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Research Priorities for a Multi-Center Child Abuse Pediatrics Network - CAPNET

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Abstract

Although child maltreatment medical research has benefited from several multi-center studies, the new specialty of child abuse pediatrics has not had a sustainable network capable of pursuing multiple, prospective, clinically-oriented studies. The Child Abuse Pediatrics Network (CAPNET) is a new multi-center research network dedicated to child maltreatment medical research. In order to establish a relevant, practical research agenda, we conducted a modified Delphi process to determine the topic areas with highest priority for such a network. Research questions were solicited from members of the Ray E. Helfer Society and study authors and were sorted into topic areas. These topic areas were rated for priority using iterative rounds of ratings and in-person

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meetings. The topics rated with the highest priority were missed diagnosis and selected/indicated prevention. This agenda can be used to target future multi-center child maltreatment medical research.

Keywords

Physical Abuse; Multi-Center Research; Delphi Method; Research; Priorities

Introduction

Child maltreatment is an important source of morbidity and mortality for children, yet child maltreatment medical research is dramatically under-represented in funding and subsequent development of the science relative to conditions with similar disease burden.(Bourgeois, Olson, Ioannidis, & Mandl, 2013) The recent approval of child abuse pediatrics as a pediatric sub-specialty has increased opportunities to conduct research specifically focused on the medical care of maltreated children.(Block & Palusci, 2006) The new sub-specialty has also increased the funneling of cases of suspected maltreatment into referral centers, and has raised the possibility of establishing a more uniform standard of care to decrease the broad variability in medical care of maltreated children.(Lindberg, Beaty, Juarez-Colunga, Wood, & Runyan, 2015; Paine, Scribano, Localio, & Wood, 2016; Wood, Fakeye, et al., 2015; Wood et al., 2012a)

Multi-center methods have particular advantages for child maltreatment medical research. As with pediatric oncology and toxicology, the diverse types and forms of maltreatment mean that no single center is likely to recruit a large sample of children with any particular injury in a reasonable time.(Keenan, 2008; Lindberg, Harper, Laskey, Berger, & Ex, 2013; US Department of Health and Human Services Administration for Children and Families, 2015) For example, even the busiest referral centers evaluate only a few dozen cases of abusive head trauma (AHT) annually, and these will have a broad range in severity, presentation, and associated injuries.(Berger et al., 2011) Several less common findings, such as oropharyngeal injuries; posterior rib fractures; and fractures of the hands, feet, spine and pelvis have been suggested to be especially specific for abuse, but these findings are too uncommon for a single center to enroll a large sample.(Karmazyn, Lewis, Jennings, Hibbard, & Hicks, 2011; Kleinman, Morris, Makris, Moles, & Kleinman, 2013; Maguire et al., 2007) Using retrospective samples or long enrollment periods to increase sample size adds other complications, as changes in definitions and terminology, clinical systems, and diagnostic testing patterns may challenge generalizability of data gathered over many years. (Bradford, Choudhary, & Dias, 2013; Christian & Block, 2009; Postema, Sieswerda-Hoogendoorn, Majoie, & van Rijn, 2014; Sieswerda-Hoogendoorn, Postema, Verbaan, Majoie, & van Rijn, 2014) Further, variable practice patterns and systems of care for medical, social and law-enforcement professionals limit the generalizability of single center results.(Hooft et al., 2015; Lindberg et al., 2015; Lindberg, Lindsell, & Shapiro, 2008; Wood et al., 2012b; Wood, 2015; Wood, 2014)

In the last decade, several prospective, multi-center studies have advanced medical care for potentially abused children.(Berger et al., 2016; Hymel et al., 2014; Lindberg et al., 2012; Lindberg et al., 2009; Pierce et al., 2016) However, in contrast to other subspecialties, there has been no sustained research network that is specifically focused on medical care of maltreated children and capable of conducting multiple, prospective, practice-altering studies over time.(Alpern et al., 2006; Fanaroff, Hack, & Walsh, 2003; Willson et al., 2006) In order to establish a relevant research agenda for such a multi-site research network dedicated to child maltreatment medical research, we conducted a modified Delphi process with an expert consensus panel to determine topic areas with the highest priority based on the potential to impact the field and feasibility within a multi-center research network.

