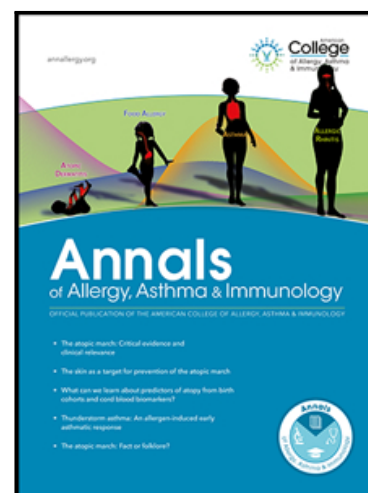


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Provider Practices in Screening for Mental Health Concerns in Caregivers of Patients with Primary Immunodeficiency

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Primary immunodeficiency disorders (PID) are a diverse group of diseases that impact the immune system and require intensive treatment. The psychosocial impact of PID may be particularly pronounced among caregivers of children diagnosed with PID who often experience disruption to work and family responsibilities related to diagnosis and treatment, and face ongoing uncertainty regarding recurrent infections, hospitalizations, and life-threatening treatment. The psychological impact of chronic diseases may influence patient medical and psychosocial outcomes as well.¹⁻³ Previous studies indicate that children with PIDs who require hematopoietic stem cell transplantation (HSCT) and their caregivers reported emotional distress,⁴⁻⁶ and caregiver depression correlated with child distress before transplantation.⁷

Routine screening for mental health concerns at immunology appointments could identify caregivers who would benefit from further psychosocial evaluation and treatment, yet it is unknown whether caregivers of patients with PID are routinely screened. The goal of this study was to assess how frequently providers screen for mental health concerns among caregivers of patients with PID and to identify providers' perceptions regarding caregiver screening.

An anonymous survey was developed to assess current screening practices among providers who routinely care for patients with PID. Questions addressed (1) the perceived importance of screening, (2) whether screening is routinely performed at visits, (3) mental health resource availability, and (4) perceived barriers to screening. After Institutional Review Board approval, the survey was created in SurveyMonkey (<https://www.surveymonkey.com/>) and the survey link was distributed by the Clinical Immunology Society and Primary Immunodeficiency Treatment Consortium. The survey was open from February to April 2016. Results were summarized and compared by primary specialty (allergy/immunology, hematology/oncology, other) using

Kruskal-Wallis, Chi-square, and Fisher's Exact tests. All analyses were completed using SAS 9.3; a p -value of .05 was considered significant.

Seventy-nine responses were received from participants in three countries (Peru, Spain, United States) and 23 US states/districts. Most respondents reported allergy/immunology (47%) or hematology/oncology (29%) as their primary specialty; 66% were focused PID specialists (i.e., $\geq 10\%$ of patient volume focused on PID).

Providers believed that it was important to address caregiver mental health during visits (median=2; 1='very important' to 5='very unimportant'). Hematologists/oncologists' ratings were slightly higher (median=1.5) than allergists/immunologists' (median=2) or other specialists' (median=2) ratings, $p = .01$. Providers also believed it was important to the caregiver that their mental health is addressed during appointments (median=2). No differences were noted based on percent of patients seen for PID. Almost all providers (95%) believed that caregiver mental health impacts patient outcomes; in an open-ended follow up question, some providers noted that poor caregiver mental health results in poor adherence to prescribed treatments. However, only 58% of providers reported feeling 'very comfortable' or 'comfortable' addressing caregiver mental health during appointments.

Few providers (23%) reported routinely screening caregiver mental health.

Allergists/immunologists (6%) were less likely to assess caregiver mental health during visits than hematologists/oncologists (32%) or other specialists (35%, $p = 0.01$). No significant differences were noted among providers based on percent of patients seen for PID treatment. Sixty-four percent of providers who reported that they routinely screen caregivers use direct questions during appointments, 23% have social workers involved in screening, and 9% have

psychologists involved in screening. Most providers (67%) who did not conduct mental health screening indicated concerns about lack of time/resources and uncertainty about the need/desire for screening.

Most providers (75%) had resources available for caregivers who have difficulty adjusting to their child's diagnosis, but only a few had access to social workers (41%) or psychologists (30%). Many providers (75%) had previously recommended caregiver mental health follow up based on their interactions with the caregiver. Allergists/immunologists (65%) were somewhat less likely to recommend mental health follow-up than hematologists/oncologists (73%) or other specialists (94%). Challenges were noted when screening families with language or cultural barriers (75%), socioeconomic challenges (67%), new diagnoses requiring referral for HSCT (64%), and new diagnoses in the newborn period (50%). The most commonly reported barriers to screening included time limitations (67%), staffing limitations (64%), lack of resources (51%), and lack of comfort (24%).

In this survey, we sought to determine if providers routinely screen for mental health disorders among caregivers of PID patients. This survey demonstrated that many providers believe that caregiver mental health has the potential to impact outcomes for patients with PID, but the majority does not routinely screen caregivers. Barriers to screening were frequently reported, including time and staffing limitations. Most providers had access to general resources, but only a few had access to social workers or psychologists to whom they could refer.

