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Empowerment in Adolescents and Young Adults with Cystic Fibrosis

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EMPOWERMENT IN ADOLESCENTS AND YOUNG ADULTS WITH CYSTIC FIBROSIS

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Abstract

Adolescence and young adulthood is a pivotal time for individuals with cystic fibrosis (CF) that is characterized by increased self-management, transition to adult-oriented healthcare, and often a decline in treatment adherence and health-related quality of life (HRQoL) (Abbott et al., 2015; Modi et al., 2008). The literature regarding which factors are important for readiness to transition, treatment adherence, and HRQoL is limited in this population. However, empowerment has emerged as a salient construct in other disease groups (Acuña Mora et al., 2019; Burström et al., 2019; Kaal et al., 2017). As such, this thesis determined the convergent validity of the Gothenburg Young Persons Empowerment Scale (GYPES), as well as examined the association among empowerment, as measured by the GYPES, and transition readiness, treatment adherence, and HRQoL. We hypothesized that that the GYPES would be significantly correlated with a measure of general self-efficacy and higher levels of empowerment would be associated with more transition readiness, better treatment adherence, and better HRQoL. Data were collected from 41 AYAs with CF (mean±SD age = 18±2.89, 80.5% White, 70.7% female) using an electronic survey. In addition to the GYPES, measures included the Generalized Self-Efficacy Scale (GSE), Transition Readiness Assessment Questionnaire (TRAQ), Treatment Adherence Rating Scale (TARS), and the Cystic Fibrosis Questionnaire-Revised (CFQ-R; physical, role, vitality, emotional, and social subscales). Hypotheses were tested using a bivariate correlation and several hierarchical linear regressions. Results indicated that the GSE and GYPES were positively correlated ($r(39) = .615$, $p < .001$), indicating convergent validity. In addition, empowerment was positively associated with transition readiness ($\beta = .630$, $p < .001$) and treatment adherence ($\beta = .485$, $p < .001$). Empowerment was not associated with physical functioning ($\beta = .076$, $p = .68$), role functioning ($\beta = .113$, $p = .47$), vitality ($\beta = .281$, $p = .021$),

emotional functioning (β = .212, p = .10), or social functioning (β = .008, p = .96) when applying a Bonferroni correction. The present study supported the convergent validity of the GYPES and associations between empowerment and both transition readiness and treatment adherence. Thus, when preparing AYAs for transition or encouraging adherence, empowering AYAs may be an important first step. Further investigation on how to best empower AYAs with CF as well as factors contributing to empowerment in this population is warranted.

Empowerment in Adolescents and Young Adults with Cystic Fibrosis

Cystic fibrosis (CF) is a progressive pulmonary disease that results from genetic mutations and causes an accumulation of excess mucus in the lungs and other organs, often resulting in frequent lung infections, poor growth, and digestive difficulties. CF is typically diagnosed within the first two years of life and requires the completion of multiple daily therapies to slow disease progression (Cystic Fibrosis Foundation, n.d.). Due to recent treatment advances, the median predicted life expectancy for an individual with CF has increased from 35 to 50 years in the last 15 years (Cystic Fibrosis Foundation, 2020). With an increase in life expectancy, the need for adult-centered care for individuals with CF has become more apparent. Research examining which variables are associated with readiness for the transition from pediatric to adult-oriented care is limited in individuals with CF; to date, self-efficacy has been found to be especially important during this transition phase (Torun et al., 2020).

One potentially important construct in transition readiness among individuals with CF that has not been studied is empowerment. Empowerment is defined as "an enabling process or outcome arising from communication with the health care professional and a mutual sharing of resources over information relating to illness, which enhances the patient's feelings of control, self-efficacy, coping abilities and ability to achieve change over their condition" (Small et al., 2013, p. 2). Thus, patients may need to be more in control of their CF management as they mature and transition to adulthood, with less reliance on parents or caregivers for daily care behaviors. Understanding the role of empowerment in transition readiness may illuminate potential targets of transition readiness regimens. The purpose of this thesis was to better understand empowerment among a sample of adolescents and young adults (AYAs) with CF by examining the convergent validity of an empowerment measure and evaluating how it was

associated with transition readiness, treatment adherence, and health-related quality of life (HRQoL) in AYAs with CF.

Adolescence and Young Adulthood in CF

CF requires intensive daily management, often consisting of a combination of inhaled and oral antibiotics, pancreatic enzymes, airway clearance, and exercise (Cystic Fibrosis Foundation, n.d.). Thus, treatment is often burdensome and time consuming. In a study by Sawicki and colleagues (2009), participants reported completing a median of seven daily therapies for CF and spending a median of 108 minutes per day on said treatments. In young children with CF, parents are often highly involved in the daily management of treatment. As children age, they become more responsible for managing their own health care and parents become less involved. This gradual shift begins in late childhood and children become increasingly responsible for their care until they are able to initiate and implement all therapies without their parents' supervision (Leeman et al., 2015). The trajectory of adolescent responsibility and parental involvement, however, is not necessarily linear. In a study by Modi and colleagues (2008), exploration of adherence during adolescence indicated that parents tended to decrease their involvement in daily care behaviors around the time their child reached the age of 15. However, they subsequently increased involvement again around ages 16 to 17. Proposed explanations for this phenomenon included the fact that adolescents did not compensate for their parents' decreased involvement, and instead failed to optimally maintain their treatment regimens, driving a reuptake in parental involvement (Modi et al., 2008). In addition, transition to greater adolescent self-management has been associated with lowered treatment adherence (Zindani et al., 2006).

Despite this need for additional parental involvement, many AYAs with CF feel that they are able to manage their own healthcare, which may be doubted by their parents and healthcare providers at times (Cronly & Savage, 2019; Peeters et al., 2014). In a qualitative study by Bregnballe and colleagues (2011), AYAs expressed a desire to begin managing their own healthcare and participating in medical decisions during adolescence. However, they noted there were several barriers to this, such as a lack of trust and reluctance to transfer responsibility from their parents. The authors hypothesized that adherence issues were related to this phenomenon and resulted from AYAs not recognizing treatments as "their problem" (Bregnballe et al, 2011). Similar sentiments were echoed in a study by Sawicki and colleagues (2015) in which adolescents noted that early training in self-management and being trusted by their parents were facilitators of treatment adherence. Thus, simply transferring the responsibility of disease management behaviors from parents to adolescents may not sufficiently promote optimal disease management. Instead, this transition is a process whereby adolescents gradually build disease-related competencies and take on more responsibilities themselves.

Transition to Adult Healthcare

In addition to increasing self-management behaviors, adolescents with CF must transition from pediatric to adult-oriented healthcare. This typically involves leaving behind a long-term healthcare team that has often cared for the individual from a very young age and navigating new expectations in a different care setting. AYAs report concerns about this transition, including increased infection risk, decrease in care quality, financial issues, and feeling unprepared (Coyne et al., 2017). However, transitioning from pediatric to adult-oriented care has been associated with positive outcomes, such as a slower decline in lung function, increased self-management and advocacy, independence, satisfaction, self-care, and lowered anxiety (Coyne et al., 2017;

Tuchman & Schwartz, 2013). Many of these outcomes have been reported when structured transition programs, consisting of varying components such as meeting the adult team or touring the adult center prior to transition, were utilized (Coyne et al., 2017). Additionally, recent literature has demonstrated better transition readiness, perception of healthcare independence, and transition-related anxiety in AYAs with CF who participated in structured transition programs (Middour-Oxler et al., 2022). Thus, preparation and planning may be important for a successful transition with positive outcomes.

Transition Readiness

In AYAs with chronic conditions, preparedness to transition to adult-oriented care (i.e., transition readiness) has largely been operationalized as the acquisition and ability to use self-management behaviors, such as keeping track of medical appointments, having knowledge of insurance coverage, filling prescriptions and using medications, asking providers questions, and preparing meals (Wood et al., 2014). Despite the availability of transition readiness assessments that measure responsibility and competency related to disease management, the timing of transition is not always guided by the attainment of these milestones. In fact, only 52% of CF clinics reported consistently using transition readiness assessments (McLaughlin et al., 2008). Instead, age and life events, such as college, marriage, or pregnancy, are often used to determine timing of transition (Flume et al., 2004).

While age and other life events are commonly associated with transition readiness, other patient characteristics, such as self-efficacy, disease knowledge, and responsibility, have also been linked to preparedness to transfer (Varty & Popejoy, 2020). Evaluation of such modifiable factors is important because they represent components of transition readiness that can be incorporated into earlier stages of the process, such as in early adolescence. However, additional

characteristics, such as level of empowerment, have not been explored extensively, particularly in AYAs with CF. To our knowledge, only one study has explored transition readiness in AYAs with CF exclusively, and self-efficacy was the only variable significantly associated with transition readiness (Torun et al., 2020).

However, the literature on variables associated with transition readiness is more robust in other populations, such as AYAs with type 1 diabetes, irritable bowel disease, congenital heart disease, renal disease, and epilepsy. In their review of the literature, Varty and Popejoy (2020) found the most common factors associated with transition readiness to be older age, female gender, self-efficacy, responsibility, and disease knowledge. While the review by Varty and Popejoy (2020) provides a valuable overview of established, associated variables with transition readiness, it also highlights the limitations of this literature base. Notably, many studies have focused on demographic variables (e.g., age, gender) that are not modifiable, and, therefore, cannot be targeted to prepare AYAs for transition. Thus, further exploration of modifiable constructs associated with transition readiness is warranted.

While not included in Varty and Popejoy's (2020) review of the literature, empowerment has recently emerged as a modifiable, multidimensional construct that has been associated with transition readiness. However, the literature exploring this association in AYAs with chronic illness is limited, and non-existent in studies including AYAs with CF. Thus, the aims of this thesis included: 1) evaluating the association between an empowerment measure and a theoretically related measure (convergent validity) in AYAs with CF and 2) examining the measure's association with transition readiness, among other factors, in this population. The following sections will describe empowerment and its measurement in other disease groups and review the literature on empowerment and transition readiness in AYAs with chronic illnesses.

