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### Medical Settings as a Context for Research on Cognitive Development

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## TOOLS OF THE TRADE

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# Medical Settings as a Context for Research on Cognitive Development

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Medical contexts provide a rich opportunity to study important theoretical questions in cognitive development and to investigate the influence of a range of interacting factors relating to the child, the experience, and the broader social context on children's cognition. In the context of examples of research investigating these issues, we consider several specific advantages of conducting research in medical settings: the diverse range of participants, experiences, and potential research paradigms and the opportunities for student training. We discuss the benefits and challenges of conducting research within medical contexts and consider ways of attempting to maximize the former and of addressing the latter.

Contemporary theorists view development as occurring within a rich social context. According to this perspective, the child actively interprets and seeks meaning from her experiences, guided by interactions with significant adults that take place during everyday emotionally laden events and activities. These interactions, "the engines of development" (Bronfenbrenner & Evans, 2000, p. 118), influence the child's knowledge, schemas, and memories and can also facilitate her ability to manage difficult emotions and experiences (Nelson & Fivush, 2004; Wareham & Salmon, 2006).

Many medical settings are a microcosm of the social and emotional world of the child. Most events and procedures involve multiple "actors" (parents, medical staff) interacting with the child and each other. Many entail the child's experiences of emotionally charged events of varying degrees of familiarity and comprehensibility that can elicit anxiety, fear, or pain. Following their occurrence, medical procedures may be discussed or avoided by the child and her family. These features lend themselves to the investigation of a raft of theoretical and applied questions concerning the effect of various kinds of information on children's interpretation, understanding,

and memory for their procedures, the factors that contribute to successful versus adverse outcomes, and the complex associations between cognition and emotion.

In part because of the great diversity of the children who attend medical settings, research in these contexts can also contribute to important theoretical issues relating to the pathways to cognitive development. One way in which this can occur is the engagement of children with atypical developmental pathways. Indeed, the investigation of the interrelationship between typical and atypical development is the cornerstone of mainstream developmental psychopathology approaches to understanding patterns of adaptation and maladaptation across the lifespan (Cicchetti, 2006).

More generally, a significant benefit of cognitive-developmental research in medical settings is the ability to inform clinical best practice. Earlier research in this area, a body of which addressed applied memory questions, was conceptualized and conducted quite separately from research in pediatric psychology, which has as its focus the health and well-being of children in medical settings (Aylward, Bender, Graves, & Roberts, 2009). Recently, however, there has been greater recognition of the ways in which these fields can inform each other. For example, research investigating children's memory for distressing or painful experiences not only has implications for understanding factors influencing children's recall under a range of circumstances, but can also provide guidance for practitioners helping children to manage recurrent and "negatively remembered" medical procedures (e.g., von Baeyer, Marche, Rocha, & Salmon, 2004). Investigations of children's experience and communication of pain via rating scales can inform applied practice and contribute to knowledge of children's symbolic understanding, their quantitative and comparative reasoning, and their understanding of sequential progressions in visual rating scales (e.g., Stanford, Chambers, & Craig, 2006; von Baeyer, 2009).

In this article, we discuss the unique elements of medical settings and, in the context of exemplar studies, the associated theoretical and applied benefits of developmental research in these contexts. Our review is selective, and we have largely (although not exclusively) focused on verbal children rather than on infants or toddlers. We also consider some challenges of working in this area as well as our own and others' experiences of how these challenges might be overcome.

## WHY CONDUCT RESEARCH IN MEDICAL SETTINGS?

What, then, are the specific advantages of conducting research in medical settings? We have selected several, which we discuss in subsequent sections: the diverse participants who can be recruited and the associated opportunities to consider theoretical questions and the relationships between physical health and cognitive development; the diverse characteristics associated with different medical procedures, which mean that a variety of experiences are available for study; the range of research paradigms that can be adopted, enabling different relations among variables to be teased apart; and the rich training opportunities available for students.

