

Letter to the Editor: Journal of Pediatric Nursing

Ethical Considerations in Undertaking Research with Children

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Bronfenbrenner's bioecological model of human development, states children and young people (CYP) are influenced by their interaction with the environment, biological characteristics, context, and time (Bronfenbrenner, 2005). Time refers to four interacting systems being the microsystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner, 2005). The microsystem includes relationships between two or more settings with family having the greatest impact on CYP's psychosocial and emotional development (Bronfenbrenner, 2005). Dependent on the child's developmental age, capacity, and desire to be involved in research, parental and/or adult proxy support may be required or requested by the child and/or researcher. Within a child centric lens, if parental, caregiver and/or adult involvement is required researchers need to critically evaluate how this may impact on the child (Huang et al., 2016; Spriggs & Gillam, 2019). This was evident in a review of 17 manuscripts which highlighted three main ethical tensions when undertaking research with CYP (Dubois et al., 2022). It

was recommended that researchers need to acknowledge CYP's position and power differential within a family, acknowledge that CYP are individuals yet are also part of a family system, and that CYP need to be provided with support, security, respect, and confidentiality (Dubois et al., 2022). To mitigate these tensions, Dubois et al (2022) suggested that researchers build a triadic partnership with families and professionals, identify appropriate methods to empower CYP, and involve parents as partners in research (Dubois et al., 2022).

In addition, Mayne et al (2018) proposed a rights-based research ethics and participation planning framework be used in research activities with younger children to ensure children's rights, power, and agency are upheld (Mayne et al., 2018). This three-step phase includes 1. consideration of the ethical foundations being the research design, researcher's perspective of children's capacities and children's perspective of research that need to be built on as research is conceptualised, 2. practical design considerations specifically informed voluntary consent/assent processes that honour children's rights, human ethics protocols, children's competence and participatory research expectations by using an interactive narrative approach such as story-telling and shared thinking, and 3. implementation of meaningful quality research participation that addresses respect, support of children's voice and agency, as well as accessible age appropriate engaging information (Mayne et al., 2018). Mayne's (2018) rights-based research ethics and participation planning framework is aligned to Hart's (1992) eight-rung ladder of participation, United Nations Convention on the Rights of the Child (1989) Article 12 (respect for the views of the child), Article 13 (freedom of expression), and United Nations International Children's Emergency Fund (2019) (Christensen & James, 2017; Hart, 1992; Mayne et al., 2018; United Nations Human Rights Office of the High Commissioner, 1989; United Nations International Children's Emergency Fund, 2019). When honoring the United Nations Conventions of the Rights of the Child (Article 12 and 13), World Health Organization, United Nations International Children's Emergency Fund, and other key ethical documents it is important that researchers take a rights-based approach to CYP's participation in research in a manner appropriate to their age and development (Powell et al., 2012; United Nations Human Rights Office of the High Commissioner, 1989; United Nations International Children's Emergency Fund, 2019; World Health Organization, 2001). A child centred care approach, Best Interests of the Child Model and Hart's ladder of participation provide useful frameworks to help researchers conceptualise how CYP's participation and involvement in research is ethically honoured (Carter et al., 2014; Foster & Shields, 2020; Hart, 1992; Kalverboer & Zijlstra, 2006).

The literature reports that undertaking research with marginalised CYP (asylum seekers; children with a disability, communication disorder or chronic illness; children from a low-income family, and/or children of the state) requires specific considerations around respect, trust, relationships, time, inclusion, diversity, choices, and comfort (Butler et al., 2020; Jenkin et al., 2020). It is recommended that marginalised CYP should be consulted by ethics committees, with researchers using a relationally constituted ethical process for ongoing informed voluntary consent/assent, and that researchers do not interpret ambiguity, interdependence, incapacity, and vulnerability as a weakness but instead view these concepts within ethical frameworks that address privacy, support, confidentiality, safety, protection, and situated moral judgements made over the course of the research through the analytic lens of micro-ethics (Jenkin et al., 2020; Spiel et al., 2018; Van Goidsenhoven & De Schauwer, 2022). Micro-ethics is defined as the "*seemingly mundane everyday activities that contribute to ethical conduct on a larger scale*" between individuals in a research project (Spiel et al., 2018) pg.9. Spiel et al (2018) states that discourse between ethical principles and what occurs in practice (micro-ethics) can occur and provided some mitigation strategies that researchers should consider. This included supporting carers, prioritising research topics, undertaking a complex risk assessment, provide opportunities for relationship building, and embody research with CYP from a professional accountable lens (Spiel et al., 2018).

Despite these recommendations, it is evident in the literature that researchers have various perceptions of what constitutes child centric ethical processes in undertaking research activities with children (Mayne & Howitt, 2015). This was evident in a review of 506 articles where 64.4% of articles placed children (0-8 years) as non-participant objects, 32% as semi-participant subjects, 3% of studies placed children in inclusive roles and 4% as co-researchers. Of concern, 70.2% of articles were identified as research conducted 'on' children, with the remaining 29.8 % as research 'with' or 'by' children and 89.7% of articles focused on what researchers could gain from children, rather than valuing children themselves (Mayne & Howitt, 2015). A further constraint in reporting child centric ethical processes in peer-reviewed publications, is the fiscal word limit which precludes authors from transparently reporting how they undertook research with CYP (Bodén, 2021; Robson, 2018). Further research is needed to highlight how CYP's rights and well-being have been honoured in research activities.

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