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## Supporting caregivers during hematopoietic cell transplantation for children with primary immunodeficiency disorders

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### Abstract

**Background**—Caregivers of children with primary immunodeficiency disorders (PIDs) experience significant psychological distress during their child's hematopoietic cell transplantation (HCT) process.

**Objectives**—This study aims to understand caregiver challenges and identify areas for healthcare system-level improvements to enhance caregiver well-being.

**Methods**—In this mixed-methods study, caregivers of children with PIDs were contacted in August to November 2017 via on-line and electronic mailing lists of rare disease consortiums and foundations. Caregivers were invited to participate in an on-line survey assessing sociodemographic variables, child's medical characteristics, psychosocial support use, and WHO-5 Well-Being Index. Open-ended questions about healthcare system improvements were included. Descriptive statistics and linear multivariate regression analyses were conducted. A modified content analysis method was used to code responses and identify emergent themes.

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**Results**—Among the 80 caregiver respondents, caregivers had a median age of 34 years (range 23–62 years), were predominantly female, white, and married with male children diagnosed with SCID. In the adjusted regression model, lower caregiver well-being was significantly associated with lower household income and medical complications. Challenges during HCT include maintaining relationships with partners and the child’s healthy sibling(s), managing self-care, and coping with feelings of uncertainty. Caregivers suggested several organizational-level solutions to enhance psychosocial support, including respite services, on-line connections to other PID caregivers, and bedside mental health services.

**Conclusions**—Certain high-risk sub-populations of caregivers may need more targeted psychosocial support to reduce long-term impact of the HCT experience upon their wellbeing. Caregivers suggested several organizational-level solutions for provision of this support.

## CAPSULE SUMMARY

Caregivers of children with primary immunodeficiencies experience unique challenges during hematopoietic cell transplantation and are at risk for poor well-being. Healthcare systems should consider facilitating peer-to-peer on-line support and targeted interventions to improve caregiver well-being among high-risk groups.

## Keywords

Hematopoietic cell transplantation; Primary Immune Deficiency; Caregiver; Psychosocial support; Well-being

## Introduction

Hematopoietic cell transplantation (HCT) is an intensive, definitive, and common treatment option for children with primary immunodeficiency disorders (PIDs). Pediatric HCTs cannot be performed unless a suitable caregiver is available to provide care since treatment requires a prolonged inpatient stay and a strict and complex medication regimen including management of central lines, clinic follow-ups, and infection control precautions (1). In addition, involvement of caregivers lead to better overall patient survival, reduced costs, and potentially decreased re-hospitalization (2,3).

In this complex setting, many caregivers suffer from acute and long-term post-traumatic stress symptoms and depression (4–7). Psychological distress has been well characterized in caregivers of children with chronic illnesses such as cystic fibrosis, hemophilia, and type 1 diabetes (8–10). Distress can arise from many factors including poorly controlled medical symptoms in child, uncertainty about child’s outcome, and feelings of incompetence about managing the child’s care (11–13). Caregiver psychological distress creates attachment disturbances that may create physical and mental problems for the child (14,15). In contrast, strong parent-child relationships during treatment significantly influences the child’s quality of life and resilience (16,17).

Prior studies suggest that caregivers experience particularly elevated periods of distress immediately preceding HCT and at the time of hospital discharge (5,18) creating opportunities for targeted interventions. Family-centered care programs in neonatal ICUs

have been shown to improve infants' clinical outcomes (higher weight gain, decreased length-of-stay, and reduced readmissions) and parent-reported outcomes (less anxiety, depression, and increased satisfaction) (19,20). Previous behavioral interventions to strengthen positive coping strategies and social support have shown mixed effects on reducing distress and increasing well-being (21–23). However, most of these studies involved caregivers of children with cancer. There is little known about caregivers of children with PID given the rarity of illness, and resulting limited resources and research. PID caregivers are also unique given their prolonged isolation prior to HCT. There is a paucity of research on how to overcome the organizational-level factors that influence caregiver well-being (6).

In this study, we sought to fill the gap in the current understanding of factors influencing long-term well-being of caregivers of children with PID, common support systems, and organizational-level factors that might improve caregiver well-being. Our findings can guide transplant physicians and directors in the strategic planning and provision of psychosocial supportive services for caregivers to improve long-term patient outcomes and satisfaction rates for patients with PID undergoing HCT.