Empowerment in AYAs with Chronic Illness

The concept of empowerment in the medical context is complex, and the literature is largely limited to adult populations. Multiple conceptualizations of empowerment have been proposed, though few have targeted AYAs. In a mixed methods study, Bravo and colleagues (2015) sought to define empowerment in the medical context. Through a thorough literature review and stakeholder interviews, the authors developed a conceptual map of empowerment. Included within this conceptual map were principles underlying patient empowerment, such as autonomy, self-determination, and power within the healthcare context. Further, the authors included indicators of patient empowerment, such as self-efficacy, participation in shared decision-making, attainment of knowledge and skills necessary to participate in healthcare, and self-management. Small and colleagues (2013) used these findings to conceptualize empowerment across five domains: shared decision-making, disease knowledge and understanding, personal control, identity, and enabling of others. While literature exploring empowerment in individuals with CF has only recently emerged, proposed conceptualizations of empowerment in this population are similar.

Fairweather et al. (2021) conducted a grounded theory study aimed at understanding the components of empowerment in young people with CF during life transitions, such as starting a new school, planning for college, increasing self-management, and considering transitioning to adult care. In this study, children and adolescents with CF, parents of individuals with CF, and healthcare providers completed qualitative interviews. The results indicated that empowerment was conceptualized as "thriving alongside CF" and included themes related to trust and communication with the healthcare team, identity, learning, and control. In addition, this conceptualization included components of social support and highlighted unique challenges

faced by individuals with CF, such as navigating infection control guidelines when engaging with others (Fairweather et al., 2021). Further, Fairweather and Jones (2021) evaluated barriers and facilitators to empowerment, defined as "feeling in control, having mastery, being in charge, having influence, having agency, or having autonomy" in young people with CF (Fairweather & Jones, 2021, p. 2). They found that facilitators to empowerment included social support and knowledge. On the other hand, prejudice related to their CF from individuals outside of their care team was the primary barrier. In addition, empowerment included components of "mastery and competence" as well as "navigating being different" (Fairweather & Jones, 2021). While these studies have furthered the understanding of what empowerment means to young people with CF, how to quantitatively measure empowerment in this population has not yet been explored.

Acuña Mora and colleagues (2018) used 5-domain conceptualization proposed by Small et al. (2013) to develop the Gothenburg Young Persons Empowerment Scales (GYPES), the first measure of empowerment for AYAs with chronic illness. Given the novelty of this instrument, literature utilizing it is limited. This instrument was evaluated in AYAs with congenital heart disease and type 1 diabetes, and the five-factor structure of empowerment proposed by Small and colleagues (2013) held with adequate fit (Figure 1; Acuña Mora et al., 2018). This study also found evidence of face and content validity, internal consistency, and responsiveness in AYAs with congenital heart disease and diabetes. However, further psychometric evaluation of this measure has not been conducted. Namely, the convergent, criterion, discriminant, predictive, and construct validity has not been established in any population, and no psychometric properties of the instrument have been examined in AYAs with CF.

Convergent validity refers to the extent to which a target measure, in this case the GYPES, is associated with a measure of a similar construct (Carlson & Herdman, 2012).

Evidence supporting the convergent validity of the GYPES is essential because it increases confidence in construct validity, or confirmation that the measure is assessing the intended construct (i.e., empowerment). Based on the theoretical underpinnings of the measure, we expected the GYPES to be positively correlated with a measure of self-efficacy. While self-efficacy represents a construct separate from empowerment, it is reasonable, given the overlap in definition, to expect the constructs to be related. Further, empowerment has been associated with self-efficacy in the psychometric evaluation of an empowerment measure for adults (Small et al., 2013). Finally, self-efficacy is a variable that is consistently associated with transition readiness (Varty & Popejoy, 2020). Thus, the first aim of this thesis was to evaluate the convergent validity of the GYPES using a well-established measure of self-efficacy, the Generalized Self-Efficacy Scale (GSE) as a first step in establishing its psychometric properties among AYAs with CF.

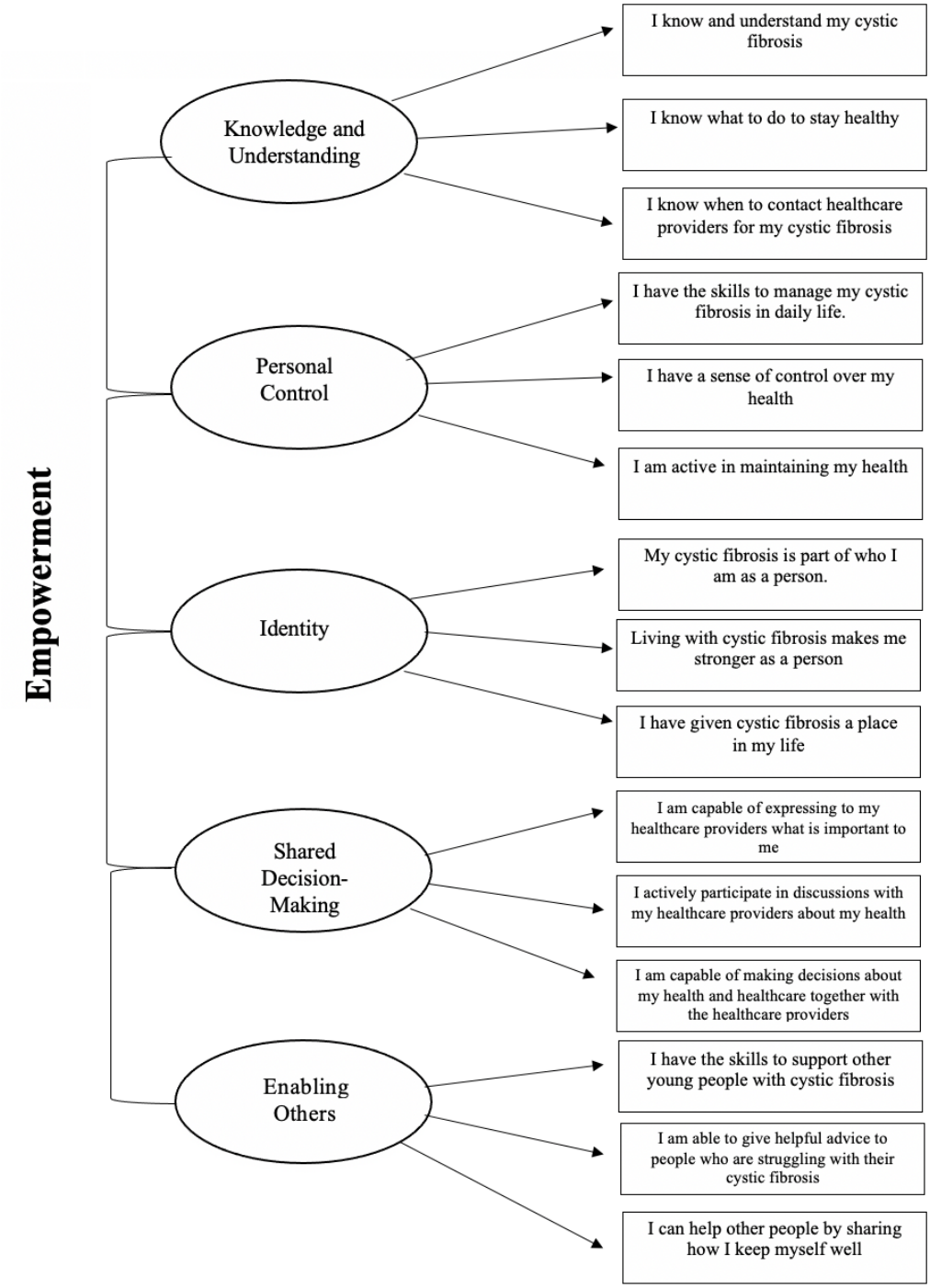

Figure 1: Five factor structure of empowerment

Empowerment and Transition Readiness

In addition to evaluating the convergent validity of an empowerment measure, this thesis also examined the association between empowerment and transition readiness. Research to date has found empowerment and transition readiness to be associated in adolescents with congenital heart disease (Acuña Mora et al., 2019; Burström et al., 2019). While these are the only studies explicitly linking empowerment as a construct to transition readiness, each of the five domains of empowerment have been linked to transition readiness in multiple disease groups (Commissariat et al., 2020; Dwyer-Matzky et al., 2018; Gilleland et al., 2012; Gilleland Marchak et al., 2015; Groot et al., 2021; Gumidyala et al., 2018; Kohut et al., 2017; Mckenzie et al., 2019; Nazareth et al., 2016; Sattoe et al., 2013; Sawicki et al., 2014; Sheanon et al., 2020; Stewart et al., 2017; Torun et al., 2020; Treadwell et al., 2016; Uzark et al., 2015; van Staa et al., 2015; Weisman et al., 2020; Zhong et al., 2020). Thus, this literature can provide support for the potential role of empowerment as a salient construct in transition readiness. In the following sections, the literature linking the five domains of empowerment (shared decision-making, knowledge and understanding, personal control, identity, and enabling of others; Figure 1) to transition readiness will be reviewed.

Shared Decision Making

Shared decision-making (SDM) refers to the ability to participate in decisions regarding the management of disease (Small et al., 2013). Promotion and facilitation of SDM has been an identified area of priority in transition care in qualitative studies of multiple disease groups, including AYAs with CF (Sliwinski et al., 2017; Zack et al., 2003). In addition, quantitative studies have supported the role of SDM in the transition to self-management and adult-oriented healthcare. AYAs with chronic conditions who engaged in regular SDM with their providers

were more likely to be prepared for transition than those who did not (Mckenzie et al., 2019). Further, adolescents who participated in medical visits partially alone showed an increase in overall independence and independent behaviors (van Staa et al., 2015). Participation in a transition program incorporating solo visits with providers was associated with more transition readiness and better perception of healthcare independence in AYAs with CF (Middour-Oxler et al., 2022). Despite this, adolescents have still reported incongruence between their preferred and actual involvement in medical decisions, often related to parent and provider attitudes and behaviors (Jordan et al., 2018, 2019). Further, this concept, SDM, has not been explored extensively in youth with CF. To date, the only studies about SDM in AYAs with CF have explored the acceptability of decision making tools for decisions related to lung transplantation and at home treatments in adults (Basile et al., 2019; Eckman et al., 2017).

