

# Health-Related Hindrance of Personal Goal Pursuit and Well-Being of Young Adults with Cystic Fibrosis, Pediatric Cancer Survivors, and Peers without a History of Chronic Illness

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**Objective** Study examined content of personal goals, health-related hindrance (HRH; i.e., impact of health on goals), and relationship of HRH to health status and psychological well-being in young adults with cystic fibrosis (CF;  $n = 48$ ), who survived childhood cancer ( $n = 57$ ), and without history of chronic illness ( $n = 105$ ). **Methods** Participants completed measures of life events, quality of life, psychological well-being, and goals. **Results** No group differences were found on goal content. HRH significantly related to subjective well-being and distress after controlling for demographics, negative life events, physical health-related quality of life, disease status, and self-efficacy. HRH related to health status variables. Cancer survivors without cancer late effects had significantly less HRH than the other groups. **Conclusions** Health status may affect pursuit of personal goals and relate to well-being of young adults. The assessment of HRH has potential clinical utility for targeting interventions and warrants further research.

**Key words** cancer survivors; cystic fibrosis; goals; hindrance; pediatric; well-being; young adults.

In recent decades, medical advances have facilitated an increase in the life expectancy of many youth with pediatric chronic illness resulting in a dramatic rise in the number young adults with chronic health conditions (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine, 2002). Cystic fibrosis (CF) and childhood cancer are exemplar pediatric diseases that have benefited from treatment advances given that survival into adulthood is a relatively recent phenomenon (Patenaude & Kupst, 2005; Stark, Mackner, Patton, & Acton, 2003). However, both groups face continued threats to health. Cancer survivors are cured, but may have physical and psychological late effects and increased potential for a new cancer diagnosis. Those with CF inevitably face a shortened life-span and deteriorating condition. These continued threats to health and related burdens may relate to changes of and impaired pursuit of personal goals and less optimal psychosocial outcomes

during the transition to adulthood. Thus, the purpose of this study is to describe the goals and explore the relationship of health to goal pursuit and well-being of young adults with CF, who survived cancer, and a healthy comparison group.

Goals are internal representations of desired states or what an individual hopes to achieve in his or her current life situation (Austin & Vancouver, 1996; Brunstein, 1993). Goals may also be developmental tasks—goals that are specific to a developmental period and shaped by sociocultural expectations (Roisman, Masten, Coatsworth, & Tellegen, 2004). Research on goals of emerging adults with a history of pediatric chronic illness has important scientific and clinical implications for several reasons: (1) adolescents and young adults are increasingly autonomous in setting goals, (2) pursuit of goals (e.g., academic and career achievement, close relationships) is related to well-being in young adulthood (Arnett, 2000; Schulenberg, Bryant, & O'Malley, 2004), (3)

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having a chronic illness in childhood may hinder the achievement of important developmental tasks or personal goals of emerging adulthood (Bauman, 2000; Schwartz & Drotar, 2006), and (4) personal goals can be an important focus of clinical interventions in illness management (Schwartz & Drotar, 2006). Therefore, understanding young adults' goals and how they may be hindered by health status can highlight areas of intervention to enhance resiliency and treatment adherence for pediatric patients transitioning to adulthood.

Although not well-studied in pediatric populations, research consistently supports the importance of goals for well-being in healthy samples and adults with chronic health conditions. Studies with Personal Projects Analysis (PPA; Little, 1983), which is a methodology to assess goals used in personality psychology, have found that well-being is related to pursuit of goals perceived to be meaningful, autonomously chosen, supported, not too stressful, and that elicit a sense of self-efficacy (Little & Chambers, 2004). During times of adversity, individuals often re-evaluate and reprioritize expectations to maintain realistic and meaningful goals (Kin & Fung, 2004; Pinguart, Nixdorf-Hanchen, & Silbereisen, 2005). Furthermore, many theories (e.g., social-cognitive, self-regulation, control) emphasize the importance of goal pursuit in the face of adversity to maintain well-being and enhance resiliency (Bandura, 2000; Carver & Scheier, 1998; Maes & Karoly, 2005). Studies have also highlighted the struggle to maintain goal pursuit and related well-being in individuals with health conditions (Affleck et al., 1998; Bloom, Stewart, Johnston, & Banks, 1998; Boersma, Maes, & van Elderen, 2005; Devins, Bezjak, Mah, Loblaw, & Gotowiec, 2006; Echteld, van Elderen, & van der Kamp, 2001; Pinguart, Nixdorf-Hanchen, et al., 2005; Rapkin et al., 1994).