## Methods

### Study participants

In this survey-based study, caregivers of children with a PID who went through HCT were contacted in August to November 2017. Because these are rare illnesses (24–26), we used sequential methods to recruit subjects: 1) electronic mailing lists from the Immune Deficiency Foundation (IDF); 2) posting on closed Facebook groups for PID families (e.g., Severe Combined Immunodeficiency Angels (SCID) for Life Foundation, Wiskott-Aldrich Syndrome (WAS) Families); and 3) distribution to families via research groups (e.g., the Primary Immune Deficiency Treatment Consortium (PIDTC) via NIH grant U54AI082973). Inclusion criteria were: caregiver at least 18 years of age; child with a PID (defined as either Wiskott-Aldrich syndrome, Severe Combined Immune Deficiency, or Chronic Granulomatous Disease for which HCT is the definitive treatment); child received HCT when <5 years old; child resided with caregiver during HCT; HCT performed in United States or Canada; and English-speaking family. Informed consent was obtained electronically and received UCSF IRB approval (IRB17–22263). To avoid duplicate entries from the same family, we asked that only one caregiver per family complete responses per affected child and create unique identifiers using child's month of birth and last three digits of zip code. These unique identifiers were then used to eliminate duplicate and incomplete responses.

### Survey instrument and measures

Caregivers were invited to participate in a confidential, on-line 66-item survey composed of questions assessing demographic and medical variables, utilization of psychosocial support systems, well-being, and open-ended questions to understand caregiver perspectives on potential organizational solutions to enhance well-being. Before dissemination, the entire survey was reviewed by five health care professionals and two PID caregivers for content

and readability. The survey took approximately 30 minutes to complete (see complete survey in Appendix E1).

**Demographic and clinical variables:** Caregiver socio-demographic variables included age, sex, race/ethnicity, geographic residence, marital status, education, employment status, and income. Medical characteristics of the affected child included age at HCT, gender, race/ethnicity, diagnosis, name of hospital and city of HCT, insurance, number of siblings, hospitalization length, complications of HCT if any, and number of post-transplant hospitalizations.

**Psychosocial support system utilization:** Caregivers were surveyed about the types of support systems utilized during HCT: close friends, extended family, religious community, medical care team, and mental health providers. Caregivers were able to identify more than one support system and utilization of each support system was assessed using a six-point Likert scale (1="At no time," 2="Some of the time," 3="Less than half of the time," 4="More than half of the time," 5="Most of the time," or 6="All of the time"). We then dichotomized utilization of each support system as low (1–3) and high (4–6) utilization for analysis.

**Well-being:** Caregiver well-being was measured by the World Health Organization (WHO)-5 Well-Being Index (WHO-5), a five item instrument used to measure subjective quality of life and has been previously shown to be a valid screening tool for depression (27). Each of the five items is scored from 5 (all of the time) to 0 (none of the time) with a total raw score ranging from 0 (absence of well-being) to 25 (maximal well-being). By convention, raw scores are multiplied by 4 and translated to a scale of 0 (absent) to 100 (maximal). Clinically, the general population mean is 70 with WHO-5 cut-off score of 50 to 29 indicating low-well-being with a recommendation to screen for clinical depression and a score of 28 indicating major depression.

**Qualitative instrument:** Caregivers were asked 11 open-ended questions regarding their HCT experience, including challenges, management of personal relationships, emotional well-being and coping strategies, support from health care team, and support group recommendations.

## Data analysis

**Quantitative analysis**—Descriptive data were used to present demographic and clinical characteristics of caregivers and patients. Pearson Chi Square and Fisher's exact two-sided tests were used for comparing support utilization between sub-groups. A linear regression model was used to examine whether certain predictor variables resulted in significant differences in caregiver well-being. Caregiver covariates included in the univariate analyses were age, sex, race/ethnicity, marital status, education, household income, and clinical variables (years since HCT, hospitalization length, complication status). Variables with significant associations ( $P < 0.1$ ) were then entered into an adjusted multivariable linear regression model: caregiver age, caregiver household income, insurance, hospitalization length, and complication status. There were no missing data for either the linear or

multivariate regression analyses. All data were analyzed using STATA version 14 (College Station, TX: StataCorp LLC, 2017). Significance was defined as  $P < 0.05$ .