Knowledge and Understanding

The second domain of empowerment is knowledge and understanding. This refers to comprehension of the medical condition and its management (Small et al., 2013). Youth with CF anticipate having adequate knowledge of CF, including its causes, effects, and treatments, by the age of 14 (Lonabaugh et al., 2018). Despite this expectation, many AYAs with CF demonstrate suboptimal education about some CF domains, particularly related to reproductive effects, family planning, and mental health (Lonabaugh et al., 2018; Siklosi et al., 2010). However, knowledge and understanding of CF may be an important component of transition readiness. In AYAs with other chronic illnesses such as chronic kidney disease, congenital heart disease, Turner syndrome, and neurofibromatosis, knowledge of one's illness across multiple domains has been associated with transition readiness (Dwyer-Matzky et al., 2018; Gilleland et al., 2012; Gilleland Marchak et al., 2015; Sheanon et al., 2020; Stewart et al., 2017; Weisman et al., 2020; Zhong et

al., 2020). In AYAs with CF, participation in a transition program that involved education about CF was associated with better transition readiness and perception of healthcare independence (Middour-Oxler et al., 2022).

Personal Control

Personal control, another domain of empowerment, refers to the degree to which an individual feels the management of their condition is within their control (Small et al., 2013). There are currently no studies exploring this concept in AYAs with chronic illness. However, two similar concepts, internal health locus of control and self-efficacy, have a more robust literature base. When an individual feels that their health is within their control and has confidence in their ability to exercise control over their health behaviors, they have an internal health locus of control and high self-efficacy respectively (Bandura, 2004; Mautner et al., 2017). Internal locus of control has been associated with transition readiness in one study of youth with chronic conditions (Nazareth et al., 2016). However, self-efficacy is one of the variables most frequently associated with transition readiness, second only to age (Varty & Popejoy, 2020). This association has been repeatedly demonstrated in multiple disease groups, including congenital heart disease, irritable bowel disease, sickle cell disease, and kidney disease (Carlsen et al., 2017; Eaton et al., 2017; Gilleland Marchak et al., 2015; Gumidyala et al., 2018; Sawicki et al., 2014; Treadwell et al., 2016; Uzark et al., 2015). Self-efficacy is currently the only variable that has been associated with transition readiness in AYAs with CF as well (Torun et al., 2020).

Identity

Illness identity, the extent to which one's illness is integrated as a part of their identity, has a limited literature base in AYAs with chronic illness (Small et al., 2013). Currently, illness identity in AYAs has been divided into four types: engulfment, rejection, acceptance, and

enrichment (Oris et al., 2016). Engulfment and rejection represent maladaptive identities, in which the individual has failed to integrate their illness into their identity and instead is overwhelmed by it or reject it respectively. Acceptance and enrichment represent more adaptive identities, in which an individual comes to term with their illness as a part of their life or believes their illness contributes positively to their identity (Oris et al., 2016). While type of illness identity has been linked to multiple outcomes, such as adherence, disease control, and quality of life, there is a paucity of research about its role in transition readiness (Commissariat et al., 2020; Griva et al., 2000; Luyckx et al., 2010, 2018; Meyer & Lamash, 2020; Oris et al., 2016). However, incorporating illness into one's identity has been associated with better self-care (Commissariat et al., 2020).

Enabling of Others

The final domain of empowerment, enabling of others, refers to the ability to pass on knowledge and self-management tools to others (Small et al., 2013). The literature on this concept is very limited in AYAs with chronic illness and most studies have been qualitative in nature. While numerous peer-mentorship programs have been developed, few have documented outcomes for the peer leaders as well as the attendees. Sattoe and colleagues (2013) found that mentors in a peer-led camp for AYAs with end-stage renal disease exhibited increased independence and subjectively reported benefit. Further, adolescents who served as a peer mentor noted that acting in that role provided them with increased confidence, willingness to disclose their diagnosis, and openness to trying new self-management strategies (Kohut et al., 2017). Finally, adolescents with respiratory illness who participated in a hospital youth advisory council reported increased confidence, support, and the ability to make positive changes because of their illness (Groot et al., 2021).

Other Outcomes Potentially Associated with Empowerment

In addition to transition readiness, empowerment may also be relevant to other factors important to AYAs with CF. Coinciding with transition readiness, both treatment adherence and health-related quality of life (HRQoL) decline with age (Abbott et al., 2015; Modi et al., 2008). Given that individuals with CF are living longer, further research on factors associated with better treatment adherence and HRQoL in this population is necessary. Thus, this thesis examined associations between empowerment and both treatment adherence and HRQoL. The following sections will review the literature on adherence and HRQoL is AYAs with CF that support empowerment as an associated variable.

Adherence

Numerous studies have reported low rates of treatment adherence in AYAs with CF, which is often associated with worse physical health outcomes. Of note, although there is some debate as to whether adherence, compliance, or sustaining daily care is the appropriate term to use, for purposes of this study, the term "adherence" will be used. Muther et al. (2020) estimated the adherence rate for individuals with CF to be around 50%, with rates ranging from 36%-86% depending on the treatment component (e.g., enzymes, airway clearance). Despite a robust literature base about adherence in this population, studying adherence in individuals with chronic conditions can be challenging. Self-report measures have been criticized as individuals tend to overestimate their rates of adherence when compared to electronic monitoring (Daniels et al., 2011). However, electronic monitoring is costly and can be manipulated by patients to indicate higher rates of adherence (Quittner et al., 2000). Measuring adherence is especially challenging in AYAs, when parent report may be less useful. Further, given the complexity of CF treatment

with multiple treatments a day (e.g., enzymes, airway clearance, antibiotics), obtaining accurate reports of adherence rates is especially complicated.

As noted previously, treatment adherence rates tend to decline during adolescence and young adulthood (Modi et al., 2008). CF is a progressive disease, and as such, AYAs can experience decline in lung function, increased frequency in pulmonary exacerbations, and more intensive treatment as they age (Bregnballe et al., 2017; Cystic Fibrosis Foundation, 2015). Amid obtaining developmental milestones such as gaining independence, developing relationships, and pursing educational and employment opportunities, this increase can be challenging to accommodate (Macdonald et al., 2019). AYAs have identified that the main barriers to treatment adherence revolve around trying to fit treatments into their everyday lives (Bregnballe et al., 2011; George et al., 2010). Barriers to adherence can take the form of being conscious about completing treatments in front of others, forgetting to take medications, or prioritizing other things. Some adults with CF do not necessarily identify with the label "non-adherent." Instead, they recognize balancing CF management while living a life with important relationships and everyday responsibilities as challenging, and refer to this balance as "working overtime" (Macdonald et al., 2019). However, other barriers to adherence, such as lack of interest, motivation, and perceived benefit, have also been reported (Santuzzi et al., 2020).

Further, psychological symptoms have been repeatedly associated with treatment adherence, such that more depressive symptoms have been linked to lower adherence to prescribed treatments (Hilliard et al., 2015; Smith et al., 2010). Given that individuals with CF exhibit depression and anxiety at higher rates than the general population, the impact of depression and anxiety on health outcomes has received increased attention in recent years (Quittner et al., 2014). Due to their potential negative impact, routine patient screening for

depression using the Patient Health Questionnaire-9 (PHQ-9) and anxiety using the General Anxiety Disorder-7 Item Scale (GAD-7) has been recommended for CF centers by the International Committee on Mental Health in Cystic Fibrosis (Quittner et al., 2016). As such, we considered both depressive and anxiety symptoms as covariates in associations between empowerment and outcome variables to ensure that these associations were not better accounted for by patient mental health.

Despite the robust literature base on factors associated with treatment adherence, the literature on the association between adherence and empowerment is very limited. However, similar to transition readiness, empirical support for the associations between individual domains of empowerment and adherence is more robust. For instance, involvement in shared decision-making has been associated with improved adherence in youth with type 1 diabetes and asthma (Kew et al., 2017; Miller et al., 2020; Miller & Drotar, 2007; Miller & Jawad, 2019). Additionally, knowledge and understanding of one's illness has been associated with improved adherence in AYAs with CF, epilepsy, type 1 diabetes, and food allergies (Balfour et al., 2014; Carbone et al., 2013; Faint et al., 2017; Keller et al., 2017; Martin et al., 2017; McLaughlin et al., 2020). Personal control, in the form of either locus of control or self-efficacy, has been associated with improved adherence in AYAs with celiac disease and type 1 diabetes (Bellini et al., 2011; Griva et al., 2000). A positive illness identity has been associated with adherence and disease control in AYAs with type 1 diabetes (Commissariat et al., 2020; Griva et al., 2000; Luyckx et al., 2010; Oris et al., 2016). Conversely, illness centrality, similar to engulfment, has been associated with worse adherence (Helgeson & Novak, 2007). Finally, enabling others has been associated with adherence in AYAs with asthma, as well as those who have had an organ transplant (Jerson et al., 2013; Rhee et al., 2012). As with transition readiness, the link between

each of these domains and treatment adherence provides support for the potential role for the overall construct of empowerment in treatment adherence as well.

Health-Related Quality of Life

Beyond treatment adherence, empowerment may also be relevant to health related quality of life (HRQoL) in AYAs with CF. HRQoL refers to patient-reported, subjective disease-related functioning across multiple domains, such as physical, psychological, social, and occupational functioning (Modi & Quittner, 2003). In AYAs with CF, better FEV_1, higher BMI, and less recent pulmonary exacerbations have been associated with HRQoL (Abbott et al., 2015; Flume et al., 2019; Gancz et al., 2018; Habib et al., 2015). CF comorbidities and complications, such as CF-related diabetes (CFRD), having a totally implantable vascular device, and certain bacterial infections, have been associated with worse HRQoL (Abbott et al., 2015; Kwong et al., 2019). In addition, demographic variables, such as age, gender, race, ethnicity, and socioeconomic status have also been linked to HRQoL in individuals with CF (Abbott et al., 2015; Gancz et al., 2018; Habib et al., 2015; Quittner et al., 2010). Moreover, higher rates of both depression and anxiety have also been associated with lower HRQoL, even more so than pulmonary function (Cronly et al., 2019; Knudsen et al., 2016; Olveira et al., 2016; Riekert et al., 2007; Yohannes et al., 2012). As such, we considered depressive and anxiety symptoms as covariates in associations between empowerment and transition readiness, adherence, and HRQoL.