As an extension of previous work, we introduce a construct called health-related hindrance (HRH) that assesses the impact of specific aspects of health on self-identified personal goals. HRH is assessed using PPA methodology (Little, 1983). Participants list personal goals and rate the impact of pain, other symptoms, and management of health on each goal. Such information is clinically meaningful (e.g., highlighting what symptoms or health behaviors are hindering certain goals) and relatively easy to assess (e.g., participants responding to standard set of questions on each personal goal). Furthermore, individual goals can be empirically coded and categorized for research or can be addressed in clinical interventions. HRH is also particularly relevant for those transitioning to adulthood because goal setting and pursuit is an important focus for both normal emerging adult development and for psychosocial or disease management interventions

(Nurmi, 1993; Pinguart, Silbereisen, & Wiesner, 2005; Schwartz & Drotar, 2006).

Other related constructs exist, but differ from HRH in a few critical ways. For example, some measures of hindrance require participants to rate the impact of aspects of disease on a specified set of items such as higher-order goals (Boersma, Maes, & van Elderen, 2005) or lifestyle domains (Devins et al., 2001). Assessment of the impact of a specific disease or health burden limits the ability to compare across groups. Also, because ratings of hindrance are made on a pre-determined set of items for many measures of related constructs (e.g., quality of life, functional disability, goal disturbance, illness intrusiveness, activity limitations), participants answer questions about domains that may not have personal significance, even when choosing preferred items from a pre-determined list (e.g., Child Activity Limitations Scale; Palermo, Witherspoon, Valenzuela, & Drotar, 2004). Such constructs/measures may not be personally relevant to individuals making the transition to adulthood who may not yet have long-term higher-order goals and/or may have developmentally appropriate goals that are not represented on such measures (e.g., make a plan with a friend, finish the semester). Other studies have used idiographic approaches that elicit personal goals and related progress or barriers through daily diaries or clinical interviews (Affleck et al., 1998; Rapkin et al., 1994). However, these goal-related constructs are not well-defined or easily measured. Finally, hope is a similar construct in that it relates to beliefs about goals (Snyder, Hoza, Pelham, Rapoff, & Ware, 1997), but represents a dispositional trait of goal-oriented agency and pathway appraisals rather than specific hindrances of personal goals. Thus, HRH uniquely assesses the impact of general aspects of health on personal self-identified goals, which facilitates comparisons between groups (e.g., various disease groups, those with or without health problems) and can also identify targets of intervention (e.g., alleviate certain hindering symptoms, change or modify personal goals that are perceived to be hindered by illness).

To our knowledge, the present study is the first to assess HRH. In particular, the relationship of health to goals and well-being in young adults with CF, long-term childhood cancer survivors, and healthy young adults without a history of chronic illness was explored. A control group without a history of chronic illness was included to allow comparisons between disease and healthy groups given the potential for never ill individuals to also experience symptoms such as pain, fatigue, and allergies, and to engage in health behaviors such as exercise and medication use.

The first aim was to describe the content of goals and test whether or not they varied as a function of disease group. Based on health-related burden and research on re-prioritization during adversity, it was expected that those with CF and a history of childhood cancer would identify more health-related, interpersonal (goals related to social connections) and intrapersonal goals (goals related to values, introspection, spirituality) than the healthy group (Kin & Fung, 2004; Pinqart, Nixdorf-Hanchen, et al., 2005; Street, 2003), but would not identify more occupational/academic, administrative/maintenance, or leisure goals.

The next objective tested the hypothesized relationship between HRH and emotional outcomes. Both negative (distress) and positive (subjective well-being) outcomes were examined in order to be consistent with previous similar studies (Palys & Little, 1983; Emmons, 1986; Emmons & King, 1988) and with research demonstrating the independence of positive and negative affect (Diener, Emmons, Larsen, & Griffen, 1985). Regression models tested the relationship of HRH to well-being and distress after accounting for variables also potentially related to the emotional outcomes. In particular, Devins and colleagues (2006) have argued that health-related and psychosocial variables should be included in goal-related models predicting well-being. Specifically, prior research and theory provides rationale for controlling for: (1) life events given their relationship to well-being and stress and potential to exacerbate illness-related stress (Devins et al., 2006; Sarason & Sarason, 1985); (2) self-efficacy given its relevance for goal pursuit and well-being (Bandura, 2000); and (3) health-related quality of life (HRQOL) given its potential relationship to well-being, to control for general perceived health status across disease groups, and to be consistent with prior related research controlled for HRQOL when examining relationships of goal-related constructs and psychosocial outcomes (Rapkin et al., 1994). In addition, because of the various disease status of the sample, group membership was also covaried in analyses.

The final study objective was to assess the relationship between HRH and health status. It was expected that HRH would be highest in those with CF given their current health problems and disease burden, would be second highest in cancer survivors given potential late effects and need for follow-up care, and that never ill peers would experience the least amount of HRH. In addition, HRH was expected to relate to the following health-related variables: the number of patient-reported late effects (medical and psychological sequelae from the cancer or its treatment) for the group of cancer survivors, pulmonary

function (average FEV<sub>1</sub>) and number of days in the hospital in the previous year for those with CF, and physical HRQOL for the entire sample.

