Journal of HOSPITAL MEDICINE www.journalofhospitalmedicine.com

BRIEF REPORTS

Pediatric to Adult-Care Transitions in Childhood-Onset Chronic Disease: Hospitalist Perspectives

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OBJECTIVE: Survey of adult-centered hospitalist perspectives on caring for adults with chronic diseases of childhood onset (CDoCO) to investigate comfort level and identify targets of future educational and policy intervention.

METHODS: We developed an on-line survey for adult-centered hospitalists based on a prior outpatient survey and introduced it to the Society of Hospital Medicine membership via e-mail. Consent was implied by completing the survey.

RESULTS: Of all respondents, 60% saw 5 or more adults with CDoCO over a 6-month period. Among internal medicine respondents, 40% did not feel comfortable caring for this population, with lack of familiarity with the literature, lack of training in CDoCO, coordinating with multiple specialists, and lack of training in adolescent development and behavior ranked as the most significant barriers to care.

CONCLUSION: The steadily growing population of adults with CDoCO and their high inpatient utilization have lead to increased care by adult-centered hospitalists, many of whom do not feel comfortable caring for them. Educational initiatives aimed at increasing medical knowledge base for common issues, training in adolescent development, increased care coordination, and access to address psychosocial issues would improve hospitalist comfort and patient care for this vulnerable population. *Journal of Hospital Medicine* 2013;8:627–630. © 2013 Society of Hospital Medicine

Over the last 40 years, innovations in medical care have dramatically improved the survival rates of children born with chronic illness or disabling health conditions; more than 90% are now expected to live beyond age 20 years, with approximately 500,000 reaching age 18 years every year.[1] The subset of these children with complex chronic disease use significant inpatient resources, accounting for 19.2% of pediatric inpatients, 48.9% of total pediatric hospital days, and 53.2% of pediatric hospital charges.[2,3] This trend for high inpatient utilization and cost continues as the population ages, posing a potentially significant burden on pediatric hospitals.[4,5] To reserve their specialized services for children, many pediatric hospitals impose age cutoffs for inpatient care; a national survey showed that 67% to 75% of patients over age 18 years with 4 specific chronic conditions (congenital heart disease [CHD], cystic fibrosis [CF], sickle cell disease [SCD], and spina bifida) were admitted to adult-centered hospitals, as opposed to those providing exclusively pediatric or mixed services.[6] Admission rates for some conditions are growing faster in adults than in children, possibly due to increasing comorbidities with age.[7]

Although outpatient general internists indicated agreement that young adults with chronic diseases of childhood onset (CDoCO) should receive adult-centered care, a majority did not feel comfortable providing it, or indicated a subspecialist should serve as the primary care provider.[8] Internal medicine residents also cite discomfort both with inpatient and outpatient management of patients with childhood onset illnesses and developmental disabilities.[9]

Due to their practice focus and the high inpatient utilization of this transitioning population, hospitalists will increasingly care for these adults. Academic hospitalists play an important role in medical education on the wards and can facilitate internal medicine residents learning about these patients. To date, no needs assessment has been completed regarding adult-centered hospitalist perspectives regarding this population. This exploratory survey was designed to investigate adult hospitalist comfort level and concerns in caring for adults with CDoCO to guide potential educational interventions and improve care for this vulnerable population.

METHODS

Participants

We developed a survey for adult-centered hospitalists to investigate comfort level with caring for adults with CDoCO and barriers to care that could be targets of educational and policy intervention. It was piloted with a small group of internal medicine

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Additional Supporting Information may be found in the online version of this article.

Received: June 27, 2013; **Revised:** September 14, 2013; **Accepted:** September 16, 2013
2013 Society of Hospital Medicine DOI 10.1002/jhm.2091

(IM)-trained and combined medicine–pediatrics (MP)-trained hospitalists for feedback regarding question clarity. The on-line survey was emailed during July/August 2012 to the Society of Hospital Medicine (SHM) membership, which consisted of 11,218 hospital-based providers and staff, of whom 61.7% identify as IM, 2.9% MP, 7.9% family medicine (FM), 3.4% pediatrics, and 24.1% other/no information. The survey was approved by our institutional review board, and was voluntary and anonymous with consent implied by participation; it was reintroduced twice to maximize response rates.