Similar to transition readiness and treatment adherence, there is a paucity of research linking empowerment to HRQoL. To date, empowerment has been associated with physical, psychological, social, religious, and overall HRQoL in AYAs with cancer (Kaal et al., 2017). In adolescents with epilepsy, participants enrolled in an empowerment intervention experienced improved physical, emotional, and overall HRQoL (Cappelletti et al., 2020; Kaal et al., 2017).

Once again, however, associations between individual domains of empowerment (e.g., shared decision-making, personal control) and HRQoL have more empirical support. Shared decision-making has been associated with better HRQoL and knowledge in youth with asthma and with improved psychosocial quality of life in AYAs with congenital heart disease (Kew et al., 2017; Taylor et al., 2018; Uzark et al., 2019, 2020). Further, self-efficacy has been associated with HRQoL in youth with chronic conditions, as well as general quality of life AYAs with CF (Cramm et al., 2013; Torun et al., 2020; Uzark et al., 2019, 2020). Additionally, Sawicki and colleagues (2011) found that the extent to which adults with CF felt control over their illness was significantly associated with psychosocial HRQoL. The current literature has linked positive illness identity to better overall and social HRQoL (Luyckx et al., 2018; Meyer & Lamash, 2020). Finally, in regards to enabling of others, Rhee and colleagues (2012) evaluated the effects of a camp-based, peer-led asthma program. They found that in addition to the positive effects experienced by the participants, the peer leaders also showed improvement in emotional HRQoL. Thus, we hypothesized that the construct of overall empowerment would also be associated with HRQoL.

Current Study

Empowerment is a newly emerging variable that is potentially important in transition readiness, treatment adherence, and HRQoL in AYAs with chronic illness. While the literature directly linking empowerment to these outcomes is limited, literature supporting the role of shared decision-making, control, identity, knowledge and understanding, and enabling others, all domains of empowerment, is more robust. However, the literature evaluating empowerment in AYAs with CF is limited, and an emerging measure of empowerment in AYAs with chronic illness, the GYPES, needs further psychometric evaluation. Thus, he current study had four aims

focused on better understanding empowerment among AYAs with CF by: 1) examining the convergent validity of the GYPES, and 2) examining associations among empowerment and transition readiness, adherence, and HRQoL (Figure 2).

Aim I: To evaluate the convergent validity of the Gothenburg Young Persons Empowerment Scale (GYPES) for AYAs with CF, using a bivariate correlation.

Hypothesis 1: The GYPES would be positively correlated with a measure of generalized self-efficacy.

Aim II: To examine the association between empowerment and transition readiness in AYAs with CF.

Hypothesis 2: Higher levels of empowerment would be associated with more transition readiness, even when controlling for covariates, such as both depressive and anxiety symptoms.

Aim III: To examine the association between empowerment and treatment adherence.

Hypothesis 3: Higher levels of empowerment would be associated with better treatment adherence even when controlling for covariates, such as both depressive and anxiety symptoms.

Aim IV: To examine the association between empowerment and HRQoL in AYAs with CF.

Hypothesis 4: Higher levels of empowerment would be associated with better HRQoL even when controlling for covariates, such as both depressive and anxiety symptoms.

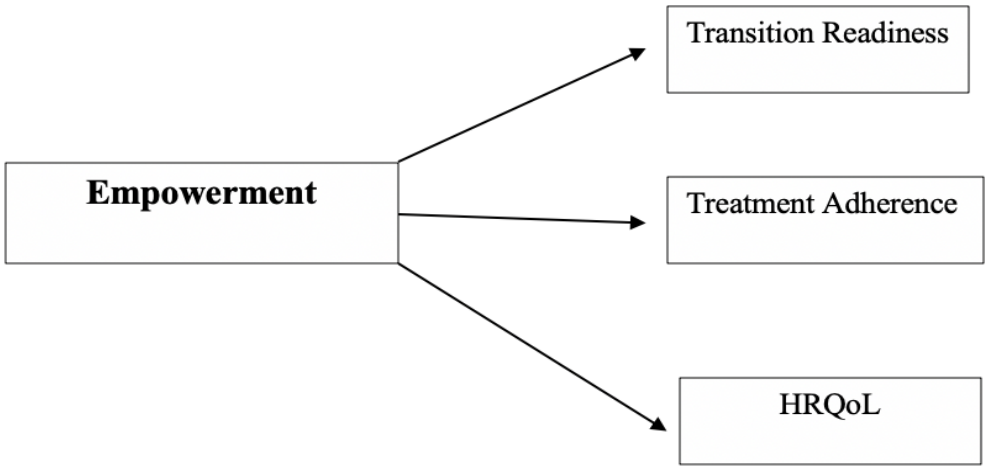

Figure 2: Empowerment and Outcome Variables of Interest

Methods

Participants

Forty-four eligible AYAs with CF completed the online measures for this study; 41 of these participants were included in the final sample (see Preliminary Analyses section for rationale for 3 excluded cases). The mean age of participants was 18 years (*SD* = 2.89) with a range of 14-23. Further demographic and clinical characteristics of the sample can be found in Tables 1 and 2. All participants were required to be 14 years of age or older and either treated in a pediatric service or be within 2 years of transfer to an adult service. The minimum age of 14 was chosen because the American Academy of Pediatrics recommends beginning to assess transition readiness at this age (White et al., 2018). Additionally, the measures included in this study have been validated for adolescents as young as 14 years of age. Due to variable age of transfer, there was no upper age limit for participants as long as they were within 2 years of transfer to adult care, which is consistent with other transition studies (Peeters et al., 2014; van

Staa et al., 2011). Potential participants were determined to be ineligible if they were younger than 14, have transferred to adult care more than two years ago, did not speak English, or were unable to complete the electronic survey. Participants were recruited through the adult and pediatric CF clinics at VCU and collaborative sites across the United States. Eligibility was verified through RedCap prior to survey administration.

Table 1

Participant Demographic Characteristics (n=41)

Variable	*n*	%
Race		
White	33	80.5
Black or African American	4	9.8
Other	4	9.8
Ethnicity		
Not of Hispanic, Latinx, or Spanish origin	37	90.2
Of Hispanic, Latinx, or Spanish origin	4	9.8
Sex		
Female	29	70.7
Male	12	29.3
Gender		
Cisgender woman/girl	22	53.7
Cisgender man/boy	11	26.8
Non-binary, genderqueer, or gender non-conforming	4	9.8
Prefer not to answer	4	9.8
Education		
Less than high school	2	4.9
Some high school	21	51.2
High school diploma/GED	2	4.9
Some college	12	29.3
Associate's degree	1	2.4
Bachelor's degree	3	7.3
Insurance		
Non-Medicaid	14	34.1
Medicaid	12	29.3
Both Medicaid/Non-Medicaid	7	17.1
Unsure	7	17.1
Region		
South	15	36.6
Northeast	13	31.7
Midwest	8	19.5
West	5	12.2
Living Situation		
Parents/Family	34	82.9
Independently	4	9.8
Roommates	2	4.9
Spouse/Significant other	1	2.4
Marital Status		
Never Married	40	97.6
Married	1	2.4

Table 2

Participant Clinical Characteristics

Variable	*M*	*SD*	Range
BMI	21.93	2.89	17.38 -30.38
FEV_1	84.65	20.12	40 - 118
CF Visits in the last year			
Virtual	1.88	2.72	0 - 15
In Person	3.63	2.33	0 - 11
Total	5.51	3.21	2 - 20
Variable		***n***	**%**
Clinic Type			
Pediatric		34	82.9
Adult		7	17.1
Comorbidity Presence/Treatment Use			
Pancreatic Insufficiency		25	61
CFRD		11	26.8
Liver Disease		4	9.8
Anxiety Disorder		18	43.9
Depressive Disorder		14	34.1
Neurodevelopmental Disorder		6	14.6
G-Tube/NG-Tube		8	19.5
TIVAD		1	2.4
B. cepacia complex		0	0
Listed for transplant		0	0
Received transplant		0	0
Most Recent Pulmonary Exacerbation			
Less than 4 weeks ago		5	12.2
4-8 weeks ago		3	7.3
More than 8 weeks ago		30	73.2
Unsure		3	7.3
Last CF Appointment			
Less than 1 month ago		17	41.5
1-3 months ago		19	46.3
4-6 months ago		3	7.3
6+ months ago		1	2.4
Unsure		1	2.4
Primary Responsibility for CF Care			
Me		21	51.2
Mother		17	41.5
Father		3	7.3
Transition Discussion (Pediatric Only)			
Yes		21	61.8
No		13	38.2

Procedure

Study approval was provided by the VCU Institutional Review Board (IRB). Information about the study and flyers were distributed to patients in the Pediatric CF Clinic at the Children's Hospital of Richmond at VCU, to CF care providers at collaborating sites through the CF Mental Health and Social Work listservs, and through Drs. Schechter and Everhart's collaborators at other CF care centers. Care teams were asked to provide their patients with a handout that included a summary of the study and a link to the RedCap survey, to email patients with an electronic version of the handout, or to include information about the study in their clinic's newsletter. In total, the study team contacted 29 sites, 10 of which agreed to actively recruit participants at their clinic. Additionally, study information was distributed via Facebook, Twitter, and Reddit. Recruitment sources can be found in Table 3. The majority of participants were recruited through their CF care team.

Table 3

Recruitment Sources

Recruitment Source	**Respondents**
CF Care Team	23
Email Listserv	13
Facebook	2
Reddit	1
Twitter	1
Other (Family)	2

Note. Participants were able to select more than one source

Participant eligibility was verified by a survey assessing diagnosis, age, and transition status. The elimination process can be found in Figure 3. Ineligible participants were notified and thanked for their time and interest on the RedCap survey. Eligible participants were directed to an electronic information sheet that asked them to indicate agreement with the consent statement prior to advancing to the survey. A waiver of parental consent was obtained from the VCU IRB. Thus, participants under the age of 18 provided assent but were not required to obtain parental consent. However, adolescents were required to provide parent email addresses when requesting their gift cards, who were copied on all communication with the adolescents. Participants were able to pause and return to the survey and were required to pass at least four of the five instruction and consistency checks to be included. All participants were offered a $15 gift card following survey completion.

