

Challenges Primary Care Providers Face When Caring for Children with Medical Complexity

Todd Savolt¹, Timothy Ryan Smith MD¹, Emily Goodwin MD², Michael Kennedy MD¹

¹University of Kansas Medical Center, ²Children's Mercy

(Presented during the 2019 Combined AACPDM 73rd Annual and IAACD 2nd Triannual Meeting)

Introduction

- Children with medical complexity (CMC) are characterized by having multiple significant health problems that affect multiple organ systems and cause functional limitations.
- These chronic health conditions and functional limitations create a higher need for healthcare and technology utilization.
- CMC populations continue to grow because of improvements in diagnosis and medical treatments and increasing public and provider awareness.
- CMC require intensive and costly care, which poses unique challenges and barriers for primary care providers (PCP).
- There are limited studies examining educational and knowledge gaps PCP face when caring for CMC in Kansas and Missouri.
- This study aims to identify barriers and education gaps that limit PCP and residents' self-efficacy when caring for CMC in rural and urban settings.

Methods

PORTRAIT:

- A onetime cross-sectional REDCap survey adapted from previously published surveys was disseminated to PCP in MO and KS through Children's Mercy Hospital, The University of Kansas Hospital, the Office of Rural Health Education, and the MO and KS chapters of the American Academy of Pediatrics.

HYPOTHESIS:

- Residents face different barriers and have different education needs than practicing PCP when providing primary care to CMC.
- The barriers and educational gaps for PCP caring for CMC are different in rural and urban settings.

STUDY POPULATION:

- 121 PCP completed the survey (30 Pediatricians, 29 Pediatric Residents, 4 Pediatric Nurse Practitioners, 32 Family Medicine Physicians, 7 Family Medicine Residents, 1 Family Medicine Nurse Practitioner and 1 Family Medicine Physician Assistant).
- 8 surveys were excluded due to incomplete surveys. 9 other surveys were excluded due to working in a complex care clinic.
- 104 surveys were included in the final analysis.

DATA COLLECTION:

- The survey was disseminated via email and data was collected through REDCap from July, 2018 to October, 2018. The data collected was self-identified and categorical.

STATISTICAL ANALYSIS:

- Statistical analysis was performed using a two-tailed ANOVA with a p value of 0.05.

Results

Table 1: PCP Perceived Barriers in Caring for CMC

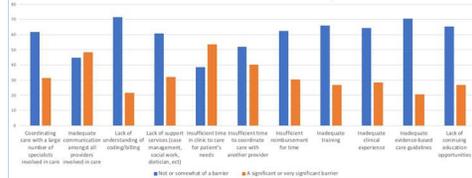


Table 2: PCP Perceived Preparedness in Handling Common Medical Concerns for CMC

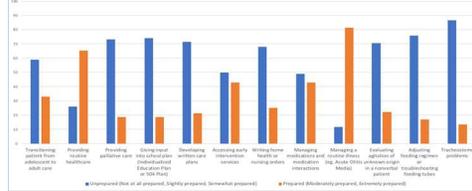


Table 3: PCP Perceived Comfort in Providing Primary Care to CMC Who Use Various Technology

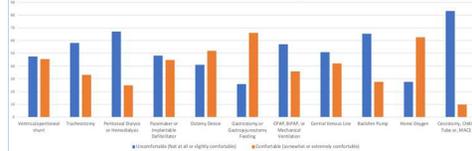


Table 4: Comparison of Perceived Barriers in Caring for CMC

| Barrier | Practicing Providers (n=104) | | Residents (n=30) | | p-value | |
|--|------------------------------|---------------------|-------------------------|---------------------|---------|--------|
| | Significant Barrier (%) | Not Significant (%) | Significant Barrier (%) | Not Significant (%) | | |
| Coordinating care with a large number of specialists involved in care | 38.2 | 25.7 | 0.2729 | 32.6 | 42.9 | 0.5463 |
| Inadequate communication amongst all providers involved in care | 58.8 | 40.0 | 0.0956 | 51.7 | 50.0 | 0.999 |
| Lack of understanding of coding/billing | 19.1 | 31.4 | 0.2385 | 23.6 | 23.4 | 0.999 |
| Lack of support services (case management, social work, dietitian, etc.) | 45.6 | 14.3 | 0.002 | 29.2 | 64.3 | 0.015 |
| Insufficient time in clinic to care for patient's needs | 56.7 | 62.9 | 0.6724 | 65.2 | 15.4 | 0.014 |
| Insufficient time to coordinate care with another provider | 44.8 | 42.9 | 0.999 | 47.2 | 21.4 | 0.087 |
| Insufficient reimbursement for time | 38.8 | 25.7 | 0.2792 | 32.6 | 28.6 | 0.999 |
| Inadequate training | 29.4 | 28.6 | 0.999 | 27.0 | 42.9 | 0.2253 |
| Inadequate clinical experience due to small number of patients | 32.4 | 28.6 | 0.823 | 28.1 | 50.0 | 0.1238 |
| Inadequate evidence-based care guidelines | 20.9 | 26.5 | 0.6172 | 21.6 | 23.1 | 0.999 |
| Lack of continuing education opportunities dedicated to children with medical complexity | 26.5 | 32.4 | 0.6423 | 28.4 | 28.6 | 0.999 |

