can be a process that is social, psychological, political, or cultural (WHO, 1998). The history of empowerment in healthcare can be traced back to 1986, when the WHO introduced the Ottowa Charter. With a greater focus on empowerment, there was a shift in healthcare to include more participatory thinking (Halvorsen et al., 2020). A synthesis of the concept analyses of empowerment to understand empowerment from the perspective of the health service user found that descriptive themes of empowerment include both intrapersonal and interpersonal aspects. Antecedents to empowerment were identified as powerlessness and loss of control or competence need, motivation and change, and support and trust. Attributes of empowerment were identified as mutual partnership, change, and self-determination strengthening. Finally, consequences of empowerment were identified as improved quality of life, mastery and control, and trusting participatory relationships (Halvorsen et al., 2020). Empowerment has been studied in caregiver populations and empowerment interventions have been found to be significantly associated with an increase in knowledge and self-efficacy (Bickman et al, 1998), decreased stress and anxiety (Etemadifar et al., 2018), and an increase in competence of caregivers (Saeui et al., 2009). Empowerment can play a role in mitigating the burden of disease in caregivers.

The aim of this review is to examine the current state of the science by reviewing, analyzing, and synthesizing the literature related to the empowerment of caregivers of children with asthma to report what is currently known about empowerment in caregivers of children with asthma.

Methods

To examine the current state of the science of caregiver empowerment for caregivers of children with asthma, a literature review was conducted. MEDLINE, CINAHL, and APA PsycInfo Databases were used to conduct this search. The search terms used included empower* and asthma* and (parent* or caregiver* or mother or father). The search returned 66 results with exact duplicates removed. After examining the abstracts, 38 articles were selected for further review. Once reviewed further, 18 articles were selected to be a part of the study as they met all inclusion and exclusion criteria (See Figure 1). Inclusion criteria were studies that used an empowerment measure or intervention related to caregiver empowerment, studies of caregivers of children with asthma, and studies that were available in full text and in English. Exclusion criteria were articles that examined personal empowerment, articles that examined healthcare provider empowerment, studies that were not completed, and studies in which an empowerment measure or intervention were not included.

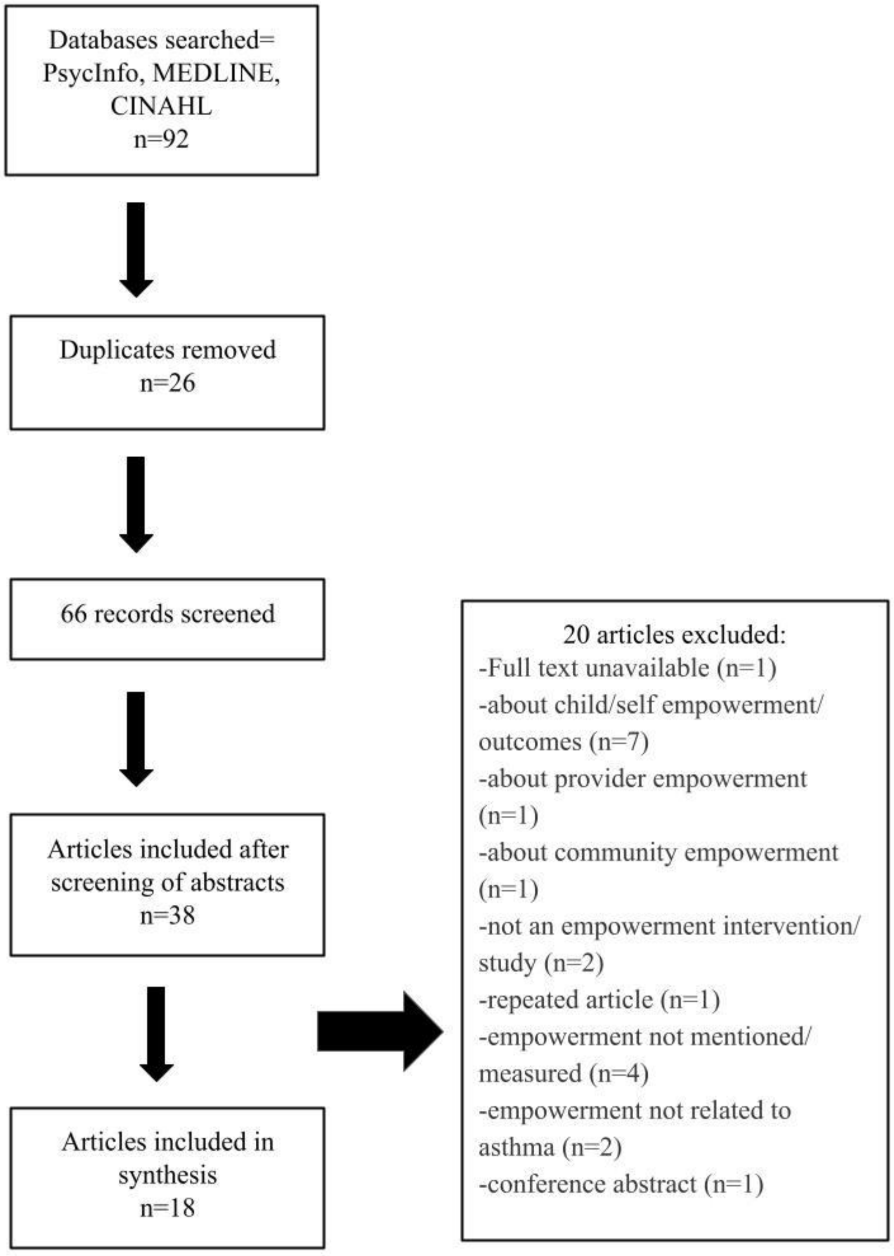

Figure 1: PRISMA Flow Diagram of Literature Review Process

Table 1: Studies included in Literature Review

Reference	***Study Type and Level***	***N***	***Tools and Measures***	***Study Aims and Factors Studied***	***Key Results***
Canino, G., Vila, D., Normand, S.-L. T., Acosta-Pérez, E., Ramírez, R., García, P., & Rand, C. (2008).	RCT Level I	221 children	Juniper Pediatric Asthma Care Quality of Life Questionnaire Caregiver Asthma Knowledge Scale Family Empowerment Scale	CALMA ("Take Control, Empower Yourself and Achieve Management of Asthma") intervention utilized to examine its effect in reducing morbidity in children who are Puerto Rican diagnosed with asthma	-Study found no difference in symptom free days b/t control/ intervention group -Caregivers receiving treatment less helpless/upset; more likely to have confidence in asthma management
Coutinho, M. T., Kopel, S. J., Williams, B., Dansereau, K., & Koinis-Mitchell, D. (2016).	Longitudinal/ self-selected participation Level III	130 children and caregivers	Family Empowerment Scale Patient Activation Scale Asthma symptoms, ED visits, caregiver nativity, demographic survey	To explore the relationship between asthma symptoms, ED use, and caregiver empowerment in a diverse urban population.	-Family empowerment was related to less asthma symptoms, while asthma service empowerment was related to more asthma symptoms -Greater empowerment existed within the family for foreign-born caregivers, while greater empowerment existed within asthma services for US-born caregivers
Dardouri, M., Sahli, J., Ajmi, T., Mtiraoui, A., Bouguila, J., Zedini, C., & Mallouli, M. (2020).	RCT Level I	37 families (experimental) 39 families (control)	Pediatric Asthma Caregiver Quality of life Questionnaire (PAQLQ) Pediatric Asthma Quality of life Questionnaire Demographics Spirometry	In children with asthma and the parents of the children, examined how an educational asthma program impacted pulmonary function and quality of life	-Quality of life was improved in both children and their parents after the intervention -Forced expiratory maneuver was better in intervention group vs control group while there was no difference in FEV1/FVC ratio between groups

Reference	***Study Type and Level***	***N***	***Tools and Measures***	***Study Aims and Factors Studied***	***Key Results***
Foronda, C. L., Jawid, M. Y., Alhusen, J., Muheriwa, S. R., Ramunas, M. M., & Hooshmand, M. (2020).	Qualitative descriptive Level III	13 healthcare providers interviewed		-Amongst healthcare providers, examined experience with gaps in healthcare system, barriers to care, and facilitators to care for caregivers of children who have respiratory disease	-Implications from the study include that nurses play a role in empowering caregivers with skills, resources, and connection to providers
Foronda, C. L., Kelley, C. N., Nadeau, C., Prather, S. L., Lewis-Pierre, L., Sarik, D. A., & Muheriwa, S. R. (2020).	Integrative review Level V	80 items		Identified psychological/ socioeconomic burdens of caregivers of children with asthma.	-Psychological= poor mental health, QOL, sleep, stress, disparities, communication (healthcare) -Socioeconomic= access to care, financial challenges -Caregiver health is linked to child's health -Facilitators of caregiver health= empowerment, education, technology, caregiver support (social)
Isik, E., Fredland, N. M., & Freysteinson, W. M. (2019).	Systematic literature review Level V	8 articles		Looks at effectiveness of education intervention programs on asthma management of school-aged children in outpatient settings	-Results= school/ community-based interventions help manage asthma well; asthma education programs need to continue beyond the inpatient setting -Asthma education leads to caregiver/ child empowerment; school nurses help empower caregivers/ children
Kashaninia, Z., Payrovee,	Quasi-experimental	45 children (6-12 years) and parents	Childhood Asthma Control Test (C-ACT)	Examined the role family empowerment	-Intervention group (empowerment intervention) had

Reference	***Study Type and Level***	***N***	***Tools and Measures***	***Study Aims and Factors Studied***	***Key Results***
Z., Soltani, R., & Mahdaviani, S. A. (2018).	Level II	(23 in intervention group, 22 in control group)	Demographics questionnaire	plays in control of asthma for school-aged children	higher post-test scores for asthma control than control group
Kelo, M., Eriksson, E., & Eriksson, I. (2013).	Qualitative descriptive Level III	12 children (age 5-12) and 19 parents Children had chronic diseases (including asthma)		School age children with chronic illness and their parents described significant education events during hospital visits	-Both positive and negative educational experiences were identified -The themes related to the educational sessions included nurse competence, didactic competence, and interpersonal competence -The educational outcome goal was empowerment (positive education) -This included sufficient information, ability to manage the disease, positive learning experiences, and satisfaction with education
Krieger, J. W., Song, L., Takaro, T. K., & Stout, J. (2000).	Descriptive (closed-ended interviews) Level III	Preliminary study= 112 enrolled households (children aged 4-12 with asthma)		Study to examine childhood asthma in low-income communities	-Upon home inspection: 37.5%- smoker present, 26.8%- mold, 64.8%- damp conditions, 76.6- carpeting in child’s bedroom -19.8% had allergy covers for bed -Study shows that methods to empower families to improve the quality of indoor environment are needed (families are part of project to empower families in indoor exposure to asthma triggers)

Reference	***Study Type and Level***	***N***	***Tools and Measures***	***Study Aims and Factors Studied***	***Key Results***
Martínez, K. G., Pérez, E. A., Ramírez, R., Canino, G., & Rand, C. (2009).	Prospective study Level III	221 caregivers of children with asthma	Center for Epidemiological Study-Depression (CES-D) Parent Asthma Self-Efficacy Scale Family empowerment, service system subscale (FES) Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) Asthma Assessment Form	Among caregivers of children with asthma who were Puerto Rican, the following relationships were studied: -depressive symptoms and 1. asthma beliefs; 2. Child asthma outcomes; 3. Caregiver quality of life	Caregivers with high depressive symptoms felt less empowered to deal with child's condition effectively
McCarthy MJ, Herbert R, Brimacombe M, Hansen J, Wong D, & Zelman M. (2002).	Quasi-experimental Level II	57 families with children with asthma	Parents sense of control scale Asthma facts	Examine the different outcomes that occurred from the traditional approach versus the empowering approach for asthma education to determine differences related to: 1. Knowledge 2. Sense of control 3. Decision-making ability 4. Asthma care ability	-Higher scores were found for the empowering approach for control, ability to make decisions, and ability to provide care
Payrovee, Z., Kashaninia, Z., Alireza Mahdaviani	Two-group semi-experimental study	45 children aged 7-11 with asthma and their parents	The Pediatric Asthma Quality of Life Questionnaire with	Aimed to assess the effect of family empowerment on the quality of life	Quality of life scores were higher after the empowerment intervention

