FACTORS ASSOCIATED WITH THE HEALTH-RELATED QUALITY OF LIFE IN PEDIATRIC STEM CELL TRANSPLANT PATIENTS

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By
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FACTORS ASSOCIATED WITH THE HEALTH-RELATED QUALITY OF LIFE IN PEDIATRIC STEM CELL TRANSPLANT PATIENTS

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ABSTRACT

FACTORS ASSOCIATED WITH THE HEALTH-RELATED QUALITY OF LIFE IN PEDIATRIC STEM CELL TRANSPLANT PATIENTS

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University of Dayton

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Stem Cell Transplants (SCT) are becoming a widely used procedure for many pediatric illnesses such as different types of cancer and immune disorders. SCT is an invasive and stressful procedure in which the child is injected with healthy stem cells. This study aims to examine the child health-related quality of life (HRQOL) post-transplant in relation to family communication. Family relationships, as they relate to the child’s quality of life have been understudied in this vulnerable population. Age of the child and socio-economic status were also examined in the relationship. In the current study, as part of a larger study on transplantation and home medication adherence, 58 caregivers answered questionnaires regarding their children’s HRQOL and family communication soon after the transplant. It was hypothesized that family communication would predict quality of life post-transplant and that age and socio-economic status would act as moderators in this relationship. Analysis indicated that family communication did not significantly
predict child HRQOL. Further, child age and SES did not significantly contribute to the relationship between child HRQOL and family communication. Future research may focus on these variables throughout the transplantation process and recovery, as well as include data from both caregivers and children receiving the SCT.

*Keywords*: health-related quality of life, pediatric stem cell transplantation, family communication
Dedicated to my parents, both of who have been inspirational in following my dreams.
ACKNOWLEDGEMENTS

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INTRODUCTION

Stem cell transplants (SCT) have increasingly become a treatment option for children with a wide array of illnesses including leukemia, blood diseases and immune disorders (National Heart Lung and Blood Institute [NHLBI], 2011). A stem cell transplant is the collection and transplantation of stem cells, which may come from a variety of different sources such as bone marrow, peripheral blood or cord blood (American Cancer Society, 2012). The source of the stem cells are important in that depending on where the stem cells are collected from, the procedure may be called a bone marrow transplant, a peripheral blood stem cell transplant or a cord blood transplant; however they are all referred to as a hematopoietic stem cell transplant (American Cancer Society, 2012). The stem cells that are collected are used to replace stem cells that may have been damaged as a result of a specific disease or medical treatments such as chemotherapy or radiation (American Cancer Society, 2012). According to the Center for International Blood and Marrow Transplant Research, approximately 2,600 children and adolescents, defined as 20 years and younger, received a hematopoietic stem cell transplant in 2009 (Pasquini & Wang, 2011). These stem cells are provided by the patient’s own stem cells (i.e., an autologous transplant) or from a donor, such as a family member or unrelated donor (i.e., an allogeneic transplant) (NHLBI, 2011). Children and
adolescents under the age of 20 make up about 20% of all allogeneic and 5% of all autologous transplant patients (Pasquini & Wang, 2011). After the transplantation is performed, it may seem that the medical concern for the child should diminish because the stem cells are infused and the transplant is finished, but in actuality this time is characterized as a critical period in terms of adverse effects from the procedure (American Cancer Society, 2012). For patients who have received a transplant, one of the most serious dangers is the vulnerability to infection soon after the transplant because the patient’s immune system must be suppressed to encourage engraftment (NHLBI, 2011). Due to the risk of infection, the child must be hospitalized in order to receive medications to aid in the transplanted stem cells cultivation and to reduce the chance of infection (NHLBI, 2011). Additionally, there is also a chance that the child may become critically ill after the transplantation in the event that their body rejects the newly implemented stem cells. If rejection happens, they may suffer from graft-versus-host disease or graft failure, which becomes another obstacle in recovery and could lead to the death of the child (NHLBI, 2011). A study that examined chronic graft-versus-host disease and nonrelapse mortality rate of the children, found that by 3 years after the diagnosis of chronic graft-versus-host disease, approximately one third of the children had died, either from relapse or nonrelapse mortality (Jacobsohn et al., 2011). Thus, this is a serious health concern for patients receiving SCT and for their families.

**Health-Related Quality of Life Following Pediatric Stem Cell Transplant**

Given this extreme medical stressor, it is important to examine the child’s adjustment to the transplantation as it may complicate physical recovery (Tanzi, 2011).
An aspect that is important to understanding a child’s transplant experience is the child’s quality of life (QOL). The World Health Organization defines QOL as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL Group, 1993, p. 153). It has been noted that QOL is usually affected by the individual’s physical health, mental state, social functioning and their relationship to their environment (WHOQOL Group, 1993). More specific to pediatric illnesses is Health-Related Quality of Life (HRQOL), which is similar to QOL in that they both are concerned with multidimensional aspects of a person’s life; however HRQOL refers more to how the person’s health is impacting their QOL (Eisen, Ware, Donald, & Brook, 1979). Varni, Burwinkle, Seid, and Skarr (2003) emphasize that an important aspect of HRQOL is the psychosocial dimensions, which include emotional, social and role functioning. They also report the importance of a HRQOL as being multidimensional; minimally, considerations for physical, mental and social health categories are needed. For example, a child’s post-transplant HRQOL may be related to their impaired physical state, the emotions associated with long-term hospitalization and the negative consequences that may come from being separated from peers and family for a prolonged time period.

The medical aspects of SCT have been intensely researched, but much less consideration has been given to the potential psychosocial effects of transplantation, such as effects on QOL (Packman, Weber, Wallace, & Bugescu, 2010). Researchers have found that at the time of the transplantation and up to 4 to 5 weeks after this procedure, children may experience a period of increased stress and hardship (Phipps, Dunavant,
Garvie, Lensing, & Rai, 2002). In a meta-analysis on HRQOL in relation to pediatric bone marrow transplant (BMT) patients, a type of SCT, Clarke, Eiser, and Skinner (2008) outlined the trajectory of the transplant experience and reported on the child’s HRQOL. They report that children may enter the hospital for the SCT with a low baseline HRQOL, however children’s HRQOL usually steadily improves 4 to 12 months post-transplant, with social, behavioral and cognitive functioning returning to a normal range within 3 years post-transplant.

