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| **ISA ISPID  Abstract Submission  Nº: 170**   |  | | --- | | Topics: **Stillbirth** | | Type: **Oral** | | **"It’s a very hard time to make decisions when you’re in the midst of grief”: Parents’ experiences of autopsy decision-making after stillbirth** | | **Boyle, Frances** 1; **Horey, Dell**2; **Wilson, Trish**3; **Ibiebele, Ibinabo**4; **Schirmann, Anne**1; **Ellwood, David**5; **Khong, Yee**6; **Jennings, Belinda**7; **Flenady, Vicki**4 *1 - School of Public Health, The University of Queensland. 2 - School of Psychology & Public Health, La Trobe University. 3 - Mater Health Services, Brisbane. 4 - Mater Research Institute, The University of Queensland. 5 - Gold Coast Hospital & Health Service and Griffith University. 6 - University of Adelaide. 7 - King Edward Memorial Hospital, Perth.* | | **Introduction** Parents whose baby is stillborn face many critical decisions at a time of intense grief. Among the most difficult is whether to consent to autopsy examination for their baby. Support in decision-making is essential to parent-centred care after stillbirth but evidence to guide best practice is scarce. The Stillbirth Autopsy Consent Study was designed to explore parents’ experiences and perceptions of the autopsy consent process. Based on findings from the study, this paper presents detailed insights into parents’ approaches to decision-making and their information and support needs.  **Material and Methods** From March 2014-September 2015, parents whose baby was stillborn were recruited from two large tertiary maternity hospitals in Brisbane, Australia. Parents were asked to complete a self-report questionnaire three months after the stillbirth and invited to participate in a semi-structured telephone interview. The questionnaire included open- and closed-questions that asked about communication processes and experiences of decision-making. The questionnaire was structured to follow the parent journey, from first discussions about autopsy, to the decision itself and follow-up including communication of results. Validated scales including the Decisional Conflict Scale and the Decision Regret Scale were also included. The semi-structured interviews enabled in-depth exploration of how parents made their decision about autopsy.  **Results** A total of 21 parents completed the questionnaire. A subgroup of 12 parents completed the telephone interview. All parents were offered an autopsy for their baby and consent was given in 12 cases. Parents entered the decision-making process with differing degrees of “preparedness” and perspectives on autopsy.  For some parents agreeing to autopsy was a clear and immediate decision as they sought to uncover all they could about their baby’s death. Other parents were equally resolute in not proceeding with autopsy for their infant. Between these two extremes were parents who described being unsure and overwhelmed by the decision they faced. The potential for health care professionals, and family members, to influence parents’ decisions was evident. Parents expressed little regret about their decision, regardless of the decision made. Parents generally reported feeling emotionally supported and well-informed about options but less certain about risks. Responses from parents indicated scope for improvement regarding how and when autopsy results were conveyed to parents.  **Conclusions** Stillbirth autopsy consent is the culmination of a complex and highly personal decision subject to the influence of multiple factors. Our findings demonstrate the need for sensitive and tailored support that incorporates both emotional and informational domains to assist decision-making. Also highlighted is the importance of viewing autopsy consent as more than a discrete event and part of the overall and longer-term care of parents. | |  |  |  |  | | --- | --- | | **CONTACT** | | | Name: | **Frances** | | Lastname: | **Boyle** | | E-mail: | **f.boyle@sph.uq.edu.au** | | Country: | **Australia** | | Institution | **School of Public Health, The University of Queensland** | | Cellphone: | **+61 0402099556** | | City: | **Brisbane** | |