## Methods

Data are from a broader study of goals and well-being of young adults. This study was approved by the internal review board of a Midwest children's hospital.

### Sample

Young adults (ages 18–28) with CF ( $n = 48$ ), survivors of childhood cancer ( $n = 57$ ), and those without a history of chronic illness ( $n = 105$ ) completed the study. See Table 1 for demographic information. Participants were required to speak English and to not have a learning disability or cognitive impairment. Additional criteria for childhood cancer survivors were: A diagnosis of cancer between the ages of 4 and 18 (age 4 criteria was established to increase the likelihood that survivors remembered their cancer), currently in remission or cured, and at least 1 year without active treatment. Control participants were ineligible if they ever had a chronic health condition or a life-threatening illness or accident or if they had an immediate family member (e.g., sibling, parent, spouse, or child) with a history of chronic illness.

### Identification of and Recruitment of Potential Participants

Potential participants with CF ( $n = 106$ ) were sent a letter by the division of pulmonology that introduced them to the study and offered them the option of "opting-in" by calling the first author ( $n = 18$  opted-in). Alternatively, recruitment took place in clinic ( $n = 37$ ) or on the in-patient floor ( $n = 8$ ). Of the 63 who agreed to participate, 48 completed the study. There were no differences between the individuals with CF who completed the study and those who did not on indices of disease severity (i.e., days in the hospital or FEV<sub>1</sub>), age, or gender. Potential participants with a history of childhood cancer ( $n = 165$ ) were sent a letter by oncologists introducing them to the study and were subsequently called to invite participation. Of the 85 participants who were able to be reached via phone, 80 agreed to participate and 57 completed the study. There were no differences on age, gender, type of diagnosis, or time since diagnosis for those who completed the study and those who did not. For both groups, there also were no differences between those who agreed to participate and those who refused participation on age and gender.

**Table I.** Sociodemographic Information on Participants ( $N = 210$ )

	CF group ( $n = 48$ )	Cancer survivor group ( $n = 57$ )	Healthy comparison group ( $n = 105$ )
Male gender	26 (54.2%)	27 (47.4%)	40 (38.1%)
Age, $M$ ( $SD$ )	21.98 (3.07)	21.70 (2.65)	22.10 (2.88)
Ethnicity/race: Caucasian*	45 (93.8%)	54 (94.7%)	89 (84.8%)
Education: More than high school***	36 (75%)	42 (73.7%)	101 (96.2%)
Marital status			
Married	6 (12.5%)	7 (12.3%)	11 (10.5%)
Involved with partner	13 (27.1%)	17 (29.8%)	44 (41.9%)
Single/separated	29 (60.4%)	33 (57.9%)	50 (47.6%)
Employment status			
Working full-time	13 (27.1%)	17 (29.8%)	36 (34.3%)
Working part-time	19 (39.6%)	21 (36.8%)	34 (32.4%)
Not working	16 (33.3%)	19 (33.3%)	35 (33.3%)
Income			
<30,000	14 (32.5%)	17 (34.7%)	25 (26.0%)
30,000–60,000	12 (28.0%)	11 (22.4%)	27 (28.1%)
>60,000	17 (39.5%)	21 (44.9%)	44 (45.8%)
Goals (avg no. listed)			
Occupational/academic	1.91 (.96)	1.98 (1.23)	2.01 (1.36)
Health	1.91 (1.21)	1.58 (.98)	1.65 (1.02)
Interpersonal	1.74 (1.24)	2.35 (1.34)	2.19 (1.45)
Intrapersonal/values	0.93 (0.88)	0.82 (0.97)	1.12 (1.38)
Leisure	1.63 (1.34)	1.02 (1.01)	1.51 (1.27)
Administrative	1.20 (1.98)	2.16 (1.49)	1.50 (1.32)
HRH total**	2.41 (2.09)	1.51 (1.77)	1.56 (1.60)
		With late effects $n = 29$	Without late effects $n = 23$
		1.92 (1.98)	.98 (1.31)
HRH—pain*	1.63 (2.03)	1.74 (2.03)	.69 (1.2)
HRH—symptoms*	2.56 (2.24)	1.78 (2.08)	.92 (1.22)
HRH—management of health*	3.03 (2.44)	2.26 (2.03)	1.33 (1.82)
			2.27 (2.24)

Percentages in each category may not equal 100% due to missing data. The non-Caucasian sample of those with CF identified themselves as: African-American ( $n = 1$ ), Asian ( $n = 1$ ), and Other ( $n = 1$ ). The non-Caucasian sample of those who survived childhood cancer identified themselves as African-Americans ( $n = 3$ ). The non-Caucasian sample of healthy group identified themselves as: African-Americans ( $n = 2$ ), Latinos ( $n = 2$ ), Asian ( $n = 5$ ), and Other ( $n = 7$ ). It is unclear if the income identified by the participants was their own or that of their family of origin given some of them still lived with their parents. Raw scores (not log transformations) are shown for HRH. Five cancer survivors did not report their number of late effects.

