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Authors

Mangurian, Christina
Scalchunes, Christopher
Yoo, Jennie
[et al.](#)

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Psychosocial services for primary immunodeficiency disorder families during hematopoietic cell transplantation: A descriptive study

Christina Mangurian, MD, MAS¹, Christopher Scalchunes, MPA², Jennie Yoo, B.S.³, Brent Logan, PhD⁴, Tiffany Henderson, PhD², Sumathi Iyengar, MD⁵, Heather Smith⁶, Morton J. Cowan, MD⁷

¹UCSF Department of Psychiatry, San Francisco, CA;

²Immune Deficiency Foundation, Towson, MD;

³UCSF Department of Psychiatry, San Francisco, CA, USA;

⁴Medical College of Wisconsin, Milwaukee, WI;

⁵Wiskott-Aldrich Foundation, Smyrna, GA;

⁶SCID, Angels for Life Foundation, Lakeland, FL;

⁷Pediatric Allergy, Immunology, Blood and Marrow Transplant Division, UCSF Benioff Children's Hospital, San Francisco, CA.

Abstract

Objective: Caregivers for patients undergoing hematopoietic cell transplantation (HCT) are susceptible to significant psychosocial distress. This cross-sectional study aimed to describe psychosocial support services offered and utilized by caregivers of pediatric primary immune deficiency (PID) during HCT at 35 hospitals across North America.

Methods: Caregivers of pediatric patients with PID were recruited by email to participate in an anonymous 140-question survey instrument between April and May 2016 (N=171).

Results: Of those meeting inclusion criteria (53%), family counseling services were only offered to less than half of caregivers (42%). Of the survey participants not offered counseling services, the majority desired family counseling (70%) and sibling counseling (73%). That said, when offered counseling, utilization rates were low, with 22% of caregivers utilizing family counseling and none utilizing sibling counseling.

Corresponding Author Information: Christina Mangurian, UCSF Department of Psychiatry Weill Institute for Neurosciences, San Francisco General Hospital, 1001 Portero Ave, Suite 7M, San Francisco, CA 94110. christina.mangurian@ucsf.edu. Tel: 415-206-5925; Fax: 415-206-8942.

COMPETING INTERESTS

Dr. Cowan discloses DSMB for Bluebird Bio, SAB for Exogen Bio and Homology Medicine with stock options.

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Significance of results: These results indicate the need to offer and tailor counseling services for families throughout the HCT process. Further research should focus on reducing barriers to utilization of counseling services such as offering bedside counseling services, online modalities, and/or financial assistance.

Keywords

Hematopoietic cell transplantation (HCT); psychosocial services; caregivers; counseling; primary immune deficiency (PID)

INTRODUCTION

Hematopoietic cell transplantation (HCT) is often indicated for children with severe primary immune deficiencies (PIDs). Families undergo significant psychological distress during the HCT hospitalization and have documented anxiety, depression, post-traumatic stress symptoms, and declines in health-related quality of life (Packman, Weber, Wallace, & Bugescu, 2010; Rodrigue et al., 1997; Taskiran, Adanır, & Özatalay, 2016). It is well-established that parental depression and anxiety impact the attachment between the parent caregiver and child, and attachment disturbances are a significant risk factor for development of mental and physical health problems for the child (Colletti et al., 2008; Wagner et al., 2003). Left unaddressed, many families may become overwhelmed by the process and utilize more hospital resources (Kazak et al., 2003).

Psychosocial services such as individual and family counseling and connection to community resources provide crucial support for patients and families affected by PID. Unfortunately, many of these non-medical services provided to patients and their families vary in quality or are lacking completely across treatment centers. Currently, there are no evidence-based interventions or literature on what psychosocial services are offered to families going through the HCT process. Additionally, there is no published information on or evaluation of the psychosocial services that are provided to families.