Results

Table 5: Comparison of Perceived Preparedness in Handling Common Medical Concerns for CMC

| Common Medical Issues | Practicing Providers (n=104) | | Residents (n=30) | | p-value | |
|--|------------------------------|--------------|------------------|--------------|---------|--------|
| | Unprepared (%) | Prepared (%) | Unprepared (%) | Prepared (%) | | |
| Transferring patient from adolescent to adult care | 48.5 | 93.7 | <.0001 | 67.4 | 42.9 | 0.1312 |
| Providing routine healthcare | 12.3 | 58.3 | <.0001 | 32.2 | 7.1 | 0.0622 |
| Getting input into school plan (individualized education plan or 504 plan) | 71.2 | 94.4 | 0.0049 | 86.4 | 35.7 | 0.0001 |
| Developing written care plans | 71.6 | 94.4 | 0.0089 | 82.0 | 64.3 | 0.1543 |
| Accessing early intervention services | 70.1 | 88.9 | 0.049 | 53.8 | 57.1 | 0.0871 |
| Writing home health or nursing orders | 38.8 | 80.6 | <.0001 | 79.3 | 50.0 | 0.999 |
| Managing medications and medication interactions | 59.7 | 97.2 | <.0001 | 76.4 | 50.0 | 0.0534 |
| Managing a routine illness (eg. Acute Otitis Media) | 36.4 | 83.3 | <.0001 | 55.7 | 35.7 | 0.2489 |
| Evaluating application of unknown origin in a nonverbal patient | 67.2 | 91.7 | 0.0072 | 76.4 | 71.4 | 0.34 |
| Adjusting feeding regimen or troubleshooting feeding tubes | 77.6 | 88.0 | 0.014 | 80.9 | 85.7 | 0.939 |
| Tracheostomy Problems | 92.5 | 94.4 | 0.999 | 93.3 | 92.9 | 0.999 |

Table 6: Comparison of Perceived Comfort in Providing Primary Care to CMC Who Use Various Technology

| Medical Technology | Practicing Providers (n=104) | | Residents (n=30) | | p-value | |
|--|------------------------------|-----------------|-------------------|-----------------|---------|--------|
| | Uncomfortable (%) | Comfortable (%) | Uncomfortable (%) | Comfortable (%) | | |
| Ventilator/ventilator shut | 34.3 | 80.6 | <.0001 | 55.1 | 28.6 | 0.0883 |
| Tracheostomy | 53.8 | 80.6 | 0.0066 | 67.8 | 35.7 | 0.034 |
| Peritoneal dialysis or Hemodialysis | 63.6 | 88.9 | 0.0097 | 76.4 | 50.0 | 0.0534 |
| Pacemaker or implantable defibrillator | 40.3 | 72.2 | 0.0035 | 56.2 | 28.6 | 0.0827 |
| Ostomy device | 31.3 | 66.7 | 0.0008 | 49.4 | 14.3 | 0.019 |
| Gastrostomy or Gastrojejunostomy feeding | 21.2 | 41.7 | 0.0889 | 30.7 | 14.3 | 0.3382 |
| CPAP, BiPAP or mechanical ventilation | 59.7 | 63.9 | 0.8224 | 62.0 | 50.0 | 0.3879 |
| Central Venous Line | 47.8 | 66.7 | 0.0965 | 58.6 | 21.4 | 0.0087 |
| Insulin Pump | 59.7 | 88.0 | 0.003 | 73.0 | 50.0 | 0.1113 |
| Home Oxygen | 37.2 | 53.4 | 0.0065 | 34.8 | 7.1 | 0.0681 |
| Coccyx, CHAT tube or, MAEC | 85.1 | 97.2 | 0.0917 | 89.9 | 85.7 | 0.6411 |

Table 7: Comparison of Perceived Ways to Improve CMC Care

| Processes to Improve Care | Practicing Providers (n=104) | | Residents (n=30) | | p-value | |
|--|------------------------------|--------------|------------------|--------------|---------|--------|
| | Mean Ranking | Mean Ranking | Mean Ranking | Mean Ranking | | |
| More time to spend with the patient | 7.00 | 7.66 | 0.146 | 7.72 | 4.00 | <.0001 |
| More time to review the patient's chart | 6.71 | 7.66 | 0.055 | 7.47 | 4.36 | <.0001 |
| Facilitation of communication with specialty providers | 7.79 | 6.49 | 0.032 | 7.55 | 7.14 | 0.664 |
| Care conferences with care team | 7.59 | 6.89 | 0.120 | 7.43 | 7.00 | 0.484 |
| Access to a comprehensive care plan | 8.19 | 7.43 | 0.180 | 8.09 | 7.29 | 0.345 |
| Telhealth meetings (with patients or specialists) | 6.13 | 6.31 | 0.738 | 6.17 | 6.50 | 0.659 |
| Comprehensive care plan training | 7.09 | 7.35 | 0.737 | 7.27 | 6.36 | 0.182 |