\* $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$ .

A snowball recruitment strategy was used to recruit the healthy group (Birnacki & Waldorf, 1981). Participants with a history of childhood chronic illness were asked to distribute flyers about the study with investigator contact information. Participation was initiated for healthy young adults that opted-in and were eligible. Additionally, of those healthy young adults that opted in, they, too, were asked to distribute information about the study to other healthy young adults. Of the 130 potential healthy participants that opted-in, 123 were eligible, and 105 completed the study. Among the healthy young adult comparison group, 28 (27%) were recruited by childhood cancer survivors, 19 (18%) were recruited by participants with CF, and 58 (55%) were recruited from other healthy young adults. There were no significant differences

between these subsamples of the healthy comparison group on gender, age, HRQOL, mood, depression, or satisfaction with life. Thus, those recruited by peers in the CF or cancer survivor group were not more distressed than those recruited by other healthy peers.

### Procedures

Participants were given or mailed a packet with questionnaires and flyers about the study to distribute to healthy young adults potentially interested in doing the study. For those who completed measures at home, phone calls were made weekly until the packets were returned or until approximately five contact attempts were made. Participants were compensated upon completion.

## Measures

### Demographics

All participants completed a demographic form that asked about age, marital status, employment status, educational status, and income.

### Health Status/Disease History

Childhood cancer survivors were asked to report their medical and psychological late effects from their cancer or treatment after reading a definition of late effects. Late effects are sequelae (e.g., heart disease, growth problems, cognitive problems, anxiety) of cancer or its treatment. The total number of late effects was used. Self-report was used because many of the patients were not receiving care and did not have updated medical records with current problems. Medical chart review identified type of cancer, date of diagnosis, and treatment end date. Illness status of the CF group was assessed via the previous year's number of days hospitalized and average pulmonary function recorded from medical charts. Pulmonary function was measured as the percentage of the predicted forced expiratory volume in 1 s (FEV<sub>1</sub>). This refers to the volume of air that can be forced out in 1 s after taking a deep breath and has been shown to be highly sensitive to changes in pulmonary functioning (Jakeways, McKeever, Lewis, Weiss, & Britton, 2003; Schünemann, Dorn, Grant, Winkelstein, & Trevisan, 2003). Percent predicted FEV<sub>1</sub> below 75% is especially indicative of airflow impairment (Jakeways et al., 2003).

### Health-Related Quality of Life

The Physical Health Summary Scale of the Short Form Health Status Questionnaire (SF-36; Ware, 1993) was used as an index of physical HRQOL for the entire group and was controlled for when testing the relationship of HRH to emotional outcomes. The importance of controlling for HRQOL is highlighted in past research on goal appraisals and well-being (Rapkin et al., 1994). Higher scores indicate better functioning. Items reflect the perceived impact of health on activities of daily living and other domains such as social and employment functioning. The Physical Health Score is a weighted composite of the eight subscales of the 36-item measure. It has good construct validity with both healthy and chronic illness populations. The Cronbach's alpha for the sample was .78 for the Physical Health Summary Score.

### Negative Life Events

The Life Experiences Survey (LES; Sarason, Johnson, & Siegel, 1978) was used to control for negative life events when testing the relationship of HRH to emotional

outcomes. The importance of controlling for negative life events is supported by research showing a relationship of negative life events to illness and depression (Sarason & Sarason, 1985). The 30 items of the measure represent life changes experienced in the general population (e.g., change in job, new relationship, death of loved one). All endorsed events are rated from 1 (very good) to 5 (extremely bad), which yields a summary score. This measure has demonstrated good reliability and validity and is related to measures of stress and depression (Sarason et al., 1978). The Cronbach's alpha for the present sample was .68.

### Goal Content and Appraisals

Personal Projects Analysis (PPA; Little, 1983) was used to assess goals (goals are referred to as projects in the measure) and relevant appraisals (i.e., HRH, self-efficacy). A modified version of the PPA, with simplified procedures and language, was successfully piloted with the eight high school students. Participants listed at least 10 or more personal projects in 10–15 min using instructions adapted from Little (PPA workbook; www.brianrlittle.com) and Ruchman & Wolchik (1998). Projects were described as: "plans, undertakings, or activities in the pursuit of some valued goal or outcome. Projects can vary in their complexity, length of time needed to complete the project, their importance, whether or not they are done with others, whether or not we chose them or others impose them on us, etc. Projects may be related to any aspect of your life whether it be family, school, work, health, relationships, home, etc."

