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Development, contributions, and future directions of a multicenter child abuse research network

M. Katherine Henry, MD, MSCE [a,*], Daniel M. Lindberg, MD [b], Kristine A. Campbell, MD, MSc [c], Joanne N. Wood, MD, MSHP [d]

[a] Division of General Pediatrics, Clinical Futures, and Department of Radiology Children's Hopsital of Philadelphia, and Department of Pediatrics, Perelman School of Medicine at the University of Pennslvania, Philadelphia, PA, 19104, USA
[b] Department of Emergency Medicine, The Kempe Center for the Prevention & Treatment of Child Abuse & Neglect, University of Colorado School of Medicine, 12631 E. 17th Ave. Mailstop C326, Aurora, CO 80045, USA
[c] Department of Pediatrics, University of Utah, Center for Safe and Healthy Families, Primary Children's Hospital, Salt Lake City, UT, USA
[d] Division of General Pediatrics, PolicyLab, and Clinical Futures, Children's Hospital of Philadelphia, Perelman School of Medicine at the University of Pennsylvania, Philadelphia, PA 19104, USA

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ABSTRACT

CAPNET is a multicenter child abuse pediatrics research network developed to support research that will make the medical care of potentially abused children more effective, safe, and fair. CAPNET currently collects detailed clinical data from child physical abuse evaluations from 11 leading pediatric centers across the U.S. From its inception, the goal of CAPNET was to support multiple research studies addressing the care of children undergoing evaluations for physical abuse and to create a flexible data collection and quality assurance system to be a resource for the wider community of child maltreatment l researchers. Annually, CAPNET collects rich clinical data on over 4000 children evaluated due to concerns for physical abuse. CAPNET's data are well-suited to studies improving the standardization, equity, and accuracy of evaluations in the medical setting when child physical abuse is suspected. Here we describe CAPNET's development, content, lessons learned, and potential future directions of the network.

Introduction

Child abuse pediatrics (CAP) was established as a new subspecialty in 2006 and tasked with generating and disseminating much-needed new knowledge in identification, evaluation, care, and protection of victims of child maltreatment.[1,2] This supported a new generation of child abuse researchers, and highlighted the need for development of multicenter research networks, specifically related to physical abuse. CAPNET, a multicenter child abuse pediatrics research network, was designed to answer multiple research questions concurrently and has the flexibility to be updated as needed with new data elements. CAPNET's mission is to conduct "rigorous, multicenter research in order to make the care of potentially abused children and their families more effective, safe and fair".[3]

Here we describe CAPNET's development, data captured, successes and lessons learned, and potential future directions.

Emergence and expansion of multicenter child maltreatment research

Multicenter research allows for creation of generalizable findings that drive changes in practice by supporting inclusion of large sample sizes, diverse patient populations and multiple clinical settings with different care practices. Initial child abuse networks began as time-limited, project-driven research networks designed to answer a specific question.[4–9] Some of the networks were subsequently leveraged for secondary analyses to answer additional research questions.[10–16] Several of these networks conducted data collection simultaneously, sometimes including participation of the same centers, creating duplication or competition for participation.

In 2014, the Institute of Medicine and National Research Council

Abbreviations: BRUE, Brief Resolved Unexplained Event; CAP, Child Abuse Pediatrician; CPS, Child Protective Services; CPT, Child Protection Team; NIH, National Institutes of Health; PI, Principal Investigator.

* Corresponding author.
E-mail address: henrym2@chop.edu (M.K. Henry).

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called for a more sophisticated research infrastructure, use of standardized definitions, cross-sector data linkage, and a process for training a pipeline of researchers in the field to advance child maltreatment research.[17,18] Federal funding priorities and opportunities were developed to support collaborative efforts to promote child maltreatment research, recognizing the role of research centers and networks.[19] In this landscape, data collection for CAPNET launched in 2021, with funding from a National Institutes of Health (NIH) award to support resource development for the wider field of CAP researchers.