Survey

To gauge comfort level and support for hospitalists caring for adults with CDoCO, hospitalists rated their agreement with the statements "I feel comfortable caring for adults with CDoCO" and "If I have a disease-specific question on an adult with a CDoCO, I know who to call" on a 4-point Likert scale. They rated 14 potential barriers related to caring for this population on a 4-point Likert scale as having "no impact" on ability to provide care to having "great impact" on care. The barriers were categorized into 3 areas: medical competence, care coordination, and psychosocial issues. Potential barriers were adapted from an outpatient survey of general internists and tailored for inpatient practice.[10] Respondents estimated the number of adults with CDoCO they had cared for in the prior 6-month period and how often this population had a primary care provider.

RESULTS

Of the email requests delivered, 2713 were opened during the initial wave and 2535 during the second wave. A total of 179 respondents completed the survey.

Demographics

The specialty distribution represents similar proportion of IM- but higher FM- and MP-trained providers than the general SHM membership. Two percent noted primary pediatric training; these responses were excluded given the survey focus on providers with some adult-centered training. Just over 60% identified their primary practice as community-based, with the remainder in academic practice (Table 1).

TABLE 1. Demographics of Survey Respondents

Demographic	No. of Respondents (%)*
Gender	
Male	71 (40)
Female	106 (60)
Residency training	
Internal medicine	122 (68)
Family medicine	30 (17)
Medicine-pediatrics	22 (12)
Pediatrics	2 (1)
Provider type	
Physician	176 (98)
NP/PA	3 (2)
Practice type	
Academic	68 (39)
Community	107 (61)
Fellowship	
Yes	30 (17)
No	147 (83)
Years in practice	
6 or less	90 (50)
7 or more	89 (50)
Nearest pediatric hospital	
At site of practice	87 (49)
<20 miles away	58 (33)
>20 miles away	32 (18)
Unsure	1 (1)

NOTE: **Abbreviations:** NP, nurse practitioner, PA, physician assistant.

*Variations in numbers reflect incomplete demographic answers.

Experience, Comfort Level, and Support

Nearly 60% of all respondents saw 5 or more adults with CDoCO over a 6-month period, with 16% of IM respondents, 31% of MP respondents, and 23% of FM respondents seeing more than 15 patients. Among IM respondents, 40% reported that they did not feel comfortable caring for this population, compared to 5% of MP and 14% of FM respondents; overall <20% of respondents "strongly agreed" they were comfortable caring for these patients. Respondents with 6 or less years in practice reported less discomfort (25%) than those practicing 7 years or more (40%). Community-based providers reported high exposure, with 59% seeing more than 15 patients in 6 months, but similar discomfort levels, with 38% not feeling comfortable providing care. Additionally, 30% of all respondents did not know who to contact with a disease-specific question.

Barriers to Care

Among IM providers, lack of familiarity with the literature, lack of training in CDoCO, coordinating with multiple specialists, and lack of training in adolescent development and behavior ranked as the most significant barriers to care (Table 2). Difficulty finding outpatient providers was also noted as a concern by all respondents, and 44% reported that these patients had an identified primary care provider less than half of the time.

Whereas the majority of respondents cited meeting psychosocial needs as impacting their ability to provide care, additional questions addressing specific psychosocial tasks were not highly ranked.

DISCUSSION

In keeping with the increasing survival of children with chronic disease, a majority of hospitalists participating in adult-centered settings were caring for adults with CDoCO. Despite their responsibility for these patients, a large proportion of both IM-trained and community-based providers in all specialties did not

TABLE 2. Mean Likert Ratings for Potential Barriers to Caring for Adults With CDoCO*

