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Méta-analyse sur l'évaluation de la qualité de vie en oncologie pédiatrique : Quel est l'accord entre parents et enfants ?

Par

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Résumé

Introduction : La qualité de vie liée à la santé est une composante essentielle des soins pour les enfants atteints de cancer. Les évaluations parentales et autorapportées de la qualité de vie ne concordent pas et des différences notables sont répertoriées dans la littérature. Une méta-analyse a été effectuée afin de synthétiser l'ampleur des niveaux d'accord et différences entre les évaluations parentales et autorapportées de la qualité de vie des enfants à tous les stades du cancer et afin d'identifier les modérateurs d'accord et différences. **Objectifs :** (1) Identifier les niveaux d'accord parents-enfants sur la qualité de vie liée à la santé, (2) Évaluer la taille des différences parents-enfants sur la qualité de vie liée à la santé, (3) Déterminer les modérateurs d'accord et différences parents-enfants parmi les caractéristiques des participants (statut clinique, âge, culture) et les caractéristiques des études (instruments, cotes de qualité) **Méthodologie :** Une recherche systématique documentaire a été effectuée. Les articles admissibles devaient évaluer la qualité de vie des enfants atteints de cancer par des mesures parentales et autorapportées. Des méta-analyses aléatoires ont comparé les évaluations globale, physique et psychologique de la qualité de vie selon les niveaux d'accord (*r)* et la taille des différences (Hedge's *g*). Des analyses catégorielles ont permis d'identifier les modérateurs. **Résultats :** Vingt articles, comptabilisant 2 093 enfants et 2 108 parents, étaient admissibles sur 1 145 éligibles. Des *r* pondérés de 0.65 (modéré), 0.64 (modéré) et 0.55 (passable) ont été obtenus pour l'accord parents-enfants sur les domaines global, physique et psychologique respectivement. Des écarts parents-enfants plus grands ont été répertoriés sur le domaine psychologique ($g = 0.50$, modéré) comparativement au domaine physique ($g = 0.22$, faible). Un meilleur accord parents-enfants était associé à un plus jeune âge chez les enfants, à la culture asiatique, à des enfants recevant actuellement un traitement contre le cancer et à des études de meilleure qualité. **Conclusion :** Les niveaux

d’accord et les différences parents-enfants soulignent l'importance d’examiner les modérateurs des écarts afin de mieux comprendre, évaluer et orienter les soins liés à la qualité de vie en oncologie pédiatrique.

Mots-clés : qualité de vie, cancer pédiatrique, parent, proxy, évaluation autorapportée, accord, différence et psychologie clinique

Abstract

Background : Health-related quality of life is an essential component of care for children with cancer. Parental and self-reported assessments do not concord and significant differences are found in the literature. A systematic meta-analysis was conducted to synthesize the extent of agreement and discrepancies between parental and children reports of child's health-related quality of life at all stages of the cancer diagnosis and to identify key moderators of agreement and discrepancies. **Objectives :** [1] Identify levels of parent-child agreement on health-related quality of life (2) Assess the size of differences between parental and children ratings on health-related quality of life (3) Determine moderators of parent-child agreement and discrepancies among participant characteristics (clinical status, age, culture) and study characteristics (instruments, quality scores) **Methodology:** A systematic literature review was conducted. To be eligible, the articles had to quantitatively measure the health-related quality of life of children with cancer through parental and self-reported assessments. Random meta-analyses compared parent-child ratings on health-related quality of life domains (global, physical, psychological) and by levels of agreement (*r*) and size of differences (Hedge's *g*). Categorical analyses served to identify the moderators of agreement and discrepancies. **Results**: Twenty studies, comprising 2 093 children and 2 108 parents, were eligible out of 1 145. Weighted *r's* of 0.65 (good), 0.64 (good) and 0.55 (fair) were obtained for parent-child agreement on the physical and psychological domains respectively. Larger gaps were found between parental and children ratings on the psychological domain ($g = 0.50$, moderate) compared to the physical domain ($g = 0.22$, low). A better parent-child agreement was associated with a younger age in children, Asian cultures, children currently receiving cancer treatment and better quality studies. **Conclusion:** Agreement levels and parent-child differences on child health-related quality of life highlight the

importance of examining moderators to better understand, evaluate and guide of the delivery of care in pediatric oncology.

Keywords**:** quality of life, pediatric cancer, parent, proxy self-reported, agreement, discrepancies and clinical psychology

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Liste des abréviations

CHQ : Child Health Questionnaire

ICC : Intraclass Correlation coefficient

PedsQL^{TM} : Pediatric Quality of Life Inventory

PedsFACT : Pediatric Functional Assessment of Cancer Therapy

POQOLS : Pediatric Oncology Quality of Life Scale

QLCC : Quality of Life for Children with Cancer

Liste des sigles

c.-a.-d. : C'est-à-dire

dx : Diagnostic

g : Hedge's *g*

i.e. : In example

N/A : Not Available

r : Corrélation

v.s. : Versus

Je dédie cet essai

À toutes les familles confrontées au cancer de leur petit humain.

Quel privilège d'être témoin de tout l'amour et l'espoir que vous donnez à vos enfants malades.

et

À ma famille à moi.

