

## How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy through tough times

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**BACKGROUND:** How parents of children with life threatening conditions draw upon religion, spirituality, or life philosophy is not empirically well described.

**METHODS:** Participants were parents of children who had enrolled in a prospective cohort study on parental decision-making for children receiving pediatric palliative care. Sixty-four (88%) of the 73 parents interviewed were asked an open-ended question on how religion, spirituality, or life philosophy (RSLP) was helpful in difficult times. Responses were coded and thematically organized utilizing qualitative data analysis methods. Any discrepancies amongst coders regarding codes or themes were resolved through discussion that reached consensus.

**RESULTS:** Most parents of children receiving palliative care felt that RSLP was important in helping them deal with tough times, and most parents reported either participation in formal religious communities, or a sense of personal spirituality. A minority of parents, however, did not wish to discuss the topic at all. For those who described their RSLP, their beliefs and practices were associated with qualities of their overall outlook on life, questions of goodness and human capacity, or that "everything happens for a reason." RSLP was also important in defining the child's value and beliefs about the child's afterlife. Prayer and reading the bible were important spiritual practices in this population, and parents felt that these practices influenced their perspectives on the medical circumstances and decision-making, and their locus of control. From religious participation and practices, parents felt they received support from both their spiritual communities and from God, peace and comfort, and moral guidance. Some parents, however, also reported questioning their faith, feelings of anger and blame towards God, and rejecting religious beliefs or communities.

**CONCLUSIONS:** RSLP play a diverse and important role in the lives of most, but not all, parents whose children are receiving pediatric palliative care.

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