CAPNET: from inception to implementation

Planning began in the mid 2010s with a needs assessment of research priorities within the field of child abuse pediatrics. Using a modified Delphi approach, child abuse pediatricians identified the following top research priorities in the field: missed diagnoses, prevention, occult injuries in suspected physical abuse, bias and variability, social and legal interventions, injury timing and mechanism in suspected physical abuse, evaluation and management of abusive head trauma, and long-term outcomes.[20] As a hospital-based system network, CAPNET focuses on the identified research priorities related to diagnosis, evaluation, care, and short-term care outcomes. CAPNET launched data collection in 2021 at nine sites with two additional sites joining in 2021 and 2022.

CAPNET currently includes data on child physical abuse evaluations submitted from 11 pediatric centers across the U.S. Children are included if they are (1) under 10 years of age at the time of evaluation, (2) undergoing evaluation due to a recent (within 1 month) concern for physical abuse, and (3) have documentation of the child protection team's recommendations in the local electronic health record. Data collected span multiple domains related to the evaluation of potentially abused children. These include: demographic data (e.g., race, ethnicity, insurance type), visit information and providers (e.g., timing, clinical location of evaluation), medical and social history, physical abuse presentation (including chief complaints, symptoms at presentation, histories of trauma), physical abuse examination and findings (e.g., skin findings, retinal findings), laboratory testing, radiologic testing, diagnoses (injuries and medical mimics), and outcomes (level of concern for physical abuse, level of medical care provided, and short term legal and child protective services (CPS) outcomes, if known). Structured data fields within these domains were developed and iteratively piloted following review of multiple center-specific child abuse databases developed for administrative, case management, or research purposes and those used in existing research networks (e.g., PECARN).[18] Free text fields are continuously reviewed to assess for trends that suggest need for addition of new structured fields or clarification of existing structured fields. A data dictionary is available online that details the data fields in CAPNET.[21] CAPNET has individual institutional review board (IRB) approval from each participating site's IRB as either exempt research or expedited with a waiver of consent and HIPAA authorization.

Lessons learned about children evaluated by CAPs due to concern for physical abuse

The first published studies using CAPNET data focused on describing the children for whom CAPs provide care, and identified the subset of children for whom concern for abuse is low at the end of the CAP evaluation as an area for further study. First, CAPNET reported the landscape of CAP consultations, describing the children, care contexts, injuries, and level of concern for abuse among children evaluated by CAPs.[22] Based on these data, we know that more than two thirds (69.4 %) of children evaluated by CAPs due to physical abuse concerns are < 3 years of age, and 44.3 % are < 12 months of age. CAPs provide evaluations in a variety of clinical settings and contexts. CAPs support colleagues with remote (i.e., telephonic) support in 20.6 % of cases. Nearly one third (30.6 %) are evaluated in-person in the inpatient setting, 6.1 % are evaluated in the emergency setting, and 42.2 % are seen in outpatient clinics. CAPs most commonly evaluate children with bruises (35.2 %), followed by fractures (29.0 %) and traumatic brain injury (16.2 %).

CAPNET data demonstrate that CAPs evaluate many children for whom they have a low level of concern for abuse upon completion of the evaluation. Specifically, more than half of cases (54.3 %) have no or low concern for physical abuse. In two thirds of cases (68.2 %), referrals to CPS are made prior to CAP consultation. Zamalin and colleagues subsequently focused on the subset of children < 5 years of age with both low concern for abuse and CPS referrals made *prior to* CAP consultation.[23] The authors found that CAPs had low concern for abuse in 38 % of these children. Further research is needed to understand the reason for these findings. As found in previous studies,[24,25] biases related to socioeconomic status and other factors may be impacting these early reporting decisions. Alternatively, the CAPs' assessment of low concern for abuse may reflect specialized understanding of injury mechanisms and alternative diagnoses. Finally, these findings may suggest differences in interpretation of mandated reporting requirements across different reporters. These data suggest there may be a role in supporting colleagues in identifying low risk cases for whom a report to CPS could potentially be avoided.