Methods

CAPNET

The Child Abuse Pediatrics Network (CAPNET) is a newly formed research network whose mission is to improve the care of children by child abuse pediatricians by conducting multi-center, collaborative, patient-oriented research. CAPNET was initially supported by the Ray E. Helfer Society, an international honorary society of physicians with substantial activity in child abuse pediatrics, and by participating institutions.(Runyan, 2001) Participating centers must include at least one board-certified or fellowship-trained child abuse pediatrician and have a recognized child protection team. At the time of this investigation, CAPNET had established governance agreements determining the network structure and function, and was led by a transition committee pending recruitment of additional participating centers.

Expert Panel

The expert panel consisted of 8 physician-researchers with experience leading externally-funded, multicenter child maltreatment research and who were also clinically active as CAPs (XXX, XXX, XXX, XXX, XX, XXX, XXX, and XXX). Panelists were selected from the CAPNET transition committee, and had an average of 19 years (range 9–34 years) of child abuse pediatrics clinical experience. Panelists included equal numbers of men and women and practiced in the United States in the states of X, X, X, X and X.

Soliciting and Sorting of Research Questions

Panelists submitted initial candidate research questions (e.g., which children evaluated for sexual abuse should have HIV post-exposure prophylaxis?; Is increased head circumference a sensitive marker for occult AHT?) based on their own clinical experience and review of the medical literature. Additional candidate research questions were solicited from the Ray E. Helfer Society using an electronic distribution list. Society members were encouraged to submit 3 research questions and were not restricted to any particular topic or area. Research questions were accepted between May 19–31, 2015, and 2 reminder emails were sent. After eliminating redundancy, collected responses were collated into broader topic areas (e.g., medical evaluation and management of suspected child sexual abuse; occult injuries in suspected physical abuse) by consensus of 3 authors [XXX, XXX, and XXX]. All suggested research questions were included in at least one topic area, and some research questions

were relevant to more than one topic area. These topic areas were the subject of further rounds of rating and discussion.

Delphi Procedure

Study authors participated in a modified Delphi process to rate the priority of topic areas. Topic areas were distributed to authors who then independently submitted priority ratings based on potential for impact and feasibility within a multi-center network. Authors used a 9-point rating scale ranging from 1 (lowest priority) to 9 (highest priority). Initial responses were tallied, with calculation of mean, median, and range of ratings for each topic area. Each study author received a de-identified table of ratings for each topic by each participant, with their own responses identified for reference. Results of the initial survey were discussed at an in-person meeting, with a focus on those topics with poor consensus. Topic titles were changed for clarification based on this discussion. A final round of blinded ratings was then performed and was felt to represent sufficient consensus to preclude the need for further rounds of discussion and rating. Topic areas were then rated by priority according to the median priority score.

In addition to ranking topic areas by priority, we also evaluated agreement and disagreement between experts on priority ratings. We used definitions of agreement and disagreement based on the RAND Appropriateness Method.(Fitch et al., 2001) Briefly, this definition suggests that agreement exists when no more than 2 panelists give ratings outside the 3-point region containing the median rating (1–3 “low”; 4–6 “middle”; 7–9 “high”). Conversely, disagreement exists when 3 or more panelists give ratings in the 1–3 region *and* 3 or more panelists rate it in the 7–9 region.

Ratings were conducted by email, and analyses were conducted using Excel (Microsoft, Redmond, WA). The final round of anonymous ratings was conducted using a Research Electronic Data Capture (REDCap; REDCap Consortium) survey hosted at the University of Colorado.

Results

Study authors and 17 additional respondents to the email solicitation submitted 96 unique research questions. These were then grouped into 19 topic areas for the initial round of priority ratings. During the in-person discussion, one topic area (mental health interventions) was split into two topics: interventions focused on physical abuse or sexual abuse, ultimately yielding 20 topic areas for rating.

Results of the ratings are shown in the Table. Missed abuse diagnoses, selected prevention, occult injuries in physical abuse and bias and variability had the highest priority scores according to raters, while topics such as universal prevention, epidemiology and neglect were rated the lowest. Raters expressed support for most topics, with 13 (65%) of the topics having a median priority rating greater than 6.