Similarly, in a longitudinal study on children who received a BMT at St. Jude’s Children’s Hospital, Phipps, Dunavant, Garvie, Lensing, and Rai (2002) examined the HRQOL throughout the transplant experience. The HRQOL was measured using a parent and child-report questionnaire that examined the specific domains of somatic distress, mood disturbance, compliance, quality of interactions, and activity. They found that upon admittance to the hospital for the transplant, the caregivers rated their children as having high levels of distress, which was characterized by frequent somatic complaints, low physical activity and higher levels of mood disturbances. In this sample the ratings on the distress scale increased and were highest about a week after the procedure. Concurrent with the findings of Clarke, Eiser, and Skinner (2008), one week before and the first month following the transplantation have been found to be very stressful periods for the children and their parents.

Further, Parsons et al. (2006) conducted a study examining the HRQOL in hematopoietic stem cell transplant (HSCT) patients in their first year of recovery. Each caregiver completed a HRQOL measure at pre-transplant baseline that measured physical functioning, role functioning, emotional functioning, and energy. Also, each caregiver
completed the measure 3, 6, and 12-month post-transplant. Like the other studies found, the lowest rating of HRQOL was right before the transplant and 3-months post-transplant. The authors found that the largest improvement of HRQOL was between the 3-month and 6-month post-transplant, and that the rating of HRQOL continued to improve to the last time point assessed. This study supports previous findings that overall HRQOL improves approximately 3 to 4-months post-transplant.

Felder-Puig et al. (2006) studied patients who had a BMT and assessed the child’s HRQOL throughout the transplant process. The researchers assessed HRQOL through the subscales of physical, emotional, social and school functioning, and additionally a cancer specific HRQOL measure. Supporting the findings of Clarke, Eiser, and Skinner (2008), Felder-Puig et al. (2006) found that the patients and their parents’ denoted that 10 days post-transplant was when the child experienced the worst HRQOL. However, it was found that following this 10-day period after the transplantation, that most of the patients HRQOL steadily improved until a year later (i.e., the last time point assessed in the study).

In addition to overall HRQOL, past research has examined the specific HRQOL domains of social, emotional, physical and school functioning. The aspect of physical functioning is important, especially to the SCT population because of how poor and compromised the child’s health may be after the transplantation. Unfortunately, after the procedure many children may be subject to experiencing many negative health symptoms as a result of the transplantation. The child undergoes a rigorous procedure in which their immune system is lowered, and the child may suffer physically, such as feeling nauseous post-transplant (Parsons et al., 2006). Felder-Puig et al. (2006) found that feelings of
nausea were rated highest at 10 days post-transplantation. Children who have endured a SCT also frequently exhibit symptoms of pain, fatigue and dry skin (Tanzi, 2011). The researchers also note that according to both parent and children report, that the child’s pain was highest at 10 days post-transplant.

Research has also indicated that the physical domain of HRQOL may also relate to the social domain. Felder-Puig et al. (2006) found that the children who received BMT who identified themselves as better physically, usually rated themselves better socially as well. Phipps and Mulhern (1995) examined social competence in children receiving a BMT pre- and post-transplant, and found a mild decline in social scores 2-12 months post-transplant, signifying a mild to moderate degree of dysfunction in terms of social competence for the children. However, Kupst et al. (2002) found in their sample of hematopoietic stem cell transplant survivors that caregivers rated their child’s social competence within normal range 2 years after the transplant. Thus, soon after the transplant may be hard socially for the child, but it is suggested that over time their social competence may return to a normal range.

In terms of the emotional functioning component of HRQOL, moderate mood disturbances in both caregiver and patient reports, especially between 1 to 2 weeks post-transplantation have been found (Phipps, Dunavant, Garvie et al., 2002). Felder-Puig et al. (2006) also state that children and parents reported having lower emotional functioning post-transplantation, and that variables such as decreased communication while in the transplant unit, and increased levels of worry and anxiety might also have negative effects on the patients’ emotional functioning. Stem cell transplants are unique compared to other pediatric illnesses because of the procedure’s intensity, which requires
extended patient hospitalization, and isolation due to a compromised immune system (Packman, Weber, Wallace, & Bugescu, 2010). The child usually stays in isolation to avoid infection and will receive very few visitors because of their lowered immune system, which can ultimately contribute to their lowered emotional functioning.

**Family Variables**

A Family Systems framework is often considered when it comes to children with medical problems because of its emphasis on the importance of evaluating the child’s behavior in the context of something bigger, in this case the family (Kazak, Simms, & Rourke, 2002). Brown (2002) emphasizes that when a child has a chronic illness, the effect on the family is inevitable and pervading, and that the family also has a substantial influence on the child with the illness. Taking a family systems model, there are many things to consider in terms of a child’s illness such as family flexibility, family needs and responsibilities, family boundaries and communication (Kazak, Rourke, & Navsaria, 2009). These researchers state that family dysfunction may influence the disease course or outcome, and that family environment can indeed influence an individual’s experience of the illness.

Phipps and Mulhern (1995) have evaluated family environment as it relates to the SCT patient’s QOL. They examined children undergoing BMT by collecting data on family functioning, self-esteem and behavioral functioning before and after the procedure (between 6 to 12 months post-transplant). It was found that there was a significant increase of family expressiveness after the BMT, however there were no significant changes in family conflict or cohesion. They found that family expressiveness and
cohesion acted as a protective factor, in terms of the child’s adjustment and that these protective factors become an even bigger influence during a highly stressful time. Both family expressiveness and cohesion, in this way, can be considered variables that promote resiliency in the face of stressors associated with BMT. It was also found that family conflict acted as a risk factor in adjustment, and that the negative influence of family conflict was manifested regardless of the families’ underlying stress levels.

Barrera, Pringle, Sumbler, and Saunders (2000) also examined the relationship between family factors and the patients’ QOL pre- and post- transplant. The authors assessed the family variables of cohesion and adaptability. They reported that pre-transplant only family cohesion was related to the child’s QOL at 6 months after the BMT. More specifically, the authors found that higher levels of cohesion were related to higher QOL scores in the child survivors. Barrera, Pringle, Sumbler, and Saunders (2000) suggest, in support of Phipps and Mulhern’s (1995) findings that family variables may serve as protective factors for the child, in terms of post-transplant QOL.

Family Communication

While some researchers have examined family variables such as expressiveness and cohesion in the context of the family, less has been done with family communication. Family communication is defined as “the act of making information, ideas, thoughts and feelings known among members of a family unit” (Olson & Barnes, n.d. p. 1). In general, Wallander and Varni (1998) report that communication and interactions amongst family members can be disrupted because of the child’s disease, and this lack of communication can be a stressor for the whole family. Supporting this, Herzer et al. (2010) found that in
a sample of 301 families of children who had chronic illnesses, 28% of caregivers perceived “unhealthy” family functioning in the area of communication. Jobe-Shields et al. (2009) also suggest that one specific stressor for SCT patients could be that frequently one parent stays with the child throughout the procedure, spending a lot of time away from home and the family, which as a result can strain the family system and the communication amongst family members.