### Diverse Participants Available for Recruitment

The range of potential participants who may be recruited includes children with typical and atypical developmental pathways and those who have chronic or acute health conditions. Relative to

engaging participants from convenience samples (e.g., schools, local communities), there is also more diverse stratification across important demographic variables (e.g., ethnicity, socioeconomic status) and other variables that may affect the generalizability of findings (e.g., parental motivation). This has enabled questions of theoretical importance to be addressed while yielding critical findings on pathways to optimal and suboptimal cognitive development.

*Theoretical questions.* Research on the role of language in the development of theory of mind (ToM) provides one example of the opportunities provided by the diversity of potential participants to address key theoretical issues in cognitive development. Investigating the relative skill of deaf children growing up with a deaf parent or hearing parent (who is unlikely to achieve the same level of proficiency in sign as a native signer), researchers have found that having a deaf (relative to hearing) parent benefits deaf children's ToM development (de Villiers & de Villiers, 2012). The critical role that an early rich-language environment plays, whether verbally or visually conveyed, for ToM development has been further highlighted by findings that children with cochlear implants (invited to participate through medical clinics) continue to manifest delayed ToM development, although not to the extent of deaf children of hearing parents (Ketelaar, Rieffe, Wiefferink, & Frijns, 2012).

A second example concerns the engagement of children with the genetic disorder Williams syndrome (WS) to address theoretical issues regarding the relationship between language and intelligence. Children with WS typically present with low IQ (range = 50–60) and poor spatial and numerical cognition, but relatively large vocabularies and proficient grammar. This pattern has led some researchers to propose that language can develop independently of intelligence, consistent with cognitive modularity of the human mind (e.g., Pinker, 1999, in Karmiloff-Smith & Thomas, 2003). Longitudinal research has identified atypical inconsistencies in the language development of children with WS; however, this research has suggested that contrary to claims of modularity, genetic disorders develop under “different neurocomputational constraints” (Karmiloff-Smith & Thomas, 2003, p. 969). Indeed, Karmiloff-Smith (2012) argues that the complexity of functioning in children with neurodevelopmental disorders, and their relationship with typical development, can be revealed only when developmental trajectories are traced over time.

A different approach is exemplified by research adopting a sociocultural developmental framework to investigate the nature and consistency in indexes of meaning making in the narratives of mothers and their children (8- to 12 years of age) suffering from chronic asthma (Fivush, Sales, & Bohanek, 2008). Narratives of negative experiences (e.g., stressful experiences associated with the child's asthma) relative to positive past events were more coherent and contained more mental-state language, suggesting that negative events require greater understanding and processing. These and related findings contribute to theory and research highlighting the importance of narratives as reflecting and contributing to the individual's attempts to make sense of their emotional experience (e.g., Fivush, Bohanek, & Marin, 2010).

*Pathways to cognitive development and health.* Longitudinal studies, enabled by the recruitment of participants through maternity wards, have provided critical information about pathways to cognitive development and health. For example, the Dunedin Multidisciplinary Health and Development Study has followed infants born between 1972 and 1973. With more than 1,100 publications, this study has yielded a diverse array of findings, including the etiological role of childhood cognitive deficits in the development of schizophrenia (Reichenberg et al.,

2010) and the effect on cognitive development of the interaction of breast-feeding and genetic variation in fatty acid metabolism (Caspi et al., 2007).

The engagement of child participants with chronic health conditions has been informative in relation to factors that impair or facilitate cognitive development and, conversely, aspects of cognitive development that influence the development of chronic conditions. For example, research on the early presence of sleep disorders has shown a long-term association with language development, educational needs, and cognitive function (Bonuck, Rao, & Xu, 2012; Touchette, Petit, Tremblay, & Montplaisir, 2009). In contrast, research investigating childhood obesity suggests that executive functions may play a contributing role, possibly through their association with a range of behaviors that contribute to obesity (e.g., food intake, physical and sedentary activity) and underpinned by poorer impulse control and planning skill (Riggs, Spruijt-Metz, Chou, & Pentz, 2012).