**Qualitative analysis**—Qualitative data were managed and analyzed using Atlas.ti qualitative analysis software, version 8 (Germany: Scientific Software Development, 2017). A modified content analysis approach was used to categorize responses and overarching themes (28). Open-ended survey responses were first organized by question, and then responses were reviewed by the primary analyst (JY) to develop codes representing key factors impacting caregiver well-being as expressed by participants. These codes were reviewed by additional members of the analytic team (MH, CM) resulting in a final codebook with 36 codes and subcodes. A sample transcript was then individually coded by two independent coders (JY and KO), and any discrepancies in coding were discussed and the codebook modified for clarity. All transcripts were then independently coded (JY and KO) and then compared to resolve any inconsistencies in coding through consensus. The data were then reviewed by code to identify the frequency of common responses to each question as well as themes addressed across questions. These results were reviewed and finalized by the primary analytic team (JY, MH, CM).

## Results

Among the 80 respondents, caregivers had a median age of 34 years (range 23–62 years), were predominantly female (98%), white (87%), married/living together (88%), had other children (65%), were employed (55%), and had an annual household income of  $> \$75K$  (52%) (Table 1). Affected children were predominantly male (79%), diagnosed with SCID (74%), had a median age of 5 months (range 1–44 months) at the time of HCT, were hospitalized for a median of 9 weeks (range 1–63 weeks), and frequently experienced complications post-HCT (65%). HCTs were performed in 36 hospitals across the United States and Canada. The number of responses was the highest after sequential social media outreach to SCID Angels for Life Foundation, followed by WAS families, and email outreach to IDF and PIDTC.

Regarding psychosocial support utilization, caregivers reported relying primarily on the medical care team (70%) and extended family (63%), but on-line support groups (45%), close friends (40%) and religious community (29%) were often used (complete details in Table 2). Use of mental health providers were significantly associated with longer hospitalizations ( $> 9$  weeks,  $P=0.03$ ) and when the child with PID had siblings ( $P=0.02$ ). Caregivers of patients with Medicaid/CHIP were significantly more likely to use on-line support groups ( $P=0.001$ ). There were no significant associations amongst psychosocial support utilization and household income, caregiver education level, and complication status.

The results of the adjusted multivariate linear regression model in Table 3 indicated 5 predictors (age, income, insurance, hospitalization length, and complications) explained 33% of the variance in well-being (adjusted  $R^2=0.33$ ,  $F(6,71)=5.40$ ,  $P=0.001$ ). Well-being was measured on a scale of 0–100 with 100 indicating maximal well-being. Compared to caregivers with household incomes of  $< \$75,000$ , caregivers with household incomes of

\$75,000-\$150,000 and \$150,000+ had (adjusted) 9.25 and 8.90 points higher well-being respectively ( $P=0.04$ ). Compared to caregivers of patients who did not experience a complication post-HCT, caregivers of patients who did experience a complication post-HCT had adjusted 7.80 points lower well-being ( $P=0.02$ ).

The qualitative analysis had several emergent themes that are broadly organized in two categories: 1) caregiver challenges and 2) caregiver suggestions to enhance psychosocial support. To illustrate each of these themes, exemplary quotes from survey responses are presented in Appendix E2. In addition to these two categories, it is notable that we also asked participants about positive aspects of being a caregiver (Appendix E1). However, we did not explore positive aspects of being caregivers in depth as this was beyond the scope of this study. Instead, below, we provide detail on the two themes as they encompassed the vast majority of the qualitative comments and could be used to help guide development of organizational solutions to reduce psychosocial stress.

### Caregiver Challenges

80% of caregivers (N=64/80) responded to the open-ended questions. Emergent themes related to challenges reported by caregivers included: 1) maintaining relationship with healthy sibling(s) during the isolation of HCT; 2) maintaining relationship with partner during the isolation of HCT; 3) managing self-care; 4) disrupted sleep; 5) coping with feelings of uncertainty; and 6) feeling unprepared for discharge.