While there is a relative lack of research on family communication as it relates to HRQOL in the pediatric SCT population, this relationship has been studied in a number of other pediatric illness populations. Herzer, Denson, Baldassano, and Hommel (2011) conducted a study on patients diagnosed with Inflammatory Bowel Disease (IBD), and the association between family factors and HRQOL. They found that families who reported more difficulties in the domain of family communication also expressed decreased feelings of well-being. Similarly, in a sample of pediatric asthma patients, Sawyer, Spurrier, Kennedy, and Martin (2001) found that emotional functioning and physical domains of QOL were significantly related to family communication. That is, children who live in a household with more open communication reported better emotional responses and fewer physical symptoms. Finally, QOL has been found to be related to family communication in pediatric patients with diabetes. Weissberg- Benchell et al. (2009) conducted a multi-site study with children who had been diagnosed with Type 1 diabetes and their families in order to examine HRQOL and diabetes-specific family variables, such as conflict, family interactions and family responsibility. In this study, higher amounts of parent reported diabetes-specific conflict was significantly related to lower levels of general and diabetes-specific HRQOL. Similarly, per child
report it was found that negative family diabetes specific communication was significantly related to reports of disease-specific HRQOL. While these studies are corralational in nature and thus directionality cannot be inferred, they still provide evidence for an underlying relationship between HRQOL and family communication in pediatric populations.

**Demographic Factors Related to QOL**

Several demographic factors have been found to relate to both HRQOL and family communication in the SCT patients and other pediatric populations. Below, age and socioeconomic status (SES) are presented as two important factors to consider in order to more accurately examine the relationship between family variables and QOL. Both demographic variables and how they relate to family variables and QOL, could contribute to the understanding of families’ post-transplant experience.

**Child Age**

According to Rolland (1988), children at different developmental time periods could be more threatened by the onset of a chronic illness. Age has been directly identified as an important factor in the SCT literature, with many studies finding older age being associated with more negative outcomes. Phipps, Dunavant, Lensing, and Rai (2002) assessed HRQOL in children who underwent a BMT, and found that as the age of the child increased, the more reported disturbance in a child’s HRQOL. So it seemed that the older the child the more likely that they reported having more problems with HRQOL. The authors reported that younger children tolerated the BMT with fewer problems while adolescents and older children experienced more distress. Tanzi (2011)
also noted the importance of age differences in children undergoing SCT, stating that it has been found that older children and adolescents usually experience higher levels of discomfort and distress compared to younger children. Similarly, in a sample of children aged 5 to 20 who had received a hematopoietic stem cell transplant, Parsons et al. (2006) found that the age of the child was significantly associated with the domains of physical and emotional functioning. Like Phipps, Dunavant, Lensing, et al. (2002), it was found that parent’s of older children and adolescents reported lower HRQOL.

In addition to the relationship between child age and reported HRQOL, age differences in terms of family interaction and communication have also been cited in literature (Laursen & Collins, 2004). Laursen and Collins (2004) stated that families with children who are transitioning from childhood to adolescence experience many changes in their interactions. For example, research has found that problems with communication within the family increase with the age of the adolescent and that younger adolescents have reported more open and positive communication with their parents as compared to older adolescents (Jackson, Bijstra, Oostra, & Bosma, 1998). It has been suggested that earlier in adolescence it may be easier for the child to accept their parent’s suggestions and perspectives, but as the child ages and different situations come up, there may be more room for conflict and differences in views (Jackson, Bijstra, Oostra, & Bosma, 1998).

Steinberg and Silk (2002) report that during adolescence there seems to be less positive expressions and emotions and therefore more negative expressions and emotions than in childhood. The authors also note that these negative expressions and emotions may be expressed in terms of less shared activities and decreased expression of affect.
Lack of positive affect and more negative emotions may contribute to a deficit in the families’ communication. Larson, Richards, Moneta, Holmbeck, and Duckett (1996) found on a sample of middle- and working-class youth as a child gets older, especially in the pre-adolescence to adolescent years, they spend increasingly less time with their parents. This could be another factor that contributes to a lack of perceived communication or miscommunication in the family life.

The link between family communication and child age has been supported within the pediatric literature. Herzer et al. (2010) performed data analysis on six independent studies that included information on the following pediatric populations: cystic fibrosis, obesity, sickle cell disease, inflammatory bowel disease, epilepsy, and a healthy comparison group. The family variables that were assessed were the following: problem solving, communication, roles, affective responsiveness, affective involvement, and behavioral control. The researchers found a significant correlation between the age of the child and the communication score on the measure administered, with older age being associated with poorer family communication. The authors suggest that this difference may be attributed to adolescence as a time when children resist parental authority and act increasingly autonomous.

Socio-Economic Status

The relationship between socio-economic status (SES) and HRQOL has been examined and supported in the pediatric SCT literature. Phipps, Dunavant, Lensing, et al. (2002) examined family SES as it related to HRQOL of children receiving SCT. The families were identified as social class “high,” “intermediate” or “low,” via family
resources and parental education. Parents in the low SES group rated their children’s HRQOL as significantly lower than the high and intermediate social groups; however, the intermediate and high groups did not differ statistically. Further, they found that during the transitional period from the hospital to home care it was determined that the SES effect was greater, with the lower SES group reporting a lower HRQOL than the other two groups.

Family variables have also been found to relate to SES in pediatric populations. Herzer et al. (2010) examined six different pediatric populations and a healthy comparison group and found an association between family income and family communication, indicating that lower family income was related to poorer family communication across the pediatric populations. Northam, Anderson, Adler, Werther, and Warne (1995) also examined the relationship between family functioning and SES in families with recently diagnosed children with insulin-dependent diabetes. The researchers utilized a questionnaire on family functioning, and SES was classified as high, middle or low based on the father’s occupation. The specific family functioning constructs measured were family cohesion and adaptability, and it was found that for mother respondents there was a significant main effect for SES on both family adaptability and cohesion. On the family adaptability scale, mothers and fathers who identified as having a high SES reported having higher scores of family adaptability, and on the cohesion scale, mothers with lower reported SES identified as having lower family cohesion scores. Likewise, Holmbeck, Coakley, Hommeyer, Shapera, and Westhoven (2002) conducted a study on family functioning in families with pre-adolescent children with spina bifida. The parents and child were administered questionnaires regarding
family functioning (such as cohesion and conflict) and were also observed during specific family interaction tasks. It was found that the families with lower SES had less self-reported and observed family cohesion, and more mother-child conflict and stressful life events. Kazak, Rourke, and Navsaria (2009), also noted the importance of how an outside factor, such as SES can shape and influence a family’s disease experience and adjustment.