In summary, engaging pediatric populations characterized by various chronic developmental and health conditions allows an examination of the complex interplay between disease states and typical and atypical development. Pathways to adaptive and maladaptive outcomes (e.g., family factors) can also be investigated and these, in turn, can be the focus of intervention (e.g., Taylor et al., 2010).

### Diverse Nature of Participants' Experiences

Medical experiences and procedures vary across a range of dimensions, a feature that has been exploited in research addressing applied memory questions. Some procedures are repeated (e.g., injections/needle prick; Goodman, Hirschman, Hepps, & Rudy, 1991) whereas others are unique (e.g., the voiding cystourethrogram [VCUG], X-ray of the kidneys; Goodman, Quas, Batterman-Faunce, Riddlesberger, & Kuhn, 1994, 1997; Merritt, Ornstein, & Spicker, 1994); they may be relatively unstressful (e.g., pediatric checkup; Baker-Ward, Gordon, Ornstein, & Larus, 1993; Brown et al., 1999; Ornstein et al., 2006) or highly distressing (e.g., lumbar punctures [LPs]; Chen, Zeltzer, Craske, & Katz, 1999, 2000). Medical procedures may also be more or less invasive (e.g., anogenital examination; Eisen, Goodman, Qin, Davis, & Crayton, 2007) and may be scheduled (e.g., surgery; Calderon et al., 2010) or not (e.g., a visit to the emergency room following an injury or accident; Peterson & Bell, 2006). We provide exemplar findings from research investigating scheduled and unscheduled potentially stressful procedures.

*Unscheduled stressful experiences.* Children's visits to emergency rooms can be associated with high levels of stress due to factors such as the prior injury, attendance at a hospital, and the unexpected nature of both. These features have generated a raft of findings underscoring the associations between emotion and cognition.

Peterson and colleagues' longitudinal study of children (2- to 13 years of age) who attended an emergency room visit following injury has yielded significant findings relating to very young children's long-term recall, which was assessed within a few days, and after 6 months and 1, 2, and 5 years (see Peterson, 2012, for a review). Although the accuracy of the children's accounts deteriorated across time, their completeness increased at the 2-year follow-up but the new information at the longer delay was less likely to be accurate than that produced in previous interviews

(see also Salmon & Pipe, 1997). Particularly noteworthy was that most children who had been younger than 26 months old at the time of the injury failed to recall any information. These data have contributed to theories of infantile amnesia and have applied implications for both pediatric and forensic settings.

How children appraise, remember, and manage unexpected and salient experiences such as admissions to emergency rooms is also relevant to understanding interlinked cognitive and emotional processes in psychopathology. Much of the research investigating the development of posttraumatic stress disorder (PTSD) in children has focused on attendees to emergency rooms following assaults, falls, or motor vehicle accidents (e.g., Meiser-Stedman, Dalgleish, Smith, Yule, & Glucksman, 2007; O’Kearney, Speyer, & Kenardy, 2007). For example, Salmond et al. (2011) reported that youth (8- to 17 years of age) whose narratives about their experience contained expressions of uncertainty and confusion manifested greater psychopathology relative to children whose narratives did not include these features. Bryant, Salmon, Sinclair, and Davidson (2007) found that appraisals of children between 7- and 13 years of age of their own vulnerability to future harm following a traumatic stressor significantly predicted child PTSD.

*Scheduled stressful experiences.* Focusing on scheduled procedures enables researchers to have greater control over the research process. For example, with respect to applied memory studies, scheduled procedures are more readily able to be recorded, providing an opportunity to code the behavior of attending adults and a record against which the child’s account can be assessed.

Research by Chen and colleagues (2000) investigating children’s memory for consecutive LPs has highlighted how children and young people’s memory for pain and painful procedures influences their future coping (see von Baeyer et al., 2004, for a review). Higher levels of distress manifested during an LP by young people (3- to 18 years of age) were associated with greater negative exaggeration of their anxiety or pain (as compared with their post-LP reports) 1 week later, and in turn, with higher distress during a subsequent LP.