The hospitalization strained personal relationships in 86% (N=55/64) of caregivers, in particular relationships with the caregiver's other healthy children (44%, N=28/64) and partner (33%, N=21/64) (Appendix E2, quotes 1a and 1b). Geographic distance between the caregiver and the immediate family was frequently mentioned as a contributor to physical isolation. Although caregivers tried alternating stays, there typically was a primary caregiver who spent more time in the hospital while the secondary caregiver managed all other responsibilities (*e.g.*, income, finances, and care of other children). Individual hospital policies varied regarding visitation restrictions with some allowing only one overnight parent caregiver. The lack of sibling visitation during immune deficiency also created hardships for many families, especially those with younger children who were unable to understand why they were not able to visit.

Almost half (41%, N=26/64) of caregivers mentioned difficulty managing self-care (*e.g.*, diet, exercise, and personal hygiene, time for socializing or relaxation activities) during the hospitalization process and its impact on their physical and emotional well-being (Appendix E2, quote 1c). Many were unable to continue their self-care due to the physical isolation and unpredictability of schedule. In particular, 31% of caregivers (N=20/64) mentioned the disruption of sleep and its impact on their well-being (Appendix E2, quote 1d). Caregivers suggested protected times for rest, particularly during the evening times. Caregivers also requested better housing accommodations and amenities in the hospital such as more comfortable beds. Families reported benefiting from hospital housing options such as the Ronald McDonald House.

Furthermore, the stress around uncertainty of the child's diagnosis, treatment plan, and long-term outcome was reported by 31% of caregivers (N=20/64) (Appendix E2, quote 1e). Caregivers appreciated being kept informed during the process. Families wanted to learn more about their child's condition before the hospitalization and what to expect when they are better able to absorb information and in a less fatigued state. Some caregivers (13%, N=8/64) commented on the discharge process and suggested improvements such as more training on care management (IV line changes, dressing changes, etc.) and advanced notice to prepare (Appendix E2, quote 1f). Caregivers appreciated the continued contact with the medical care team after discharge but wanted more information on how to inform local hospitals of the post-HCT status of child in case of emergencies, resources on preparing the home, and transitions back to child care.

### Caregiver Suggestions to Enhance Psychosocial Support

Emergent sub-themes related to improving the HCT experience included: 1) offering respite services; 2) acknowledgement of psychological distress from healthcare team; 3) connecting new caregivers with online PID caregiver support groups; 4) providing counseling and mental health services at the bedside; and 5) accessing financial assistance. These suggestions included comments from participants describing specific resources or services they found helpful and/or explicit suggestions from participants about resources or services that they felt would be helpful to others.

Hospital-based respite services were referenced by 53% of caregivers who both received and/or made suggestions for more (N=34/64). Hospital-based respite services positively impacted caregiver well-being, allowing time for caregivers to manage their self-care and/or attend to other duties (Appendix E2, quote 2a). Consistent repeat encounters with the same nurse or volunteer providing the respite service were important in building sufficient trust to allow parents to relax and feel confident about taking a break from their child's bedside.

Caregivers appreciated when healthcare teams checked in with them regarding their well-being, and 34% (N=22/64) expressed interest in receiving more acknowledgment of their psychological distress (Appendix E2, quote 2b). Caregivers felt supported when healthcare teams checked in and requested more time with providers to discuss about medical decisions.

Given the intensity of HCT and specific precautions for PID, 31% of caregivers (N=20/64) utilized and/or suggested connecting with other PID caregivers for support and guidance (Appendix E2, quote 2c). Foundations like the SCID Angels for Life were referenced as providing a community and informative resource. Online support groups were favored over in-person support groups by 64% of caregivers (N=41/64) due to the easy access, convenience, and decreasing infection risk. That said, 33% of caregivers (N=21/64) were also interested in in-person support group check-ins. Regular check-ins were favored, ranging from once-a-week to once-a-month starting as early as the initial diagnosis and ranging to post-discharge. Moderators and facilitators were viewed as helpful in guiding discussions.