Table 8: Comparison of Preferred Education Content Delivery

| Education Content Delivery | Practicing Providers (n=104) | | Residents (n=30) | | p-value | |
|--|------------------------------|--------------|------------------|--------------|---------|-------|
| | Mean Ranking | Mean Ranking | Mean Ranking | Mean Ranking | | |
| Webinar | 6.98 | 7.63 | 0.127 | 7.35 | 6.95 | 0.143 |
| Tool kits | 6.31 | 7.37 | 0.008 | 6.90 | 6.14 | 0.259 |
| Simulation (including written or printed) | 5.43 | 7.03 | 0.005 | 6.24 | 4.64 | 0.047 |
| Online Modules or webinars | 7.00 | 6.37 | 0.233 | 6.87 | 6.33 | 0.998 |
| Monthly Email Bulletins | 4.81 | 4.37 | 0.433 | 4.55 | 5.26 | 0.295 |
| Discussion Board or Blog | 4.26 | 4.35 | 0.878 | 4.36 | 3.71 | 0.409 |
| Lectures or content with continuing education credit | 7.24 | 6.43 | 0.114 | 7.14 | 6.21 | 0.194 |

Discussion

Table 9: Common Barriers Found in this Study Compared to Barriers Found in the Literature

| Barriers to Adequate Care for CMC in the Literature | Barriers Found in Our Study |
|---|--|
| Inadequate time to spend with patients | Insufficient time in clinic to care for patients |
| Large number of specialists involved in care | Inadequate communication amongst all providers |
| Insufficient reimbursement for time | |
| Coding and billing | |
| Lack of support services | |

- Providers in this study did not feel that reimbursement for services, coding and billing or lack of support services was a significant barrier in caring for CMC, which is a surprising difference from the current literature. This change signals that MO and KS providers who care for CMC face unique barriers. This study also found that providers were not prepared and did not feel comfortable in handling a variety of common medical concerns or providing primary care to CMC when those patients use a variety of medical technology. This information will be important in the primary or continuing education of providers who care for CMC in order to ensure the best possible care.
- Interestingly, the perceived barriers, preparedness to handle common medical concerns and comfort in using various technology differed between practicing providers and residents as well as between providers in urban and rural practice location.
- PCP also differed on the best ways to receive education and improve care for CMC.

Conclusions

- Children with Medical Complexity pose unique challenges to primary care providers.
- Barriers to providing care for CMC can negatively impact patient care.
- Providers identified specific medical conditions and technologies that pose unique opportunities for continuing education.
- Providers identified specific barriers that can be used to guide resource development for primary care providers to better care for CMC.
- We found that perceived barriers, level of preparedness, and preferred education intervention while caring for CMC varied based on level of training and practice location.
- When developing strategies for education and improving care delivery for CMC these factors must be considered.

Limitations

- External validity of the results may be restricted due to the cross-sectional nature of our study.
- External validity of the results for rural providers may be restricted due to the small sample size.

Contact

Todd Savolt
University of Kansas Medical Center
Email: tsavolt@kumc.edu
Phone: 620-640-7617

References

- Cohen, E., Berry, J. G., Camacho, K., Anderson, G., Woodhull, W., & Guttmann, A. (2012). Patterns and costs of health care use of children with medical complexity. *Pediatrics*, 130(6), e1403-1470. doi:10.1542/peds.2012-0275
- Cohen, E., Friedman, J. N., Mahant, S., Adams, S., Anonuevo, V., & Rosenbaum, P. (2015). The impact of a complex care clinic in a children's hospital. *Child Health Care*, 36(6), 774-782. doi:10.1177/1097118015200109
- Cohen, E., Kuo, D., Agrawal, R., Berry, J. G., Bhagat, S. K., Simon, T. D., & Sivastava, R. (2015). Children with medical complexity: an emerging population for clinical and research innovation. *Pediatrics*, 137(1), S25-S38. doi:10.1542/peds.2010-0910
- Kuo, D., Cohen, E., Agrawal, R., Berry, J. G., & Casey, P. K. (2013). A national profile of caregiver challenges among rare medical complex children with special health care needs. *Arch Pediatr Adolesc Med*, 167(11), 1000-1004. doi:10.1001/archpediatrics.2013.172
- Kuo, D., & Holtzman, J. (2015). Recognition and Management of Medical Complexity. *Pediatrics*, 138(5). doi:10.1542/peds.2014-3021
- Kuo, D., Malgouyres, M., Gaudin, A., Hols, T. C., Robbins, J. M., & Casey, P. K. (2015). Variation in child health care utilization by medical complexity. *Matern Child Health J*, 19(11), 40-46. doi:10.1007/s10995-014-1483-0
- Kuo, D., Z. Robbins, J. M., Burns, K. H., & Casey, P. K. (2013). Individual and practice characteristics associated with physician provision of recommended care for children with special health care needs. *Clin Pediatr (Phila)*, 52(8), 704-711. doi:10.1177/0009892813509861