Following identification of their 10 most important projects from their initial list, participants were directed to think about Project 1 and to complete the 22 goal appraisal items for that project using a 10-point scale. They repeated this step for each goal identified. Of the 22 items, four represented self-efficacy to achieve the goal and three were created to represent HRH. (The other items were not used in this study.) The HRH items asked the extent to which pain, other physical symptoms, and management of health affects the pursuit or achievement of each personal project. These items were chosen to represent potential health-related burdens of all individuals, independent of disease status. The items asked of each project were averaged among the 10 projects. HRH had an alpha of .91 and self-efficacy was .75.

Following a previously established coding scheme, projects were coded as: (1) Occupational/Academic (e.g., finish school, get a promotion), (2) Health/Body (e.g., do my treatments when I should, exercise more), (3) Interpersonal (e.g., get married, spend more time with

friends), (4) Intrapersonal/Values (e.g., be more confident, do something meaningful), (5) Leisure (e.g., plan a vacation, make plans for the weekend), and (6) Administrative/Maintenance (e.g., finish my applications, get my car fixed; Chambers, 2003; Little & Chambers, 2004). Two trained raters independently rated the goals and subsequently reviewed any discrepancies. With the exception of three goals, which were reviewed with the author of the coding scheme (N. Chambers), the two raters easily attained consensus on the goal coding. After completing the coding, the frequency of the content categories was determined for each participant.

PPA has been used with a variety of populations including adolescents (Nurmi, 1989), college students (McGregor & Little, 1998), community samples of adults (Little, 1998), and depressed individuals (Salmelo-Aro, 1992). The validity of the measure in a sample of young adults is provided by a large database with thousands of college students who rated their self-identified personal projects as relatively meaningful (a mean of 7.5 out of 10 on appraisals of importance and 7.7 on ratings of value-congruency), thus indicating that personal projects reflect salient and nontrivial aspects of individuals' lives (Little, 1989).

### **Emotional Outcomes**

Studies examining emotional correlates of PPA have included measures of positive and negative affect and life satisfaction and depression (Palys & Little, 1983; Emmons, 1986; Emmons & King, 1988). Many have used composite scores of subjective well-being and distress (Brunstein, 1993; McGregor & Little, 1998; Sheldon & Elliot, 1999), but no factor analysis had been reported to support their validity. Therefore, to reduce data and identify valid and reliable outcomes, the items of emotional outcome measures previously used in PPA studies to measure well-being and distress were submitted to exploratory factor analysis in this sample. The Brief Mood Rating Scale (Diener & Emmons, 1985) assessed positive and negative affect. Using a 7-point scale, participants rate how likely adjectives describe them in the past week (four adjectives describing positive affect and five adjectives describing negative affect). The 20-item Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) assessed depressive symptomatology by asking individuals to rate their actions and feelings in the past week on a 4-point scale. Finally, the Satisfaction with Life Scale (SWLS; Diener et al., 1985) asks respondents to indicate the extent to which they agree with five global statements of life satisfaction on a 7-point scale.

## **Data Analyses**

### **Descriptive Statistics**

Descriptive statistics were provided on disease, demographic, and goal variables. *T*-tests and chi-squared analysis compared groups on demographics.

### **Factor Analysis of Emotional Outcome Items**

The number of factors to retain was decided using parallel analysis (PA; Horn, 1965) and minimum average partial correlation (MAP; Velicer, 1976)<sup>1</sup>. Principal axis factoring (PAF), a method of exploratory factor analysis, was used with promax rotation and with the set number of factors designated by MAP and PA. Following the PAF, items with factor loadings  $<.40$  were removed one at a time. Thus, after removal of each item judged to be the worst (i.e., had lowest factor loadings), the PAF was re-run and another item was removed if necessary until all items had a factor loading  $\geq .40$  on one factor only.

### **Hypothesis Testing**

Pearson and Spearman correlations demonstrated relationships between demographic variables and emotional outcomes, HRH and emotional outcomes, and HRH and disease severity variables. Hierarchical regressions tested the relationship of HRH to subjective well-being and distress after controlling for theoretically relevant covariates and demographic correlates of emotional outcomes. In particular, for each regression with subjective well-being and distress as the dependent variables, the following variables were entered into the first step: demographic correlates, the life events score on the LES, goal-related self-efficacy, the Physical Health Summary Score on the SF36, and health status using the dummy variables representing CF group and cancer survivor group. HRH was entered in the second step. ANCOVAs were used to test group differences on goal content and HRH. Post-hoc analyses were conducted to compare the means of the groups using Fisher's least significant difference (LSD) post-hoc test of pairwise multiple comparisons. A statistical level of  $p < .05$  was used for all analyses.

<sup>1</sup>PA and MAP were chosen as the methods to decide on the number of factors to retain based on their proven superiority to other related methods including the Kaiser test (Velicer, Eaton, & Fava, 2000; Zwick & Velicer, 1986). The advantage of PA is that it accounts for sampling error by comparing the eigenvalues of the observed data to randomly generated data instead of a fixed value of 1.0 (Velicer et al., 2000). The advantage of MAP is that it separates common and unique variance and retains only components consisting of common variance (Velicer et al., 2000).