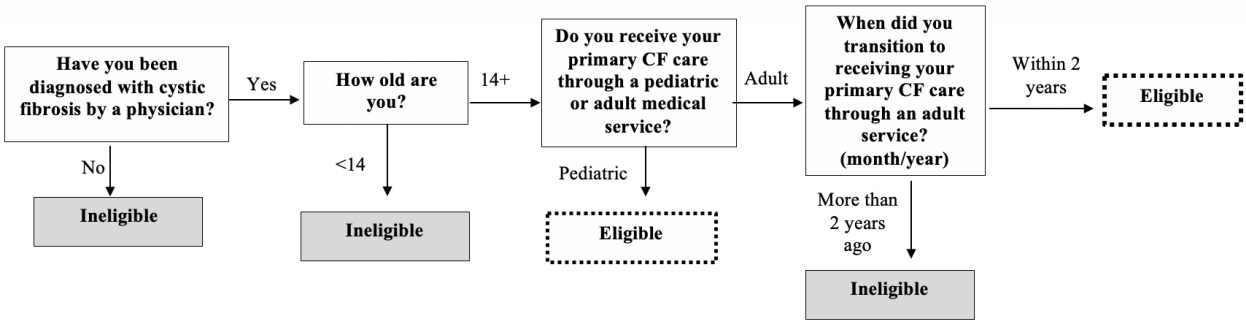

Figure 3: Elimination Process

Measures

Demographic Variables

Participants were asked to report their sex, gender identity, race, ethnicity, type of insurance (Medicaid, non-Medicaid, both, not sure), region, medical center, educational level, marital and parental status, and living situation (independently, with family, with roommates, with spouse or significant other). They were also asked to report their most recent FEV_1 score,

height, weight, transplant status, transition status, most recent pulmonary exacerbation, most recent visit with their CF team, and CF-related comorbidities or complications (e.g., a diagnosis of CF-Related Diabetes [CFRD], liver disease, mood or anxiety disorders). Because participants may not have known some of these variables, a "don't know" option was added to the questionnaire. Participants were notified of the need for these variables before beginning the survey in case they needed to consult a parent for their recent FEV_1 score, for instance. These variables were used to both describe the sample and as potential covariates.

Generalized Anxiety Disorder 7-item Scale (GAD-7)

The GAD-7 is a 7-item measure of generalized anxiety symptoms (Spitzer et al., 2006). Respondents are asked to indicate how often they have been bothered by symptoms of generalized anxiety disorder (GAD) over the last two weeks. Response options fall on a 4-point Likert scale: not at all, several days, more than half the days, and nearly every day. Scores are summed and have a possible range from 0-21, with higher scores indicating more severe anxiety symptoms. Scores are categorized as minimal (0-4), mild (5-9), moderate (10-14), and severe (15-21). Sample symptoms include: "Feeling nervous, anxious or on edge" and "Becoming easily annoyed or irritable." The GAD-7 has demonstrated acceptable criterion, construct, factorial, and procedural validity, as well as excellent internal reliability (Cronbach's $\alpha = .92$) in an adult, primary care sample (Spitzer et al., 2006). The scale demonstrated excellent internal reliability in the current sample (Cronbach's $\alpha = .92$)

Patient Health Questionnaire 8-item Scale (PHQ-8)

The PHQ-8 is an 8-item measure of depressive symptoms (Kroenke & Spitzer, 2002). Respondents are asked to indicate how often they have experienced symptoms of major depressive disorder (MDD) over the last two weeks. Response options fall on a 4-point Likert

scale: not at all, several days, more than half the days, and nearly every day. Scores range from 0-24, with higher scores indicating a greater severity of depressive symptoms. Scores are categorized as minimal (0-4), mild (5-9), moderate (10-14), moderately severe (15-19), and severe (20+). Sample symptoms include: "Feeling down, depressed, or hopeless" and "Feeling tired or having little energy." The PHQ-8 has demonstrated acceptable criterion and construct validity and good internal reliability in an adult, primary care sample (Kroenke et al., 2001; Kroenke & Spitzer, 2002). Cronbach's alpha in the current sample was .92.

Generalized Self-Efficacy Scale

The GSE is a 10-item, self-report measure of perceived self-efficacy. Respondents are asked to indicate how true statements describing general self-efficacy are of them. Responses fall on a 4-point Likert Scale: not at all true, hardly true, moderately true, and exactly true. Scores are a sum of all items and range from 10-40, with higher scores indicating more self-efficacy. Sample items include: "It is easy for me to stick to my aims and accomplish my goals" and "I can usually handle whatever comes my way." The GSE has displayed adequate internal consistency with Cronbach alphas ranging from .76-.90 in the general population (Schwarzer & Jerusalem, 1995). The GSE demonstrated excellent internal reliability in the current sample (Cronbach's $\alpha = .91$).

Gothenburg Young Persons Empowerment Scale (GYPES)

The GYPES is a 15-item measure of patient empowerment for AYAs with chronic health conditions (Acuña Mora et al., 2018). It assesses empowerment through five dimensions: Knowledge and Understanding, Personal Control, Identity, Shared Decision Making, and Enabling of Others (Figure 1). Respondents are asked to indicate how much they agree with statements using a five-point Likert scale: strongly disagree, disagree, neither agree nor disagree,

agree, or strongly agree. Sum scores on each of the dimensions range from 3-15 with overall empowerment scores ranging from 15-75. Higher scores indicate a higher level of empowerment. Sample items include: "I know what to do to stay healthy" (Knowledge and Understanding), "I have the skills to manage *my condition* in my daily life" (Personal Control), "*My condition* is a part of who I am as a person" (Identity), "I actively participate in discussions with my healthcare providers about my health" (Shared Decision Making), and "I have the skills to support other young people with *my condition*" (Enabling of Others). Evidence of construct and structural validity were found in AYAs with congenital heart disease and type 1 diabetes (Acuña Mora et al., 2018). The GYPES has also demonstrated acceptable internal consistency in AYAs with type 1 diabetes with a Cronbach's alpha of .858 for the entire scale. Cronbach's alpha values for the dimensions range from .609 (Identity) to .833 (Enabling Others). To our knowledge, this is the first study to utilize the GYPES in a sample of AYAs with CF. The Cronbach's alpha for the overall scale in this sample indicated excellent internal reliability (Cronbach's $\alpha = .92$), and the dimensions of Knowledge and Understanding (Cronbach's $\alpha = .78$), Personal Control (Cronbach's $\alpha = .73$), Identity (Cronbach's $\alpha = .76$), Shared Decision-Making (Cronbach's $\alpha = .79$), and Enabling Others (Cronbach's $\alpha = .83$) all demonstrated adequate internal reliability.

Transition Readiness Assessment Questionnaire (TRAQ)

The TRAQ is a 20-item scale that measures readiness to transition to adult care in AYAs with special healthcare needs (Wood et al., 2014). It consists of five subscales: Appointment Keeping, Tracking Health Issues, Managing Medications, Talking with Providers, and Managing Daily Activities. Respondents are asked to indicate their skill level across various tasks using a five-point Likert scale: (1) No, I do not know how, (2) No, but I want to learn, (3) No, but I am learning to do this, (4) Yes, I have started doing this, (5) Yes, I always do this when I need to.

Overall scale scores range from 20-100, with higher scores indicating more readiness to transition. Subscale scores are also calculated. Sample items include: "Do you reorder medications before they run out?" (Managing Medications), "Do you know what your health insurance covers?" (Appointment Keeping), "Do you make a list of questions before the doctor's visit?" (Tracking Health Issues), "Do you answer questions that are asked by the doctors, nurse, or clinic staff?" (Talking with Providers), "Do you help plan or prepare meals/food?" (Managing Daily Activities). Only the overall score will be analyzed for this study. The overall scale has demonstrated excellent reliability in AYAs with chronic illness (Cronbach's $\alpha = .94$), and all subscales have demonstrated at least acceptable reliability with Cronbach's alpha values ranging from .67 (Managing Daily Activities) to .90 (Appointment Keeping). In the current sample, the overall scale demonstrated excellent reliability (Cronbach's $\alpha = .94$) and each of the subscales demonstrated adequate internal reliability ranging from .78 (Managing Daily Activities) to .94 (Appointment Keeping). The exception was the Talking with Providers subscale, which demonstrated subpar reliability (Cronbach's $\alpha = .59$). Of note, this subscale was not included in the analyses; only the overall scale was included.

The Treatment Adherence Rating Scale-Adolescent Version (TARS)

The TARS is a 16-item self-report measure of treatment adherence specifically for individuals with CF (DeLambo et al., 2004). It consists of four subscales: Airway Clearance/Aerosolized Medications, Pancreatic Enzymes, Antibiotics, and Nutrition. Respondents are asked to report how often they followed treatment recommendations over the past 2 weeks (Airway Clearance/Aerosolized Medications, Pancreatic Enzymes, Nutrition) or 6 months (Antibiotics) using a 5-point Likert scale: (1) never followed recommendations, (2) rarely followed recommendations, (3) followed recommendations 50% of the time, (4) usually

followed recommendations, most of the time, (5) always followed recommendations. A "not applicable" response option is also included. Overall scores are calculated by averaging the responses and range from 1-5, with higher scores indicating better treatment adherence. Sample items include: "I did my airway clearance for as long as recommended" (Airway Clearance/Aerosolized Medications), "I took calorie supplements as recommended" (Nutrition), "I took my enzymes before eating a meal or a snack" (Pancreatic Enzymes), and "In the past 6 months, I took oral antibiotics as often as recommended" (Antibiotics). To account for new treatments available to individuals with CF, we included one additional question: "I took my CFTR modulator(s) as recommended." This item was incorporated into the calculation of the overall score. In mothers of children and adolescents with CF, the subscales have demonstrated satisfactory reliability with Cronbach's alpha values ranging from .65 (Antibiotics) to .84 (Airway Clearance/Aerosolized Medications). In older children and adolescents (ages 9-16) with CF, the Pancreatic Enzymes and Antibiotics subscales were not interpretable due to high cross-factor loadings (DeLambo et al., 2004). In the current sample, the overall Cronbach's alpha was .93, with subscale values ranging from .65 (Nutrition) to .91 (Airway Clearance/Aerosolized Medications).