Lessons learned about systems of care in child abuse pediatrics and implications for data analysis

In the development and maintenance of CAPNET, themes have emerged regarding models of care that can impact study designs and interpretation of data. Hospital-based child protection teams (CPTs) differ in the maltreatment concerns they evaluate, and the settings where care is provided. This in turn impacts the data available. For example, some CPTs commonly see children with ingestions, others may commonly be consulted in failure to thrive cases, while others may not. CPTs also differ in when and where they evaluate referrals for child physical abuse. Some may see children after discharge in the outpatient setting or only provide consultation by phone in certain cases. Others typically provide assessments while the child is in the emergency department or admitted. Some centers routinely evaluate children that are identified by routine screening tools or by hospital protocol, even if there is not a specific clinician who initiates a consult for a specific concern. These "per protocol" evaluations are often more cursory than other consultations but can sometimes evolve into more traditional consultations if the physician identifies concerns that were initially missed by the clinical team. Understanding consult patterns can impact how investigators develop inclusion criteria for their studies. If limiting to children who were evaluated in the inpatient setting, an investigator may inadvertently bias a study towards more severely injured children, not recognizing that other sites evaluate children with minor injuries in the outpatient setting. To this end, CAPNET conducts a recurring survey to understand consult indications.

The CAPNET research community has also supported increased understanding of CPT practice differences and how varying definitions of key study populations and outcomes (i.e., asymptomatic infants, occult head trauma) have contributed to variation in findings in prior research. For example, there are wide-ranging neuroimaging yields reported when neuroimaging is obtained to screen for clinically occult head trauma.[10,12,26–32] Current work using CAPNET is assessing how site-specific imaging patterns and differences in study definitions in prior studies contribute to variation in previously-reported findings.[33] CAPNET therefore has the ability to help contextualize and interpret prior research findings and suggest standardized definitions for other researchers to consider in future work.

Lessons learned about data quality monitoring and assurance

A robust infrastructure is needed to ensure high-quality data and that researchers understand data nuances.

Data are collected in REDCap, a secure online data-entry tool.[34] REDCap allows for multiple embedded checks regarding out-of-range fields and dynamic, interactive, just-in-time data entry support. CAPNET sites are divided into 3 different nodes, each led by one of the 3 CAPNET principal investigators (PIs). Initial data quality checks occur at each node on a routine basis. The Data Coordinating Center (DCC) concurrently runs multiple checks to ensure completeness (to reduce missing values), consistency (e.g., to assess if a child with an extremity fracture lacks skeletal imaging), and conformance (e.g., to assess whether subjects are within CAPNET's age inclusion criteria). Double data entry is conducted on a 10 % random monthly sample of cases to identify inconsistencies and to clarify data elements. Frequently asked questions are available to data enterers, and CAPNET conducts periodic assessment and training for data operators. To ensure that researchers understand nuances of data, data structure, and availability of data fields over time, the CAPNET reviews data requests with investigators and requires review of analyses before publication.

Why use CAPNET data?

Based on the data fields and structure, CAPNET is ideally suited for studies focused on evaluating or improving the standardization, equity, and accuracy of abuse evaluations in the medical setting. Such studies can assess yield of imaging evaluations in detection of occult injuries, variation in care across sites and providers, disparities in abuse evaluations, the importance of historical or physical exam findings to the diagnosis of abuse, and the epidemiology of injuries evaluated by CAPs. Multiple published studies and works in progress highlight how current CAPNET data are being leveraged to answer questions related to these themes.[35] At the 2023 annual meeting of the Ray E. Helfer Society, the professional society of physicians in the field of child maltreatment, 5 CAPNET-based studies were presented, with 3 related to occult injury screening.[36–40] CAPNET also has the research infrastructure to support new studies with the addition of new data fields and linkage to additional data sources, such as the Pediatric Health Information System,[41] Children's Opportunity Index,[42] and CDC Social Vulnerability Index.[43]

CAPNET is an ideal data source for trainees and junior investigators who have limited time and resources to collect primary data. During training and early career, an investigator's early work may focus on single center databases with limited sample sizes and laborious chart abstraction. CAPNET has high-quality data available to junior researchers. At the recent Ray E. Helfer Society 2023 Annual Meeting, all 5 CAPNET presentations of original research were presented by trainees or junior investigators. To date, CAPNET is supporting one Career Development Award.

Why use CAPNET's network?