31% of caregivers (N=20/64) expressed interest in receiving counseling and/or mental health services throughout the hospitalization process (Appendix E2, quote 2d). However, even when services were made available, many caregivers were unable to schedule or attend appointments due to logistical challenges and inability to leave their child unattended. Many believed it would be useful to receive these services at bedside to minimize these impediments.

Twenty-eight percent of families (N=18/64) experienced difficulty with finances during the hospitalization and expressed the need for scholarships and other resources (Appendix E2, quote 2e). Caregivers frequently mentioned the unexpected challenge of managing finances. They reported experiencing distress over billing and insurance costs. While caregivers were appreciative of housing services and vouchers for parking and food, they would have liked to have more information available about scholarships and funding sources available to them.

## Discussion

To our knowledge, this is the first study to describe sub-populations of caregivers of children with PID at particularly high risk for poor well-being and the psychosocial supports most commonly used by them, and to identify some patient-centered organizational solutions to improve the HCT experience. We used our findings from this nation-wide study to identify pragmatic organizational-level solutions to enhance well-being. Such organizational solutions could optimize hospital policies, adjust provider workflows, provide support services, and enhance provider-patient communication to address key challenges facing these families, including vulnerable subpopulations (Table 4).

We found that caregivers who were low income and/or had children with complications experienced significantly lower well-being after the hospitalization. This is consistent with previous literature on the general pediatric population and mothers of hospitalized newborns, which show that hospital experiences such as the patient's clinical course, distance between home and the hospital, and degree of social support influence the risk of caregiver post-partum depression and/or post-traumatic stress symptoms (22,29,30). Furthermore, studies have shown interventions for caregivers of children undergoing HCT have a greater impact among those with fewer psychosocial resources (21). These findings suggest that screening and intervention development might target caregivers with additional social stressors (*e.g.*, further distance away from home, single parents, additional children) and more complicated medical courses (*e.g.*, longer hospitalizations, graft-versus-host disease, and multiple hospitalizations).

We also found that caregivers primarily relied on the medical care team and extended family, but online support groups, close friends, and religious communities were also used. The use of on-line support groups is likely due to the unique challenges during HCT isolation phase. Studies have shown that positive experiences of social support—either informal (*e.g.*, family, friends, and peers) or formal (*e.g.* physicians, nurses, and social workers)—build resilience to stress and lower caregiver burden (31,32). In particular, peer-to-peer support models have been effective in supporting new caregivers and mediating caregiver stress through information sharing, skill-building, and setting expectations (33). This use of on-line

support groups is consistent with prior literature focusing on caregivers of children with a life threatening illness or injury (34–36), but has not been described in this population before. Similarly, families with other children significantly utilized more mental health treatment, which is consistent with the pediatric oncology literature demonstrating increased levels of stress and sibling conflict (37,38).

We found key challenges of maintaining relationships with the healthy sibling(s) and partner during misolation, managing self-care, disrupted sleep, coping with feelings of uncertainty, and feeling unprepared for discharge. These problems have been identified before in case reports for the caregiver of children with PIDs (39), and also in the pediatric oncology caregiver population (40,41). Our study was unique in eliciting caregiver organizational-level suggestions to enhance psychosocial support. We found that these solutions addressed the challenges and included offering of respite services, acknowledgement of psychological distress from healthcare team, connections to other caregivers of children with PIDs via on-line communities, providing bedside counseling and mental health services during hospitalization, and facilitating access to financial assistance.

Changes at the organizational level, including changes in hospital policies, provider workflows, available support services (e.g., financial, social) and provider-patient communication, could all play a role in improving the well-being of caregivers and, by extension, their children. For example, healthcare systems could facilitate social support through social media platforms (42) and minimize overnight disruptions (41). Problem-solving therapy (PST), a five-step cognitive-behavioral intervention, could be delivered at bedside to reduce caregiver stress with sustained results in multiple chronic illness settings (43). As such, we triangulated our quantitative and qualitative findings to develop possible organizational-level interventions to address the challenges reported, paying particular attention to high-risk groups (low-income, complications) (Table 4).