Cystic Fibrosis Questionnaire-Revised Teen/Adult (CFQ-R)

The CFQ-R is a 50-item measure of HRQoL specific to individuals with CF (Quittner et al., 2012). It measures HRQoL across 9 domains: Physical Functioning, Vitality, Emotional Functioning, Social Functioning, Role Functioning, Body Image, Eating Problems, Health Perception, and Treatment Burden. Scores are calculated for each subscale, but no overall HRQoL score is calculated. Respondents are asked to indicate how often they have felt a certain way in the last two weeks using a 4-point Likert scale: always, often, sometimes, never. Sample

items include: “I get together with my friends a lot” (Social Functioning) and “I have to limit vigorous activities, such as running or playing sports” (Physical Functioning). For the purposes of this study, we used the Physical Functioning, Role Functioning, Vitality, Emotional Functioning, and Social Functioning subscales in concordance with previous literature (Cappelletti et al., 2020; Cramm et al., 2013; Kaal et al., 2017; Kew et al., 2017; Luyckx et al., 2018; Meyer & Lamash, 2020; Rhee et al., 2012; Sawicki et al., 2011; Taylor et al., 2018; Torun et al., 2020; Uzark et al., 2019, 2020) The scale has demonstrated good discriminant validity and most domains have demonstrated acceptable internal consistency. Domain Cronbach’s alpha scores range from .51 (Treatment Burden) to .94 (Physical Functioning). In the present study, the Cronbach’s alpha values for the Physical Functioning (.90), Role Functioning (.76), Vitality (.72), Emotional Functioning (.85), and Social Functioning (.70) indicated acceptable internal reliability.

Instruction and Consistency Checks

Respondents were asked to complete two consistency checks, two multiple choice instruction checks, and one free text instruction check as a test of effort and attention. For consistency checks, participants were asked to report both their region and state of residence, as well as their age and year of birth. The instruction checks required participants to respond with a designated answer (e.g., “Please select ‘Agree’”). Respondents who completed at least four out of five of these correctly were included in analyses.

Analytic Plan

G*Power (Faul et al., 2009) was used to determine an appropriate sample size for Aims I-IV. Using a power of .8 and an alpha of .05, a sample size of 29 participants was sufficient to detect a large effect size of .5 for Aim 1 and 31 participants was sufficient to detect a large effect

size of .35 (f^2) for Aims II-IV, per Cohen (1988). This was calculated using two predictors, the IV and covariates. Thus, the sample size of 41 participants was appropriate for the present analyses.

Preliminary Testing and Missing Data

IBM SPSS Statistics, Version 28 was used for all analyses. Prior to hypothesis testing, the GYPES, TRAQ, TARS, CFQ-R subscales, GAD-7, PHQ-8, and GSE, as well at BMI, age, and FEV_1, were tested for univariate outliers by assessing the standardized values for each variable. The data were also tested for assumptions of linearity, normality of residuals, linearity of residuals, multicollinearity, multivariate outliers, and homoscedasticity. Missing data were largely addressed by pairwise deletion. However, missing responses within summed scales were imputed using the average from the other items within that subscale, which occurred in 0.002% of the fields. The mean, standard deviation, and range were calculated for the GYPES, TRAQ, TARS, CFQR, GAD-7, PHQ-8, and GSE.

Covariate Testing

Bivariate correlations were used to test associations between all dependent variables and potential covariates including age, sex, race/ethnicity, insurance, transition status, BMI, FEV_1, depressive symptoms, anxiety symptoms, and general self-efficacy. Primary responsibility for healthcare was also considered as a covariate, but was excluded due to a strong correlation with age ($r(40) = .718$, $p < .001$). Prior to analysis, multicategorical variables were recoded to be dichotomous. Due to the small number of participants who reported their race as Black/African American ($n = 4$) and their race as "other" and ethnicity as Hispanic/Latinx ($n = 4$), race and ethnicity were combined to one category and recoded as dichotomous (White and Non-Hispanic/Latinx or of a minoritized racial/ethnic group). We recognize that this ignores the

varying experiences among individuals who belong to different marginalized racial and ethnic groups and have noted this as a limitation. Insurance type was also recoded as a dichotomous variable (Medicaid or No Medicaid).

Hypothesis Testing

A bivariate correlation was used to evaluate Aim I while a series of hierarchical regressions were used to test Aims II-IV. Due to the high number of independent variables in Aim IV, we used a Bonferroni correction and the significance of associations was evaluated using a *p*-value cut-off of .01 (derived from .05/5).

Results

Preliminary Analyses

Two cases were removed prior to analyses for failing to pass the instruction or consistency checks. One case was removed as the participant reported an age 21 years older than the mean of the rest of the sample, resulting in a final sample of 41 participants. In addition, two FEV_1 values were removed from the dataset. Both values were below 4%, which would indicate very severe lung disease (if accurate). Given other indicators of physical health for these participants (e.g., most recent pulmonary exacerbation, number of annual outpatient visits) did not point to severe lung disease, it was determined these outlying values were likely due to respondent error. The rest of the data from these cases were retained and the FEV_1 values were treated as missing data. Finally, there were two significant BMI outliers, which fell within the obese range and were over three points higher than the next highest value. The data were windsorized such that the two outlying values were modified to be 5% higher than the next highest value. Finally, the TRAQ and Role Functioning subscale of the CFQ-R, had slight

outliers, with approximately 7% of the standardized values falling above 1.96 but below 2.58. Given these were only slight outliers, the original data were retained.

Following removal or transformation of univariate outliers, all variables had skewness and kurtosis values less than +/- 1 with the exception of kurtosis values of the Physical Functioning (-1.36) and Social Functioning (-1.38) subscales of the CFQ-R, and participant age (-1.05). Square root, log 10, and inversion transformations were attempted without significant improvements in normality. Thus, original values were retained. The assumption of multicollinearity was met with the exception of the GAD-7 and PHQ-8, which were highly correlated ($r(39) = .821$, $p < .001$). Given the correlation coefficient was less than .9 and the scales represent distinct but related constructs, both scales were included in the models. All other assumptions were met.

Descriptive Analyses

The results of descriptive analyses can be found in Table 4. According to GAD-7 and PHQ-8 scores, 34.1% of the sample would likely meet diagnostic criteria for an anxiety disorder and 34.7% would likely meet criteria for a depressive disorder at the time of survey completion. Additionally, the sample demonstrated high rates of adherence, transition readiness, physical functioning, role functioning, and self-efficacy. Bivariate correlations were conducted with the GYPES and several demographic/clinical variables: age, sex, race/ethnicity, FEV_1, BMI, time since last CF appointment, transition status, who participants reported was primarily responsible for their healthcare, and whether pediatric patients had discussed transition with their provider. Of these, empowerment was only associated with participants rating themselves, rather than their parents, as primarily responsible for their healthcare ($r(40) = .366$, $p = .02$).

Table 4

Descriptive Statistics

Variable	*M*	*SD*	Range
GYPES	**59.37**	**9.76**	**35 - 75**
Knowledge and Understanding	13.02	1.96	8 - 15
Personal Control	11.90	2.10	7 - 15
Identity	11.17	2.79	5 - 15
Shared Decision-Making	12.27	2.07	7 - 15
Enabling Others	11.00	2.82	3 - 15
TRAQ	**75.36**	**17.68**	**36 - 100**
Managing Medications	16.17	3.97	6 - 20
Appointment Keeping	22.78	9.01	7 - 35
Tracking Health Issues	13.98	4.52	4 - 20
Talking with Providers	9.27	1.10	6 - 10
Managing Daily Activities	13.17	2.33	3 - 15
TARS	**3.98**	**0.75**	**1.71 - 5**
Airway Clearance/Aerosolized Medications	3.85	0.99	1.25 - 5
Pancreatic Enzymes	4.19	0.89	1 - 5
Nutrition	3.77	0.97	1.25 - 5
Antibiotics	4.01	1.07	1 - 5
CFTR Modulator	4.58	0.87	1 - 5
CFQR	-	-	-
Physical Functioning	74.20	21.33	41.67 - 100
Role Functioning	78.86	17.79	33.33 - 100
Vitality	51.22	21.37	16.67 – 91.67
Emotional Functioning	63.25	26.50	6.67 - 100
Social Functioning	70.16	21.19	33.33 - 100
GAD-7	**6.97**	**6.13**	**0 - 21**
PHQ-8	**7.21**	**6.18**	**0 - 21.71**
GSE	**29.70**	**5.51**	**17 - 40**

Covariate Testing

Results from the bivariate correlation analyses can be found in Table 5. Briefly, analyses revealed that age, sex, transition status, and BMI were covariates for transition readiness, such that transition readiness was correlated with older age, female sex, post-transition status, and higher BMI. Anxiety and depressive symptoms were negatively correlated with treatment

adherence. Regarding HRQoL, physical functioning was negatively associated with age, anxiety symptoms, and depressive symptoms and positively associated with FEV_1 and self-efficacy. Only level of depressive symptoms was a covariate for role functioning, such that more depressive symptoms were associated with worse role functioning. Older age, male sex, more anxiety symptoms, and more depressive symptoms were associated with vitality. Fewer anxiety and depressive symptoms and more self-efficacy were associated with emotional functioning. Finally, social functioning was negatively associated with age, anxiety symptoms, and depressive symptoms and positively associated with self-efficacy. Significant covariates were controlled for in subsequent analyses focused on that outcome variable (e.g., TRAQ, TARS, CFQ-R).

Table 5

Bivariate Correlation Analyses for Covariates

			CFQ-R				
Variables	TRAQ	TARS	Physical	Role	Vitality	Emotional	Social
Age	**.584****	.009	**-.397***	-.146	**-.398***	-.211	**-.331***
Sex	**.372***	.114	-.268	-.113	**-.428****	-.139	-.160
Race/Ethnicity	.032	-.004	-.237	-.137	.044	-.014	-.135
Insurance	-.071	-.118	-.155	-.067	.020	-.255	-.077
Transition Status	**-.416****	.195	-.140	.009	-.174	.174	-.082
BMI	**.346***	-.029	-.118	-.079	-.088	-.212	-.133
FEV_1	-.148	.055	**.327***	.216	.147	.210	.258
Anxiety Symptoms	.211	**-.355***	**-.501****	-.251	**-.591****	**-.715****	**-.473****
Depressive Symptoms	.165	**-.494****	**-.392***	**-.313***	**-.630****	**-.633****	**-.407****
Self-Efficacy	.243	.220	**.431****	.061	.160	**.487****	**.501****

*Note. * p<.05, **p<.01*

Hypothesis Testing

Correlation Analysis

For Aim I, a bivariate correlation was conducted to assess the association between the GYPES and the GSE. Results indicated a positive correlation between the variables, $r(39) = .615$, $p < .001$, which exceeded the threshold of 0.5 for convergent validity.