To help healthcare providers, patient foundations, and researchers better understand what types of psychosocial care services are provided to patients and their families and learn more about how these services can be improved, we undertook an electronic survey of families of patients with one of three severe PIDs: Severe Combined Immunodeficiency Disease (SCID), Wiskott Aldrich Syndrome (WAS) and Chronic Granulomatous Disease (CGD). SCID is the result of absence of T cell immunity and inability to make specific antibodies (Dorsey, Dvorak, Cowan, & Puck, 2017) with more than 90% of affected children currently being diagnosed with newborn screening in the U.S. (Kwan & Puck, 2015). WAS and CGD are often diagnosed later in life and depending on the severity of the disease may not necessarily need an HCT (Griffith et al., 2009). For all three PIDs, HCT is associated with a lengthy hospitalization of anywhere from 2–6 months. The objective of this study was to describe the psychosocial services that were offered and utilized by patients and their families affected by PID during HCT.

METHODS

Research design and participants

Families were recruited by email invitation containing a link to an anonymous un-incentivized web-based survey between April and May 2016. The survey was distributed through the following organizations given that PIDs are rare illnesses: Immunodeficiency Foundation (IDF); Primary Immune Deficiency Treatment Consortium (PIDTC, NIH grant U54AI082973); Severe combined immunodeficiency (SCID) Angels for Life; Wiskott-Aldrich Foundation; and the Chronic Granulomatous Disease Association. Inclusion criteria were caregiver age ≥ 18 years of child with SCID, WAS, or CGD who received a HCT. Exclusion criteria included patients and families living outside the United States. Responses were reviewed for duplicates and potential overlap by examining demographic and medical characteristic details (*e.g.*, age, place of transplant, date of transplant, and current residency). The study received an Institutional Review Board exemption from the Schulman IRB.

Measures

A 140-question survey instrument took approximately 30–45 minutes to complete and included some basic information about the caregiver including, age, additional children, and household income. Additional information was collected about the child, including demographics (age, gender, race, and ethnicity), type of health insurance, type of PID, years since transplant, and hospital name and location in which transplant occurred.

The survey also included whether the family was offered a variety of counseling services, including individual, family and sibling counseling during the HCT hospitalization. The importance of each counseling service was ranked on a 5-point Likert scale. If these services were offered, we asked about which member of the care team (physicians, nurses, or social worker) offered these services. Among those offered counseling services, we asked whether services were utilized and, if so, the family's satisfaction with each of these services on a 5-point Likert scale. Survey respondents were also asked the reasons for not utilizing counseling services. When the affected child or sibling was too young to be offered services, they were excluded from the analysis of individual or sibling counseling, respectively. Among those families not offered counseling services, survey respondents were asked whether they would have wanted these counseling services.

The need for financial assistance for medical costs in addition to housing was assessed. In addition, we collected the types of assistance received (foundation, self-fundraising, combination, none). The full survey instrument is available on-line (Appendix A).

Statistical analyses

Analyses were generally descriptive in nature, with categorical data summarized as frequencies/percents and numeric data summarized as median/range. Comparisons between groups were done using the Fisher's exact test for categorical data and Kruskal-Wallis test for quantitative data.

RESULTS

Caregiver and patient characteristics

Among the 173 individuals who responded, 53% (91/171) met criteria for inclusion for this study across 35 hospitals. Eighty people were excluded because their child did not receive a HCT (71), they were not living in the US (7), or there were duplicate entries for the same patient (2). Caregivers' median age was 39 years (range 25–67) with a median household income of \$75,000–\$99,000. The majority of the children with PID were male (76%, 63/91), white (83%), privately insured (71%), and had siblings (72%). The majority (88%) were diagnosed with SCID, had a HCT at a median age of 0.62y (range: 0.42–15.56y), with 50% having complications post-transplant. Complete details are provided in Table 1. Because respondents were allowed to skip portions of the survey and not required to answer all questions, the remaining results have variable denominators reported per variable in the tables. There were no significant differences between SCID and WAS/CGD families (Table 1).

Psychosocial resources

Figure 1 shows availability and utilization of different counseling services offered to families: 1) individual counseling for the pediatric patient; 2) family counseling, 3) sibling counseling, and 4) sibling donor counseling. Among pediatric patients who were old enough to receive counseling, 39% (7/18) were offered individual counseling and, among those offered, 58% (4/7) utilized these services and 75% (3/4) reported satisfaction. Among the 42% (36/80) of families who were offered counseling, only 22% (8/36) completed the treatment and 85% (17/20) reported satisfaction. Among the siblings who were old enough to receive counseling, 23% (9/39) were offered these services and none completed the counseling. Among sibling donors who were old enough to participate in counseling, 71% (5/7) were offered counseling and 80% (4/5) completed the services.

