

The first step in an exciting journey

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Many advances in the understanding of pathobiology of critical illness, innovations, and improved outcomes in acutely ill children represent the fruits of research conducted in emergency departments (EDs). EDs are usually busy, crowded, and staffed by overburdened clinicians whose prime responsibility is the provision of timely care to the critically ill and injured. Thus, clinicians rightly place heavy emphasis on triage, timely treatment, and prompt disposition of children. Given the competing need of families versus the intellectual pursuits and duties of clinicians, we can all agree that the EDs are not the ideal environment to conduct research. Yet, these demands offer a compelling rationale that ED research is very important if we are to improve patient experience and outcomes. I would argue that these demands dictate that research in the EDs is absolutely necessary if we are to improve efficiency, patient experience, and outcomes. However, to be successful, we need to be innovative and smarter in our approaches.

In all research conducted in children, parents facilitate or impede research. For us to be successful in research, parental preferences matter. Indeed, this recognition has led to a tsunami of efforts in children's hospitals to involve parents in all aspects of care, including research. Thus, the report in this issue of *CJEM* is timely. Stang et al. sought to determine parental experiences and preferences regarding the background of research personnel, location, and time of research discussions and factors influencing consent refusal to participate in research.¹ In this Web-based survey of 227 parents, most (87%) were comfortable being approached by a university student to discuss the proposed research, most (68%) would be more comfortable to be approached in a private setting rather than in waiting rooms, and most (83% email and 80%

telephone) felt comfortable with follow-up using technology. Side effects or complications were the most common (69%) for declining consent to participate. These findings are not surprising and offer us the opportunity to engage families as facilitators and partners in research in EDs. We must, however, be cautious in generalizing the findings of this study because the bias of the population studied is unlikely to represent the opinion or many parents whose children are potential research subjects.

Most of the parents in this study are young (median age: 37), Caucasian (69%), English is their predominant language (81%), and most have a college or graduate professional degrees (63%) and, not surprisingly, high incomes (> \$80,000 CAD). In addition, a quarter of the parents have participated previously in research themselves, and a quarter have also previously consented to having their children enrolled in studies. So, can we be reassured that the opinion of this group reflects that across Canada? This question is relevant in that about 22% of Canadians are foreign born, and 40% of children are of immigrant parentage.² While immigrants are usually skilled, many do not have English or French as their native language and may arrive from cultures where the vagaries of a high power distance index render them vulnerable.³ In addition, this study does not include members of our First Nations communities. Although Canadians fare reasonably well, in general, individuals with these backgrounds are likely to be vulnerable and deserve special consideration, according to the Belmont report on research.⁴ The vulnerable groups include the sick, impoverished, and minorities who may be frequent visitors to EDs, and, because of these circumstances, they may have a limited capacity for consent and are usually in a subordinate position.⁵ Indeed, the Public Health Agency of Canada reports

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CJEM 2018;20(3):325-326

DOI 10.1017/cem.2018.400

identified lower income, education, indigenous groups, rural and remote populations, as well as immigrants as particularly vulnerable.⁶ Thus, their voices need to be heard to fully understand parental preferences in ED research in the Canadian context.

Another question is, how do we incorporate opinions of families in the ED care so that research options do not conflict with other aspects of the patient and family experience? In addition to outcomes, patient and family experiences are an important aspect of care that have recently been incorporated as a standard by Accreditation Canada. Taking an equity approach involving families as partners in practice and care weaves consideration of parental opinions and choices as a paramount guide to all aspects of care. It seems that research efforts also improve the patient experience and should be included as an integral part of patient-centred care. Doing so may have downstream benefits in the ED of safety, better outcomes, and higher levels of satisfaction with care.⁷ Indeed, this approach is congruent with the opinion that the traditional paternalistic “best interest standard” is problematic and that the parents’ decision should be respected unless they are deemed unreasonable.⁸ We must also take into consideration that 60% of adults in Canada are not health literate and hence support to improve understanding in research and usage of ED services efficiently for their children as needed.⁹

Although research preference and confidentiality issues are an important start, we also need to address the involvement of parents in research design. Thus, this report should be the beginning of investigations to delve into the myriad of issues that plague research efforts in EDs. Clearly, the most clinically relevant outcome measures in any research are those most important to families rather than clinicians. Indeed, parental and patient preferences are becoming central in guideline development to provide care and are becoming an important consideration in research endeavours.

I want to congratulate this team for conducting this study and look forward to similar studies from different locales and involving more diversity that represents the Canadian cultural mosaic. Only then will we be able to further research in the EDs while best serving patients and their families. As the saying goes, every journey starts with a single step.

Keywords: pediatrics, parental preferences, research, emergency

Competing interests: None declared.

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