Statement	Average Likert(IM Only)	Average Likert (Overall)	Category
Lack of familiarity with the latest literature on specific illnesses	2.82	2.67	MC
Lack of training in CDoCO	2.64	2.45	MC
Difficulty meeting psychosocial needs of young adults with CDoCO	2.53	2.46	PS
Lack of training in adolescent development and behavior	2.53	2.26	MC
Difficulty coordinating with multiple specialists to manage complex problem	2.52	2.47	MC/CC
Difficulty finding outpatient providers to follow up	2.50	2.50	CC
Expectations for significant time/attention needed for proper care	2.41	2.36	PS
Lack of patients'/families' familiarity with adult healthcare systems	2.40	2.37	CC
Lack of physician and patients'/families' familiarity with available outpatient providers to follow up	2.40	2.45	CC
Difficulty assessing patient readiness to assume responsibility for medical plan	2.38	2.20	PS
Difficulty coordinating transitions from pediatric caregivers	2.37	2.40	CC
Difficulty balancing family involvement and patient independence/privacy	2.36	2.27	PS
Difficulty facing severe disability in young patients	2.18	2.02	PS
Reluctance of pediatricians to let go of their patients	1.68	1.73	CC

NOTE: **Abbreviations:** CC, care coordination; CDoCO, chronic diseases of childhood onset; IM, internal medicine respondents; MC, medical competence; PS, psychosocial.

*Likert scale rated 1–4, with 1 = no impact, 4 = great impact.

feel comfortable caring for them. These results correlate with an outpatient survey that showed less than a third of IM providers felt comfortable caring for specific CDoCO (CHD, SCD, CF).[8] The increased comfort of FM and MP hospitalists is consistent with their additional training in pediatric disease and development; however, a majority of hospitalists continue to be IM trained, highlighting the need for intervention for these providers. Increased comfort among providers closer to residency may reflect increased exposure to this growing population during training or fledgling educational initiatives.

Among IM providers, medical competence in adolescent development, behavior, and disease-specific issues emerged as major concerns, likely compounded by insufficient subspecialty access. Outpatient internists similarly report insufficient training as a top barrier, although clinic-based issues, such as lack of appointment time and reimbursement, were also highly rated.[10,11] This survey indicates that educational initiatives should include hospitalists and highlights access to a medical knowledge base and disease-specific support. Although specific training in all conditions would be out of the scope for most busy practitioners, targeting common conditions and issues, such as developmental disability and supportive devices, would be high yield. Extending educational interventions into trainee education has been postulated and well received by IM residents, who favor a multidimensional curricula in which hospitalists can play an important part.[12]

IM providers cited identifying partnering providers, both subspecialists and outpatient providers, to support ongoing care as a secondary theme. An outpatient survey of pediatric and IM providers showed at least half felt identifying an adult-centered primary care provider would be difficult and care coordination inadequate; poor outpatient subspecialty access for common conditions was less prevalent.[11] The discomfort of outpatient IM providers may be limiting; however, early identification of need, improved coordination throughout inpatient stay, and discharge planning could ease this transition for all providers. Care coordination support staff would benefit from familiarizing themselves with this population's needs, which are different from typical adult inpatients. Even though meeting psychosocial needs was a highly rated barrier, clarifying questions about those needs did not show a pattern in this or prior outpatient surveys, limiting targeted interventions.

Engaging the community of adult-centered providers is key to providing "appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood" as charged by a joint consensus statement on transition of patients with CDoCO.[13] Overall comfort level is likely affected by the interaction between insufficient knowledge base on CDoCO and perception of insufficient subspecialty support or unclear outpatient follow-up. Future directions should center on curricular development surrounding high-yield CDoCO topics and improved inpatient care coordination.

Limitations

This survey is limited by the low response rate, raising the possibility that responses may not be fully representative of the national sample. Low response rate was likely due in part to email alert fatigue, as the number of survey requests opened represented a significant drop from those delivered. Poor response may also be due to low recognition for this population, another indicator that education and increased awareness are needed. Although decreased responses by providers who are comfortable with this population could also play a role, the correlation between our survey findings and those of prior outpatient surveys support our findings.

CONCLUSIONS

The steadily growing population of adults with CDoCO and their high inpatient utilization have lead to increased care by adult-centered hospitalists, many of whom do not feel comfortable caring for them. Educational initiatives aimed at increasing the medical knowledge base for common issues, training in adolescent development, increased care coordination, and access to address psychosocial issues would improve hospitalist comfort and patient care for this vulnerable population.

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