Among survey participants *not* offered individual counseling services, 64% (7/11) reported they would have liked these services for the pediatric patient. Similarly, of those not offered family counseling services, 70% (35/50) reported wanting these services. Among the 30 families not offered sibling counseling, 73% (22/30) wanted these sibling counseling services. All parents of sibling donors who were not offered counseling services wanted counseling for their healthy child(ren). More details are found in Table 2.

Material needs

69% (62/80) of families reported needing housing during the transplantation. The majority (60%) of families also required financial assistance, with 46% (39/84) of those families receiving this aid from foundations.

DISCUSSION

Our findings, while specific to families with PID, have broad implications for provision of psychosocial support for caregivers of all pediatric patients undergoing HCT. Our study found that less than half of families with PID were offered counseling services during the

HCT process. Moreover, for those not offered counseling more than half of the families indicated that they would like to have more individual, family and sibling counseling. Family-based psychosocial interventions have been shown previously in other pediatric chronic illness populations such as diabetes to demonstrate sustained long-term improvements in health outcomes for both the child and family (Distelberg et al., 2016; Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005; Peris, Rozenman, Sugar, McCracken, & Piacentini, 2017).

Involvement of non-medical services such as early palliative care consultations during inpatient hospitalization have been shown in prior research to decrease hospital resource utilization by facilitating transitions of care to outpatient settings (Ananth, Melvin, Berry, & Wolfe, 2017; Conte, Mitton, Trenaman, Chavoshi, & Siden, 2015). Initiating counseling services before hospitalization and tailoring sessions to specific issues relevant to each treatment phase including post-discharge and transitions home may improve completion rates (Fife et al., 2017). Further inquiry is needed to determine what the best timing, frequency, and type of intervention is needed for these non-medical services.

Of those families offered counseling, few families completed counseling and/or declined counseling altogether due to time, financial cost, and lack of outpatient counseling options. This is consistent with the literature which reports difficulty of initiating and completion of counseling services due to availability of services, clinical staff not having time to offer services, transportation difficulties, and financial cost (Drotar et al., 1997). Technology-enhanced services such as tele-counseling can be used to reduce these barriers and increase access for families (Dorstyn, Mathias, Denson, & Robertson, 2012; Duan-Porter et al., 2017). When patients and their families completed counseling offered by the hospital, the overwhelming majority of families were very satisfied or satisfied indicating the need to reduce barriers and improve completion rates.

For patients and families that received financial assistance within the last 5 years, assistance was more likely to come from a combination of foundations and self-fundraising compared to only self-fundraising more than 5 years ago. Foundations play a major role in reducing the burden of financial hardship patients and families face. Perhaps connecting these families with foundations early will help provide the much-needed financial and psychosocial resources. Furthermore, community-based, family-to-family support has been demonstrated to reduce caregiver burden through shared experiences (Mittelman & Bartels, 2014).

Study limitations included small sample size, homogenous population, and convenience sampling. However, notably these limitations are commonly reported with this PID population with small sample sizes generally ranging from 10 to 250 and fairly homogenous populations with infrequent diagnoses in nonwhite, non-Hispanic subjects (Bazregari et al., 2017; Cozon et al., 2018; Macginnitie, Aloï, & Mishra, 2011; Picard et al., 2015; Sowers, Litwin, Lee, & Galantino, 2018; Sultan et al., 2017). Given the rarity of PIDs, this study is the first to explore the offering and utilization of psychosocial services in this population during the HCT process. That said, further research is needed to survey sub-populations such as racial, ethnic minorities, non-English speaking immigrants, and low-income

populations. Further, this study has broader implications for offering psychosocial services to caregivers of children with life-threatening and/or chronic illnesses with long hospitalizations.

Only a minority of families are offered counseling during hospitalization for HCT for PID. Patients, caregivers and siblings undergoing HCT, or similar long hospitalization stays, may all benefit from various psychosocial support mechanisms. Hospitals should consider offering individual, family and sibling counseling to more PID patients and their families on early and frequently in the HCT process. Future research should focus on reducing barriers in accessing and completing counseling services such as online treatment modalities with telemedicine consultations, bedside counseling services, and broadening psychosocial support through connections to PID foundations.