**Current Study**

The present study was designed to examine the relationship between family variables, specifically that of communication and health-related quality of life in children and adolescents who have recently undergone a stem cell transplant. The literature in many different pediatric illnesses (e.g., asthma, diabetes & IBD), support the relationship between family communication and HRQOL. Particularly, poorer communication has been shown to relate to lower reports of HRQOL. Some research has also been done in SCT patients in terms of other family variables, such as cohesion and adaptability, suggesting that family variables indeed play a role in children’s adjustment to a SCT. If the family variable of communication acts in the same protective manner as many other variables that have been studied (i.e., cohesion and adaptability) in SCT patients, this could provide useful knowledge both clinically and for future research, of how the family environment relates to the child’s overall quality of life.

In the current study, the following hypotheses were predicted and examined: (1) Parent’s perception of family communication would predict parent report of child HRQOL, (2) Age of the child would moderate the relationship between family
communication and HRQOL, with older age significantly strengthening the relationship and finally, (3) SES would also act as a moderator between the family communication and HRQOL, with lower SES strengthening the relationship.
METHOD

Participants

 Seventy-four families whose child had received a SCT agreed to participate as part of a larger post-transplant study at Cincinnati Children’s Hospital Medical Center (CCHMC) (Pai, 2013). In all, 83% of the families who were eligible for the larger study agreed to participate. The inclusion criteria for the study were as follows: (a) the patient was under the age of 19 years, (b) the patient received a stem cell transplant, (c) the patient, upon discharge, had been prescribed a medication regimen, (d) the patient lived with the caregiver, (e) the patient had at least one caregiver that helped with the patient’s medical care that was willing to participate, (f) the legal guardian was willing to give informed consent and the patient was willing to give assent, and (g) the patient and caregiver were fluent in English. Out of the 74 caregivers, 16 were removed due to incomplete data in accordance with the scoring of the PedsQL, resulting in a final sample of 58 caregivers. The 16 (22%) excluded families were not significantly different on any demographic information compared to the 58 used in the current study.

 Due to the young age of some of the children receiving the transplant ($M = 8.19$, $SD = 4.49$) parent reports were used for the current study; in other SCT literature, the primary respondent for the child has been the caregiver as well (e.g., Parsons et al. 2006,
Barrera et al. 2000). In fact, Felder-Puig et al. (2006) examined HRQOL in children undergoing allogeneic stem cell transplants and BMT, having both parents and children fill out questionnaires. It was found that the agreement between child and parent reports on the HRQOL measure was moderate to good, with the best agreement in the time points of 10 days and 28 days after the transplantation (Felder-Puig et al. 2006). The questionnaires in this study were given right before discharge from the hospital, so it was close to the time period Felder-Puig et al. (2006) found good agreement between the child report and caregiver report.

Demographic information for the 58 participants is presented in Table 1. The mean age of the caregiver respondent was 36.14 (SD = 8.14). As shown in Table 1, there were four disease types represented in the sample, and they were: oncology, hematology, immunology and metabolic patients. The average length of inpatient stay for the current hospital admission was 37.03 (SD = 24.83) days for the patients in the study.

**Measures**

**Demographic Form**

Each caregiver was asked to complete a demographic form at baseline. This demographic form included: patient age, gender, ethnicity, caregiver relationship status, caregiver income, and caregiver education (See Appendix A).

**Pediatric Quality of Life Inventory 4.0 (PedsQL)**

The PedsQL is a 23-item self-report measure of health-related quality of life, consisting of four subscales: physical functioning, emotional functioning, social
<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
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<tr>
<td>5-7</td>
<td>15</td>
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<td>8-12</td>
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<td>13-17</td>
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<tr>
<td><strong>Child Gender</strong></td>
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<tr>
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<tr>
<td>Male</td>
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<td>58.6%</td>
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<tr>
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<td><strong>Child Disease Type</strong></td>
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<td><strong>Socioeconomic Status</strong></td>
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<td>3.4%</td>
</tr>
<tr>
<td>$90,000- 99,999</td>
<td>3</td>
<td>5.2%</td>
</tr>
<tr>
<td>More than $100,000</td>
<td>11</td>
<td>19.0%</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>5.2%</td>
</tr>
<tr>
<td><strong>Family Communication Level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Low</td>
<td>4</td>
<td>6.9%</td>
</tr>
<tr>
<td>Low</td>
<td>7</td>
<td>12.1%</td>
</tr>
<tr>
<td>Moderate</td>
<td>6</td>
<td>10.3%</td>
</tr>
<tr>
<td>High</td>
<td>22</td>
<td>37.9%</td>
</tr>
<tr>
<td>Very High</td>
<td>19</td>
<td>32.8%</td>
</tr>
</tbody>
</table>
functioning and school functioning (Varni, Burwinkle, Katz, et al., 2002). The parent-
report of the child/adolescent functioning is rated on a 5-point Likert scale, ranging from
(0) “Never a problem,” to (4) “Almost always a problem” (Varni, Burwinkle, Katz, et al.,
2002). Parent reports are available for the following age ranges: 2-4, 5-7, 8-12 and 13-18.
Parents are asked if the child has had difficulties in past seven days regarding: physical
functioning, emotional functioning, social functioning and school functioning (Varni,
1998). Previous studies have reported internal consistencies of .90 for the Total Scale
Score (Varni, Burwinkle, Seid, & Skarr, 2003). In particular, the PedsQL parent report
has been showed to be reliable in many different pediatric illnesses, such as children with
cancer, (α = .93), diabetes (α = .89) and asthma (α = .91) (Varni, Burwinkle, Katz, et al.
2002; Varni, Burwinkle, Jacobs, Gottschalk, & Kaufman 2003; Varni, Burwinkle,
Rapoff, Kamps, & Olson 2004). The internal reliability for this study was .85 for the full-
scale score and the individual scale scores ranged from .76 to .88.

Scoring of the HRQOL measure was done in accordance to Varni’s (2013)
scoring rubric. Because of this, some data sets were considered incomplete (less than
50% of questions answered), and were not used in analysis. This left a total of 58 data
sets with full-scale HRQOL scores for analysis.