Regression Analyses

For Aim II, a hierarchical linear regression was conducted to test the association between empowerment and transition readiness. Age, sex, transition status, and BMI were entered as covariates in step one of the regression model. GYPES scores were entered in step two and overall TRAQ scores were designated as the dependent variable. Results indicated the first model was significant and accounted for 62.5% of the variance in transition readiness, $R^2=.625$, $F(4, 36) =5.76$, $p <.001$. When empowerment was added to the model, it accounted for an additional 34.1% of the variance in transition readiness, $R^2=.855$, $F(5, 35) =19.09$, $p <.001$. In the second model, age ($\beta = .586$, $p <.001$) and empowerment ($\beta = .630$, $p < .001$) emerged as significant predictors of transition readiness. The results of the second model can be found in Table 6.

Table 6

Final Regression Model for Transition Readiness

Variables	B	*SE B*	β	t	p
Age	**3.59**	**0.83**	**.586**	**4.33**	**<.001**
Sex	2.98	3.85	.078	0.77	.44
BMI	-0.19	0.74	-.029	-0.27	.79
Transition Status	-4.87	5.61	-.111	-0.87	.39
Empowerment	**1.14**	**0.17**	**.630**	**6.67**	**<.001**

For Aim III, the association between empowerment and treatment adherence was tested using a hierarchical linear regression. Given depressive and anxiety symptoms were significant covariates, the PHQ-8 and GAD-7 scores were entered in step one of the regression model. GYPES scores were entered in step two and overall TARS scores were entered as the dependent variable. Results indicated the first model was significant and accounted for 25.2% of the variance in transition readiness, R^2=.252, $F(2, 38)$ =6.39, p = .004. When empowerment was added to the model, it accounted for an additional 22.6% of the variance in treatment adherence, R^2=.478, $F(1, 37)$ =11.27, p <.001. In the second model, depressive symptoms (β = -.546, p = .013) and empowerment (β = .485, p < .001) emerged as significant predictors of treatment adherence. Details of this model can be found in Table 7.

Table 7

Final Regression Model for Treatment Adherence

Variables	B	*SE B*	β	t	p
Anxiety Symptoms	0.02	0.02	.180	0.861	.39
Depressive Symptoms	**-0.07**	**0.02**	**-.546**	**-2.61**	**.01**
Empowerment	**0.04**	**0.01**	**.485**	**4.00**	**<.001**

For Aim IV, a series of hierarchical linear regressions were used to test the associations between empowerment and HRQoL (physical functioning, role functioning, vitality, emotional functioning, and social functioning). A Bonferroni correction was used such that results were considered significant with p-values <.01. The final models for all HRQoL regression analyses can be found in Table 8. For physical functioning, age, FEV_1, depressive symptoms, anxiety symptoms, and self-efficacy were all entered as covariates in step one of the model. GYPES

scores were entered in step two. The first model was significant and accounted for 64.2% of the variance in physical quality of life R^2=.642, F(5, 31) =4.35, p = .004. The second model, which included GYPES scores, was also significant and accounted for an additional 0.3% of variance R^2=.645, F(6, 30) =3.56, p = .01. In this model, no variables were independently significant.

In the regression testing the association between role functioning and empowerment, depressive symptoms were entered in step one of the model, and GYPES scores were entered in step two. The first model was significant and accounted for 9.8% of the variance in role QoL, R^2=.098, F(1, 39) =4.25, p = .046. After GYPES scores were included, the second model accounted for an additional 1.2% of the variance but was not significant at the .01 level, R^2=.111, F(2, 38) =2.36, p = .11. In the second model, no variables were independently significant.

For vitality, age, sex, and depressive and anxiety symptoms were entered as covariates with GYPES scores entered in step two of the model. The first model was significant and accounted for 50.7% of the variance in vitality, R^2=.507, F(4, 36) =9.26, p < .001. When empowerment was added to the model, it accounted for an additional 7.1% of variance and the overall model was significant, R^2=.578, F(5, 35) =9.59, p < .001. In the second model, no variables were independent predictors of vitality at the p =.01 level.

In the regression testing the association between emotional functioning and empowerment, depressive and anxiety symptoms, and self-efficacy were entered as covariates and empowerment was entered as the primary independent variable. The first model was significant and accounted for 62.1% of the variance in emotional functioning, R^2=.621, F(3, 37) =20.19, p < .001. The second model accounted for an additional 2.8% of the variance and was also significant, R^2= .649, F(4, 36) =16.61, p < .001. In the second model, only anxiety symptoms (β = -.553, p = .003) was a significant independent predictor.

Finally, with respect to the social functioning subscale of QOL, age, depressive symptoms, anxiety symptoms, and self-efficacy were entered in step one of the model and empowerment was entered in step two. The first model was significant and accounted for 42.6% of the variance in social functioning, R^2= .426, $F(4, 36)$ =6.67, $p < .001$. When empowerment was added, the second model was also significant, but accounted for no additional variance, R^2= .426, $F(5, 35)$ =5.19, p = .001. In the second model, no variables were independently significant.

Table 8

Final Regression Model for Health-Related Quality of Life

Variables	B	*SE B*	β	t	*p*
Physical Functioning					
Age	-1.56	1.18	-.206	-1.32	.20
FEV_1	0.20	0.17	.182	1.17	.25
Anxiety Symptoms	-1.40	0.92	-.398	-1.53	.14
Depressive Symptoms	0.32	0.90	.094	0.36	.72
Self-Efficacy	1.13	0.69	.283	1.63	.11
Empowerment	0.18	0.43	.076	0.41	.68
Role Functioning					
Depressive Symptoms	-0.84	0.45	-.291	-1.87	.07
Empowerment	0.21	0.28	.113	0.72	.47
Vitality					
Age	-1.54	0.92	-.208	-1.68	.10
Sex	-12.34	5.78	-.266	-2.14	.04
Depressive Symptoms	-1.28	0.68	-.369	-1.87	.07
Anxiety Symptoms	-0.36	0.70	-.104	-.52	.61
Empowerment	0.61	0.25	.281	2.42	.02

Emotional Functioning					
Depressive Symptoms	-0.39	0.75	-.091	-0.52	.60
Anxiety Symptoms	**-2.39**	**0.75**	**-.553**	**-3.17**	**.003**
Self-Efficacy	0.98	0.61	.204	1.61	.12
Empowerment	0.57	0.34	.212	1.68	.10
Social Functioning					
Age	-1.59	1.01	-.217	-1.58	.12
Depressive Symptoms	-0.18	0.77	-053	-.236	.81
Anxiety Symptoms	-0.90	0.81	-.261	1.12	.27
Self-Efficacy	1.62	0.63	.422	2.55	.02
Empowerment	-0.02	0.36	.008	-0.05	.96

Discussion

The present study was aimed at furthering psychometric support of the Gothenburg Young Person's Empowerment Scale (GYPES) and determining whether empowerment could be potentially targeted for improved transition readiness, treatment adherence, and HRQoL in AYAs with CF. Specifically, this study evaluated the convergent validity of the GYPES and evaluated its association with transition readiness, treatment adherence, and health-related quality of life, including physical, vitality, role, emotional, and social domains. Overall, results indicated that the GYPES was moderately correlated with a measure of self-efficacy, supporting convergent validity. Additionally, empowerment was significantly associated with both transition readiness and treatment adherence in regression models. However, no associations were significant between empowerment and any domain of health-related quality of life when applying a Bonferroni correction to account for multiple subscales of the HRQoL measure.

Convergent Validity of the GYPES

Consistent with the first hypothesis of the study, the GYPES demonstrated evidence of convergent validity with self-efficacy. Prior literature has shown associations between measures of empowerment with the same theoretical basis of the GYPES and self-efficacy in older adults (Small et al., 2013), but no studies have evaluated this association using the GYPES. The current results have added further support to the construct validity of the GYPES, meaning one can be more confident that the measure is assessing empowerment rather than another construct. However, further evaluation of its psychometric properties, particularly in AYAs with CF, is warranted. Namely, the criterion, discriminant, predictive, and overall construct validity has not been tested in any population and the factor structure needs to be confirmed in AYAs with CF. Findings from this study, however, are an important first step in supporting the GYPES as a potentially useful measure of empowerment among AYAs with CF.

Empowerment and Transition Readiness

The results of this study also indicated that empowerment was significantly associated with transition readiness, such that individuals who reported more empowerment also reported greater proficiency in transition behaviors. These results are consistent with the limited literature linking empowerment to transition readiness in other disease groups (Acuña Mora et al., 2019; Burström et al., 2019). The current study takes the literature on empowerment in CF one step further by evaluating variables that are associated with the construct. The current study also strengthens support for the association between empowerment and transition readiness by measuring transition readiness with the TRAQ, which is focused on engagement in self-management behaviors. In prior studies with AYAs with congenital heart disease, transition readiness was operationalized as participants' perceptions of their readiness to take complete

responsibility for their healthcare and transition to adult care (Acuña Mora et al., 2019; Burström et al., 2019). The current study, however, suggests a link between empowerment and the presence of skills needed to self-manage healthcare, rather than just a perception of readiness.

The association between empowerment and transition readiness in this study illuminates another potential target for transition readiness programs. Empowering AYAs by enhancing their sense of personal control, increasing their involvement in medical decisions, educating them on their disease and its management, encouraging incorporation of their disease into their identity, and providing opportunities for them to share their knowledge and experiences with others may all be important components of transition programs. In practice, healthcare providers may empower their patients as they move through adolescence and young adulthood by incorporating these components into routine CF care. For instance, providers may encourage gradual steps toward independence and responsibility, such as suggesting the patient participate in visits partially alone, encouraging patient involvement in medical decisions, and addressing disease management concerns with AYAs rather than their parents. In prior literature, participation in a transition program that included education about CF, solo visits with pediatric providers, and a joint, pre-transition visit with pediatric and adult providers was associated with more transition readiness, better perception of healthcare independence, and less transition-related anxiety (Middour-Oxler et al., 2022). Thus, there is evidence that utilizing transition programs that incorporate components of empowerment may be associated with more positive outcomes over traditional transition preparation.