Reference	***Study Type and Level***	***N***	***Tools and Measures***	***Study Aims and Factors Studied***	***Key Results***
, S., & Rezasoltani, P. (2014).	Level II	(Intervention group =23, control group=22)	Standardized Activity (PAQLQ) 27 demographic questions	of asthmatic school-aged children	
Prather, S. L., Foronda, C. L., Kelley, C. N., Nadeau, C., & Prather, K. (2020).	Integrative review Level V	40 studies included		Examine both barriers and facilitators in the management of asthma for African American caregivers	-Barriers to management that were identified were caregiver burden, and lack of home/ neighborhood safety -Facilitators to management included family/ community support, education/ empowerment, and healthcare providers who were culturally competent
Sander, N. (2002).	Expert opinion Level V			Identify the role of nurses as educators and advocates to help empower families of children with asthma	-Asthma/ allergies/ anaphylaxis are life-threatening conditions (immediate emergency treatment is essential) -Nurses are educators and can help empower families in the health of children with asthma/ allergies -Education/ advocacy = important solutions
Sullivan, C. E. (2008).	Phenomenological thematic analysis Level III	An online parent support group		Better understand the lives of caregivers of children with asthma	-Mothers shared about decisions/ regimens to empower other mothers -Authors suggest that online support groups can empower caregivers through confidence and competence building -Feelings of empowerment can come from Internet use, allowing caregivers to

Reference	***Study Type and Level***	***N***	***Tools and Measures***	***Study Aims and Factors Studied***	***Key Results***
					participate in healthcare more fully
Trollvik A, & Severinsson E. (2005).	Qualitative (interviews) Level III	9 parents of 5 children with asthma		Examine the influence that an asthma education program has for parents of children with asthma	-By participating in a program, parents were able to identify an increased understanding of their child's asthma experience -Themes included: accepting the illness, sharing experiences, and partnership building
Valery, P. C., Whop, L. J., Morseu, D. N., Garvey, G., Masters, I. B., & Chang, A. B. (2016).	Randomized control trial (RCT) Level I	88 children with asthma (and 81 parents)	Standardized forms with structured and open-ended questions	Develop themes that describe an asthma education intervention clinical model based on caregiver's perspectives	-97.5% of parents rated asthma education as good, very good, or excellent -Researchers state that empowerment in parents is apparent because they learn to manage the asthma of their child (after education sessions with trained indigenous healthcare workers)
Yeh, H.-Y., Ma, W.-F., Huang, J.-L., Hsueh, K.-C., & Chiang, L.-C. (2016).	Randomized control trial (RCT) Level I	65 (families)	Parental stress index Family Environment Scale	-Examine effect of family empowerment program on parental stress, family environment, pulmonary function, and asthma symptoms	With program: -parental stress decreased -family function increased -PEF/ FEV1 improved -coughing/ wheezing/ dyspnea improved

Results

In the articles selected, there was varying quality of evidence as selected articles included randomized control trials (n=4), qualitative studies (n=4), quasi-experimental studies (n=3), longitudinal studies (n=1), descriptive studies (n=1), prospective studies (n=1), expert opinion (n=1) and literature reviews (n=3). John Hopkins Evidence-Based Practice Model was used for critical appraisal (The Johns Hopkins Hospital/ Johns Hopkins University School of Nursing, 2022a; The Johns Hopkins Hospital/ Johns Hopkins University School of Nursing, 2022b). Common themes were identified related to caregiver empowerment. Articles included either an empowerment intervention or mentioned the concept of empowerment. Themes related to empowerment interventions included asthma management and quality of life. Themes related to the concept of empowerment include facilitators for empowerment, consequences of empowerment, and the need for further development of empowerment methods (see Table 1).

Empowerment Interventions

Asthma management/control

Empowerment interventions were associated with greater control of asthma and management of symptoms. One study found significantly better asthma symptoms (coughing, wheezing, and dyspnea) in children after participation in a family empowerment intervention compared with a control group (Yeh et al., 2016), while another study by Dardouri et al. (2020), found that child forced expiratory maneuver improved, but FEV1/FVC did not improve. A third study by Canino et al. (2008) found that an empowerment intervention led to caregivers having a greater likelihood of being confident in asthma management. Yet another study showed that empowering asthma education led to a greater sense of control in asthma management and a greater increase in ability to make decisions and provide care (McCarthy et. al., 2002).

Quality of life

Caregiver empowerment interventions were shown to improve quality of life in both parents and in their children. One study on empowerment education in families found an increase in quality of life for both parents and their children. Parents quality of life, measured on the

Pediatric Asthma Caregiver Quality of Life Questionnaire, showed a significant overall increase, and increase in all subscales after the intervention compared with baseline data and the control group, except for in the activity limitation subscale. Child quality of life, measured by the Pediatric Asthma Quality of Life Questionnaire, showed a significant overall increase, and increase in all subscales after the intervention compared with baseline data and the control group in all areas (Dardouri et al., 2020). Another study on a family empowerment intervention found a significant increase in the total and subscale scores for quality of life for children who had asthma on the Pediatric Asthma Quality of Life Questionnaire (Payrovee et al., 2014). According to a study by Canino et al. (2008), caregivers who took part in an empowerment intervention felt significantly less helpless after the intervention as seen by scores on the Pediatric Asthma Care Quality of Life Questionnaire. Finally, a study by Yeh et al., (2016) that examined the impact of a family empowerment intervention showed a decrease in parental stress and increase in family functioning.

Concept of Empowerment

Facilitators of Empowerment

Education

Education about asthma is one facilitator of empowerment for caregivers (Isik, 2019). A study by Kelo et al. (2013) mentions asthma empowerment as the result of education sessions and says that it includes the attainment of sufficient information, disease management, and satisfaction with education. Another study with an online group of caregivers of children with asthma showed that mothers shared about their regimens and decisions to empower other mothers. The authors suggest that confidence and competence building in online support groups can empower caregivers (Sullivan, 2008). In a third study researchers state that empowerment in parents is apparent after education sessions because parents learn to manage the asthma of their child (Valery et. al., 2016).

Healthcare providers

A qualitative descriptive study by Foronda, Jawid, et al. (2020), suggests that healthcare providers have a role in helping to empower parents of children with respiratory diseases. Sander (2002) also comments on the role of the healthcare provider in the empowerment process, saying that education and advocacy are important components of empowerment, and nurses can be important contributors to family empowerment.

Consequences of Empowerment

Asthma Control/ Management

A study by Coutinho et al. (2016), found that family empowerment was related to asthma control, while health system empowerment was related to more asthma symptoms. Another study of African American caregivers found empowerment to be a facilitator of asthma management (Prather et al., 2020). One study found that an education program with parents of children with asthma helped parents better understood their child's experience with asthma after taking part in the program (Trollvik & Severinsson, 2005).

Caregiver Health

According to a literature review by Foronda, Kelley, et al. (2020), research suggests that empowerment can be a facilitator of caregiver health in caregivers of children with asthma.

Need for Empowerment Methods

While a few studies have mentioned the use of empowerment interventions for caregivers, other studies recognize the need for further research to better understand empowerment and its function. Krieger et al. (2000), mentions the need for the development of methods to empower families to improve their indoor environment.

Discussion

As asthma is a common chronic disease, much research has been conducted to better understand the disease. Empowerment has also been studied in many different fields, including in healthcare. This literature review showed both the importance of empowerment in caregivers of children with asthma, as well as gaps that exist related to the concept in this population. The gaps identified by this review are related to asthma demographics, measurements of empowerment, environment and caregiver empowerment, and components of empowerment.

Asthma Demographics

When examining the concept of empowerment related to caregivers of children with asthma, few studies have been done with large diverse samples. Most studies are with small cohorts and tailored to specific populations. There is a need for more studies with larger experimental groups as well as studies that examine demographics and their relationship to the empowerment of caregivers of children with asthma. Specifically, the effect of socioeconomic status on empowerment for this population has not been well- studied. As asthma is more prevalent in children of families with low income (Zahran et al., 2018), this would be an important demographic to study.

Caregiver vs. Personal Empowerment

Another gap in the literature exists related to the study of caregiver empowerment specifically. While empowerment and empowerment interventions have been mentioned in the asthmatic population, few studies have looked at empowerment in relation to caregivers of children with asthma. As asthma is a disease largely prevalent in the pediatric population (Zahran et al., 2018), empowering caregivers is an important topic to study.

Measurements of Empowerment related to Caregivers of Children with Asthma

Instruments to measure caregiver empowerment exist, but few have been used in the population of caregivers of children with asthma. There is a need for further assessment of the instruments that have been used in this population to ensure they are measuring all components of empowerment in this population. Additionally, many studies mention empowerment interventions, but do not mention how they will measure the concept of empowerment. To truly understand if the empowerment intervention was effective, there must be measurable outcomes of empowerment itself including all components of the concept of empowerment.

Environment and Caregiver Empowerment

While it is well known that the environment has a large influence on asthma triggers and asthma control, little has been done to study the relationship with the environment and caregiver empowerment. According to Diette et al. (2008), both indoor and outdoor environmental exposures must be considered in asthma management. Indoor environmental exposures include air pollution, particulate matter, nitrogen dioxide, secondhand smoke, ozone, and indoor allergens like mold, rodents, cockroaches, dust mites, and pets. Outdoor environmental exposures include air pollution, particulate matter, ozone, nitrogen dioxide, sulfur dioxide, and pollen allergens. As asthma management has been shown to be a result of empowerment interventions, it is important to examine the role that environmental exposures play in empowerment. In this literature review, only one study mentioned the environment in relationship to empowerment, and this study was only a preliminary report on home conditions prior to an intervention to help empower families of children with asthma to reduce indoor asthma trigger exposure (Krieger et al., 2000).

Support and Empowerment

This literature review identifies both education and healthcare provider support to be facilitators of empowerment for caregivers of children with asthma. However, there is little evidence that shows what types of provider support and which types of educational interventions are most effective in supporting caregiver empowerment. There is a need for further research related to the best types of support that help to facilitate empowerment in caregivers of children with asthma.

As improvements in both asthma management and quality of life were found to be associated with empowerment interventions, it is important for providers to understand what empowerment is and to incorporate it into asthma management practice. Healthcare providers were shown to be facilitators of empowerment, so they can play a large role in the development of competent and confident caregivers by both learning about and incorporating empowerment techniques into their practice with their patients.

With education being a key facilitator of empowerment, it is important to continue to emphasize caregiver education in asthma management practice. Integration of effective education techniques can lead to greater empowerment. Since nursing bears much of the burden of parent and patient education, it is important for nurses to understand how to effectively educate. This includes nurses having characteristics of good educators, respect for patients, both subject and didactic knowledge and skills, and encouraging patient participation in learning (Kelo et al., 2013). Creating and implementing asthma education resources for nurses and caregivers that focus on these aspects can help to facilitate greater empowerment in caregivers of children with asthma.

Empowerment is a key concept that has been addressed in many different populations and disciplines. When looking at caregiver empowerment, however, there is less known about how it can be facilitated and what components exist. This literature review showed that in caregivers of children with asthma, studies related to empowerment have mainly focused on empowerment interventions, and facilitators and consequences of empowerment. There is a need for further research in this area, specifically in relation to caregiver opposed to self-empowerment, and examining the impact mitigating factors like the environment, social support, and demographics have on caregiver empowerment.

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CHAPTER 3: SOCIAL SUPPORT AND EMPOWERMENT AMONG CAREGIVERS OF CHILDREN WITH ASTHMA

Background

Asthma is a highly prevalent disease worldwide (World Health Organization [WHO], 2020). According to the World Health Organization (WHO) (2020), asthma is the most common noncommunicable disease in children and can be found in countries of all development levels. In the United States, 8.3% of children (age 0-17) were reported to have asthma in 2016. Among these children 54% had an asthma attack, 49% missed one or more days of school and 4.7% were hospitalized (Zahran et al., 2018). In 2012, the annual median cost for medical care for an asthmatic child was $983. In addition to the medical costs, children, on average, missed 2.2 days of school per person per year due to asthma (Nurmagambetov et al., 2017).

It is important to consider the burden on caregivers of children with asthma. Decreased quality of life, high levels of stress and exposure to stressors such as caregiving activities, parenting responsibilities, the burden of finances, and personal stress have been reported in caregivers of children with asthma (Ekim & Ocakci, 2016). Empowerment can help to reduce caregiver burden. Empowerment is defined as, “a process through which people gain greater control over decisions and actions affecting their health” (WHO, 1998, p. 16). It can be a social, psychological, political, or cultural process through which individuals and communities can help to express and meet their needs (WHO, 1998). Empowerment interventions are associated with increased knowledge and self-efficacy in parents of children seeking mental health treatment (Bickman et al, 1998), decreased stress and anxiety in caregivers of patients with epilepsy (Etemadifar et al., 2018), and increased competence for caregivers of children with leukemia undergoing chemotherapy (Saeui et al., 2009). In these ways, empowerment can play a role in mitigating the burden of disease, specifically in caregivers.

Social support has also been shown to have an influence on caregiver burden. Social support is a predictor of asthma control (Scheckner et al., 2015), which can help to reduce caregiver burden. Low levels of family social support have been correlated with increased Emergency Department use for asthma care (Rand et al., 2000). Finally, social support is an important predictor of psychological empowerment (Peterson & Hughey, 2002).

The Caregiver Empowerment Model (see Figure 2) helps to explain the concept of empowerment in relation to caregivers and was developed by Jones et al. (2011) to help promote positive outcomes for family caregivers. The model’s key components include background, filial values, appraisal, caregiving demands, and resources, whose combined interactions lead to caregiver outcomes (Jones et al., 2011). This study focuses on the components of resources and caregiver outcomes as social support falls under the categories of personal, family, and community resources. Empowerment is ultimately accomplished when caregiver outcomes are achieved.