Family Communication Scale (FACES-IV Companion Scale)

The Family Communication Scale is a companion self-report assessment to the
Family Adaptability and Cohesion Evaluation Scales (FACES- IV). The Family
Communication Scale, which is used in the present study, is a 10-item assessment
measure of family communication satisfaction (Olson and Barnes, n.d.). The Family Communication Scale was based off of the Parent-Adolescent Communication Scale, which measures communication between adolescents and their families (Olson and Barnes, n.d.). Conversely, the Communication Scale is a shorter scale that is not limited to adolescents and their families; this scale allows for families experiencing various and different life cycles (Olson and Barnes, n.d.). The Communication Scale asks questions such as “Family members are satisfied with how they communicate with each other,” “Family members are very good listeners,” and “Family members express affection to each other.” Respondents are asked to respond on a 5-point Likert scale ranging from (1) “Does not describe our family at all” to (5) “Very well describes our family.” Olson and Barnes (n.d.) provide an interpretation scale for scores which indicate the family’s communication level based on the total score; Table 1 highlights the levels for the families in the current study. The internal consistency reliability of the scale is .90 (Olson and Barnes, n.d.). In the current studies sample the internal consistency reliability for the Family Communication Scale was .91.

**Procedure**

The present study is a part of a larger study on stem cell transplantation and home medication adherence conducted at CCHMC (Pai, 2013). The CCHMC IRB committee approved the study. Each family had a child who received a SCT, and was visited in their hospital room before they were discharged from the hospital. During the visit, the researcher informed the family of the study, and collected parental consent and child assent if the family agreed to participate. The researcher then administered the battery of questionnaires to the caregiver of the child in the order as follows: Consent form,
Psychosocial Assessment Tool (PAT 2.0)*, Demographic Form, Pediatric Quality of Life Inventory (PedsQL), Adherence Expectations Scale (AES-C)*, Parent Medication Barriers Scale (PMBS)*, Social Problem- Solving Inventory for Adults (SPSI-R:S)*, Family Communication Scale (FACES IV), Collective Family Efficacy Beliefs (PCFE)*, Medical Adherence Measure (MAM)* and Permission to recontact form*. The baseline battery of questionnaires took the families about 60-75 minutes to complete. The researcher was available for questions while the families completed the questionnaires, and reimbursed the family afterwards.

1 Note: asterisk (*) indicates measures not included in current study.
RESULTS

Preliminary Analyses

Data analysis was conducted in three stages. First, the primary variables of interest (HRQOL score and the family communication score) were calculated. Table 2 summarizes the mean and standard deviations for these continuous variables in the study.

Preliminary analyses were conducted to examine the relationship between the criterion variables (i.e., family communication and health-related quality of life) and participant demographic variables in order to assess for the possibility of confounding variables. First, correlations were completed between study and demographic variables (Table 3). There were no significant correlations between HRQOL and family communication, in regards to child age or gender.

Since the child’s gender could be a possible confounding variable, it was examined in regards to its relationship with the main variables in the study. The association between the child’s gender and HRQOL was analyzed using an independent sample T-test. The results revealed no significant differences between child gender and HRQOL, $t(56) = -0.87, p = .39$. The association between child gender and family communication was also analyzed using an independent sample T-test; there was no significant differences, $t(56) = -1.60, p = .13$. There were also no significant differences in
Table 2

*Descriptive Statistics for Main Study Variables*

<table>
<thead>
<tr>
<th>Variables</th>
<th>Mean</th>
<th>Std. Dev.</th>
</tr>
</thead>
<tbody>
<tr>
<td>PedsQL Total Score</td>
<td>58.02</td>
<td>20.29</td>
</tr>
<tr>
<td>Physical</td>
<td>45.42</td>
<td>29.08</td>
</tr>
<tr>
<td>Emotional</td>
<td>62.41</td>
<td>19.45</td>
</tr>
<tr>
<td>Social</td>
<td>74.09</td>
<td>24.00</td>
</tr>
<tr>
<td>School</td>
<td>65.58</td>
<td>24.46</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>67.34</td>
<td>19.22</td>
</tr>
<tr>
<td>Family Communication</td>
<td>41.28</td>
<td>6.35</td>
</tr>
<tr>
<td>Number of Days Since Transplant</td>
<td>37.03</td>
<td>24.83</td>
</tr>
</tbody>
</table>
Table 3: Correlational Matrix

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Age</td>
<td>0.012</td>
<td>0.211</td>
<td>0.166</td>
<td>0.077</td>
<td>0.0</td>
<td>0.23</td>
<td>0.0</td>
<td>0.0</td>
<td>0.070</td>
<td>0.070</td>
<td>0.1</td>
<td>0.0</td>
</tr>
<tr>
<td>Patient Gender</td>
<td>0.135</td>
<td>0.204</td>
<td>0.166</td>
<td>0.091</td>
<td>0.087</td>
<td>0.178</td>
<td>0.0</td>
<td>0.0</td>
<td>0.087</td>
<td>0.070</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Type of Illness</td>
<td>0.135</td>
<td>0.204</td>
<td>0.166</td>
<td>0.091</td>
<td>0.087</td>
<td>0.178</td>
<td>0.0</td>
<td>0.0</td>
<td>0.087</td>
<td>0.070</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Family Communication Score</td>
<td>0.04</td>
<td>0.04</td>
<td>0.076</td>
<td>0.76</td>
<td>0.786</td>
<td>0.863*</td>
<td>0.44</td>
<td>0.44</td>
<td>0.865*</td>
<td>0.544</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>HRQOL Total Score</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Physical Subscale</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Emotional Subscale</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Social Subscale</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Psychosocial Subscale</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>School Subscale</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Days Inpatient</td>
<td>0.03</td>
<td>0.02</td>
<td>0.23</td>
<td>0.053</td>
<td>0.004</td>
<td>0.007</td>
<td>0.0</td>
<td>0.0</td>
<td>0.088</td>
<td>0.070</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Family Income</td>
<td>0.003</td>
<td>0.022</td>
<td>0.76</td>
<td>0.43</td>
<td>0.001</td>
<td>0.07</td>
<td>0.0</td>
<td>0.0</td>
<td>0.087</td>
<td>0.070</td>
<td>0.0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

Notes: *p < .05; **p < .01
child gender, examining SES and child age, \( t(53) = 0.66, p = 0.51 \) and \( t(56) = -0.09, p = 0.93 \) respectively.