Using the RAND Appropriateness Method definition of agreement, panelists agreed that 8 topic areas had high priority, two topic areas (forensic evaluation of suspected child sexual

abuse; and medical mimics and differential diagnosis) had middle priority, and one topic area (universal prevention) had low priority. While no topic areas had ratings that met the definition of “disagreement,” evaluation and management of child trafficking victims showed a wide dispersion of ratings, ranging from 2–9.

Discussion

We report the results of a modified Delphi process to determine the priority for topics to be addressed by a prospective, multi-center child maltreatment research network. The most highly rated topics included missed diagnosis, selected/indicated prevention, occult injuries and bias and variability while topics such as universal prevention and epidemiology were rated lowest. Together, the highly rated topics suggest that panelists felt that the most likely contribution of a multi-center network dedicated to child maltreatment medical research would be to standardize testing to improve early recognition of abuse, and then to improve the interventions to protect abused children.

It is not surprising that one of the highest rated topics was bias and variability. A substantial body of research has identified important variability in the evaluation and care of potentially maltreated children along racial and socio-economic lines. These findings suggest that implicit biases of medical providers may contribute to disproportionately high rates of child abuse evaluation and reporting for poor or African-American families, and disproportionately high rates of missed abuse in affluent, or White families.(Jenny, Hymel, Ritzen, Reinert, & Hay, 1999; Lindberg et al., 2015; Wood et al., 2012a; Wood, French, Song, & Feudtner, 2015; Wood et al., 2010)

Research highlighting child abuse prevention within populations at increased risk of abuse —such as those commonly referred for child abuse pediatrics consultation — was also identified as a high priority. Relatively high ratings for topics of social and legal interventions, evaluation and management of abusive head trauma, long-term outcomes and mental health interventions suggest that child abuse pediatricians are interested in increasing focus on the care of maltreated children after a diagnosis of abuse has been made. While early recognition of abuse is certainly key to preventing the worst outcomes of abuse, recent studies have suggested that child abuse pediatricians, and the medical community as a whole, can, and should, address the special medical and social needs of victims of maltreatment.(Campbell, Cook, LaFleur, & Keenan, 2010; Greiner et al., 2015; Hewes, Keenan, McDonnell, Dudley, & Herman, 2011; Ludwig, 2010) Our results also recognize the need for greater effectiveness in the interdisciplinary systems involved in the support, safety and prevention of further maltreatment of this pediatrics population.(Deans et al., 2013; Putnam-Hornstein, Simon, Eastman, & Magruder, 2014)

We suspect that our results are affected not just by the clinical impact and the feasibility of multi-center research, but also by the evolving role of the child abuse pediatrician and the current state of child abuse pediatrics medical research. For example, the relatively low priority rating for child neglect topics may reflect that many cases of neglect do not require subspecialty medical training so much as they require marshalling of social resources. Similarly, the relatively low rating for epidemiology likely reflects the fact that child abuse

pediatricians see a skewed population with the most severe or most complicated abuse concerns, which is a poor setting from which to conduct generalizable epidemiological research.

In general, even topics with lower aggregate priority scores had support from at least one panelist, but scores were lower because there was less agreement among panelists. Topics such as epidemiology, child trafficking, child neglect and education of medical professionals may have had lower levels of consensus because (as distinct from the highly rated topics) they are not a core part of daily clinical activity for all CAPs. These topics may have increased priority in the future as the specialty of child abuse pediatrics evolves.

This study is subject to at least four limitations. Most notably, ratings reflect only the beliefs of the 8 authors invited to participate. While all are clinically active in the care of maltreated children and have experience conducting multi-center studies, other, similarly qualified researchers were not included in the ratings and may have identified other research questions or topic areas, or may have rated priority differently. This effect was moderated by our outreach to other child abuse pediatricians for candidate research questions, and by the large number of questions submitted. But results are likely to have been affected by each panelist's personal experience or interests. These personal interests may also have affected the level of agreement for topic areas. Second, while the solicitation to the members of the Helper Society distribution list increased the scope and range of topics considered, this solicitation occurred over a relatively short period of time. Different responses may have been obtained if the solicitation had occurred at a different time, or if responses were accepted over a longer period. Third, the RAND Appropriateness Method's definition of disagreement was designed for ratings of appropriateness, not research priority, and may not be strictly applicable in this setting.