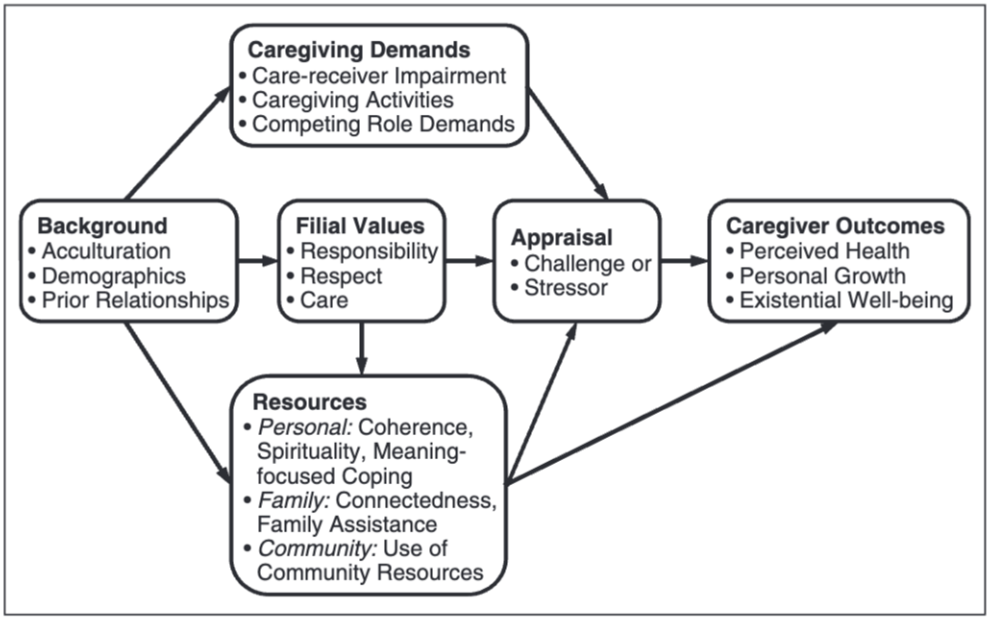

Figure 2: Caregiver Empowerment Model

Note. from "Development of a caregiver empowerment model to promote positive outcomes," by Jones, P. S., Winslow, B. W., Lee, J. W., Burns, M., & Zhang, X. E., 2011. *Journal of Family Nursing*, *17*(1), p. 13 (https://doi.org/10.1177/1074840710394854). Copyright 2011 by the Authors. Reprinted with permission.

Currently, there have been limited studies conducted to measure caregiver empowerment in caregivers of children with asthma. Published studies have shown that caregiver empowerment interventions are associated with improved asthma symptoms (Yeh et al., 2016), increased caregiver confidence in asthma management (Canino et al., 2008), improved caregiver quality of life (Dardouri et al., 2020), and decreased caregiver stress along with increased family functioning (Yeh et al., 2016). Education has been shown to facilitate empowerment (Isik, 2019), and nurses may help to empower caregivers through the development of skills and access to resources (Foronda, Jawid, et al., 2020). Finally, published consequences of empowerment include decreased asthma symptoms (Coutinho et al., 2016) and improved caregiver decision making (Chen et al., 2015).

As both social support and empowerment are key concepts related to caregiving in children with asthma, the relationship between the concepts needs to be further explored. An integrative literature review by Foronda, Kelley et. al. (2020) reported that both social support and empowerment for caregivers facilitated improved health outcomes in children with asthma. Another study of an online group of mothers of children with asthma showed that mothers shared about their regimens and decisions to empower other mothers. The authors suggest that confidence and competence building in online support groups can empower caregivers (Sullivan, 2008). The relationship between social support and empowerment has been explored in other areas of healthcare, finding computer mediated social support to influence empowerment for patients (Audrain-Pontevia & Menvielle, 2018), family social support to be correlated with empowerment during the postpartum period in mothers (Abdollahpour & Keramat, 2016), and community support to have a large association with empowerment in adult patients with type 2 diabetes (Simonsen et al., 2021).

Income is another important factor to consider when looking at empowerment in caregivers of children with asthma. Income plays a large role in asthma experience throughout many studies. Asthma is more prevalent in children of families living at incomes below the federal poverty level (FPL) than in those with incomes equal to or greater than 250% above the federal poverty level (Zahran et al., 2018). According to a systematic review (Ekim & Ocakci, 2016) on caregiving burden for caregivers of children with asthma, demographic factors like low socioeconomic status, decreased educational status, and marital status (single parent) are risk factors for poor caregiver quality of life. Risk factors that cause stress among caregivers of children with asthma include income and marital status (Ekim & Ocakci, 2016).

While studies have shown the effectiveness of empowerment interventions in caregivers of children with asthma and the relationship between social support and empowerment, there are gaps in the literature when examining the relationship between social support and caregiver empowerment in this population. Additionally, while studies have shown the significance of income related to asthma and caregiving, there have not been any studies to examine the link between income and caregiver empowerment for caregivers of children with asthma. The purpose of this study is to examine the relationship between social support and empowerment, and income and empowerment among caregivers of children with asthma. These are two important relationships to study, as they can lead to increased understanding of caregiver empowerment and better understanding of steps that can be taken to improve care for caregivers and children with asthma.

Methods

Study Design

This study followed a quantitative descriptive design.

IRB approval

This study was approved by the University of Central Florida Institutional Review Board.

Subjects

Participants were recruited from an asthma camp. All caregivers who registered a child for camp were offered to participate. Additionally, subjects were recruited from an online caregiver asthma support group and from an organization that supports asthma education and management. Subjects were eligible for inclusion if they self-identified as a primary caregiver of a child with asthma, were over the age of 18, and could read and write in English. Subjects were excluded if they were caregivers who did not live with the child or if the child was age 18 or above.

Recruitment

An email and text with a link to the anonymous survey were sent to all caregivers of children aged 0-17 diagnosed with asthma who signed up for the camp and consented to having their contact information shared. The email and text contained an explanation of the study and a link to an anonymous survey. A follow up email was sent two weeks after the initial email, and a third reminder email was sent a month later. In the caregiver support group, the survey was posted on social media with a reminder posted one week later. The organization that supports asthma education distributed the survey via their email blast and posted to their social media.

Power Analysis

Sample size was determined by an a priori power analysis using G*Power (G*Power, version 3.1.9.6). The calculation was powered for the main comparison of social support scores and empowerment scores. With an estimated moderate effect size of 0.5, alpha of 0.05, and 1-**β** of 0.8, the proposed sample size was 26. The goal was to recruit at least 30 participants to account for incomplete surveys.

Measures

Data Collection

Data were collected through anonymous online surveys through Qualtrics (Qualtrics, 2021). The link to the survey was included in emails and texts sent to identified possible participants and was also posted on social media for an online asthma support group and distributed by an organization that supports asthma education via their email blast and social media. Individuals filled out the surveys on their own time using their personal electronic device or a device provided by the camp. Data were de-identified when the researcher reviewed it.

Instruments

Demographics

Basic demographic data were collected from each caregiver including caregiver age, child's age, parental role, race, ethnicity, educational level, income, and family size. Household income and family size were used to calculate poverty scores based upon percent above or below the Federal Poverty Level. This score was calculated based upon the HHS Poverty Guidelines for 2022 (U.S. Department of Health and Human Services, 2022).

Family Empowerment Scale

The Family Empowerment Scale (FES) (Koren et al., 1992) was used in this study to measure caregiver empowerment. This scale was originally developed to measure empowerment in caregivers of children with emotional disabilities. It is a 34-item scale divided into three subscales of Service System (12 items), Family (12 items), and Political/ Community (10 items). Items developed in each subscale were related to the expressions of caregiver attitudes, knowledge, and behavior. Each item is a statement in which the participant is given five response items ranging from not true (1) to very true (5). This scale has good validity and reliability. Internal consistency of the FES has been reported to be adequate ($\alpha = 0.87$-0.88) and test-retest reliability has been reported between 0.77 to 0.85 (Koren et al., 1992). Validity was confirmed through independent item ratings, factor analysis, and group differentiation. The kappa coefficient for agreement among raters was 0.77 overall (Koren et al., 1992), and the average kappa coefficient for agreement with original item classification scheme was 0.83 (Koren et al., 1992). Factor analysis found 52% of variance related to four main factors (Koren et al., 1992).

Group differentiation was confirmed by dividing activities based upon type, running MANOVA, and finding multivariate effects that were significant (Koren et al., 1992). The Dutch version of the Family Empowerment scale has been validated in the population of caregivers of children with chronic disease (Segers et al., 2019). Additionally, this scale has been adapted and used to study caregiver empowerment in urban caregivers of children with asthma, in which good internal consistency was found (α=0.85-0.89 for each subscale) (Coutinho et al., 2016). This instrument was used with permission from the publisher.

MOS Social Support Survey

The MOS Social Support Survey (MOS) was used to measure social support for caregivers. This scale consists of 19-items which measure social support in five different domains. These domains include emotional support, informational support, tangible support, positive social interaction, and affectionate support. For each item, the respondent must answer how often the support is available to them with five choices ranging from none of the time to all the time (Sherbourne & Stewart, 1991). This survey was originally developed by Sherbourne and Stewart (1991) and was used as a tool to measure social support in chronically ill individuals. Reliability and validity measures were confirmed in the development of the scale. Internal consistency was found to be adequate (α=0.91-0.97) and one year stability coefficients were between 0.72-0.78 (Sherbourne & Stewart, 1991). Validity measurements showed high discriminant and convergent validity. There was high correlation between subscales (r=0.69 to 0.82) and the subscales were supported by multitrait and confirmatory factor analysis (Sherbourne & Stewart, 1991). The scale has since been adapted for use in the caregiver population and was found to have good internal consistency (α=0.90-0.97 for each category) in a study on early caregiving and social support (Shifren, 2008). The 18-item, one factor version of the scale was also validated in a group of low-income caregivers of African American children with asthma. This study found a Chi squared value of 308.319 ($p > 0.001$), RMSEA of 0.077, comparative fit index of 0.990, Tucker Fit Index of 0.988, and Cronbach's alpha of 0.97 (Margolis et al., 2019). This instrument is a public document, so permission was not required for its use.

Procedures

General Procedures

Data were collected anonymously through an online link. No identifying information was collected from the participants in the survey except an email address to send a gift card to after the survey was completed.

Statistics

Data were analyzed using traditional descriptive statistics. All demographic variables were converted into categorical data and categorical variables were summarized using frequency and percent. For analysis, four categories were used for income level (Under FPL, 100-200% above FPL, 200-400% above FPL, and Greater than 400% above FPL). Continuous variables (MOS and FES scores) were summarized using mean and standard deviation. Pearson's correlation was calculated to look at the relationship between social support and empowerment scores. A correlation coefficient (r) of 0.1 to 0.3 was considered a small positive correlation, 0.3 to 0.5 was considered a medium positive correlation, and 0.5 to 1 was considered a large positive correlation (Laerd Statistics, 2018). An ANOVA with a post hoc Bonferroni test was run to examine the relationship between income level and empowerment. Correlations were considered significant if $p<0.05$. SPSS v. 29 (IBM Corp., 2022) was used to analyze the data.

Results

A total of 59 people completed the survey: 50 people answered the survey from the online distribution through the asthma support group and asthma education organization, and nine people answered from the asthma camp. Responses were not included from the online distribution if they were not complete, so all 50 responses that were retained were complete. From the asthma camp, one participant had incomplete data and was excluded from analysis.

Demographics:

Demographic data collected included caregiver age, child's age, race, ethnicity, parental role, education level, and poverty level (calculated by income and family size). All 58 participants responded to all questions, except for one participant who did not answer the ethnicity question. Most of the sample was white (75.9%) Non-Hispanic/ Latino (52.6%) and mothers (51.7%). Most of the participants had an education level of some college or higher (81%). Additionally, most of the participants fell 200% or more above the poverty level (77.6%). Demographic data is available in Table 2.

Table 2: Demographic Data

	Frequency (n=58)	Percent (%)
Race		
Prefer not to answer	1	1.7
Black	9	15.5
White	44	75.9
American Indian or Alaska Native	4	6.9
Ethnicity (n=57)		
Prefer not to answer	8	14.0
Not Hispanic or Latino or Spanish Origin	30	52.6
Hispanic or Latino or Spanish Origin	19	33.3
Parental Role		
Prefer not to answer	2	3.4
Mother	30	51.7
Father	17	29.3
Guardian	9	15.5
Education Level		
Some high school	3	5.2
Graduated high school or received GED	8	13.8
Some college	16	27.6
College diploma	18	31.0
Graduate degree	13	22.4
Poverty Level		
Under FPL	3	5.2
100-200% above FPL	10	17.2
200-400% above FPL	25	43.1
Greater than 400% above FPL	20	34.5
Caregiver Age		
18-30 years	8	13.8
30-40 years	22	37.9
40-50 years	23	39.7
50+ years	5	8.6
Child Age		
0-2 years	4	6.9
3-5 years	21	36.2
6-12 years	25	43.1
13-17 years	8	13.8

Social Support and Empowerment

Scores were calculated for the MOS-Social Support Survey including a total score (average of all items) and scores for four subscales (emotional, tangible, affectionate, and social). There was an additional "other" item that was included in the total score but not calculated as a part of a subscale. Scores for the Family Empowerment Scale were calculated as three subscales (family, service, and community) and a total score (all subscales added together). The average of the MOS Total was 3.54 (SD=0.64) and the average of the FES Total was 11.29 (SD=1.64). The highest average subscale on the MOS Scale was the Affectionate Scale (M=3.67, SD=0.89). The highest average subscale for the FES was the Service Subscale (M=3.96, SD=0.60). The mean scores are outlined in Table 3.