Several studies investigating children’s memory for stressful emotional experiences have focused on the VCUG, an invasive radiological assessment requiring catheterization, which is typically carried out when children experience recurrent urinary tract infections (e.g., Brown et al., 1999; Merritt et al., 1994; Pezdek et al., 2004; Quas et al., 1999). Research by Goodman and colleagues using the VCUG has contributed to the “mapping” of the complex factors that influence recall, showing that attachment influences children’s memory and suggestibility for negative emotional events (see Chae, Ogle, & Goodman, 2009, for a review). For example, parents with an avoidant (rather than secure) attachment style have children who manifest poorer recall of the VCUG, particularly if the children had been highly distressed, and children of avoidant parents show greater suggestibility when recalling a VCUG (Goodman et al., 1994, 1997). Parents with an avoidant attachment style are less responsive to their children during the procedure and, perhaps because they lack effective emotion regulation strategies, their children manifest greater distress, which may reduce or alter what is encoded and available for later recall (e.g., Alexander et al., 2002).

Together, these studies contribute to understanding factors that shape the relationship between emotion and memory and the role of memory in children’s subsequent management of their emotional experiences (for reviews, see Levine & Edelstein, 2009; Marche & Salmon, 2013; Salmon & O’Kearney, in press).

## Opportunity to Adopt Diverse Research Paradigms

*Cross-sectional, longitudinal, experimental research.* As is evident from the preceding examples, medical settings lend themselves to diverse research paradigms. A number of studies have adopted cross-sectional or longitudinal designs to examine associations among variables (e.g., Peterson, 2012; Salmon, Price, & Pereira, 2002). For example, using a cross-sectional design with infants, Bremner et al. (2011) recruited participants from a maternity unit and investigated the development of intersensory perception.

Other researchers have adopted experimental paradigms. Chen et al. (1999) targeted young (3- to 18 years of age) peoples' negatively exaggerated memories of an LP postprocedure by highlighting the coping strategies that they had used and found that this reduced their distress before and during subsequent LPs. Salmon, McGuigan, and Pereira (2006) aimed to reduce anxiety and prevent problematic memories for children (3- to 7 years of age) undergoing the VCUg by providing information about the procedure as it unfolded (e.g., This is our big camera. It will come down over your tummy but it won't touch you). Relative to standard care, children in a combined distraction and narration condition manifested less distress during the procedure and provided more complete memory reports 1 week later. These studies potentially enable stronger conclusions to be drawn about causal relations between key variables than is possible with correlational designs.

*Middle ground between field and laboratory research.* Medical settings potentially provide the middle ground between field-study research and laboratory-based empirical studies for considering questions about various aspects of cognitive development. Although field studies have the advantage of addressing the research question in the context in which it occurs, compromises must be made regarding experimental control. Conversely, laboratory-based studies tend to have high levels of experimental control but may be criticized in terms of ecological validity when considering the extent to which findings can be applied to real-world contexts (Chae, 2010). In many instances, medical settings are able to go some way toward mitigating these limitations in studying cognitive development, particularly when considering questions with an applied focus.

For example, Karen Salmon's work with colleagues and students has tested social-constructionist theories of the role of parent-child conversations in the development of autobiographical memory both in laboratory-based studies and in medical settings. We have found, for example, that adult-child talk before an event (i.e., the provision of verbal preparatory information) has a very weak impact on 3- to 7-year-old children's understanding and memory of the experience unless supplemented by visual cues or props, particularly when compared with talk during or after the experience (McGuigan & Salmon, 2004; Salmon, Yao, Berntsen, & Pipe, 2007; see also Hedrick, Haden, & Ornstein, 2009). This, in turn, has implications for strategies of preparing children for medical procedures (Jaaniste, Hayes, & von Baeyer, 2007; Salmon, 2006).

