

Whose life is it anyway? Proxy v. self reported quality of life in childhood cancer survivors

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Health related quality of life (HRQL) has recently emerged as an important outcome measure in paediatrics. Although usually assessed by self-report; there may be occasions when a child is unable to self-complete, making use of a parent completed proxy-report necessary. Thus knowing whether parents and children differ in the assessment of child well-being is essential. This study compared mother and child ratings on the Pediatric Quality of Life Inventory (PedsQL™) a measure for children aged 8-18 years. In total 474 healthy children (213 males and 261 females) and 70 cancer survivors (35 males and 35 females) and their mothers completed PedsQL™. Agreement was better for cancer survivors and mothers on all PedsQL™ scales. The most marked difference in agreement was for Physical Functioning: agreement was good for cancer survivors and mothers (ICC=0.68, $p<0.001$), and poor for healthy children and mothers (ICC=0.19, $p<0.001$). It is suggested that parents and children are more likely to share information about an issue if it is perceived as a problem, which will impact positively on the accuracy of parental ratings for children with chronic health problems; however proxy ratings should still be conducted with the knowledge that they only provide an estimate of child HRQL.