Table 3: MOS and FES Scores

	Mean	**Standard Deviation**
MOS Total	3.54	0.64
Emotional	3.53	0.64
Tangible	3.59	0.82
Affectionate	3.67	0.89
Social	3.47	0.72
FES Total	11.29	1.64
Family	3.89	0.56
Service	3.96	0.60
Community	3.44	0.73

Correlations were run for the MOS total related to the FES total, for all subscales of the MOS related to the FES total score and for all subscales of the FES related to the MOS total score. There was a significant medium correlation between FES total and MOS total (*r*=0.478, *p*<0.001). There was a significant, direct correlation between FES total and all MOS subscales. FES total had a medium positive correlation with the MOS emotional (*r*=0.446, *p*<0.001), a medium positive correlation with MOS tangible (*r*=0.433, *p*<0.001), a medium positive correlation with the MOS affectionate (*r*=0.352, *p*=0.007), and a medium positive correlation with the MOS social (*r*=0.400, *p*=0.002). There was also a significant correlation between MOS total and all FES subscales. MOS total had a medium positive correlation with FES family (*r*=0.391, *p*=0.002), a small positive correlation with FES service (*r*=0.291, *p*=0.027) and a large positive correlation with FES community (*r*=0.538, *p*<0.001). See Table 4.

Table 4: Correlations between Social Support and Empowerment

	r	***p***
MOS Total and FES Total	0.478	<0.001
FES Total		
MOS-Emotional	0.446	<0.001
MOS-Tangible	0.433	<0.001
MOS-Affectionate	0.352	0.007
MOS-Social	0.400	0.002
MOS Total		
FES-Family	0.391	0.002
FES-Service	0.291	0.027
FES-Community	0.538	<0.001

Poverty Level and Empowerment

An ANOVA was run to compare empowerment scores and income level (measured by FPL). No significant differences in total empowerment scores were noted between individuals based upon poverty level (Under FPL (n=3), 100-200% above FPL (n=10), 200-400% above

FPL (n=25), and Greater than 400% above FPL (n=20). No significant differences in empowerment score subscales were noted between individuals of different income levels. See table 5 for results.

Table 5: Federal Poverty Level and Empowerment Scores

	Mean	Standard Deviation
FES-Total		
Under FPL	11.44	2.49
100-200% above FPL	10.77	2.00
200-400% above FPL	11.20	1.58
>400% above FPL	11.64	1.44
FES-Family		
Under FPL	4.03	0.86
100-200% above FPL	3.80	0.75
200-400% above FPL	3.84	0.47
>400% above FPL	3.99	0.55
FES-Service		
Under FPL	4.08	1.06
100-200% above FPL	3.93	0.75
200-400% above FPL	3.94	0.60
>400% above FPL	3.96	0.48
FES-Community		
Under FPL	3.33	0.67
100-200% above FPL	3.04	0.86
200-400% above FPL	3.42	0.74
>400% above FPL	3.67	0.59

*no significant difference between groups were found: p>0.05 for all groups

Discussion

The results from this study show that there is a significant positive correlation between all aspects of social support and overall empowerment as well as between all aspects of empowerment and overall social support in caregivers of children with asthma. Social support is an important predictor of psychological empowerment (Peterson & Hughey, 2002) and low awareness of social support has been associated with decreased empowerment in families raising children with developmental disorders (Wakimizu et al., 2011). This is the first study that has specifically examined the relationship in caregivers of children with asthma. Additionally, in discovering that there is a correlation between the different subscales of social support and empowerment, it is apparent that the type of social support might not be as significant as the overall experience of having social support. This shows that future interventions to increase caregiver empowerment should all include a component of assessing for and offering social support. Social support interventions that have been beneficial in the caregiver population include programs using community health workers to connect families to education, clinical, and social services (Peretz et al., 2012), and collaborative programs including community coalitions and community engagement to help change asthma management policies and practices (Clark et al., 2010). In adults with asthma, the use of patient navigators can also help to increase social support (Black et al, 2010). Implementation of further interventions to help increase social support should continue to be studied to find more ways to help increase caregiver empowerment.

Additionally, one of the goals of the study was to compare income level with empowerment. Most of the participants who responded had income levels at 200% or more above the poverty level, which led to a disproportionate sample size of higher income individuals. This led to results that were not fully representative of the lower income population. Additionally, it is possible that the results were not significant because income was not measured in a significant way. For this study, income was measured based on percent above or below the FPL and divided into four categories based upon percentage. It is possible that the categories were too large, so no significant difference could be detected. For future research, a more meaningful way to measure income should be considered. Another factor that could have affected the outcome was the assumption that income is directly related to empowerment.

According to the Caregiver Empowerment Model, income is a background factor that influences caregiving demands, filial values, and resources. These factors are then addressed through the lens of appraisal, which in turn influences caregiver outcomes (Jones et al., 2011). It is possible that income does not play a large enough role in the final empowerment outcome when taking into consideration the other factors of resources, filial values, and caregiving demands. For example, total annual medical costs for asthma were lowest in patients with Medicaid, and highest in patients with private insurance (Nurmagambetov et al., 2017). This could be a factor that helps to mitigate the importance of income when evaluating how it impacts empowerment.

Study Limitations

All the data for this research was collected from online surveys in which individuals had to answer questions to self-select if they were eligible for participation. Limitations of this method include the possibility of fabrication of responses, and the lack of a controlled environment which could lead to rushing or distraction. Additionally, asthma camp recruitment was difficult, leading to the necessity to recruit from other sources including the online support group and organization for asthma education. Another limiting factor was the fact that the survey was only accessible online. As technology costs and technology literacy could be barriers to survey completion, making the survey accessible via paper could help to mitigate this barrier.

Future Research

This study shows that there is a significant correlation between social support and empowerment, leading the way for further research into specific instruments to improve social support in the healthcare setting, specifically in the population of caregivers of children with asthma. Additionally, more robust research with a larger sample size is needed to confirm these correlations and study more directly the causality of the relationship. While this study focuses on the resource component of the Caregiver Empowerment Model (Jones et al., 2011), caregiving demands were not a component of this study. Examining this component of the model can help to better understand appropriate interventions to help increase empowerment. This study begins to add to the knowledge of empowerment for caregivers of children with asthma, but further studies are needed to confirm this research and better understand how specific interventions help to influence this relationship.

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CHAPTER 4: INSTRUMENTS TO MEASURE EMPOWERMENT

Background

The concept of empowerment has been widely used across many disciplines and has developed considerably since the mid 1900s. Early definitions of empowerment focused on power, control, and political participation (Bartunek & Spreitzer, 2006). A second evolution of defining empowerment arose later including the concepts of pride, increased self-worth, and increased knowledge, resources, and connectedness. Finally, a third evolution of definitions arose in the late 1990s, which focused on productivity. These definitions included decision-making, responsibility, and ownership (Bartunek & Spreitzer, 2006). Empowerment has been studied across many disciplines including religion, sociology, psychology, education, management, and social work (Bartunek & Spreitzer, 2006). Throughout different fields, empowerment can be divided into three types: Individual psychological empowerment, community empowerment and organizational empowerment. These types of empowerment can also be found in nursing literature (McCarthy & Freeman, 2008).

In healthcare, empowerment has been defined by the World Health Organization (WHO) as "a process through which people gain greater control over decisions and actions affecting their health" (World Health Organization [WHO], 1998, p. 16). It can be a social, psychological, political, or cultural process (WHO, 1998). In caregiver populations, empowerment interventions can increase knowledge and self-efficacy (Bickman et al, 1998), decrease stress and anxiety (Etemadifar et al., 2018), and increase the competence of caregivers to perform skills (Saeui et al., 2009).

In 1986, the WHO introduced the Ottawa Charter, which helped to establish the foundation of healthcare empowerment. The Ottawa Charter increased the emphasis on empowerment, shifting healthcare to a more participatory focus (Halvorsen et al., 2020). A thematic synthesis of concept analyses of empowerment was conducted to better understand empowerment from the perspective of the health service user, and found descriptive themes of empowerment (intrapersonal and interpersonal aspects), antecedents of empowerment (powerlessness and loss of control, motivation and change, and support and trust), attributes of empowerment (mutual partnership, change, and self-determination strengthening), and consequences of empowerment (improved quality of life, mastery and control, and trusting participatory relationships) (Halvorsen et al., 2020). Understanding the development of healthcare empowerment allows for a base of understanding when looking at the management of chronic disease processes, such as asthma.

Asthma is a chronic disease process that has been examined in relation to empowerment. Studies have shown that caregiver empowerment leads to better asthma management and control (Coutinho et al., 2016; Prather et al., 2020; Trollvik & Severinsson, 2005) and caregiver health (Foronda, Kelley, et al., 2020). Empowerment interventions have also led to improved caregiver quality of life (Canino et al., 2008; Dardouri et al., 2020; Payrovee et al., 2014; Yeh et al., 2016) and improved asthma management and control (Canino et al., 2008; Dardouri et al., 2020; McCarthy et al., 2002; Yeh et al., 2016).

It is important to have valid and reliable instruments to measure caregiver empowerment so that an accurate representation of the concept is rendered. A variety of different instruments have been utilized in the past and have been applied to different populations. However, no current review exists that compares all the different instruments or identifies which instruments would be most appropriate for use in caregivers of children with asthma. The goal of this review is to examine the different instruments available to measure caregiver empowerment and discuss which instruments might be most appropriate to use in this population.

Methods

Design

The goal of this integrated review was to identify and evaluate instruments used to measure caregiver empowerment. A literature search was completed for research using instruments to measure caregiver empowerment. Selected articles were then evaluated for instrument utilized, sample size, population, setting, and internal consistency (see Table 6). John Hopkins Evidence-Based Practice Model for Nursing and Healthcare Professionals was used for critical appraisal to evaluate the level of evidence of each article (The Johns Hopkins Hospital/ Johns Hopkins University School of Nursing, 2022). All identified instruments were further evaluated to determine construct studied, target population, number of questions, number of scales, response options, and internal consistency of the original instrument (see Table 7).

Search Methods

Four databases were used to search for instruments: CINAHL, MEDLINE, APA PsycInfo, and Health and Psychosocial Instruments. Search terms included (measure* or tool or scale or assess* or test or questionnaire or measure or inventory or instrument or survey) AND SU empower* AND AB (caregiver* or mother or father or parent*). Articles were included if they used an instrument to measure caregiver empowerment, studied the population of caregivers, were available as a full text, were written in English, and were published between 2012 and 2022. Articles were excluded if a specific instrument to measure empowerment was not mentioned, if they were not research studies, or if they did not mention caregiver empowerment. The initial search returned 932 results. After duplicates were removed, 724 articles remained. After review of abstracts, 155 articles were selected for a full-text review. Once full text articles were reviewed, 79 studies (see Table 6) were evaluated further as a part of this review (see Figure 3).