CAPNET's network and existing infrastructure has the potential to be leveraged for a variety of studies that would require collection of additional data. Currently CAPNET's physical abuse data collection is observational. In the future, investigators could leverage CAPNET's research infrastructure for clinical trials to assess the effectiveness of clinical interventions on care and outcomes of potentially abused children. CAPNET currently captures imaging performed and injuries identified during evaluations for physical abuse, but not the images themselves. Broadening CAPNET's data types to include images (such as radiographs), would expand analyses to include approaches to improve imaging interpretation through machine learning approaches.[44] These types of image-analysis studies have already begun for classic metaphyseal lesions and rib fractures, but are hindered by single-center imaging data,[45–47] making a multicenter network such as CAPNET ideal for future work.

Beyond child physical abuse, CAPNET's infrastructure could be leveraged to create new data collection instruments needed to answer questions related to the care of victims of child sexual abuse, neglect, and medical child abuse.

Data limitations

Investigators using CAPNET data should understand its limitations. By design, CAPNET only collects data on children who undergo evaluations for physical abuse by CAPs. Children who may have been at lower risk of abuse or less severely injured, telephone consults and outpatient evaluations are also included in an effort to capture the broader denominator of child in who abuse may be considered. Studies resulting from CAPNET can inform care of children with CAP involvement but may have limited generalizability to other settings (e.g., ED populations without CAP involvement). Linkage with other datasets, such as the Pediatric Health Information System (PHIS), may help provide context on the larger denominator of injured children without CAP involvement. Second, CAPNET is not designed to capture data related to a specific question and therefore may detailed information available about specific presentations and certain injuries. Third, as an observational data source, CAPNET data is limited to the data documented in the electronic medical record. While CAPNET includes encounters in which CAP guidance was provided by telephone, these may differ in the amount of information available. Finally, CAPNET only includes children evaluated for physical abuse. Investigators interested in evaluating non-physical abuse-related presentations (such as ingestions and Brief Resolved Unexplained Events [BRUEs]), will be limited to only those children presenting with an ingestion or a BRUE who also underwent evaluations for physical abuse based on the data currently available.

Looking ahead: sustainability and expansion

Ensuring ongoing robust high-quality data across multiple centers requires a large team and funding models to support this team and infrastructure. CAPNET is run with 3 PIs, PIs principal investigators from each site, 3 nodal administrators, a data coordinating center with biostatistical support, and multiple physicians and non-physicians trained in chart abstraction across sites. To ensure CAPNET maintenance, generation of analytic datasets, and ongoing data collection beyond the timeline of NIH support will require additional funding streams. Expansion of CAPNET to include additional sites or data fields will also require additional funding resources.

Beyond identification

Improving the standardization, equity, and accuracy of abuse evaluations in the medical setting are vital goals but are not the only outcomes that impact children. CAPNET is currently built for the former but not optimized to evaluate broader outcomes. Research in our field is needed to both define and evaluate outcomes—beyond initial diagnosis—that impact children, families, and their communities. CAPNET gathers select short-term outcome data regarding safety interventions of CPS only when known to the physician. Long term and legal outcomes, impacts of family separation, and success of CPS at tertiary prevention are generally unknown to physicians. Models are needed to define outcomes that matter most to families and child wellbeing and identify how to capture and quantify these outcomes. As some centers are slowly improving the ability to link medical and child welfare data for research purposes,[48] CAPNET hopes to increase its ability to assess the impact of medical interventions on longitudinal, patient-relevant outcomes.

Conclusion

CAPNET is the first multicenter child abuse research network designed to support multiple studies towards the goal of making evaluations of potentially abused children more effective, safe, and fair. CAPNET currently collects detailed clinical data surrounding medical evaluations for child physical abuse and is ideally suited to generate

evidence to improve the standardization, equity, and accuracy of these evaluations. There are opportunities to expand current data collection and extend CAPNET beyond observational data collection. Ultimately, efforts are needed to move beyond abuse identification to outcomes that affect children and families long-term.

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Declaration of competing interest

Drs. Henry's, Campbell's and Wood's institutions have been paid in cases with concern for child maltreatment for which they have been subpoenaed to provide expert testimony. Dr. Lindberg has provided paid expert witness testimony in cases with concern for child maltreatment.

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