## Results

### *Descriptive and Factor Analyses*

Most of the participants in the cancer survivor group had leukemia (33%) or lymphoma (35%), while the rest had solid tumor cancers including brain tumors. The average age at diagnosis was 11.35 ( $SD = 3.91$ , range = 4–18), the average number of years of treatment was 1.23 ( $SD = 0.92$ , range = 0.21–3.76), the average number of years since treatment ended was 9.25 ( $SD = 4.41$ , range = 1.78–18.83), and the average number of late effects reported was 1.05 ( $SD = 1.27$ , range = 0–6), which indicates that this sample was not reporting many current problems because of their cancer or treatment. Of those with CF, the average percent predicted FEV<sub>1</sub> was 70.87 ( $SD = 23.71$ , range = 25.64–115.34), thus indicating that the sample was experiencing significant airflow impairment (<75%). The average number of days hospitalized was 14.42 ( $SD = 21.53$ , range = 0–97). There was a significant difference between the groups on minority status [ $\chi^2(2,209) = 4.97$ ,  $p < .05$ ] and education [ $\chi^2(2,210) = 20.02$ ,  $p < .05$ ], with individuals in the healthy comparison group more likely to be of minority status and more educated. Thus, minority status and education were used as covariates in all between-group analyses.

When using MAP and PA methodology for determining the number of factors to retain for the emotional outcome measures (CES-D, Mood Rating Scale, SWLS), both methods suggested retaining two factors. Thus a PAF was run forcing two factors with promax rotation. As hypothesized, two factors emerged that represented subjective well-being and distress.<sup>2</sup> The alphas were .92 for subjective well-being and .91 for distress.

Tests of normality revealed that HRH and distress were positively skewed; logarithm transformations were subsequently used to improve normality and are noted as subscript, “log”, to notate the transformed variables.

### *Group Differences on Goal Content*

The mean number of projects identified in each goal content category for the groups are shown in Table I. Contrary to hypothesis, there was no main effect for group on

<sup>2</sup>Five items from the CES-D were removed based on their weak loadings (<.40). These items included “poor appetite,” “felt like everything was an effort,” “thought life had been a failure,” “felt like I was just as good as others,” and “sleep was restless.” The subjective well-being factor included the items from the SWLS, the positive affect items from the Mood Rating Scale, and three items reflecting happiness on the CES-D. The distress factor included most of the items on the CES-D and the negative affect items on the Mood Rating Scale.

number of health-related goals [ $F(2,210) = 1.20$ ,  $p = .31$ , partial  $\eta^2 = 0.01$ ], interpersonal goals [ $F(2,210) = 2.12$ ,  $p = .12$ , partial  $\eta^2 = 0.02$ ], or intrapersonal goals [ $F(2,210) = 1.00$ ,  $p = .37$ , partial  $\eta^2 = 0.01$ ]. As expected, no group differences were found on the number of leisure, administrative, or academic/career goals.

### *Relationships between HRH and Emotional Outcomes*

As hypothesized, HRH<sub>log</sub> was significantly correlated with subjective well-being ( $r = 0.20$ ,  $p < .01$ ) and distress<sub>log</sub> ( $r = 0.17$ ,  $p < .05$ ). Hierarchical regressions tested the relationship of HRH<sub>log</sub> to subjective well-being and distress<sub>log</sub> after controlling for related demographics, life events, goal-related self-efficacy, HRQOL, and chronic illness history. Education ( $r = 0.23$ ,  $p < .01$ ) and minority status ( $r = -0.20$ ,  $p < .01$ ) correlated with subjective well-being and were used as covariates in the first regression. Education ( $r = -0.20$ ,  $p < .01$ ) correlated with distress<sub>log</sub> and was used as a covariate. Tables II and III summarize the regressions. The model that tested the main effects of goal appraisals accounted for 43% of the variance of subjective well-being ( $p < .001$ ) and 35% of distress<sub>log</sub> ( $p < .001$ ). As predicted, HRH<sub>log</sub> related to subjective well-being (standardized  $\beta = -0.14$ ,  $p < .05$ ) and distress<sub>log</sub> (standardized  $\beta = 0.13$ ,  $p < .05$ ) after accounting for the other variables. Education, life events, and self-efficacy were also related to emotional outcomes.