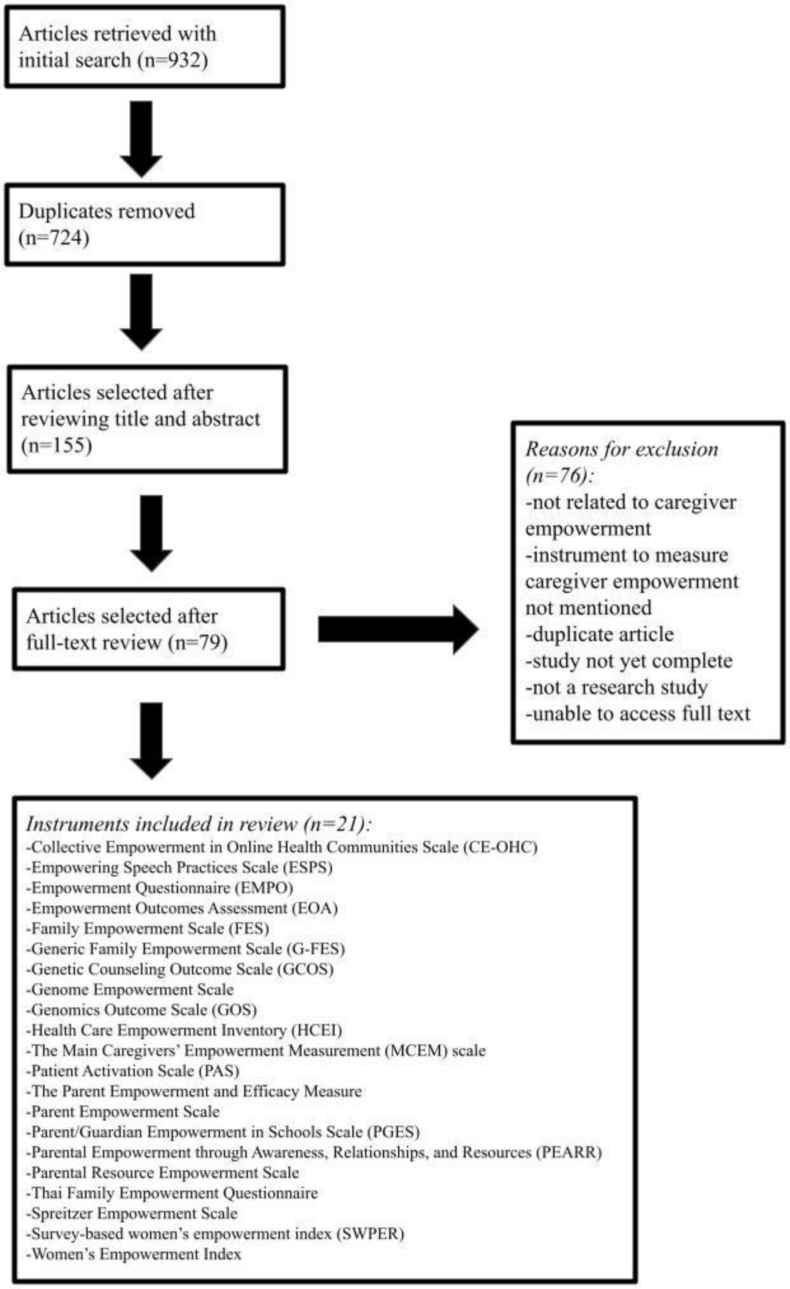

Figure 3: Search and Selection Flowchart for Instruments to Measure Caregiver Empowerment

Results

General Characteristics of Included Instruments

From the 79 articles reviewed, there were 21 different instruments to measure empowerment (see Table 7). These instruments included the Empowering Speech Practices Scale (Kettunen et al., 2006), Collective Empowerment in Online Health Communities Scale (Atanasova & Petric, 2019), Empowerment Questionnaire (Damen et al., 2017), Empowerment Outcomes Assessment (Alameda-Lawson, 2014), Family Empowerment Scale (Koren et al., 1992), Generic Family Empowerment Scale (Vuorenmaa et al., 2014), Genetic Counseling Outcome Scale (McAllister et al., 2011), Genome Empowerment Scale (McConkie-Rosell, 2019), Genomics Outcome Scale (Grant et al., 2019), Health Care Empowerment Inventory (Johnson et al., 2012), The Main Caregivers' Empowerment Measurement scale (Liu & Guo, 2021), Patient Activation Scale (Coutinho et al., 2016), The Parent Empowerment and Efficacy Measure (Freiberg et al., 2014), Parent Empowerment Scale (Ameral et al., 2020), Parent/Guardian Empowerment in Schools Scale (Ball, 2014), Parental Empowerment through Awareness, Relationships, and Resources (Figueroa et al., 2020), Parental Resource Empowerment Scale (Jurkowski et al., 2014), Thai Family Empowerment Questionnaire (Wacharasin et al., 2015), Spreitzer Empowerment Scale (Spreitzer, 1995; Spreitzer, 2008), Survey-based women's empowerment index (Ewerling et al., 2017) and Women's Empowerment Index (Tuladhar et al., 2013). Once the instruments were identified, characteristics and psychometrics of each instrument were summarized. The most widely used instrument (49 studies) was the Family Empowerment Scale. Most instruments focused on the construct of empowerment and had multiple subscales examining different faucets or dimensions of empowerment. Many of the subscales were tailored to the specific population that the instrument was created to study. All the instruments except two used a Likert scale for scoring.

Most instruments showed good internal consistency (Cronbach's alpha ≥ 0.70).

Table 6: Summary of Articles Reviewed for Instruments to Measure Caregiver Empowerment

Reference	*Level of Evidence**	*Sample Size & Population*	*Setting*	*Tool used*	*Cronbach's alpha*
Adam et. al., 2018	Level I	106 Parents of children with early-onset epilepsy of unknown cause	Automated email link to survey	Genetic Counseling Outcome Scale (GCOS-24)	Not mentioned
Alameda-Lawson, 2014	Level II	32 Parents of children 3rd grade and above residing in Jeffersonville Manor	Unknown	Empowerment Outcomes Assessment	0.79
Alsem et al., 2019	Level I	128 Parents of children with disabilities	Unknown	Family Empowerment Scale (Family and service subscale)-Dutch version	Not mentioned
Ameral et. al., 2020	Level III	545 Parents of youth (age 14–26) with a substance use disorder	Unknown	Parent Empowerment Scale	0.74 (first four questions)
An et al., 2019	Level I	18 Children with disabilities and their mothers	Unknown	Adapted Family Empowerment Scale (family and service subscales)	0.87 (service) and 0.88 (family) for original study
Bagur et al., 2022	Level III	135 Families of children with developmental disabilities in the Balearic Islands	Unknown	Family Empowerment Scale (FES)	0.74
Ball & Skrzypek, 2019	Level II	21 Parents of children in fourth and fifth grade	Unknown	Parent/-Guardian Empowerment in Schools Scale (PGES)	0.87
Baye et al., 2021	Level III	6113 Woman-child (age 6-23 months) pairs in Ethiopia	Unknown	Survey-based women's empowerment index (SWPER)	Not mentioned

Reference	*Level of Evidence**	*Sample Size & Population*	*Setting*	*Tool used*	*Cronbach's alpha*
Berry et. al., 2019	Level II	24 Single parents who are the main carer for their children following domestic abuse	Unknown	The Parent Empowerment and Efficacy Measure	Not mentioned
Blankestein et al., 2022	Level II	111 Adolescents from residential youth care institutions and their caregivers	Unknown	Family Empowerment Scale (FES)- Family subscale	0.91
Blizzard et. al., 2016	Level III	44 Caregivers of children leaving intensive psychiatric care and participating in a post-inpatient transition program	Unknown	Family Empowerment Scale (FES)	0.92
Bode et al., 2016	Level III	525 Parents of children receiving school-based services for disruptive behavior disorders	Unknown	Family Empowerment Scale (FES)	0.94
Borges Rodrigues et al., 2020	Level III	25 (nurses) 82 (families) Nurses involved in the 5 year health visit and families scheduled to have their health visit with those nurses	Unknown	Empowering Speech Practices Scale (ESPS)- Portuguese version	0.91
Bourke-Taylor et al., 2019	Level II	36 Mothers of school aged children with disabilities/ chronic medical conditions	Unknown	Family Empowerment Scale (FES)- family subscale	Not mentioned
Burke, 2017	Level III	65 Latino family members of students with disabilities	Paper and pencil survey	Family Empowerment Scale (FES)- service system subscale (translated to Spanish)	0.82
Burke et al., 2019	Level II	34	Online survey	Family Empowerment	0.83 (post-survey)

Reference	*Level of Evidence**	*Sample Size & Population*	*Setting*	*Tool used*	*Cronbach's alpha*
		Mothers of children with intellectual or developmental disabilities		Scale (FES)-service subscale	
Burke & Sandman, 2017	Level II	41 Parents of children with disabilities	Unknown	Family Empowerment Scale (FES)	0.81 (family subscale), 0.82 (service system subscale), and 0.86 (community subscale)
Burton et al., 2018	Level I	87 Families of children with a developmental disability	Unknown	Family Empowerment Scale (FES)	0.87-0.88 (original study)
Casagrande & Ingersoll, 2017	Level III	249 Parents of children with autism spectrum disorder	Online survey through Qualtrics (with a paper option)	Family Empowerment Scale (FES)	0.93
Chiu et al., 2013	Level II	109 Caregivers	Unknown	Family Empowerment Scale (FES)	Not mentioned
Chou et al., 2018	Level III	71 Pregnant women entering substance use disorder treatment	Unknown	Family Empowerment Scale (FES)-service subscale	0.89
Choy & Nakamura, 2022	Level III	351 Caregivers of children up to the age of 18	Unknown	Family Empowerment Scale (FES)	0.95 (FES total score)
Coutinho et al., 2016	Level III	130 Latino, African American and non-Latino White urban caregivers and their children with asthma	Unknown	Family Empowerment Scale (FES), Patient Activation Scale (PAS)-modified version	FES=0.85 (family subscale), 0.89 (service subscale) and 0.88 (community subscale) PAS=0.81
Damen et al., 2019	Level II	621 Families that were supported by family-centered service or child-centered service	Unknown	Empowerment Questionnaire (EMPO)	T1= 0.79; T2 = 0.86

Reference	*Level of Evidence**	*Sample Size & Population*	*Setting*	*Tool used*	*Cronbach's alpha*
Damen et al., 2020	Level II	296 Families that were supported by Intensive Family Treatment	First survey given to parents to be filled out, second survey received in an email	Empowerment Questionnaire (EMPO)	T1 = 0.79; T2 = 0.85
Damen et al., 2021	Level II	275 Families supported by Intensive Family Treatment	First survey given to parents to be filled out, second survey received in an email	Empowerment Questionnaire (EMPO)	T1 = 0.81; T2 = 0.86; T3 = 0.81
Fordham et al, 2012	Level III	130 Families attending early childhood intervention services in Australia	Unknown	Family Empowerment Scale (FES)	0.87 to 0.88
Fox et al., 2015	Level III	135 Fathers of children in the Tennessee Early Intervention System (or recently transitioned)	Paper survey completed by parents in their own setting/ timing	Adapted version of the Family Empowerment Scale (FES)	0.91
Gago et al., 2022	Level II	623 Parents of preschool aged children attending Head Start	Paper survey filled out at home	Parental Empowerment through Awareness, Relationships, and Resources (PEARR)	0.83-0.90
Gengoux et. al., 2019	Level II	22 Children aged 2-6 with autism spectrum disorder and their primary caregiver	Unknown	Family Empowerment Scale (FES)	Not mentioned
Geva & Werner, 2021	Level III	123 Jewish Israeli parents of children with disabilities.	Online survey through Qualtrics	Hebrew version of the family empowerment scale (FES)	0.93
Ghoneim, 2018	Level II	30 Children with developmental	Unknown	Family Empowerment Scale (FES)	Family = 0.88, Service System = 0.87,

Reference	*Level of Evidence**	*Sample Size & Population*	*Setting*	*Tool used*	*Cronbach's alpha*
		disabilities and their families			Community/Political= 0.88 (from original scale)
Golubović et al., 2021	Level III	99 Parents of children with disabilities and normally developing children	Unknown	Family Empowerment Scale	0.81 to 0.94
Han et al., 2018	Level III	236 Families of children with special needs attending special needs schools	Self-administered completed in own setting/ time	Family Empowerment Scale (FES)	0.96
Hancock et al., 2022	Level II	58 Parents of children with bicuspid aortic valve	Online survey via REDCap	Genomics Outcome Scale (GOS)	Not mentioned
Hielkema et al., 2020	Level I	43 Infants at high risk of cerebral palsy (0-9 months old) and their caregivers	Unknown	Family Empowerment Scale- Dutch version (family and service system subscales)	Not mentioned
Huscroft-D'Angelo et. al., 2017	Level III	120 Caregivers of youth who had recently discharged from a therapeutic residential program	Unknown	Family Empowerment Scale (FES)	0.87 to 0.88 (from original scale- not recalculated for study)
Jurkowski et al., 2014	Level II	154 Parents of children enrolled in Head Start	Unknown	Adaption of Spreitzer Empowerment Scale	0.96 (baseline), 0.93 (post-intervention)
Kalleson et al., 2020	Level II	58 Children registered in the Cerebral Palsy Register and their parents	Survey completed on rehabilitation unit	Family Empowerment Scale (FES)	Not mentioned
Kalleson et al., 2022	Level III	56 Children (age 12-56 months) with cerebral	Unknown	Family Empowerment Scale (family and	Not mentioned