Although limited by a somewhat homogenous population, this study was able to recruit a fairly large sample for a rare disease cohort. This limitation of small and homogenous sample has been commonly reported in prior studies of pediatric PID populations (44–49). As such, further research is needed to assess the challenges and needs of specific sub-populations, such as populations with limited English proficiency and/or minority populations in addition to families who experienced fatal outcomes. Responses may also be subject to recall bias with the range of time since HCT. Finally, clinical characteristics were obtained by caregiver reports, which has its limitations, particularly when children are older. Given the young median age of the sample it is appropriate to use caregiver report. Future studies should explore the effectiveness of implementation of some of the proposed organizational solutions to enhance well-being of caregivers, impact of fatal outcomes, and measurements of adverse social outcomes such as divorce rates during or after HCT in prospective studies.

In summary, this is the first, large nation-wide study to assess well-being of caregivers of children with PIDs and to identify patient-centered organizational-level solutions to enhance their well-being. In addition, this study may have implications for caregivers of children with other life-threatening and/or chronic illness. We hope that the findings can inform the

design of systemic changes and guide hospital administrators, transplant physicians, nurses and social workers in their efforts to improve psychosocial services to support caregivers.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Conflict of interests

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## ABBREVIATIONS

<b>HCT</b>	Hematopoietic Cell Transplantation
<b>PID</b>	Primary Immunodeficiency
<b>SCID</b>	Severe Combined Immune Deficiency

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**KEY MESSAGES**

- Caregivers at high-risk for poor well-being after the HCT hospitalization include those with lower household income and more complicated hospital courses.
- To address caregiver isolation, healthcare organizations could facilitate peer-to-peer support via on-line social media platforms.
- Provision of psychosocial services at the ill child's bedside is particularly necessary for this caregiver population.

**Table 1.**

Baseline characteristics of caregivers and children with PID (n=80)

	N (%)
<i>Caregivers</i>	
Age, median (range), years	34 (23–62)
Sex, n (%)	
Female	78 (98%)
Race, n (%)	
American-Indian or Alaska Native	1 (1%)
Asian	5 (6%)
Black or African American	1 (1%)
White	69 (87%)
Mixed	4 (5%)
Ethnicity, n (%)	
Hispanic or Latino	6 (8%)
Non-Hispanic or Latino	74 (92%)
Geographic residence, n (%)	74 (92%)
United States, n (%)	
Midwest	22 (27%)
Northeast	8 (10%)
South	23 (29%)
West	21 (26%)
International	6 (8%)
Marital status, n (%)	
Married/living together	70 (88%)
Education, n (%)	
College or above	58 (73%)
Employment status, n (%)	
Employed	44 (55%)
Annual household income \$, n (%)	
<75K	38 (48%)
75–150K	26 (32%)
>150K	16 (20%)
<i>Children with PID</i>	
Age at BMT, median (range), months	5 (0.5–27)
Years since BMT, median (range), years	5 (0.5–24)
Sex, n (%)	
Male	63 (79%)
Race, n (%)	
American-Indian or Alaska Native	1 (1%)
Asian	3 (4%)
Black or African American	1 (1%)



	N (%)
White	64 (80%)
Mixed	11 (14%)
Ethnicity, n (%)	
Hispanic or Latino	7 (9%)
Non-Hispanic or Latino	73 (91%)
Place of HCT, n (%)	
United States	76 (95%)
Midwest	21 (26%)
Northeast	11 (14%)
South	23 (29%)
West	21 (26%)
Canada	4 (5%)
Diagnosis, n (%)	
SCID	59 (74%)
WAS or Other	21 (26%)
Insurance, n (%)	
Private or Other	63 (79%)
Medicaid/CHIP	17 (21%)
Number of siblings, n (%)	
0	28 (35%)
1	27 (34%)
2	25 (31%)
Hospitalization length, median (range), weeks	9 (1–63)
Complications, n (%) <sup>*</sup>	52 (65%)
Graft-versus-host disease	30 (38%)
Infection	27 (34%)
Respiratory Distress	13 (16%)
Organ Damage	6 (8%)
Graft Failure	5 (6%)
Other	15 (19%)
Number of post-transplant hospitalizations, median (range)	1 (0–30)

<sup>\*</sup>Subjects could report more than one complication.