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REFERENCES

- Ananth P, Melvin P, Berry JG, & Wolfe J (2017). Trends in Hospital Utilization and Costs among Pediatric Palliative Care Recipients. *Journal of Palliative Medicine*, *jpm.2016.0496*. 10.1089/jpm.2016.0496
- Bazregari S, Azizi G, Tavakol M, Asgardoost MH, Kiaee F, Tavakolinia N, ... Aghamohammadi A (2017). Evaluation of infectious and non-infectious complications in patients with primary immunodeficiency. *Central European Journal of Immunology*, *42(4)*, 336–341. 10.5114/ceji.2017.72825 [PubMed: 29479289]
- Colletti CJM, Wolfe-Christensen C, Carpentier MY, Page MC, McNall-Knapp RY, Meyer WH, ... Mullins LL (2008). The relationship of parental overprotection, perceived vulnerability, and parenting stress to behavioral, emotional, and social adjustment in children with cancer. *Pediatric Blood & Cancer*, *51(2)*, 269–74. 10.1002/pbc.21577 [PubMed: 18454464]
- Conte T, Mitton C, Trenaman LM, Chavoshi N, & Siden H (2015). Effect of pediatric palliative care programs on health care resource utilization and costs among children with life-threatening conditions: a systematic review of comparative studies. *CMAJ Open*, *3(1)*, E68–E75. 10.9778/cmajo.20140044
- Cozon GJN, Clerson P, Dokhan A, Fardini Y, Sala TP, & Crave J-C (2018). In-depth interviews of patients with primary immunodeficiency who have experienced pump and rapid push subcutaneous infusions of immunoglobulins reveal new insights on their preference and expectations. *Patient Preference and Adherence*, *12*, 423–429. 10.2147/PPA.S156983 [PubMed: 29618922]
- Distelberg BJ, Emerson ND, Gavaza P, Tapanes D, Brown WN, Shah H, ... Montgomery S (2016). A Cost-Benefit Analysis of a Family Systems Intervention for Managing Pediatric Chronic Illness. *Journal of Marital and Family Therapy*, *42(3)*, 371–382. 10.1111/jmft.12166 [PubMed: 27282311]
- Dorsey MJ, Dvorak CC, Cowan MJ, & Puck JM (2017). Treatment of infants identified as having severe combined immunodeficiency by means of newborn screening. *Journal of Allergy and Clinical Immunology*, *139(3)*, 733–742. [PubMed: 28270365]
- Dorstyn D, Mathias J, Denson L, & Robertson M (2012). Effectiveness of telephone counseling in managing psychological outcomes after spinal cord injury: a preliminary study. *Archives of Physical Medicine and Rehabilitation*, *93(11)*, 2100–2108. 10.1016/j.apmr.2012.06.002 [PubMed: 22705237]
- Drotar D, Eckl CL, Beitzel M, Gil E, Kocik S, Kuekes K, ... Agle D (1997). Psychosocial services for children and adolescents with hemophilia and their families: Results of a national survey. *Children's Health Care*.