Reference	*Level of Evidence**	*Sample Size & Population*	*Setting*	*Tool used*	*Cronbach's alpha*
		palsy and their families		service situation subscales	
Kosyluk et al., 2022	Level III	89 Young adults aged 18-30 who had been diagnosed with a mental health disorder	Via Amazon's MTurk	Family Empowerment Scale (FES)	0.95
Lepisto et al., 2022	Level III	453 Parents of children and parents expecting children	Surveys administered in primary healthcare and hospital settings	Generic Family Empowerment Scale (G-FES)	Not mentioned
Lim et. al., 2017	Level III	721 Parent-child pairs participating in Connect for Health randomized trial	Survey over the phone	Parental Resource Empowerment Scale	0.87
Lim & Cho, 2022	Level III	205 Parents of children diagnosed with cancer	Online survey in South Korea	Modified version of empowerment scale by Koren (FES)	0.91
Lin et al., 2019	Level III	182 Mothers of children between the age of 11-17	Online survey through Qualtrics	Adapted empowerment scale (name not listed)	self-efficacy (0.91), perceived competence (0.77), control (0.69), collective action (0.67) interpersonal relationships (0.70)
Liu & Guo, 2021	Level III	189 Primary caregivers of post-stroke patients with disability	Survey filled out in hospital ward	The Main Caregivers' Empowerment Measurement (MCEM) scale	0.89
Luelmo et al., 2021	Level I	24 Parents of a child with an IEP	Unknown	Family Empowerment Scale (FES)	0.87-0.88 (original scale)
McConkie-Rosell et al., 2018	Level III	31 Parents who have a child with an	Questionnaire completed at UDN evaluation	Health Care Empowerment Inventory (HCEI)	0.82 (original survey)

Reference	*Level of Evidence**	*Sample Size & Population*	*Setting*	*Tool used*	*Cronbach's alpha*
		undiagnosed chronic illness			
McConkie-Rosell et. al., 2022	Level III	158 Parents of children enrolled in the Duke Clinical Site of the Undiagnosed Diseases Network and the Duke Genomic Sequencing Clinic	Unknown	Genome Empowerment Scale	Not mentioned
McLeod et al., 2020	Level I	101 Children age 3-6 with a speech and/or language delay/disorder and their caregivers	Unknown	Family Empowerment Scale - 18 items	Not mentioned
Minjarez et al., 2013	Level II	17 Parents of children with autism spectrum disorder	Unknown	Family Empowerment Scale (FES)	Not mentioned
Morin & St-Onge, 2017	Level III	58 Parents receiving services from a specialized clinic for treating psychotic illness in early stages	Interviews to fill out questionnaire	Family Empowerment Scale- translated	Not mentioned
Muthukaruppan et al., 2022	Level II	308 Caregivers of children with developmental delays	Questionnaire collected using mVBR-El mobile application	Family Empowerment Scale (FES)- family subscale	Not mentioned
Nieuwboer et al., 2015	Level I	96 Parents over the age of 18	Online questionnaire	Adapted version of the Family Empowerment Scale (FES)- subscales: self-confidence as a parent, confidence in network support and ability to obtain informational support	Subscales: self-confidence as a parent (0.85), confidence in network support (0.88), ability to obtain informational support (0 .73)

Reference	*Level of Evidence**	*Sample Size & Population*	*Setting*	*Tool used*	*Cronbach's alpha*
Nissley-Tsiopinis et al., 2022	Level I	11 Families of children with ADHD	REDCap Survey	Family Empowerment Scale - Children's service system subscale	0.87 (original scale)
Palmer et al., 2018	Level II	35 (adult participants) 67 (parents) Adult participants and parents of child participants in the Undiagnosed Diseases Network	Link to online survey or paper copy provided	Genetic Counseling Outcome Scale (GCOS-24)	0.87 (in previous studies)
Pandya, 2020	Level I	110 (pretest) 84 (posttest) Grandparent-grandchild dyads (children diagnosed with ADHD raised by grandparents as primary caregivers)	Unknown	Family Empowerment Scale (FES)	0.88
Peltekova et al., 2021	Level III	113 Families of a child referred for an evaluation of neurodevelopmental disorder for which genetic testing was recommended	Online questionnaires	Genetics Counseling Outcome Scale-24 (GCOS-24)	Not mentioned
Pierce et al., 2021	Level III	41 Children with cerebral palsy and their caregivers	Unknown	Family Empowerment Scale (FES)	Not mentioned
Pisula & Banasiak, 2020	Level III	112 Fathers of children with Down syndrome, autism, and typically developing children	Questionnaires completed at home	Polish version of the Family Empowerment Scale (FES)	0.73 (family), 0.79 (service system), 0.70 (community)
Poudel et. al., 2022	Level III	300 Mothers of children aged 6-59 months	Face to face interviews	Women's Empowerment Index	Not mentioned
Taylor et al., 2017	Level I	41 Parents of children with autism	Unknown	Family Empowerment Scale (FES)	0.92 (pre-test) and 0.95 (post-test)

Reference	*Level of Evidence**	*Sample Size & Population*	*Setting*	*Tool used*	*Cronbach's alpha*
Trout et al., 2020	Level I	187 Child-caregiver dyads of youths departing residential group care settings	Unknown	Family Empowerment Scale (FES)	0.91 (Family), 0.93 (System), 0.87 (Community)
Uhm & Kim, 2022	Level III	198 Mothers of children with type 1 diabetes	Web survey	Collective Empowerment in OHC Scale	0.84
van der Perk et al., 2022	Level III	228 Parents of children who were discharged from Emma Children's Hospital	Web-based survey	Family Empowerment Scale (FES)-Dutch version	Not mentioned
Vlaskamp et. al., 2021	Level II	63 (55 parents) Patients or parents referred for genetic testing for epilepsy	Letters mailed with questionnaires which could be completed on paper or electronically	Dutch version of the Genetic Counselling Outcome Scale (GCOS)	0.77
Vuorenmaa et. al., 2017	Level III	955 Parents of children aged 0-9 in Finland	Mailed questionnaire	Generic Family Empowerment Scale (G-FES)	0.90 (family subscale), 0.84 (service situation subscale), 0.90 (service system subscale)
Vuorenmaa, Halme et. al., 2016	Level III	955 Parents of children aged 0-9 in Finland	Mailed questionnaire	Generic Family Empowerment Scale (G-FES)	Not mentioned
Vuorenmaa, Perälä et. al., 2016	Level III	955 Parents of children aged 0-9	Mailed questionnaire	Generic Family Empowerment Scale (G-FES)	0.90 (family subscale), 0.84 (service situation subscale), 0.90 (service system subscale) - from previous study
Wacharasin et. al., 2015	Level II	56 Caregivers for children with thalassemia	Self-administered	Thai Family Empowerment Questionnaire	0.79
Wakimizu et al., 2017	Level III	93 Parents who live with children with	Paper survey filled out at participants home	Japanese version of the Family Empowerment Scale	Not mentioned

Reference	*Level of Evidence**	*Sample Size & Population*	*Setting*	*Tool used*	*Cronbach's alpha*
		developmental disabilities			
Wakimizu et al., 2018	Level III	1659 Primary caregivers of a child with severe motor and intellectual disabilities	Paper survey filled out in own time/ setting	Japanese version of the Family Empowerment Scale (J-FES)	Not mentioned
Wakimizu et al., 2020	Level III	789 Siblings of children with disabilities and their primary caregivers	Questionnaires provided via schoolteachers	Japanese version of the Family Empowerment Scale (J-FES)	Not mentioned
Weiss et al., 2012	Level III	228 Parents of children diagnosed with autism	Online survey	Family Empowerment Scale (Family subscale)	0.90
Weiss et al., 2015	Level III	156 Mothers of children diagnosed with ASD (age 4-21)	Online survey	Family Empowerment Scale (Family subscale)	0.88
Wilunda et al., 2022	Level III	72,032 women and their singleton children (age 6-59 months old)	interviewer administered questionnaires	Survey-based women's empowerment index	Not mentioned
Wright & Wooden, 2013	Level II	69 Parents recruited by the Parent Forum	Before / after program or during first/ final session	Family Empowerment Scale (FES)	0.31 for attitudes, 0.75 for knowledge, 0.77 for behaviors
Zand et al., 2017	Level III	71 Pregnant women with substance use disorder	Unknown	Family Empowerment Scale- Service Subscale	0.89

*Based on Johns Hopkins Evidence-Based Practice Model for Nursing and Healthcare Professionals Evidence Appraisal Tool (The John Hopkins Hospital/ Johns Hopkins University School of Nursing, 2022). © The Johns Hopkins Hospital/ Johns Hopkins University

Table 7: Characteristics of Instruments

Instrument name	*Construct*	*Target Population*	*# Questions*	*# Subscales*	*Response options*	*Internal Consistency*	*Studies Used in*
Collective Empowerment in Online Health Communities Scale (CE-OHC) (Atanasova & Petric, 2019)	Collective empowerment	Online health communities	11	2 subscales- Knowledge of resources and resource mobilization for collective action	5-point Likert Scale	α = 0.86	Uhm & Kim, 2022
Empowering Speech Practices Scale (ESPS) (Kettunen et al., 2006)	Empowerment of counseling discussion	Nurses and patients after a counseling session in a hospital setting	44	2 subscales- nurses' action, families' action (Borges Rodrigues et al., 2020)	3-point Likert scale (yes/ no/ ambiguous)	α = 0.52 to 0.83	Borges Rodrigues et al., 2020
Empowerment Questionnaire (EMPO) (Damen et al., 2017)	Parental empowerment in raising their children	Dutch parents	12	3 subscales- intrapersonal, interactional, and behavioral control	5-point Likerrt scale	α = 0.86	(Damen et al., 2019); (Damen et al., 2020); (Damen et al., 2021)
Empowerment Outcomes Assessment (EOA)* (Alameda-Lawson, 2014)	Parental empowerment	Parents	25	None	5-point Likert scale	α = 0.89	(Alameda-Lawson, 2014)
Family Empowerment Scale (FES)	Empowerment	Families who have children with severe emotional disabilities	34	3 subscales- Family, Service System, Community/ Political	5-point Likert Scale	α = 0.87-0.88	Alsem et al., 2019; An et al., 2019; Bagur et al., 2022; Blankestein et al., 2022; Blizzard et. al.,

Instrument name	*Construct*	*Target Population*	*# Questions*	*# Subscales*	*Response options*	*Internal Consistency*	*Studies Used in*
(Koren et al., 1992)							2016; Bode et al., 2016; Bourke-Taylor et al., 2019; Burke, 2017; Burke et al., 2019; Burke & Sandman, 2017; Burton et al., 2018; Casagrande & Ingersoll, 2017; Chiu et al., 2013; Chou et al., 2018; Choy & Nakamura, 2022; Coutinho et al., 2016; Huscroft-D'Angelo et. al., 2017; Fordham et al, 2012; Fox et al., 2015; Gengoux et. al., 2019; Geva & Werner, 2021; Ghoneim, 2018; Golubović et al., 2021; Han et al., 2018; Hielkema et al., 2020; Kalleson et al., 2020; Kalleson et al., 2022; Kosyluk et al., 2022; Lim & Cho, 2022; Luelmo et al., 2021; McLeod et al., 2020; Minjarez et al., 2013; Morin & St-Onge, 2017; Muthukaruppan et al., 2022; Nieuwboer et al., 2015; Nissley-Tsiopinis et al., 2022; Pandya, 2020; Pierce et al., 2021; Pisula & Banasiak, 2020; Taylor et al., 2017; Trout et al., 2020; van der Perk et al., 2022; Wakimizu et al.,

Instrument name	*Construct*	*Target Population*	*# Questions*	*# Subscales*	*Response options*	*Internal Consistency*	*Studies Used in*
							2017; Wakimizu et al., 2018; Wakimizu et al., 2020; Weiss et al., 2012; Weiss et al., 2015; Wright & Wooden, 2013; Zand et al., 2017
Generic Family Empowerment Scale (G-FES) (Finnish Family Empowerment Scale) (Vuorenmaa et al., 2014)	Empowerment	Parents with small children	32	3 subscales- Family, Service System, Community	5-point Likert Scale	α = 0.84-0.90	Lepisto et al., 2022; Vuorenmaa, Halme et. al., 2016; Vuorenmaa, Perälä et. al., 2016; Vuorenmaa et. al., 2017
Genetic Counseling Outcome Scale (GCOS) (McAllister et al., 2011)	Empowerment	Individuals and parents of children with genetic conditions	24	None	7-point Likert scale	α = 0.87	Adam et. al., 2018; Palmer et al., 2018; Peltekova et al., 2021; Vlaskamp et. al., 2021
Genome Empowerment Scale (McConkie-Rosell, 2019)	Parental Empowerment	Families with undiagnosed disease	28	Four factors- Meaning of a diagnosis, Emotional management of the process, Seeking information and support, Implications and Planning	7-point Likert scale	α = 0.77	McConkie-Rosell et. al., 2022
Genomics Outcome Scale (GOS)	Empowerment	Individuals using genetic counseling	6	None	5-point Likert scale	Unknown	Hancock et al., 2022