Disease type was also examined before analysis to determine if it could be considered a confounding variable. The association between patient disease type (oncology, immunology, hematology and metabolic) and criterion variables (HRQOL, family communication) was analyzed using a one-way Analysis of Variance (ANOVA). The metabolic group was excluded from the ANOVA analysis due to only having one participant in the sample. The results revealed no significant differences between HRQOL and patient disease type, \( F(2, 54) = 0.76, p = 0.47 \). There were also no significant differences between family communication and patient disease type \( F(2, 54) = 0.01, p = 0.99 \). There was no significant differences between patient age and disease type, \( F(2, 54) = 2.19, p = 0.12 \). Finally, there was also no significant differences in regards to patient age and SES, \( F(2, 51) = 0.02, p = 0.98 \).

**HRQOL and Family Communication**

Next, the predictions addressed in the hypotheses were analyzed. The first hypothesis stated that parent’s perception of family communication would predict parent report of child HRQOL. A linear regression model was used to test this hypothesis. The results from the linear regression did not suggest that a significant proportion of the variation in the HRQOL was predicted by family communication (Table 4).

The second hypothesis stated that the age of the child would moderate the relationship between family communication and HRQOL, with older age significantly strengthening the relationship. A linear regression model was used to test this hypothesis;
the predictor variables were centered before tested, as suggested by Preacher (2003). To test this relationship, HRQOL was entered into the model as a dependent variable, followed by family communication and child age; then the interaction of the centered variables of family communication and age were entered into the equation, as the predictors. The results yielded no significant Family Communication x Age interactions for HRQOL (Table 5).

The third hypothesis predicted that SES would also act as a moderator between family communication and HRQOL, with lower SES strengthening the relationship. Three participants were excluded from analysis, due to no indication of income on the demographic measure. A linear regression model was used to test this hypothesis. The families SES was defined as the amount of income indicated on the demographics questionnaire divided by the number of individuals in the family. Both predictor variables were centered before analyzed. To test this relationship, HRQOL was entered into the model as a dependent variable; then family communication and the SES variable were entered, and finally interaction of the centered family communication and SES interaction were entered, as the predictors. The results yielded no significant Family Communication x SES interactions for HRQOL (Table 6).
Table 4

*Linear Regression Analysis Predicting Health-Related Quality of Life from Family Communication*

<table>
<thead>
<tr>
<th>Variable</th>
<th>b</th>
<th>Beta</th>
<th>t</th>
<th>$R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Communication</td>
<td>.012</td>
<td>.004</td>
<td>.028</td>
<td>.000</td>
</tr>
</tbody>
</table>
Table 5

*Linear Regression Analysis Predicting Health-Related Quality of Life from Family Communication x Age Interaction*

<table>
<thead>
<tr>
<th>Variable</th>
<th>b</th>
<th>Beta</th>
<th>t</th>
<th>(R^2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>.054</td>
<td>.017</td>
<td>.125</td>
<td>.017</td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>.360</td>
<td>.080</td>
<td>.581</td>
<td>.017</td>
</tr>
<tr>
<td>Step 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FC X A</td>
<td>-.077</td>
<td>-.102</td>
<td>-.769</td>
<td>.017</td>
</tr>
</tbody>
</table>

*Notes: FC x A = Family Communication x Age interaction*
Table 6

Linear Regression Analysis Predicting Health-Related Quality of Life from Family Communication x Socioeconomic Status (SES) Interaction

<table>
<thead>
<tr>
<th>Variable</th>
<th>b</th>
<th>Beta</th>
<th>t</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>-.212</td>
<td>-.069</td>
<td>-.462</td>
<td>.012</td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SES</td>
<td>.341</td>
<td>-.016</td>
<td>-.106</td>
<td>.012</td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FC x SES</td>
<td>-.464</td>
<td>-.106</td>
<td>-.678</td>
<td>.012</td>
</tr>
</tbody>
</table>

**Notes:** FC x SES = Family Communication x SES interaction
DISCUSSION

The transplant process can be considered an extreme stressor for the child and their family; therefore research on the population is important to learn more about how the families cope with this medical stressor. Few studies have investigated the relationship between family variables and HRQOL in children who received a SCT (Phipps & Mulhern, 1995; Barrera, Pringle, Sumbler, and Saunders, 2000), and more specifically, no study has assessed the relationship between HRQOL and the specific variable of family communication. The current study investigated this relationship, as well as the potential moderating effects of SES and child age.

The current study found that following SCT parent reports of their child’s health-related quality of life is low. Mean parent report for child HRQOL was 58.02 (SD = 20.29), which is in accordance with research suggesting lower levels of HRQOL in the initial post-transplant period (Phipps, Dunavant, Garvie et al., 2002; Felder- Puig et al., 2006). The quality of life reported in this study is also lower than those that have been reported in oncology patients and a healthy comparison groups. Varni et al. (2002) found in a sample of oncology patients that the mean parent-rated HRQOL for the children was 69.70. The current sample was lower than this oncology sample, but this may be because in Varni et al. (2002)’s sample, only about half of the sample was actively receiving treatment; many were in remission and some were survivors. This is different than the current study, in which the participants may have been more medically compromised
when assessed. The scores in the current study also convey a much lower HRQOL score than a healthy comparison group Varni, Burwinkle, Seid, and Skarr (2003) sampled, whose average total score was 82.29. The results of the current study yielded no evidence in support for the proposed hypotheses. First, it was hypothesized that the parent’s perception of family communication would significantly predict the parent report of child HRQOL. However, data analysis yielded no significant relationship between the HRQOL and family communication. Further, it was predicted that there would be moderators in the relationship between child HRQOL and family communication. More specifically, age and SES would moderate the relationship, with older age and lower SES strengthening the relationship. Analysis indicated that the child’s age and SES did not significantly contribute to the relationship between child HRQOL and family communication.

These results come as a surprise, particularly because other family variables (i.e., expressiveness and cohesion) have previously been shown to be related to HRQOL in the SCT population (Phipps & Mulhern, 1995; Barrera, Pringle, Sumbler, & Saunders, 2000). Further, the relation between HRQOL and family communication has also been supported in the broader pediatric literature, such as in families who have children with asthma, IBD and diabetes (Sawyer et al., 2001, Herzer et al., 2011; Weissberg-Benchell, et al., 2009). However, there are some differences between the current study and other studies, which examined pediatric SCT population and family variables that may provide some speculation as to why the current studies results were not similar to others.

The current study is unique in that the families answered the questionnaires right before discharge from the hospital. Both Phipps and Mulhern (1995) and Barrera et al.
(2000) assessed the families prior to the transplantation and six months to twelve months after the transplant. The current study utilized measures assessed around a month after the transplant, so it was much sooner than that assessed in the two other studies mentioned. Also, because the Phipps and Mulhern (1995) and Barrera et al. (2000) studies assessed the family variables before and after the transplant, it could be deduced that family variables acted as a protective factor. The current study only measured these variables at one time point, so it is hard to tell from this study if family communication has the potential to be a protective factor in the pediatric SCT population, like adaptability and cohesion have previously been found to be.