### *Relationship of HRH to Health Status and Related Variables*

As shown in Table I and as predicted, there was a significant main effect for disease group on HRH<sub>log</sub> [ $F(2,210) = 3.15$ ,  $p < .05$ , partial  $\eta^2 = 0.03$ ]. Post-hoc comparisons showed that the CF group significantly differed from the cancer group ( $p < .05$ ). As predicted, HRH was significantly correlated with patient reported late effects for the cancer survivor group ( $r = 0.36$ ,  $p < .05$ ), with average percent predicted FEV<sub>1</sub> ( $r = -0.36$ ,  $p < .05$ ) and number of days spent in the hospital in the previous year ( $r = 0.38$ ,  $p < .01$ ) for the CF group, and with physical HRQOL ( $r = -0.50$ ,  $p < .01$ ) for the whole group.

### *Post-Hoc Analyses*

Because, contrary to expectation, the cancer survivor group demonstrated the lowest HRH, a post-hoc ANCOVA was run with the cancer survivor group divided into two groups: those who reported having at least one late effect ( $n = 29$ ) and those who did not ( $n = 23$ ). It was believed that those with late effect(s) would endorse

**Table II.** Summary of Hierarchical Regression Analyses for Subjective Well-Being ( $N = 210$ )

Regression	Standardized $\beta$	$df$	$R^2$	$\Delta R^2$	$F$	$p$ -value
Step 1: Demographics/life events/health		7.201	0.41	0.41	19.84	.00
Education	.13					.03
Ethnicity	-.09					.11
Life events	-.26					.00
Self-efficacy	.46					.00
Physical HRQOL	-.07					.25
CF group	-.11					.09
Cancer group	-.08					.20
Step 2: HRH		1.200	0.43	0.02	18.51	.00
HRH	-.14					.02

Note. Education was coded as graduated high school or not; ethnicity was coded as Caucasian or not.

**Table III.** Summary of Hierarchical Regression Analyses for Distress ( $N = 210$ )

Regression	Standardized $\beta$	$df$	$R^2$	$\Delta R^2$	$F$	$p$ -value
Step 1: Demographics/life events/health		6.202	0.34	0.33	17.14	.00
Education	-.15					.01
Life events	.30					.00
Self-efficacy	-.41					.00
Physical HRQOL	.10					.15
CF group	.03					.68
Cancer group	-.06					.38
Step 2: HRH		1.201	0.35	0.01	15.50	.00
HRH	.13					.04

Note. Education was coded as graduated high school or not.

more HRH than the never ill group. There was a significant main effect for group [ $F(3,208) = 5.11, p < .01$ , partial  $\eta^2 = 0.08$ ]. The cancer survivor group without late effects had the lowest HRH and significantly differed from the group without a history of chronic illness ( $p < .01$ ), the cancer late effects group ( $p < .01$ ), and the CF group ( $p < .001$ ). Using a MANCOVA, post-hoc analyses also examined the group differences of the individual subscale scores of Pain<sub>log</sub>, Other Symptoms<sub>log</sub>, and Management of Health<sub>log</sub>. The model was significant [ $F(3, 210) = 3.6, p < .01$ , partial  $\eta^2 = 0.05$ ]. The cancer group without late effects endorsed significantly less HRH-Pain<sub>log</sub> compared to all other groups ( $p < .01$ ) and reported significantly less HRH-Management of Health<sub>log</sub> than the CF group ( $p < .01$ ) and the healthy group ( $p < .05$ ). The CF group endorsed significantly more HRH-Symptoms<sub>log</sub> compared to the cancer group without late effects ( $p < .05$ ) and the healthy group ( $p < .01$ ).<sup>3</sup>

<sup>3</sup>A Bonferroni correction for comparisons among the three HRH subscales would result in a significance level of  $p < .017$ . Thus, if correcting for the three comparisons, some comparisons that were significant at the level of  $p < .05$  would not be significant.

## Discussion

To our knowledge, for the first time in the literature, hindered personal goal pursuit (i.e., HRH) was studied in young adults with compromised health. To achieve the study aims, methodology typically used in personality psychology (i.e., PPA) was used to assess goals and HRH. This methodology proved to be feasible and findings show initial evidence of internal consistency and validity of the HRH construct given its hypothesized relationship to health-related variables and well-being.

As predicted, HRH related to psychological distress (positive relationship) and subjective well-being (negative relationship) even after controlling for other potentially related variables. This finding is consistent with research showing that general goal constructs (Little & Chambers, 2004) and hindered goal pursuit are related to well-being (Affleck et al., 1998; Bloom et al., 1998; Boersma et al., 2005; Devins et al., 2006; Echteld et al., 2001; Pinquart, Nixdorf-Hanchen, 2005; Rapkin et al., 1994), especially during emerging adulthood when goal pursuit is critical for adult identity development and life satisfaction



(Nurmi, 1993; Piquart, Silbereisen, et al., 2005; Schulenberg et al., 2004). The study also contributes to the burgeoning work on goal-related research in health psychology as represented by applications of motivational interviewing and social-cognitive theory (Bandura, 2004; Resnicow et al., 2002) and highlights the potential to empirically study personal goals in pediatric populations.