Instrument name	*Construct*	*Target Population*	*# Questions*	*# Subscales*	*Response options*	*Internal Consistency*	*Studies Used in*
(Grant et al., 2019)		and testing services					
Health Care Empowerment Inventory (HCEI) (Johnson et al., 2012)	Patient-controlled engagement and involvement in health care	Individuals with human immunodeficiency virus (HIV)	27	2 subscales- HCE ICCE, HCE TU	5-point Likert scale	Sample 1- HCE ICCE (ρ=.78; 95% CI=.73,.83) and HCE TU (ρ=.86; 95% CI=.82,.89) Sample 2- HCE ICCE (ρ=.87; 95% CI=.84,.90) and HCE TU (ρ=.90; 95% CI=.88,.92)	McConkie-Rosell et al., 2018
The Main Caregivers' Empowerment Measurement (MCEM) scale* (Liu & Guo, 2021)	Empowerment	Caregivers in China and Japan	51	9 dimensions- "personal resources, subjectivity of caregivers, faith in care, knowledge and skills of care, scruples about the surroundings, relationship with the person being cared for, goodwill care, understanding of care role, expectation for care outcomes" (Liu & Guo, 2021, p. 3)	4-point Likert scale	α = 0.89	Liu & Guo, 2021
The Parent Empowerment	Parent empowerment	Parents of children aged 5 to 12	20	2 sub-factors- efficacy to parent and efficacy to connect	10-point Likert Scale	α = 0.85-0.92	Berry et. al., 2019

Instrument name	*Construct*	*Target Population*	*# Questions*	*# Subscales*	*Response options*	*Internal Consistency*	*Studies Used in*
and Efficacy Measure (Freiberg et al., 2014)							
Parent Empowerment Scale (Ameral et al., 2020)	Parents' perceptions and experiences related to coping with their child's substance use disorder	Parents of children with substance use disorders	4	None	11-point Likert Scale	α = 0.74	Ameral et. al., 2020
Parent/-Guardian Empowerment in Schools Scale (PGES) (Ball, 2014)	Parent/ guardian empowerment in the school context	Parents of school-aged children	22	2 factors- Parent/Guardian Knowledge, Parent/Guardian Perceived Competence	5-point Likert scale	α = 0.91	Ball & Skrzypek, 2019
Parental Empowerment through Awareness, Relationships, and Resources (PEARR) (Figueroa et al., 2020)	Psychological empowerment	Parents of children in a family-centered, community-based obesity prevention program	21	3 subdimensions- resource empowerment, critical awareness, relational empowerment	4-point Likert scale	α = 0.83–0.90	Gago et al., 2022
Parental Resource Empowerment Scale	Parental empowerment (resource component)	Parents of children who are obese	15	3 subscales- children's weight, physical activity, and diet	4-point Likert scale	α = 0.93-0.97	Lim et. al., 2017

Instrument name	*Construct*	*Target Population*	*# Questions*	*# Subscales*	*Response options*	*Internal Consistency*	*Studies Used in*
(Jurkowski et al., 2014)							
Patient Activation Scale (PAS)* (Coutinho et al., 2016)	Patient's engagement in behaviors that increase their collaboration with the healthcare provider	Patients	9	None	10-point Likert Scale	α = 0.82 (English version)	Coutinho et al., 2016
Thai Family Empowerment Questionnaire (Wacharasin et al., 2015)	Family empowerment	Families managing care for children with thalassemia	25	7 subscales- routine care, nutrition and elimination, activity and rest, safety, medical care, reducing stress, and emotional support	5-point Likert scale	α = 0.79	Wacharasin et. al., 2015
Spreitzer Empowerment Scale (Spreitzer, 1995; Spreitzer, 2008)	Psychological empowerment	Employees	12	4 dimensions- meaning, competence, self-determination, impact	7-point Likert scale	α = 0.62-0.72	Jurkowski et al., 2014
Survey-based women's empowerment index (SWPER) (Ewerling et al., 2017)	Women's empowerment	Women in Africa (low- and middle-income countries)	15	3 domains- attitude to violence, social independence, decision-making	Differed based on question	Unknown	Baye et al., 2021

Instrument name	*Construct*	*Target Population*	*# Questions*	*# Subscales*	*Response options*	*Internal Consistency*	*Studies Used in*
Women's Empowerment Index (Tuladhar et al., 2013)	Women's empowerment	Nepalese women	5	5 indicators- woman's involvement in household decision-making, woman's membership in community groups, woman's cash earnings, woman's ownership of house/ land, woman's education	Scales of 0-1 or 0-2 (dependent on subscale)	Unknown	Poudel et. al., 2022

*unable to access original study

Findings/ Psychometric Properties

Constructs Studied:

While most instruments focused on the construct of empowerment, some instruments specified the type of empowerment including collective empowerment (Atanasova & Petric, 2019), parental empowerment (Alameda-Lawson 2014; Ball, 2014; Damen et al., 2017; Freiberg et al., 2014; Jurkowski et al., 2014; McConkie-Rosell, 2019), psychological empowerment (Spreitzer, 1995), family empowerment (Wacharasin et al., 2015), and women's empowerment (Ewerling et al., 2017). Two instruments measured the construct of patient engagement, not empowerment. They were included in the review as they were utilized in studies to measure empowerment (Coutinho et al., 2016; Johnson et al., 2012). No instrument directly mentioned the construct of caregiver empowerment, but caregivers and parents were mentioned as the target population (Alameda-Lawson, 2014; Ameral et al., 2020; Ball, 2014; Damen et al., 2017; Figueroa et al., 2020; Freiberg et al., 2014; Jurkowski et al., 2014; Liu & Guo, 2021; McAllister et al., 2011; Vuorenmaa et al., 2014).

Population studied:

In the original studies, the target population for each instrument ranged widely including parents (Alameda-Lawson, 2014), caregivers (Liu & Guo, 2021), families (Wacharasin et al., 2015), those providing parent education (To et al., 2022), employees (Spreitzer, 1995; Spreitzer, 2008), women (Ewerling et al., 2017), and individuals with a health condition or utilizing specific healthcare resources (Johnson et al., 2012). Additionally, the target population included different population demographics with studies focused on individuals who were Dutch (Damen et al., 2017) and Nepalese (Kathmandu, 2013), lived in China and Japan (Liu & Guo, 2021), lived in Africa (Ewerling et al., 2017), and were a part of an online community (Atanasova &

Petric, 2019). Finally, a range of different health conditions existed for the target population including severe emotional disabilities (Koren et al., 1992), genetic conditions (McAllister et al., 2011), undiagnosed disease (McConkie-Rosell, 2019), human immunodeficiency virus (HIV) (Johnson et al., 2012), obesity (Figueroa et al., 2020; Jurkowski et al., 2014), and thalassemia (Wacharasin et al., 2015).

While the original studies were tailored to specific populations, these instruments were adapted and used with different people groups as well. Other health conditions to which these instruments were applied include intellectual and developmental disorders (Bagur et al., 2022), genetic conditions (Wacharasin et. al., 2015), chronic conditions (Coutinho et al., 2016), mental health disorders (Blizzard et. al., 2016), and neurological disorders (Adam et. al., 2018).

Psychometrics:

Most instruments in this review used Cronbach's α to determine internal consistency. The Health Care Empowerment Inventory (Johnson et al., 2012) reported a correlation coefficient and confidence interval. The Genomics Outcome Scale, the Survey-based women's empowerment index, and the Women's Empowerment Index did not report a measure for internal consistency. All other studies reported a Cronbach's $\alpha \geq 0.70$, except for the Spreitzer Empowerment Scale ($\alpha = 0.62$-0.72) and Empowering Speech Practices Scale ($\alpha = 0.52$-0.83). All individual studies measuring internal consistency also reported Cronbach's $\alpha \geq 0.70$ except for one adapted empowerment scale ($\alpha = 0.67$-0.91) (Lin et al., 2019) and the attitude subscale of the Family Empowerment Scale ($\alpha = 0.31$) in a study by Wright & Wooden (2013).

Commonly Used Instruments:

The most frequently used instrument was the Family Empowerment Scale (Koren et al., 1992). This instrument was used in 62.03% (49 of 79) of the included studies. While this instrument was originally developed for families of children with severe emotional disabilities, it was utilized in a variety of different populations including parents of children with intellectual and developmental disabilities, caregivers of children with psychiatric conditions, pregnant women undergoing treatment for substance use disorder, and parents of children with chronic medical conditions (autism spectrum disorder, asthma, cancer, cerebral palsy, ADHD, and Down syndrome). The Generic Family Empowerment Scale (Vuorenmaa et al., 2014) was used in four studies. It was created with a target population of parents with small children, which is consistent with its use in the published studies. The Empowerment Questionnaire (EMPO) (Damen et al., 2017) was utilized in three studies and created to measure empowerment in Dutch families. Finally, the Genetic Counseling Outcome Scale (GCOS) was utilized in three studies, all of which focused on the target population of individuals and parents of children with genetic conditions (Adam et al., 2018; Palmer et al., 2018; Peltekova et al., 2021).

Instrument Adoption:

The literature reflected how the 21 instruments were adapted to apply to different target populations. The Family Empowerment Scale, while the most widely used, was also the most widely adapted. Many of the studies just used one or two of the subscales (Nissley-Tsiopinis et al., 2022; Weiss et al., 2012), while other studies adapted it to better fit their target population's needs. This included translation into Spanish (Burke, 2017), and creation of Dutch (van der Perk et al., 2022), Polish (Pisula & Banasiak, 2020), Hebrew (Geva & Werner, 2021), and Japanese (Wakimizu et al., 2017) versions of the instrument. The instrument was also adapted in other ways to fit the target population being studied by creating different subscales (Fox et al., 2015; Nieuwboer et al., 2015) and selecting a limited number of items to use from the instrument (McLeod et al., 2020). Other studies utilized adapted versions of the Empowering Speech Practices Scale (Borges Rodrigues et al., 2020), Spreitzer Empowerment Scale (Jurkowski et al., 2014), and the Patient Activation Scale (Coutinho et al., 2016).

Discussion

Application to Caregivers of Children with Asthma

While no instrument was specifically created to measure empowerment in caregivers of children with asthma, the Family Empowerment Scale and Patient Activation Scale were utilized in this population. A study by Coutinho et al. (2016) used the Family Empowerment Scale and a modified version of the Patient Activation Scale to study white urban caregivers and their children with asthma. The Family Empowerment Scale seems to be the best instrument to utilize in this population at this time, as it not only has been used in research with this population, it also has been utilized in a wide variety of similar populations of caregivers of children with chronic disease. The instrument is divided into three subscales (Family, Service System, and Community/ Political) (Koren et al., 1992), which allows for the application of either all or only a selection of the subscales to best capture the aspect of empowerment desired for the study.

Other instruments that have the potential for further research in the population of caregivers of children with asthma include the Main Caregivers' Empowerment Measurement and the Parent Empowerment and Efficacy Measure. The Main Caregivers' Empowerment Measurement (Liu & Guo, 2021) focuses on nine different dimensions of empowerment including "personal resources, subjectivity of caregivers, faith in care, knowledge and skills of care, scruples about the surroundings, relationship with the person being cared for, goodwill care, understanding of care role, [and] expectation for care outcomes" (Liu & Guo, 2021, p. 3). These dimensions of empowerment can be important in understanding a caregiver's empowerment experience and can be adapted to the population of caregivers of children with asthma for further understanding of empowerment in this population. The Parent Empowerment and Efficacy Measure (Freiberg et al., 2014) shows promise in this population as it has specifically been created to measure parental empowerment in parents of children aged 5-12. In this review, the instrument was not studied yet in the population of caregivers with chronic disease, so it would need to be validated in this population and potentially be adapted for this population. These two instruments have the potential to be used for caregivers of children with asthma in future research.

Limitations

This study only focused on research from the past 10 years to ensure that current instruments were captured in this integrated review. However, this leaves a gap for missing other instruments that could be reviewed or adapted to better understand what makes an instrument effective in measuring caregiver empowerment. Additionally, the instruments discovered focus on a variety of different types of empowerment, including empowerment of parents of normally developing children, women, and caregivers of adults. As the needs and characteristic of these populations could differ from caregivers of children with a chronic disease, the instruments might include items that would not be suitable for the population of caregivers of children with asthma and would need to be tested more thoroughly in this population and potentially adapted before they would be acceptable for use. Finally, for three instruments, the original study validating the instrument could not be found (Alameda-Lawson, 2014; Coutinho et al., 2016; Liu

& Guo, 2021). This limited the evaluation of these instruments as reported findings were based solely upon the research studies in which these instruments were used.

Conclusion

Caregiver empowerment is a construct that continues to be developed and researched in relation to many different populations, including in caregivers of children with asthma. Development and research of different instruments to measure caregiver empowerment allows for a better understanding of the construct and gives quantitative ways in which to qualify information surrounding the construct. This study found 21 different instruments that have been used to measure caregiver empowerment in many different populations. The Family Empowerment Scale was by far the most widely utilized and researched and was found to be the most effective instrument for caregivers of children with asthma. With knowledge of the different instruments that exist, there is an avenue for continued research on the construct of caregiver empowerment and development of instruments that can be helpful to measure this construct in different populations.

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CHAPTER 5: CONCLUSION

This dissertation examines the concept of empowerment among caregivers of children with asthma. It examines what is already known in the literature, how social support and income are related to caregiver empowerment, and the instruments that exist to measure caregiver empowerment.