Interestingly, this study found that self-efficacy, which has been repeatedly associated with transition readiness in multiple disease groups (e.g., Varty & Popejoy, 2020), was not associated with transition readiness. There are several possible explanations for this. For

instance, much of the prior transition readiness literature used measures of self-efficacy specific to healthcare (e.g., Carlsen et al., 2017; Gumidyala et al., 2018; Treadwell et al., 2016) while the current study utilized a measure of general self-efficacy. It is possible that self-efficacy related to healthcare, rather than generalized self-efficacy, is more strongly associated with transition readiness and that one's general feeling of being able to accomplish goals and solve problems does not translate to healthcare behaviors. Second, it is possible that self-efficacy alone is not sufficient to promote self-management behaviors. Social cognitive theory posits, in part, that knowledge about one's condition and the potential risks and benefits is a necessary prerequisite for change (Bandura, 2004). Thus, it is possible that even in the presence of a strong sense of self-efficacy, a lack of knowledge about CF, which was not measured in the present study, may serve as an impeding factor for transition readiness. The differences in findings between the current study and published literature further support the need to empower AYAs preparing for transition rather than just promoting self-efficacy.

Empowerment and Treatment Adherence

Consistent with our hypothesis, empowerment was positively associated with treatment adherence. To our knowledge, this is the first study to link these two constructs in a sample of AYAs with chronic illness. However, the domains of empowerment have been separately linked to treatment adherence in prior studies (Balfour et al., 2014; Bellini et al., 2011; Carbone et al., 2013; Commissariat et al., 2020; Faint et al., 2017; Griva et al., 2000; Helgeson & Novak, 2007; Jerson et al., 2013; Keller et al., 2017; Kew et al., 2017; Luyckx et al., 2010; Martin et al., 2017; A. M. McLaughlin et al., 2020; Miller et al., 2020; Miller & Drotar, 2007; Miller & Jawad, 2019; Oris et al., 2016; Rhee et al., 2012). In the current study, depressive and anxiety symptoms were both correlated with treatment adherence, but consistent with previous literature, only depressive

symptoms were significantly associated with treatment adherence in the final model (Hilliard et al., 2015; Smith et al., 2010). Additionally, empowerment was associated with treatment adherence over and above depressive symptoms. Thus, empowerment represented a unique factor associated with adherence, even in the context of mental health symptoms. This suggests that, although depressive symptoms should still be treated as a risk factor for poor adherence, empowerment may represent a modifiable factor that can be targeted to improve treatment adherence in this population.

Empowerment and Health-Related Quality of Life

In this study, empowerment was not linked to quality of life across physical functioning, role functioning, vitality, emotional functioning, or social functioning domains. These results are inconsistent with the present hypotheses and prior literature, which has indicated empowerment is associated with physical, psychological, social, religious, and overall HRQoL in AYAs with cancer and the domains of empowerment are associated with quality of life in multiple disease groups (Cramm et al., 2013; Kaal et al., 2017; Kew et al., 2017; Luyckx et al., 2018; Meyer & Lamash, 2020; Rhee et al., 2012; Sawicki et al., 2011; Taylor et al., 2018; Torun et al., 2020; Uzark et al., 2020, 2019).

It is unclear why this discrepancy occurred in the current study. It is possible that use of a Bonferroni correction resulted in a significance threshold that was too conservative, or that the sample size was not large enough to detect the magnitude of effect. It is also notable, however, that factors previously associated with HRQoL in this population, such as FEV_1, were also not associated with HRQoL in the final models of the current study (Abbott et al., 2015; Flume et al., 2019; Gancz et al., 2018; Habib et al., 2015; Kwong et al., 2019). Thus, it is probable that factors contributing to HRQoL in this sample, such as the COVID-19 pandemic, were not captured by

the measures included in this study. Data were collected when social distancing and remote work/school were still being practiced. Emerging literature has indicated that individuals with CF have faced stigma, mental health impacts, increased rates of food insecurity, limitations on physical activity, and social isolation during the COVID-19 pandemic (Collaço et al., 2021; Lim et al., 2022; Radtke et al., 2021; Taheri et al., 2022; Westcott et al., 2021). It is possible that although individuals may have been empowered to engage in activities beneficial for their well-being and quality of life, their ability to do so might have been limited by the pandemic. In essence, the impact of the COVID-19 pandemic may have buffered the possible association between empowerment and HRQoL by limiting individuals' abilities to act on motivation to engage in HRQoL-promoting behaviors, such as participating in social activities and exercising.

Limitations

There are several notable limitations to this study. First, the GYPES, while psychometrically promising, is a new measure. The factor structure has not been evaluated in AYAs with CF, though it has been confirmed in two similar populations, AYAs with congenital heart disease and type 1 diabetes. While qualitative work in CF generally supports the conceptualization of empowerment captured by the GYPES, there may be unique considerations in AYAs with CF that are not captured with this measure, such as the impact of infection concerns (Fairweather et al., 2021). Additionally, the criterion, discriminant, predictive, and construct validity of the GYPES have not been examined, indicating the current study is limited by utilizing a measure that, while promising, has not been confirmed to capture the targeted construct. Second, the sample for this study was small. Though the sample size was sufficient to detect the large effects seen in Aims II and III, a larger sample would allow for detection of smaller effects.

Additionally, the current sample was not diverse and primarily White, female, and had lower rates of physical comorbidities and better lung functioning than seen in other research studies (e.g., Abbott et al., 2015); however, when compared to current population averages, the clinical characteristics of our sample, such as FEV_1 scores, BMI, and rates of liver disease were fairly consistent (Cystic Fibrosis Foundation, 2020). While the differences between the current sample and those of prior research studies may reflect the younger age of our sample or treatment with CFTR modulators, these results should be replicated in a sample with more demographic and clinical diversity. The current sample also demonstrated higher rates of psychological comorbidities than the overall population of individuals with CF. Compared to adults with CF, the current sample demonstrated much higher rates of diagnoses of both anxiety (43.9% vs. 25.5%), and depression (34.1% vs. 28.2%; Cystic Fibrosis Foundation, 2020). This may limit the generalizability of the present findings. However, given rates of anxiety have increased for individuals with CF during the COVID-19 pandemic (Westcott et al., 2021), the elevated rates within the current sample may be partially explained by the pandemic. Additionally, while the racial and ethnic characteristics of the current sample were similar to the overall CF population, the small sample size limited our ability to evaluate differences among minoritized racial and ethnic groups, which should be a focus of future research with larger samples.

Finally, there are risks inherent to online data collection. Numerous safeguards were implemented to ensure quality data and study staff were conservative in retaining data that appeared suspicious. However, study staff had no way to verify eligibility for the study, particularly for participants recruited through social media. Additionally, all data were self-report. Prior literature has indicated self-report data can be inaccurate, as even small changes in

the way questions are worded may impact the answers (Schwarz, 1999). In particular, self-report data related to adherence can be misleading as individuals tend to overestimate their rates of adherence when compared to electronic monitoring (Daniels et al., 2011).

Implications and Future Directions

The current study adds to the limited literature on factors associated with transition readiness by finding an association between empowerment and transition readiness in AYAs with CF. While there are limitations to the current study, it provides promising evidence that empowerment may be a modifiable construct that can be targeted to improve both transition readiness and treatment adherence in AYAs with CF. Current recommendations for promoting transition readiness and self-management in youth with chronic illness focus on gradually increasing the responsibility of the youth beginning in early adolescence and taking a person-centered and strengths-based approach (White et al., 2018). The results of the present study suggest that empowering adolescents may help prepare them to transition to self-management and adult-oriented healthcare. In this study, empowerment was operationalized as promoting knowledge and understanding of one's condition, a sense of personal control over health, integration of their condition into their identity, involvement in healthcare decisions, and sharing knowledge with others. These are all potential areas of empowerment to strengthen among AYAs with CF.

The present study is especially poignant in the era of CFTR modulators. As new, promising treatments have emerged, individuals with CF have also reported shifts in illness identify, perceptions of health stability, and reevaluations of their future (Havermans & Duff, 2020). Additionally, CF care may soon look different, particularly for children who are able to initiate CFTR modulators early in life. For those eligible for CFTR modulator therapy,

recommendations around more burdensome treatments, such as airway clearance, may be changing (Rowbotham & Daniels, 2022). As such, individual variation in CF care and choice related to treatments may increase, and empowering AYAs to evaluate their priorities, voice their preferences, and engage with their CF care may become even more important.

However, future research is needed to establish the GYPES as a valid measure with strong psychometric properties. Additionally, the present findings need to be replicated in a larger, more diverse sample, and while utilizing other measures of treatment adherence, such as electronic monitoring or pharmacy refill data. Finally, research is needed to understand how to best empower AYAs with CF during this transition and what factors may promote or impede empowerment. Prior synthesis of the literature has identified barriers and facilitators to empowerment in young people with CF, including social support, knowledge, and respect as facilitators and prejudice as a barrier (Fairweather & Jones, 2021). However, research into additional barriers and facilitators to empowerment, particularly those that are salient to transitioning AYAs, is warranted. Specifically, future research may focus on the role of responsibility and mental health in empowerment during this time. As this study demonstrated, empowerment was correlated with perceived primary responsibility for one's healthcare. It is unclear whether empowered AYAs perceive more responsibility for their healthcare or those encouraged or required to take more responsibility for their healthcare feel more empowered. Thus, future research may focus on exploring this association, as well as its implications for parents and providers. Additionally, depressive symptoms were associated with treatment adherence alongside empowerment. However, the present study did not evaluate how depression and empowerment may interact in regard to treatment adherence. Thus, future research should evaluate how other variables, such as depressive symptoms, may promote or hinder

empowerment.

Conclusions

In summary, empowerment was associated with transition readiness and treatment adherence in the current study, but not HRQoL. An overly conservative significance threshold, a small sample size, or contextual factors may have contributed to the lack of a significant association between empowerment and HRQoL in the current study. These findings highlight the need to empower AYAs as they prepare to transition to adult care and take complete responsibility for their healthcare. However, the current study is limited by a small, fairly homogenous sample and the reliance on online recruitment and self-report data. Future research should further evaluate the psychometric properties of the GYPES, replicate the current findings in a larger, more diverse sample, and evaluate the impact of other variables on levels of empowerment.

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