Finally, while research questions were solicited from an international society of child abuse pediatricians and other physician specialists with clinical expertise in the care of maltreated children, all panelists practiced in the US. If one purpose of a multi-center network is to study differences in local laws, practice patterns, and collaboration between medical providers and public agencies that care for potentially abused children, studies that compare outcomes internationally would seem to have high-priority. Policies to improve abuse recognition and selected prevention have been implemented at the national level, but these policies are difficult to evaluate empirically. For example, an international network capable of measuring outcomes between countries that mandate reporting to child protective services, or universal abuse screening in emergency departments, could better assess the utility and cost-effectiveness of these policies. (Louwers et al., 2012)

The identification of high-priority research topics is but the first step toward a sustainable network for child abuse pediatrics medical research. Centers must also take steps to ensure "apples-to-apples" comparisons for outcomes across centers. Ideal outcomes for child abuse pediatrics research will need to be both patient-centered and objective. Because many patient-centered outcomes might systematically differ between centers – such as determinations or interventions by child protective services, or the level of medical care

provided – standardized, core data elements should be developed that overcome, to the extent possible, the degree to which subjective assessments are used as research outcomes.

These data should not be interpreted to suggest that low-rated topics are not worthy of research. Even topics that were rated relatively low still garnered support from some raters. Furthermore, these priority ratings were based in large part on the appropriateness of using a multi-center network to address the specific topics in question. Some topics that are ill-suited to multi-center research for reasons of cost, feasibility and organization, are certainly worthy of research.

Conclusion

Several topics were identified with high priority for a prospective, multi-center research network focused on child maltreatment medical research. Panelists suggested that research focused on decreasing missed abuse, and improving the protection (indicated prevention) of abused children had highest priority for a multi-center network of child abuse pediatricians. As the formation of CAPNET, a multi-center child abuse research network, is underway, a research priority agenda now exists to target these relevant and feasible topics for future study.

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Table

Ratings of Child Maltreatment Topics by Priority for a Prospective, Multi-Center Research Network

Topic Area	Median	Mean	Standard Deviation	Range	Agreement ^d
Missed diagnosis	8	8.38	0.52	8–9	Yes
Selected/indicated prevention	8	8.00	1.07	6–9	Yes
Occult injuries in suspected physical abuse	8	7.88	0.99	6–9	Yes
Bias and variability	7.5	7.63	1.30	6–9	Yes
Social and legal interventions	7.5	7.25	0.89	6–8	Yes
Injury timing and mechanism in suspected physical abuse	7.5	7.13	1.46	5–9	Yes
Evaluation and management of suspected abusive head trauma	7	7.00	1.20	5–9	Yes
Long-term outcomes	7	7.00	1.63	5–9	Yes
Psychosocial risk factors	6.5	6.63	2.07	5–9	No
Mental health interventions for physical abuse	6.5	6.38	1.85	5–9	No
Mental health interventions for sexual abuse	6	6.63	1.30	5–9	No
Forensic evaluation of suspected child sexual abuse	6	6.50	1.31	5–9	Yes
Medical evaluation and management of suspected sexual abuse	6	6.43	1.27	5–8	No
Education of medical professionals	5	4.88	1.55	3–7	No
Medical mimics and differential diagnoses	5	4.75	0.71	4–6	Yes
Evaluation and management of suspected child trafficking victims	4.5	4.38	2.26	2–9	No
Systems of care for child abuse pediatricians	4.5	4.38	1.60	2–6	No
Evaluation and management of suspected child neglect	3.5	4.13	1.73	2–7	No
Epidemiology	3.5	3.88	1.55	2–7	No
Universal prevention	2.5	2.88	1.81	1–6	Yes

Raters were asked to rate topics by *priority* taking account of 1) the impact of each topic and 2) the feasibility of research within a multi-center network.

^d As defined by RAND Appropriateness Methodology (Fitch et al., 2001) No topic areas met the definition of “Disagreement.”