A further example of the unique place of medical contexts as part way between the laboratory and field is research investigating optimal strategies for interviewing children in forensic settings. A significant body of work has utilized a range of medical experiences as an analog paradigm for child maltreatment (e.g., Goodman et al., 1991; Greenhoot, Ornstein, Gordon, & Baker-Ward, 1999; Steward & Steward, 1996). When considered together with laboratory-style event memory studies (e.g., Brown, Pipe, Lewis, Lamb, & Orbach, 2007, 2012; Goodman & Aman, 1990) and

research conducted in the field involving interviews with children who have experienced maltreatment (e.g., Aldridge et al., 2004; Teoh, Yang, Lamb, & Larsson, 2010), consistent patterns have emerged to build a mosaic of children's capabilities under a range of circumstances. For example, in general, children's free-recall accounts, elicited in response to open-ended prompts, tend to be highly accurate, although younger children recall significantly less information than do older children. Additional open-ended prompts can elicit more detailed accounts without compromising accuracy. As is evident from our previous discussion, research investigating medical procedures has identified a range of individual difference factors that also influence how children recall these experiences (see Lamb & Brown, 2006; Pipe & Salmon, 2008, for reviews).

In summary, medical settings provide a unique opportunity, between the laboratory and the field, to test questions of theoretical and applied importance. The convergence of findings from these diverse paradigms can lead to more robust conclusions than are possible when considering findings from each separately.

### Student Training

Apart from its theoretical and applied contributions, the conduct of the research also offers rich experience for students. The wealth of research paradigms, designs, and methodologies that can be employed as well as the experience in the contribution that research makes to applied practice offer valuable research training opportunities. Beyond the research training, working in this context also provides exposure to the complexities of medical systems and systemic and structural processes that affect children and their families as they engage with health care providers. Students must develop professionalism, sensitivity, and respect for the families and health care providers who allow them access to their experiences. They must grapple with the ethical issues that present when inviting parents and children to allow them to be present during highly personal experiences. Finally, the considerable effort that must go in to setting up the research and developing important relationships is also an invaluable source of research training for students.

## CONDUCTING RESEARCH IN MEDICAL SETTINGS AND THE KEY CHALLENGES

We have found working in medical settings to be uniquely stimulating and rewarding, but there are a number of important considerations and associated challenges.

### Building Relationships

Successfully conducting research in medical settings relies crucially on building strong relationships with staff at all levels (service managers, doctors, nursing and administrative staff). As, of course, the primary concern of medical staff is the well-being of the patients in their care, a strong case must therefore be put forth with respect to the significance of the research, its potential benefits and costs, and its implications for staff and patients. In the interests of engaging staff at all levels, we have found it to be useful to present our proposal to staff meetings at all levels, to seek

feedback about its research questions and the implications for staff workloads, and to continue to review these issues. Moreover, given the reciprocal relationship between researchers and medical staff, research outcomes (the findings and their implications, materials where relevant) should be provided to staff at the project's completion. Even where staff support and engage with the research, it is important to ensure that additional or unnecessary demands on them are minimized.

### Ethical Issues

A number of ethical issues require planning and thought. First, it can be necessary to seek consent through both university and medical committees, or with respect to the latter, it may be necessary to seek consent at a higher level such as a board or committee serving a local health area covering several hospitals. This can be a prolonged process.

Second, to the extent that they are observed or actively involved in administering aspects of the research, ethical consent will need to be sought from staff.

Third, thought must be given to when, and how, participants may be invited to engage in the research. For example, it is necessary to exercise caution when approaching parents whose children has been brought into the emergency room and all are highly distressed. Researchers have, however, found sensitive ways to manage this issue. For example, in her research investigating children's memory for injury and their visit to the emergency room described earlier, Peterson and her research assistants approached families only when the appropriateness of so doing was indicated by nursing staff, and then only to request contact information and give written information about the research so that parents could read it at their leisure (C. Peterson, personal communication, 2012).