Limitations

The current study has several limitations that should be considered. First, a limitation for the current study may be the issue of sample size and the statistical power. Post hoc analysis revealed very low power for each analysis, ranging from 5% to 10%. This becomes an important limitation because power is essentially, the “probability of not making a type II error” (Rosenthal & Rosnow, 1991, p. 439). That is, with low power, the relationship between communication and HRQOL may not have been detected. A way to add power to this study would be to increase the sample size, which may be difficult because of the unique population used in this study. Considering pediatric psychology research tends to have small sample sizes (Holmbeck, 1997), the sample size in this study may be considered adequate considering the number of variables measured. However, the current study would benefit from a larger sample size, particularly given the low effect sizes found in the analyses for this project.
There also may be reason to be concerned with the measures utilized in this study. First, even though the PedsQL has been tested on similar populations (i.e., children with cancer), there may have been different characteristics in the current studies population that the PedsQL failed to capture. For example, the PedsQL asks the respondent to report if their child has had difficulties in the past seven days on physical, emotional, social and school related questions. However, in the current study the child had been hospitalized for an extended period, so many of the caregiver respondents may have not found these domains applicable, which may have contributed to a lack of full scale scores available to use in analysis. The Family Communication scale may also have failed to capture communication issues the families in the study may have been experiencing. The Family Communication scale has been normed on many families, however it may be possible that families whose child received a stem cell transplant may respond differently to a more sensitive measure, which encapsulates more issues that might be special to their current experience, such as communication with medical staff, communication during hospitalization and possibly being away from other family members during the hospital stay. It seems that both the PedsQL and the Family Communication scale may not have been sensitive enough to the particular population in the study; special considerations may be needed for this population in future studies.

Another limitation of the current study may be the reliance on parent report for the measures. However, due to the large number of young children in the study (77.6% were between the ages of 2 to 12), it was not appropriate to use child report. It is unknown if children perceive their family communication the same way as their caregivers, especially since the child is continually in the hospital; they may miss what
the family goes through ‘behind the scenes’ so to speak. This may be an important factor; determining if there are any discrepancies between child and parent report for the Family Communication scale. There is no research to date on the agreement between parent and child report in terms of the Family Communication scale utilized in this study. The parent report on quality of life may have also been problematic. Research has found that parents usually report a more compromised HRQOL score than a child would; however research has also found that in the acute stages of the SCT transplantation recovery period, that parent-child agreement is usually good (Clarke, Eiser & Skinner, 2008).

Finally, a limitation to the study may be the variable of SES and how it was calculated. In the current study, SES was calculated by the families’ income divided by the number of individuals in the family. It is unknown if this is the best way to calculate the families SES level. This may appear to be a good way of calculating the families true SES, however, there are special considerations to take into account with this particular population. First, because the study took place at a large hospital, many of the families had to travel to the hospital and stay in the area. Some of the caregivers may not even live in the same city, and may have had to leave their job to be with their child in the hospital. Because of this, the income the families identified on the demographic form may not have been a true indicator of their actual income.

**Future Directions**

Even though the literature has suggested that immediately following transplant is the hardest time for children and their families (Phipps, Dunavant, Garvie, et al., 2002; Clarke et al., 2008), future studies may want to look at the variables examined in this
study throughout the transplantation process. For example, before the transplant, factors such as family communication and HRQOL may be lower than that after a transplant because of the extreme stressors of being sick and the illness uncertainty associated with the disease type represented in the study. Likewise, the literature also has found that HRQOL is still low up to three months later and may not return to normal until around a year later (Parsons et al., 2006). With these differences in HRQOL, there may be differences in how HRQOL relates to family communication throughout the transplant trajectory. One time point may be more stressful for families, and a variable such as family communication may be more vital at different time points.

Related, having families answer questionnaires at different time points in regards to the Family Communication scale may be important to consider. In the current study, the families answered questionnaires before they were discharged from the hospital, and although this is certainly a stressful time, the next couple weeks or months may also be stressful for them. For example, families receive support for the medical care of their child and may also get psychological support from the hospital staff. After discharge, the family must take primary control over their child’s medication regimen and reintegrate into their daily lives post-transplant. When the family is discharged and goes back to their life, which includes a families normal stressors and additionally, stressors related to the transplantation, it is quite possible that at that time period they may experience more problems with family variables, such as communication. This should be investigated empirically.

It may also be beneficial to create more appropriate measures for the population in the study. Because SCT are becoming increasingly popular as a treatment option, this
may become important for future research on the population. There were concerns over the PedsQL and the Family Communication scale, in terms of whether they were sensitive enough for the population. Both of these measures did not account for long-term hospitalization and separation from their family. Both of these factors may be unique to the SCT experience, and should be reflected in measures used, to achieve accurate information. Developing measures which take into account the long and strenuous experience the families go through in terms of HRQOL and family communication may be an important in the next step in research on the SCT experience.

Finally, it may be intriguing to measure the caregiver and child’s optimism and benefit finding throughout the transplant process. This may be an interesting direction because, in the past decade much research has been dedicated to examining a specific construct called “benefit finding” which represents the ways in which people’s lives are positively changed as a result of experiencing a traumatic life event (Helgeson, Reynolds, Tomich, 2006). Benefit finding may aid someone in viewing things in more favorable light, possibly even family variables. If one was to examine benefit finding and how it may relate to the current study and to HRQOL and family communication, although speculative in nature, it may offer a different framework in which to interpret the surprising results.

This idea of benefit finding has emerged as a specific topic of research in pediatric psychology as well. A study, which utilized maternal reports on having a child who was chronically ill, found that 80% of the mothers reported finding benefits in terms of their family from the child’s illness, such as closer family relationships and 70% reported that they believed their family was stronger as a result of their child’s illness.
(Chernoff, List, DeVet & Ireys, 2001). Chernoff, et al. (2001) suggest that families with a child who is chronically ill may believe that they experience positive benefit from this hard life experience; so much that they may even believe that this life event made them closer as a family unit,

More specific to the SCT population in the current study, benefit finding has also been an area of interest in the pediatric cancer literature. Because many consider cancer a traumatic event, and more children are surviving cancer, benefit finding has become an important construct to research in the resiliency of children (Phipps, 2007). Rini et al. (2004) examined mothers’ whose children received a SCT and their perception of benefit finding during and after the transplantation. The authors found that dispositional optimism was the strongest predictor of the mothers’ benefit finding. It was also found that mothers of children who were at greater medical risk (e.g., risk for mortality, severity of transplant risk) used more benefit finding during their child’s hospitalization and six months post-discharge from the hospital.