Allergists/immunologists were less likely than other specialties to screen or recommend mental health follow up. This may be related to hematologists/oncologists' long history of psychosocial inclusion in their multidisciplinary teams. This disparity could also reflect time and staff

limitations for allergists/immunologists. Further information differentiating allergists/immunologists based on whether or not they perform transplants for PID could potentially clarify these findings as well, but were not available in this study.

Notable limitations include a small sample size, the retrospective, self-report nature of the data, and a lack of information regarding patients' age ranges and specific PID diagnoses, as it is possible that risks to caregiver mental health vary based on child age and/or PID diagnosis. Future studies should assess these variables, as well as caregivers' perceptions of mental health screening and the impact of mental health screening on mental health referrals, patient outcomes, and clinic efficiency. Future research should also study the impact of caregiver mental health on medical and psychosocial outcomes among PID patients.

Although there is perceived need to address the mental health concerns of caregivers of patients with PID, providers acknowledged that barriers exist for mental health screening to be widely implemented. Potential strategies to ameliorate these barriers could include improved inclusion of multidisciplinary team members and the use of validated mental health screening tests in the care of children with PID and their caregivers.

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Conflict of Interest

The authors declare no commercial or financial conflicts of interest.

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Table 1: Attitudes towards caregiver mental health (CMH) screening by specialty

	Overall	Primary Specialty			
		Allergy/Immu.	Hem/Onc	Other	p

		(n = 37)	(n = 23)	(n = 19)	
Rated importance, perceived importance, and comfort of addressing caregivers' mental health during visits: Median (IQR) ¹					
Importance to provider:	2 (1-2)	2 (2-3)	1.5 (1-2)	2 (1-2)	0.008
Importance to caregiver:	2 (2-3)	2 (2-3)	2 (1-2)	2 (2-2)	0.39
Provider Comfort	2 (2-3)	3 (2-3)	2 (2-3)	2 (2-2)	0.13
Categorical screening, resource, and recommendation variables: N (%) ²					
Routinely screen caregivers for mental health issues					0.01
Yes	18 (23.38)	2 (5.88)	7 (31.82)	6 (35.29)	
No	59 (76.62)	32 (94.12)	15 (68.18)	11 (64.71)	
Have resources available for caregivers					0.12
Yes	57 (75.00)	21 (61.76)	19 (86.36)	14 (82.35)	
No	19 (25.00)	13 (38.24)	3 (13.64)	3 (17.65)	
Therapists/mental health resources at institution					0.47
Yes	67 (88.16)	28 (82.35)	20 (90.91)	16 (94.12)	
No	9 (11.84)	6 (17.65)	2 (9.09)	1 (5.88)	
Ever recommended CMH follow-up					0.06
Yes	57 (75.00)	22 (64.71)	16 (72.73)	16 (94.12)	
No	19 (25.00)	12 (35.29)	6 (27.27)	1 (5.88)	
Believe CMH affects patient outcomes					0.81
Yes	72 (94.74)	33 (97.06)	20 (90.91)	16 (94.12)	
No	4 (5.26)	1 (2.94)	2 (9.09)	1 (5.88)	
Feel able to ease CMH during appointments					0.66
Yes	55 (73.33)	22 (66.67)	17 (77.27)	13 (76.47)	
No	20 (26.67)	11 (33.33)	5 (22.73)	4 (23.53)	
Specific populations for whom screening for CMH is particularly challenging ³					N/A
New dx, newborn period	38 (50.00)	18 (48.65)	8 (34.78)	11 (57.89)	
New dx, HSCT referral	49 (64.47)	20 (54.05)	14 (60.87)	13 (68.42)	
Disadvantaged families	51 (67.11)	23 (62.16)	14 (60.87)	12 (63.16)	
Language/cultural barriers	57 (75.00)	24 (64.86)	17 (73.91)	14 (73.68)	
Perceived barriers to mental health screening ³					N/A
Time limitations	51 (67.11)	24 (64.86)	14 (60.87)	10 (52.63)	
Staffing limitations	49 (64.47)	24 (64.86)	14 (60.87)	8 (42.11)	
Lack of resources	39 (51.32)	18 (48.65)	11 (47.83)	7 (36.84)	
Lack of comfort	18 (23.68)	11 (48.65)	5 (21.74)	1 (5.26)	
Percentage of caregivers who would benefit from MH management					0.56
1-25%	16 (22.22)	8 (25.00)	4 (19.05)	4 (25.53)	
26-50%	23 (31.94)	11 (34.38)	5 (23.81)	6 (35.29)	
51-75%	19 (26.39)	9 (28.13)	8 (38.10)	2 (11.76)	
76-100%	14 (19.44)	4 (12.50)	4 (19.05)	5 (29.41)	
¹ p-value based on Kruskal-Wallis test (primary specialty) or Wilcoxon-Mann-Whitney test (percent of patient population seen)					
² p-values based on Chi-square or Fisher's exact test, as appropriate					
³ Percentages represent percent of total endorsing that item					
Numbers in bold significant at p < 0.05					