That HRH, but not HRQOL, related to psychological outcomes is consistent with previous research (Rapkin et al., 1994). This finding highlights the relationship between goal pursuit and well-being and the potential value of assessing HRH as a psychosocial outcome of disease or common health problems. Unlike HRQOL and other similar measures of functional status that may have varying degrees of relevance to responders, HRH provides a measurement of how health is impacting what is personally important to the individual.

That self-efficacy was the strongest correlate of outcomes is not surprising given its established theoretical and empirical link to goal pursuit and well-being (Bandura, 2000). This finding should not negate the significance of HRH, as HRH helps target potentially modifiable health burdens or goals burdened by health. It provides practical information potentially useful to multidisciplinary medical teams deciding on treatments and ways to improve adherence or well-being for those with health problems. Furthermore, improvements in HRH may be partially attributable to improvements in self-efficacy, or vice versa, making them compatible targets of interventions.

It was somewhat surprising that the cancer survivors without late effects demonstrated the least amount of HRH, especially that related to pain. However, this “paradoxical” finding is consistent with previous studies showing that childhood cancer survivors “underreport” symptoms relative to norms or controls (Elkin, Phipps, Mulhern, & Fairclough, 1997; Schwartz, Feinberg, Jilinskaia, & Applegate, 1999). As noted in the literature, potential reasons for underreport of symptoms include response bias that minimizes distress (O’Leary, Diller, & Recklitis, 2007) and response shift whereby evaluation of current well-being may be based on a different internal standard (e.g., comparing selves to those still suffering cancer-related problems; Schwartz et al., 1999). Alternatively, survivors may be resilient—they may engage in positive growth that enhances their view of their quality of life and sense of triumph over cancer. The low HRH related to management of health for cancer survivors without late effects is not surprising given findings that cancer survivors often exercise and engage in other health promoting behaviors at the same or lower rates compared to peers (Florin et al., 2007).

Despite differences on HRH, there were no group differences on the content of goals. Interpersonal and Academic/Occupational goals were most frequently identified. The findings suggest that young adults, irrespective of their illness history or health-related burdens, aim to achieve goals in domains of functioning that are normative for their age group (Little, 2000; Nurmi 1989; Schulenberg et al., 2004) rather than focusing on disease-specific goals.

Several limitations of the study should be considered. Given the limited demographics of the sample, replication is recommended with samples that include a broader range of ages, health histories, and ethnic identities. The use of snowball recruitment may also affect the characteristics of some of the control group participants when recruited by young adults with chronic illness histories with whom they have a close relationship. In addition, although phone calls were made to answer participants’ questions and assure compliance with measure completion, the “mail-in” procedures may limit quality control and investigators’ ability to observe how measures were completed. Another limitation was the reliance on self-report data, including self-report of late effects for the cancer survivors. In addition, it is unknown if results would be similar if HRH was assessed as a specific construct apart from a broader assessment of goals, if a smaller response scale were used to reduce the potential for positively skewed data, and if HRH were compared to other measures of HRQOL or functional status. However, it should be noted that HRH was the most internally consistent factor among the larger goal measure and warrants the development of its own measure to further test the psychometrics of HRH. Last, the content coding of the goals represents broad categories and do not reflect variations in significance, specificity, or timing of the goals.

Because of the potential importance of goals to well-being and disease management in pediatric patients, especially those transitioning to adulthood and adult health care, there are many research and clinical implications of this study related to pediatric populations. Longitudinal research is needed to examine: (1) whether HRH and emotional outcomes is a linear or bidirectional relationship, (2) the process of setting personal and disease-related goals during emerging adulthood, (3) how content of goals and related appraisals change when having a chronic illness, and (4) the relationship of goals and HRH to treatment adherence and disease management (Schwartz & Drotar, 2006). Such research would ideally begin in adolescence, as this is the developmental stage when youth begin to autonomously set and pursue goals related to transition to adulthood, have the cognitive capability to reflect on the impact of health on those goals, may be

especially vulnerable to HRH given adolescent desire for normalcy and tendency to maintain developmentally typical goals, and are more likely to be nonadherent to treatment regimens and health-promoting behaviors. Finally, the sensitivity of HRH to the impact of chronic health problems and outcomes of psychosocial interventions with pediatric chronic illness populations should be documented in future research (Drotar, 2006).

It is clinically important to elicit goals of patients and perceived health burdens to guide interventions. Motivational interviewing or paper and pencil techniques such as that in the current study are potential methodologies. Important foci of interventions may include setting feasible health-related goals and changing the burden of health and treatment on personal goals. For example, interventions that enhance goal-related efficacy and reduce HRH by helping patients pursue more realistic goals, or altering treatment regimens to be more compatible with personal goals, may improve psychosocial outcomes and adherence to treatments. The success of such interventions is likely dependent on support from families and providers to help with goal pursuit or modifying personal and/or treatment goals.

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