- Duan-Porter W, Van Houtven CH, Mahanna EP, Chapman JG, Stechuchak KM, Coffman CJ, & Hastings SN (2017). Internet Use and Technology-Related Attitudes of Veterans and Informal Caregivers of Veterans. *Telemedicine Journal and E-Health : The Official Journal of the American Telemedicine Association*. 10.1089/tmj.2017.0015
- Fife BL, Von Ah DM, Spath ML, Weaver MT, Yang Z, Stump T, & Farag S (2017). Preliminary efficacy of a brief family intervention to prevent declining quality of life secondary to parental bone marrow transplantation. *Bone Marrow Transplantation*, 52(2), 285–291. 10.1038/bmt.2016.267 [PubMed: 27869806]
- Griffith LM, Cowan MJ, Notarangelo LD, Puck JM, Buckley RH, Candotti F, ... W. T. Shearer (2009). Improving cellular therapy for primary immune deficiency diseases: Recognition, diagnosis, and management. *The Journal of Allergy and Clinical Immunology*, 124(6), 1152–60.e12 10.1016/j.jaci.2009.10.022 [PubMed: 20004776]
- Kazak AE, Boeving CA, Alderfer MA, Hwang W-T, & Reilly A (2005). Posttraumatic stress symptoms during treatment in parents of children with cancer. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 23(30), 7405–10. 10.1200/JCO.2005.09.110 [PubMed: 16157936]
- Kazak AE, Cant MC, Jensen MM, McSherry M, Rourke MT, Hwang WT, ... Lange BJ (2003). Identifying psychosocial risk indicative of subsequent resource use in families of newly diagnosed pediatric oncology patients. *Journal of Clinical Oncology*, 21(17), 3220–3225. 10.1200/JCO.2003.12.156 [PubMed: 12947055]
- Kwan A, & Puck JM (2015). History and current status of newborn screening for severe combined immunodeficiency. *Seminars in Perinatology*, 39(3), 194–205. [PubMed: 25937517]
- Macginnitie A, Aloï F, & Mishra S (2011). Clinical characteristics of pediatric patients evaluated for primary immunodeficiency. *Pediatric Allergy and Immunology*, 22(7), 671–675. 10.1111/j.1399-3038.2011.01167.x [PubMed: 21449988]
- Mittelman MS, & Bartels SJ (2014). Translating research into practice: case study of a community-based dementia caregiver intervention. *Health Affairs (Project Hope)*, 33(4), 587–595. 10.1377/hlthaff.2013.1334 [PubMed: 24711319]
- Packman W, Weber S, Wallace J, & Bugescu N (2010). Psychological effects of hematopoietic SCT on pediatric patients, siblings and parents: a review. *Bone Marrow Transplantation*, 45(7), 1134–1146. 10.1038/bmt.2010.74 [PubMed: 20383219]
- Peris TS, Rozenman MS, Sugar CA, McCracken JT, & Piacentini J (2017). Targeted Family Intervention for Complex Cases of Pediatric Obsessive-Compulsive Disorder: A Randomized Controlled Trial. *Journal of the American Academy of Child and Adolescent Psychiatry*, 56(12), 1034–1042.e1 10.1016/j.jaac.2017.10.008 [PubMed: 29173737]
- Picard C, Al-Herz W, Bousfiha A, Casanova JL, Chatila T, Conley ME, ... Gaspar HB (2015). Primary Immunodeficiency Diseases: an Update on the Classification from the International Union of Immunological Societies Expert Committee for Primary Immunodeficiency 2015. *Journal of Clinical Immunology*, 35(8), 696–726. 10.1007/s10875-015-0201-1 [PubMed: 26482257]
- Rodrigue JR, MacNaughton K, Hoffmann RG, Graham-Pole J, Andres JM, Novak DA, & Fennell RS (1997). Transplantation in Children: A Longitudinal Assessment of Mothers' Stress, Coping, and Perceptions of Family Functioning. *Psychosomatics*, 38(5), 478–486. [PubMed: 9314717]
- Sowers KL, Litwin BA, Lee ACW, & Galantino MLA (2018). Exercise Perception and Behaviors in Individuals Living with Primary Immunodeficiency Disease. *Journal of Clinical Immunology*, 38(2), 174–184. 10.1007/s10875-017-0472-9 [PubMed: 29307028]
- Sultan S, Rondeau É, Levasseur M-C, Dicaire R, Decaluwe H, & Haddad É (2017). Quality of Life, Treatment Beliefs, and Treatment Satisfaction in Children Treated for Primary Immunodeficiency with SCiG. *Journal of Clinical Immunology*, 37(5), 496–504. 10.1007/s10875-017-0409-3 [PubMed: 28597145]
- Taskiran G, Adanır AS, & Özatalay E (2016). Living with the unknown: Posttraumatic stress disorder in pediatric bone marrow transplantation survivors and their mothers. *Pediatric Hematology and Oncology*, 0018(4), 1–10. 10.3109/08880018.2016.1149749
- Wagner JL, Chaney JM, Hommel KA, Page MC, Mullins LL, White MM, & Jarvis JN (2003). The influence of parental distress on child depressive symptoms in juvenile rheumatic diseases: The

moderating effect of illness intrusiveness. *Journal of Pediatric Psychology*, 28(7), 453–462.
10.1093/jpepsy/jsg036 [PubMed: 12968037]