**Table 2.**

Description of psychosocial support utilization \*

	Types of psychosocial support with high utilization by caregivers, <i>n</i> (%)						
	Extended Family	Close friends	Religious community	Medical care team	Mental health providers	In-person support groups	Online support groups
<b>Overall use (N=80)</b>	<b>50 (63)</b>	<b>32 (40)</b>	<b>23 (29)</b>	<b>56 (70)</b>	<b>10 (13)</b>	<b>7 (9)</b>	<b>36 (45)</b>
<i>Caregiver variables</i>							
Household income							
<\$75,000 (N=38)	24 (63.2)	17 (44.7)	9 (23.7)	27 (71.1)	3 (7.9)	3 (7.9)	18 (47.4)
\$75,000-\$150,000 (N=26)	16 (61.5)	7 (26.9)	8 (30.8)	18 (69.2)	5 (19.2)	3 (11.5)	11 (42.3)
>\$150,000 (N=16)	10 (62.5)	8 (50.0)	6 (37.5)	11 (68.8)	2 (12.5)	1 (6.3)	7 (43.4)
Education							
No college (N=22)	12 (54.5)	10 (45.5)	7 (31.8)	14 (63.6)	4 (18.2)	2 (9.1)	7 (31.8)
College and above (N=58)	38 (65.5)	22 (37.9)	16 (27.6)	42 (72.4)	6 (10.3)	5 (8.6)	29 (50.0)
<i>Patient variables</i>							
Diagnosis							
SCID (N=59)	37 (62.7)	25 (42.4)	19 (32.2)	42 (71.2)	7 (11.9)	4 (6.8)	23 (39.0)
WAS or Other (N=21)	13 (61.9)	7 (33.3)	4 (19.0)	14 (66.7)	3 (14.3)	3 (14.3)	13 (61.9)
Insurance							
Private or Other (N=62)	39 (62.9)	25 (40.3)	16 (25.8)	41 (66.1)	6 (9.7)	4 (6.5)	<b>22 (35.5)**</b>
Medicaid/CHIP (N=18)	11 (61.1)	7 (38.9)	7 (38.9)	15 (83.3)	4 (22.2)	3 (16.7)	<b>14 (77.8)**</b>
Siblings of child with PID							
0 (N=28)	17 (60.7)	8 (28.6)	5 (17.9)	19 (67.9)	<b>0 (0.0)**</b>	0 (0.0)	12 (42.9)
1 (N=27)	17 (63.0)	12 (44.4)	8 (29.6)	20 (74.1)	<b>7 (25.9)**</b>	4 (14.8)	14 (51.9)
2+ (N=25)	16 (64.0)	12 (48.0)	10 (40.0)	17 (68.0)	<b>3 (12.0)**</b>	3 (12)	10 (40.0)
<i>Medical variables</i>							
Complication							
No complication (N=28)	18 (64.3)	11 (39.3)	8 (28.6)	19 (67.9)	2 (7.1)	2 (7.1)	12 (42.9)
Complication (N=52)	32 (61.5)	21 (40.4)	15 (28.8)	37 (71.2)	8 (15.4)	5 (9.6)	24 (51.9)
Hospitalization length							
Short 9 weeks (N=42)	29 (69.0)	21 (50.0)	12 (28.6)	29 (69.0)	<b>2 (4.8)**</b>	2 (4.8)	16 (38.1)
Long >9 weeks (N=38)	21 (55.3)	11 (28.9)	11 (28.9)	27 (71.1)	<b>8 (21.1)**</b>	5 (13.2)	20 (52.6)

\* Denominator for each variable is reported in the first column. Chi-squared and Fisher's Exact analyses are for sub-groups between each variable for each type of psychosocial support (e.g. close friend support utilization among household income group).

