Parents as advocates: stories of surplus suffering when a child is diagnosed and treated for cancer.

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Abstract: Twenty-nine parents of children who had been diagnosed with cancer were interviewed through long and relatively unstructured interviews conducted via telephone by a mother whose own daughter once had cancer. Parents were asked to tell the story of their experiences during the time that they were 'going through' cancer. Parents usually began their narrative in the months, weeks, or days prior to the diagnosis. They spoke of various parts of the story. In this paper, the focus is on one topic that parents talked about a lot. We call this 'problems with the system' or 'surplus suffering.' Here parents reported on their perceptions of mistakes, and delays in diagnosis, errors, carelessness, and unkindness during treatment. They talked of how they felt they had to be on constant guard, and at times, to intervene in their child's care. This paper provides a picture of parental expectations and their violation during the treatment of their children for cancer. It begins to demonstrate how parents see themselves as advocates for their children in a context of fragile power relations.

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