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Availability and Utilization of Counseling*

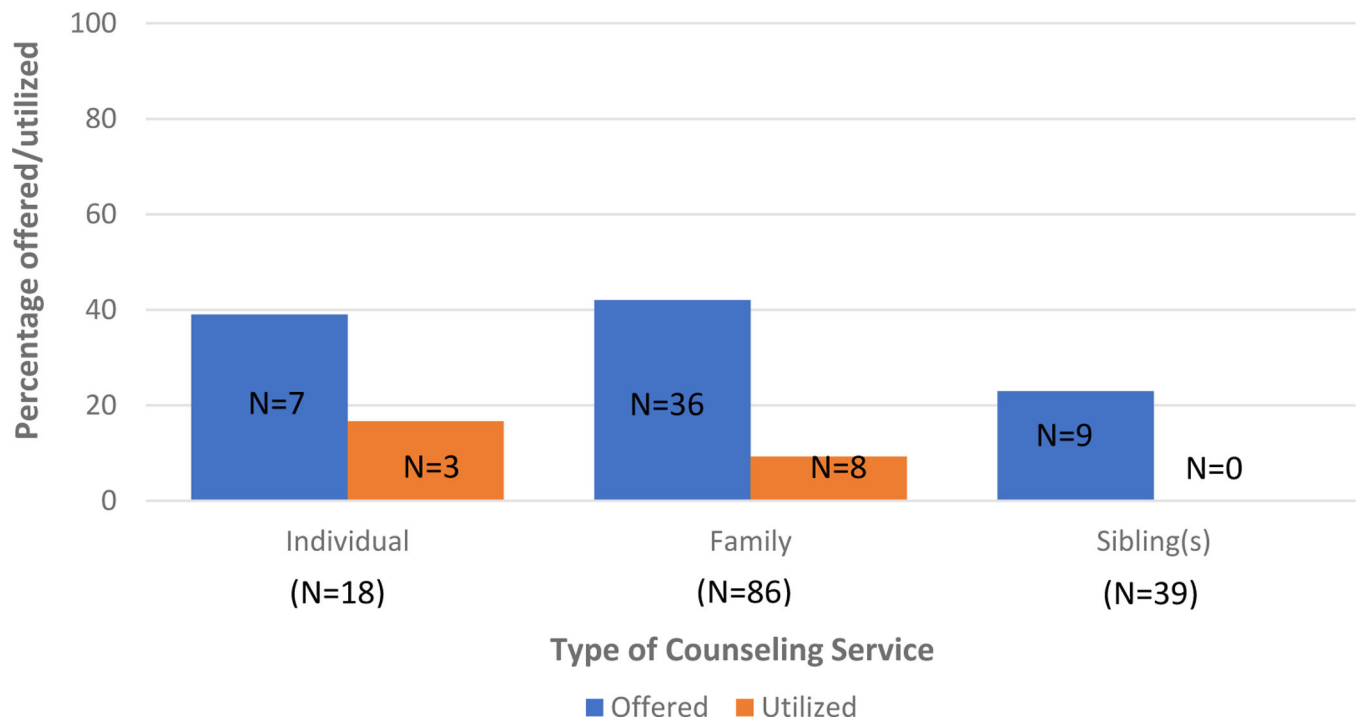


Figure 1. Availability and utilization of counseling

*There was missing data for several variables. Specifically, the missing data for the following variables were: individual counseling (N=74, 68 not included because patient was/is too young), family counseling (N=5), sibling counseling (N=52, 24 not included because no siblings, 23 not included because sibling was/is too young).

Table 1.