\*\*  $P < 0.05$

**Table 3.**

Influences upon caregiver well-being after HCT for child with PID

Variables	Adjusted Regression Coefficient* $\beta$ (95% CI)
Caregiver age	3.11 (-0.18 to 6.41)
Caregiver household income	
<\$75,000	Ref
\$75,000-\$150,000	<b>9.25 (2.38 to 16.12)**</b>
>\$150,000	<b>8.90 (0.67 to 17.14)**</b>
Insurance	
Private or Other	Ref
Medicaid/CHIP	-6.82 (-14.56 to 0.92)
Hospitalization length (weeks)	-0.20 (-0.41 to 0.01)
Complication	
No	Ref
Yes	<b>-7.80 (-14.15 to -1.44)**</b>

\* Adjusting for all other covariates  $P < 0.1$  in the model (7 df)\*\*  $P < 0.05$

**Table 4.**

## Organizational-level solutions for healthcare systems

<b>Strengthening community support</b>	
Maintaining relationships with healthy sibling(s) and partner during isolation	<ul style="list-style-type: none"> <li>• Revise hospital policies to allow for more than one caregiver to stay overnight.</li> <li>• Encourage caregivers to utilize social media and online resources (e.g., Skype, FaceTime), to keep in-touch with partner and healthy-sibling during isolation.</li> <li>• Encourage parents to schedule several hours a week together with healthy sibling(s).</li> <li>• Encourage parents to schedule daily or weekly time together as a couple.</li> </ul>
Connections to other PID caregivers	<ul style="list-style-type: none"> <li>• Connect caregivers to PID foundations and on-line support networks such as Immune Deficiency Foundation, SCID Angels for Life, Wiskott-Aldrich Foundation.</li> <li>• Establish a community of volunteer peer support contacts and group therapy services through regular hospital programming and newsletters.</li> </ul>
<b>Promoting self-care</b>	
Managing self-care	<ul style="list-style-type: none"> <li>• Encourage caregivers to use on-line platforms to leverage external support systems (e.g., family, friends, co-workers) to help provide extra support during the hospitalization (e.g., Lotsa Helping Hands, and CaringBridge).</li> <li>• Promote self-care (e.g., personal hygiene, diet, exercise, etc.) during hospitalization through offering of classes and services such as child coverage, yoga, and meditation.</li> </ul>
Disrupted sleep	<ul style="list-style-type: none"> <li>• Modify nursing workflows to minimize overnight disruptions (e.g., central line changes) and protect blocks of evening times to allow caregivers rest and sleep.</li> <li>• Develop and provide sleep hygiene resources for caregivers.</li> </ul>
Respite services	<ul style="list-style-type: none"> <li>• Offer respite services (e.g. child-care coverage through nursing staff and/or volunteer services) to allow caregivers time and space for self-care.</li> </ul>
<b>Anticipating the hospital course</b>	
Coping with feelings of uncertainty	<ul style="list-style-type: none"> <li>• Create weekly and/or daily schedules for caregivers with pertinent information such care team rounding times, procedure times, and appointments to allow caregivers to plan.</li> <li>• Help families anticipate the psychosocial distress prior to hospitalization</li> </ul>
Feeling unprepared for discharge	<ul style="list-style-type: none"> <li>• Begin working on discharge planning at least half way through visit, especially for caregivers of children with complications.</li> <li>• Provide training and practice time for managing child's care (e.g. central line cap changes, dressing changes, etc.)</li> </ul>
<b>Providing mental health and social services</b>	
Acknowledgement of psychological distress from healthcare team	<ul style="list-style-type: none"> <li>• Check-in with caregivers at least once a week about personal well-being, especially after any complications.</li> </ul>
Providing bedside mental health services during hospitalization stay	<ul style="list-style-type: none"> <li>• Offer bedside evidence-based counseling (e.g., Problem Solving Therapy) throughout hospitalization with child care coverage during appointments. This may be especially critical after unforeseen complications.</li> <li>• Screen caregivers for depression and PTSD during hospitalization at regular intervals (on-arrival to establish baseline, 3 months, 6 months, and immediately following complications etc.).</li> <li>• Provide positive coping strategies and training for caregivers, especially following complications (e.g., seeking support, problem-solving, exercise, relaxation) .</li> </ul>
Financial assistance	<ul style="list-style-type: none"> <li>• Expand financial scholarships eligibility criteria to include PID and offer more financial services to caregivers (e.g., parking vouchers, on-site hospital housing facilities, etc.), especially to those who are low-income.</li> <li>• Consider connecting families with wish fulfillment and charitable organizations like Make-a-Wish Foundation, Give Kids the World, Hope Kids, and Kids Wish Network.</li> </ul>