With this context of positive psychology, it may be possible that at the time of discharge in the study (i.e., when caregivers completed questionnaires), the caregivers felt more optimistic about their child’s and families future. After surviving a traumatic event and getting through the long hospitalization period, things may have been looking bright for these families, who had already been through so much. For many, it may have never even been a consideration leaving the hospital because of complications and adverse effects. It is also possible that the caregivers, because of the long process and hospitalization, had already begun to find benefit and clarity from everything that had happened with their child. If the transplant is viewed in this way, it may provide
speculation into why the caregivers were so positive or optimistic about their family or future.

Because Rini et al. (2004) was the only research that could be found of benefit finding, future studies may want to examine this variable in regards to not only family communication, but also other family variables that have been researched in the SCT population, such as cohesion and adaptability. Optimism may also be a variable of interest, as it may relate to the caregiver’s view of their family system, and how they perceive it when they are going through a significant life stressor. It is also unknown how optimism and benefit finding may affect a more objective measure such as HRQOL, and how this may influence the relationship with family communication. Future studies may examine these variables in regards to family variables to investigate if there is an underlying relationship during the transplant process.

Family functioning is important to research in terms of the well being of children. These variables may be modifiable and may be easy to target in future interventions for families. With this being said, even though family communication did not seem to be a variable of interest as it related to the HRQOL in this sample of pediatric SCT patients, this does not mean that it should be discounted completely. This study addressed communication at only one time point in the transplant process; it is unknown how important family communication may be before the transplant or months after the transplant. Like stated above, this is a future direction that may be crucial to understanding the families’ experience. Knowing what family factors to target and how they affect the family becomes another important step in ensuring that clinicians can ultimately help the family work together through this truly stressful and difficult time.
REFERENCES


outcomes. Bone Marrow Transplantation, 29, 425-434. doi: 10.1038/sj.bmt.1703377


### APPENDIX A

#### Demographics Information

<table>
<thead>
<tr>
<th>Caregiver Information</th>
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<tbody>
<tr>
<td><strong>Age:</strong> __ __</td>
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**Occupational Status:**

- [ ] Full Time
- [ ] Part Time
- [ ] Unemployed
- [ ] Retired
- [ ] Seeking Employment
- [ ] Not Working,
  Disabled
- [ ] Other _____________________________

**Occupation:** ________________________ **Employer:** ________________________

**Income Level:**

- [ ] Less than $9,999
- [ ] $10,000-$19,999
- [ ] $20,000-$29,999
- [ ] $30,000-$39,999
- [ ] $40,000-$49,999
- [ ] $50,000-$59,999
- [ ] $60,000-$69,999
☐ $70,000-$79,999
☐ More than $80,000

Marital Status:
☐ Single ☐ Married ☐ Divorced
☐ Separated ☐ Widowed ☐ Living as Married
☐ Other ________________________________

Is there another adult caregiver living in your home?
☐ Yes ☐ No  **IF NO**, please skip to page 2.

**IF YES**, what is their relationship to you and/or the patient?
☐ Biological Mother ☐ Biological Father
☐ Grandmother ☐ Grandfather ☐ Foster Parent
☐ Other Family ________________________________
☐ Other

______________________________________________________________

What is his/her date of birth? ___ ___/___ ___/___ ___

What is his/her Marital Status:
☐ Single ☐ Married ☐ Divorced
☐ Separated ☐ Widowwed ☐ Living as Married
☐ Other ________________________________
What is her/her Highest Grade Completed:

- ☐ 7th grade or lower
- ☐ High School Graduate or GED
- ☐ 8th or 9th grade
- ☐ Partial College (at least 1 year)
- ☐ 10th or 11th grade
- ☐ College Graduate (BS, BA)
- ☐ Graduate or Professional Degree
- ☐ Other __________________

What is his/her Occupational Status:

- ☐ Full Time
- ☐ Part Time
- ☐ Unemployed
- ☐ Retired
- ☐ Seeking Employment
- ☐ Not Working,
  Disabled
- ☐ Other __________________

<table>
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<tr>
<th>Child’s Household Information</th>
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How many individuals are living in child’s primary household? ____

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<th>Relation to Child</th>
<th>Age</th>
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How many caregivers help with the child’s health care in the home (for example: giving medication, making meals for the child, taking the child to clinic appointments)?

_____

For the caregivers that help with the child’s health care what is their relationship to the child and their age:

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<th>Relation to Child</th>
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Does anyone living in child’s primary household have a serious illness or condition?

☐ No ☐ Yes (list ages and illness/condition)

What is the total household income?

☐ Less than $9,999
☐ $10,000-$19,999
☐ $20,000-$29,999
☐ $30,000-$39,999
☐ $40,000-$49,999
☐ $50,000-$59,999
☐ $60,000-$69,999
☐ $70,000-$79,999
☐ $80,000-$89,999
□ $90,000-$99,999
□ More than $100,000

<table>
<thead>
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<th>Child Information</th>
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<tbody>
<tr>
<td>Where does the child go to school? ______________________________</td>
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<tr>
<td>Is the child currently receiving any special class placements, services, or tutoring?</td>
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<tr>
<td>□ No □ Yes (please check one)</td>
</tr>
<tr>
<td>□ Developmental Handicapped (DH) class □ Tutoring</td>
</tr>
<tr>
<td>□ Severe Behavioral Handicapped (SBH) class</td>
</tr>
<tr>
<td>□ Gifted Program</td>
</tr>
<tr>
<td>□ Learning Disability (LD) class</td>
</tr>
<tr>
<td>□ Other (Describe ______________________________)</td>
</tr>
</tbody>
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Does the child have any significant behavioral problems at home or school? □ No □ Yes

If so, please describe: ____________________________________________

_________________________________________________________________

Does the child have an IEP? □ No □ Yes

If so, what services do they receive? ______________________________

_________________________________________________________________

What was your child’s grade point average last quarter (the last grading period)?__________

In the past month has your child missed school? Yes_______ No__________

If yes, how many times ___________
In the past week has your child missed school?  Yes________ No________
If yes, how many times

In the past month did they earn detention?  Yes________ No________
If yes, how many times

In the past week did they earn detention?  Yes________ No________
If yes, how many times

In the past month has your child been expelled?  Yes________ No________
If yes, how many times

In the past week has your child been expelled?  Yes________ No________
If yes, how many times