Fourth, it is crucial that information is communicated with all partners in the research (e.g., health care providers, participants, research assistants) in a way that is complete and accurate but, particularly for parents and children, also accessible and easily disseminated. Child-consent and/or -assent procedures must be developed considering the age and cognitive and social maturity of the child. Although there is much debate about the rather poorly defined concept of child assent, there is nonetheless general agreement that seeking assent enables researchers to engage with the children about their research participation and to show respect for their autonomy (Sibley, Sheehan, & Pollard, 2012). To address some of these issues, it may be useful to consider a familiarization meeting with the parents and child prior to the medical event to present the information, discuss the researcher's role, answer any questions or worries, and develop rapport with the child.

Fifth, consideration must be given to storage of, access to, and destruction of video records of medical consultations or procedures and associated documentation. For example, protocols need to be developed regarding whether any data gathered for research purposes (e.g., measures of cognitive and/or neuropsychological function) should become available to the health care providers (e.g., through inclusion in medical records).

Finally, a particular issue that can arise is that parents who are asked to participate in research may assume that the researchers are aware of the health issues affecting their child and are able to provide clinical consultation. Relatedly, parents, who may have received limited preparatory information about an upcoming procedure, may ask the researchers to provide clinically related information. These issues underscore the critical importance of clear information provided to

parents and clear boundaries between the researcher/clinician roles. Specifically, it is important that parents understand that the researcher's role does not extend to their child's clinical condition and that clinicians are not also researchers—that is, the child's clinicians, even if involved in the research, must not attempt to recruit participants or discuss the research with them. It may well also be important to clarify for parents that a child or family may not receive any benefit from participation in the research. Although this is evident to researchers, it may be at odds with parents' other experiences in the medical setting where an expectation of benefit is explicit (Rae, Brunquell, & Sullivan, 2009).

## SUMMARY

Medical contexts provide an extensive array of research opportunities to consider questions of cognitive development and how it is influenced by social processes and physical and developmental states. It also allows consideration of how cognitive development, in turn, may influence health and well-being. Such work requires extensive preparation and planning for successful progress, but the challenges are surmountable with attention to relationship building and an ethical approach to research that is respectful of medical staff and prioritizes the needs of the children and their families.

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## ADDITIONAL RESOURCES

Further reading, particularly in relation to research ethics in medical contexts:

- Cico, S. J., Vogeley, E., & Doyle, W. J. (2011). Informed consent language and parents' willingness to enroll their children in research. *IRB; Ethics & Human Research*, 33, 6–13.
- Note: Presents findings showing that common terms used in pediatric research (e.g., research project, study, experiment) are not taken as identical by potential participants and provides brief recommendations to address this issue.
- Henderson, E. M., Law, E. F., Palermo, T. M., & Eccleston, C. (2012). Case study: Ethical guidance for pediatric e-health research using examples from pain research with adolescents. *Journal of Pediatric Psychology*, 37, 116–126.
- Note: Aims to provide ethical guidance for psychologists who are engaged in pediatric e-health research. There is a particularly useful discussion of ethical issues relating to recruitment, informed consent and debriefing, privacy and confidentiality, and safety.
- Rae, W. A., Brunnquell, D., & Sullivan, J. R. (2009). Ethical and legal issues in pediatric psychology. In M. C. Roberts & R. G. Steele (Eds.), *Handbook of pediatric psychology* (4th ed., pp. 19–34). New York, NY: The Guilford Press.
- Note: A useful general overview, from a pediatric psychology framework, of issues to consider when conducting research in pediatric settings.
- Sibley, A., Sheehan, M., & Pollard, A. J. (2012). Assent is not consent. *Journal of Medical Ethics*, 38, 3.
- Spriggs, M., & Caldwell, P. H. Y. (2011). The ethics of paediatric research. *Journal of Paediatrics and Child Health*, 47, 664–667.
- Note: Written for medical practitioners, both Sibley et al. (2012) and Spriggs and Caldwell (2011) provide interesting perspectives on issues surrounding child assent.