This research shows that caregiver empowerment is an important concept to understand and utilize in caregivers of children with asthma, and there is room for more research related to this concept. The results of the survey show that there is a clear correlation between social support and caregiver empowerment in this population. Future research should focus on social support interventions and their effect on caregiver empowerment. A randomized control trial in which participants are assigned to a social support intervention group or a control group, and empowerment is measured both before and after the intervention would be most effective in furthering this research. Social support interventions should focus on emotional, tangible, affectionate, and social aspects of social support, as all these components were correlated with increased empowerment. To address limitations of access, fabrication of responses, and lack of a controlled environment, paper surveys can be offered, and data can be collected during the time that participants are present for the intervention.

Limitations from this study can be addressed with future research. To further understand the relationship between income and empowerment, a study should be conducted with more evenly distributed income levels, including more individuals living at or below the Federal Poverty Level. Additionally, future research should focus on measuring income in a more meaningful way and look at other factors that could mitigate the impact that income has on empowerment.

Overall, this dissertation adds to the body of knowledge of caregiver empowerment among caregivers of children with asthma. This study shows the correlation between social support and caregiver empowerment, setting a foundation for further research on the relationship between social support, income, and caregiver empowerment. Ultimately, this study allows for an expanding understanding on how to help support caregivers in managing care for their children with asthma.

APPENDIX A: PERMISSION TO USE FAMILY EMPOWERMENT SCALE

Family Empowerment Scale

Portland State
UNIVERSITY

We are pleased that you would like to use the **Family Empowerment Scale (FES)** in your research.

Citation: Koren P., DeChillo, N., & Friesen, B. (1993). Family Empowerment Scale (FES). Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Portland State University.

The following are included in this PDF:

1) The FES instrument
2) The FES scoring guide
3) A list of published studies that have used the scale

Please cite properly, whether the citation be in printed form or on a website. We would be very interested to hear about your experiences and findings, and to receive a copy of any publication referencing the scale.

For further specific or technical information, contact Dr. Barbara Friesen at friesenb@pdx.edu.

Research and Training Center for Pathways to Positive Futures
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Portland, OR 97207-0751
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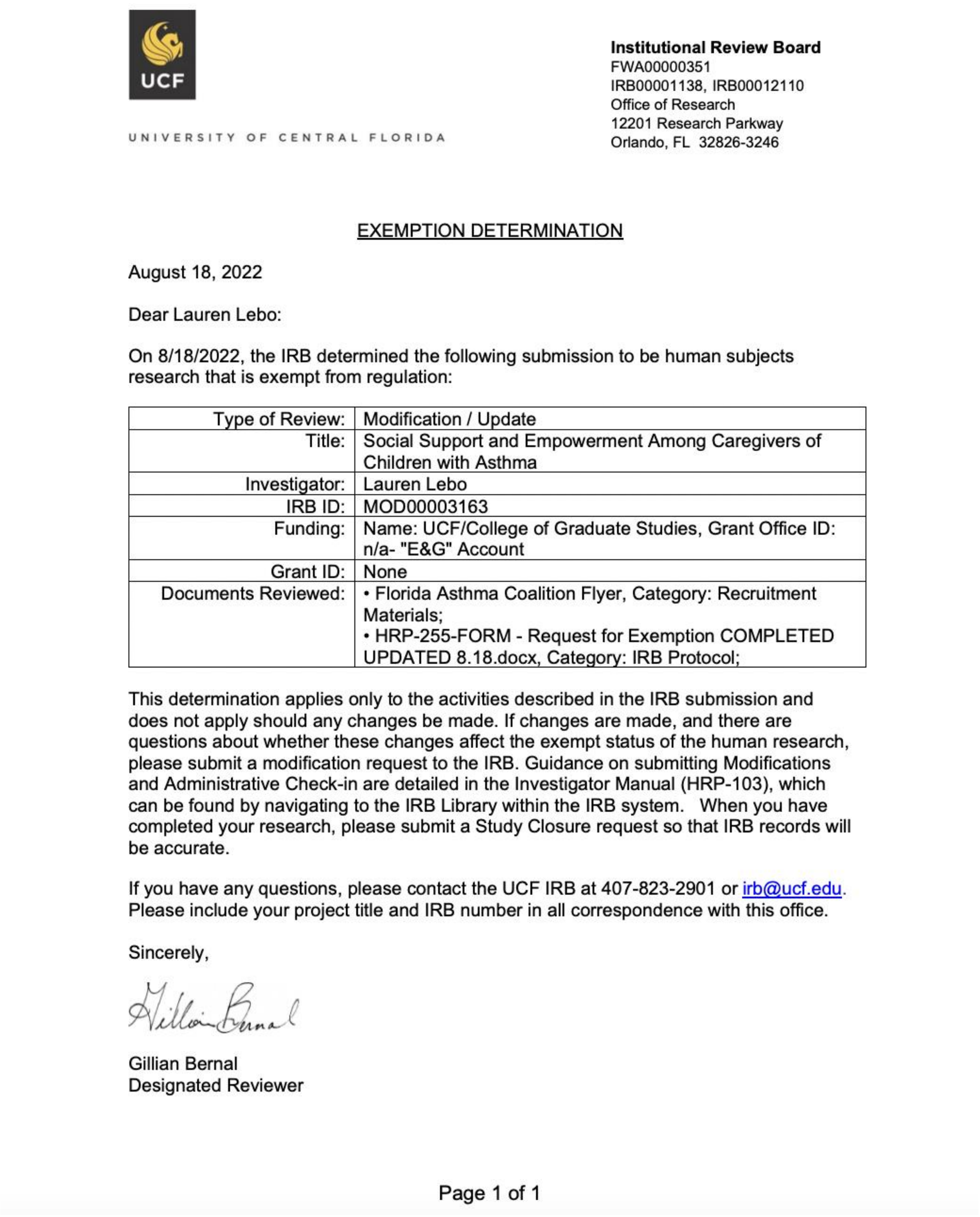
APPENDIX B: IRB LETTER



UNIVERSITY OF CENTRAL FLORIDA

Institutional Review Board
FWA00000351
IRB00001138, IRB00012110
Office of Research
12201 Research Parkway
Orlando, FL 32826-3246

EXEMPTION DETERMINATION

August 18, 2022

Dear Lauren Lebo:

On 8/18/2022, the IRB determined the following submission to be human subjects research that is exempt from regulation:

Type of Review:	Modification / Update
Title:	Social Support and Empowerment Among Caregivers of Children with Asthma
Investigator:	Lauren Lebo
IRB ID:	MOD00003163
Funding:	Name: UCF/College of Graduate Studies, Grant Office ID: n/a- "E&G" Account
Grant ID:	None
Documents Reviewed:	• Florida Asthma Coalition Flyer, Category: Recruitment Materials; • HRP-255-FORM - Request for Exemption COMPLETED UPDATED 8.18.docx, Category: IRB Protocol;

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made, and there are questions about whether these changes affect the exempt status of the human research, please submit a modification request to the IRB. Guidance on submitting Modifications and Administrative Check-in are detailed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system. When you have completed your research, please submit a Study Closure request so that IRB records will be accurate.

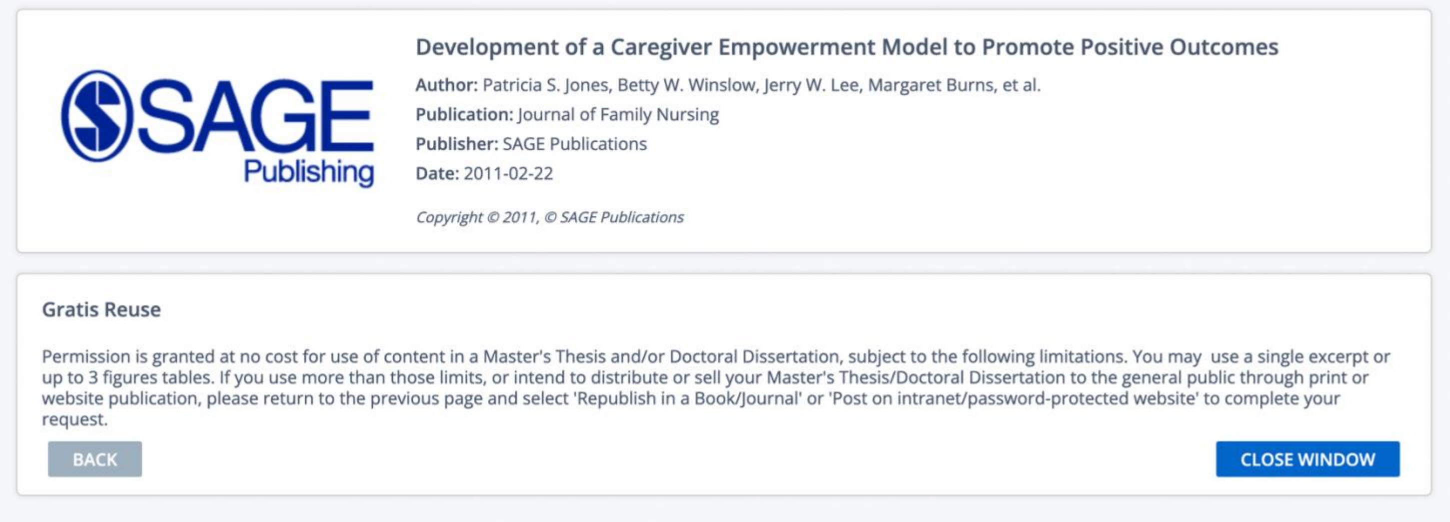
If you have any questions, please contact the UCF IRB at 407-823-2901 or irb@ucf.edu. Please include your project title and IRB number in all correspondence with this office.

Sincerely,

Gillian Bernal

Gillian Bernal
Designated Reviewer

APPENDIX C: PERMISSION TO USE CAREGIVER EMPOWERMENT MODEL (FIGURE 2)



Development of a Caregiver Empowerment Model to Promote Positive Outcomes

Author: Patricia S. Jones, Betty W. Winslow, Jerry W. Lee, Margaret Burns, et al.

Publication: Journal of Family Nursing

Publisher: SAGE Publications

Date: 2011-02-22

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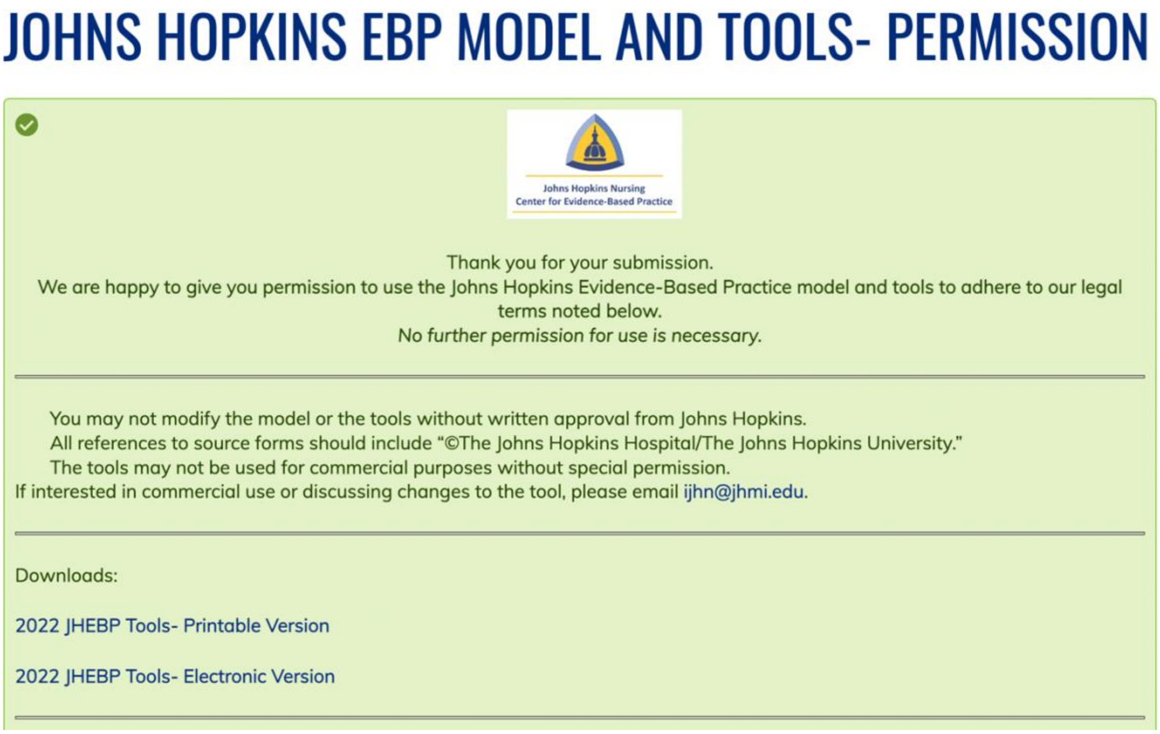
APPENDIX D: PERMISSION TO USE JOHN HOPKINS EBP MODEL AND TOOLS



JOHNS HOPKINS EBP MODEL AND TOOLS- PERMISSION

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