Selected demographic and medical characteristics of caregivers and patients

<i>Characteristics</i>	Total <i>n = 91 (%)</i>	SCID <i>n = 80 (%)</i>	WAS/CGD <i>n = 11 (%)</i>	P-value
<i>Caregivers</i>				
Age in years (n=54), median (min- max)	39.0 (25.0 – 67.0)	39.5 (25.0 – 67.0)	36.5 (27.0 – 42.0)	0.160
Annual income \$ (n=81)				
< 25 000	10 (12%)	10 (12%)	10 (12%)	
25 000 – 49 999	13 (16%)	13 (16%)	13 (16%)	
50 000 – 74 999	14 (17%)	14 (17%)	14 (17%)	
75 000 – 99 999	13 (16%)	13 (16%)	13 (16%)	0.466
100 000 – 149 999	14 (17%)	14 (17%)	14 (17%)	
> 150 000	17 (21%)	17 (21%)	17 (21%)	
<i>Patients</i>				
Sex (n=90)				
Male	63 (76%)	53 (73%)	10 (100%)	0.214
Race (n=83)				
African American	3 (4%)	2 (3%)	1 (10%)	
American Indian	1 (1%)	1 (1%)	0 (0%)	
Asian/Pacific Islander	2 (2%)	2 (3%)	0 (0%)	
Multiple	7 (8%)	5 (7%)	2 (20%)	0.435
Other	1 (1%)	1 (1%)	0 (0%)	
White	69 (83%)	62 (85%)	7 (70%)	
Ethnicity (n=82)				
Hispanic or Latino	9 (11%)	7 (10%)	2 (22%)	0.256
Diagnosis (n=91)				
SCID	80 (88%)	80 (100%)	0 (0%)	
WAS	8 (9%)	0 (0%)	8 (73%)	
CGD	3 (3%)	0 (0%)	3 (27%)	< 0.001
Siblings (n=86)				
Yes	62 (72%)	55 (72%)	7 (70%)	1.000
Age at BMT (n=82), median (min-max)	0.62 (–0.42 – 15.56)	0.60 (–0.42 – 14.41)	1.09 (–0.03 – 15.56)	0.304
Years since BMT (n=82), median (min-max)	4.5 (0.1 – 29.2)	5.0 (0.2 – 29.2)	2.0 (0.1 – 14.4)	0.060
Primary health insurance at initial diagnosis and treatment (n=85)				
Employer Sponsored Group Plan	60 (70%)	52 (69%)	8 (89%)	
Individual Policy	4 (5%)	4 (5%)	0 (0%)	
COBRA	4 (5%)	4 (5%)	0 (0%)	0.927
Medicaid	13 (15%)	12 (16%)	1 (11%)	
State Children’s Health Insurance Plan	4 (5%)	4 (5%)	0 (0%)	
BMT Donor (n=91)				0.079
Umbilical cord blood (unrelated)	17 (19%)	14 (18%)	3 (27%)	
Sibling	12 (13%)	12 (15%)	0 (0%)	

<i>Characteristics</i>	Total <i>n = 91 (%)</i>	SCID <i>n = 80 (%)</i>	WAS/CGD <i>n = 11 (%)</i>	P-value
Parent	34 (37%)	33 (41%)	1 (9%)	
Unrelated	27 (30%)	20 (25%)	7 (64%)	
Don't Know/Not Sure	1 (1%)	1 (1%)	0 (0%)	
U.S. Region of BMT (n=84)				0.009
Midwest	27 (30%)	19 (24%)	8 (73%)	
Northeast	12 (13%)	12 (15%)	0 (0%)	
South	31 (34%)	30 (37%)	1 (9%)	
West	21 (23%)	19 (24%)	2 (18%)	
Complications related to transplant (n=91)				0.500
Yes	45 (50%)	38 (48%)	7 (64%)	
No	41 (45%)	37 (46%)	4 (36%)	
Don't Know/Not Sure	5 (5%)	5 (6%)	0 (0%)	
Complications status (n=42) *				0.246
On-going	11 (26%)	11 (31%)	0 (0%)	
Now Resolved	17 (41%)	13 (36%)	4 (67%)	
On-going, Some Resolved	14 (33%)	12 (33%)	2 (33%)	

* Complication status was only asked of those who stated there were complications.

Table 2.

Desire for counseling services among those who were not offered these in the hospital

<i>Characteristics</i>	<i>n (%)</i>
Individual counseling (n=11)	
Yes	7 (64%)
No	4 (36%)
Family counseling (n=50)	
Yes	35 (70%)
No	15 (30%)
Sibling counseling (n=30)	
Yes	22 (73%)
No	8 (27%)

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