Quel privilège de vous aimer et d'être aimée par vous.

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Chapitre 1. Introduction

Cet essai doctoral présente les enjeux associés à l'évaluation de la qualité de vie liée à la santé chez les enfants tout au long de la trajectoire du cancer pédiatrique. D'abord, en introduction, l'essai aborde les séquelles du cancer pédiatrique, définit la qualité de vie liée à la santé et compare les évaluations parentales et autorapportées des enfants avec un cancer. Ensuite, en tant que corps de l'ouvrage, l'essai présente un article scientifique qui est une méta-analyse de l'accord et des différences parents-enfants sur la qualité de vie liée à la santé en oncologie. Enfin, en discussion, l'essai revient sur les résultats, présente les forces et limites de l'étude, et mentionne les implications cliniques et avenues d'investigations possibles pour les études prospectives dans ce domaine de recherche.

Le cancer pédiatrique

Le cancer pédiatrique constitue une épreuve difficile pour la famille et l'enfant malade, portant directement atteinte à l'intégrité physique et psychologique de ce dernier. Au cours de la maladie, l'enfant avec un cancer compose avec des difficultés significatives et sérieuses (Agence de Santé Publique du Canada, 2017). En effet, les traitements pour le cancer pédiatrique sont invasifs, prolongés et exigeants sur le plan physique (Bryant, 2003; Hewitt, Weiner, et Simone, 2003). Les enfants sont souffrants durant cette période et peuvent avoir des ulcères, gonflements, nausées, perdre leurs cheveux et ressentir une grande fatigue (Bryant, 2003; Hewitt et al., 2003). De même, les traitements pour le cancer influencent la vie quotidienne familiale par de multiples périodes d'hospitalisations où les enfants se retrouvent séparés de leur famille, routine et fratrie (Adler, 2008; Eiser, 2004). Tout comme, le développement normatif des enfants est freiné étant donné que la scolarisation et les occasions de socialisation avec leurs pairs sont interrompues (Barrera, Shaw, Speechley, Maunsell, et Pogany, 2005).

Chez les enfants, les traitements pour le cancer engendrent des effets tardifs qui sont des complications découlant spécifiquement des régimes thérapeutiques (Dreyer, Blatt et Bleyer, 2002; Oeffinger et al., 2006). Les complications ou séquelles varient d'intensité allant de légères à sévères, peuvent apparaître chroniquement ainsi que sporadiquement durant les soins ou se développer plusieurs années après la guérison (Dreyer et al., 2002; Robison et Hudson, 2014). Notamment, plus de 60 % des jeunes patients sont particulièrement à risque de souffrir d'au moins une complication physique qui peut affecter soit les systèmes métabolique, pulmonaire, cardiaque ou le développement musculosquelettique (Bhakta et al., 2017; Robison et Hudson, 2014).

De manière similaire, des sous-groupes de jeunes atteints du cancer qui sont plus vulnérables voient leur état psychologique se détériorer face à des sentiments de perte d'estime de soi, d'impuissance et de peur de la mort (Andrykowski, Lykins et Floyd, 2008; Castellano-Tejedor, Perez-Campdepadros, Capdevila et Blasco-Blasco, 2016). Les patients peuvent également ressentir des niveaux cliniques d'anxiété et dépression ou vivre un stress post-traumatique (Brinkman et al., 2016; Patel et al., 2011).

La qualité de vie

L'une des complications principales associées aux thérapies médicales pour traiter le cancer chez les enfants et les adolescents est la détérioration de la qualité de vie liée à la santé (Bhakta et al., 2017; Eiser, 2004). Le concept de qualité de vie liée à la santé fait référence à l'impact subjectif du cancer sur les différentes dimensions de vie de la personne, soit les composantes physique, cognitive, sociale et psychologique (Bottomley, 2002; Martin et Peretti, 2004). La qualité de vie liée à la santé est considérée comme la satisfaction individuelle associée

aux conditions de la santé, avec comme dimensions plus importantes les sphères physique et psychologique (Bottomley, 2002; Martin et Peretti, 2004).

Vetsch et ses collègues (2018) confirment dans une revue systématique sur la qualité de vie liée à la santé en oncologique pédiatrique que les enfants ont une qualité de vie moins bonne que celle de leurs pairs en santé. Face à l'ampleur des séquelles et leurs conséquences sur la qualité de vie des enfants, les guides de pratique cliniques en oncologie pédiatrique stipulent l'importance d'évaluer de manière périodique la qualité de vie liée à la santé (Landier et al., 2004; National Cancer Care Network, 2014).

L'évaluation de la qualité de vie est cruciale pour assurer le suivi clinique des patients. D'abord, elle permet de déceler la présence de détresse, symptômes ou difficultés d'ajustement découlant des traitements (Bandayrel et Johnston, 2014; Movsas, 2003). Également, l'évaluation sert à mesurer l'état global du patient dans une optique de prise de décision clinique optimale (Landier et al., 2004). Aussi, l'évaluation favorise les échanges entre les équipes soignantes et les familles en plus de contribuer au développement d'une alliance thérapeutique (Soulas et Brédart, 2012). Tout autant, l'estimation de la qualité de vie liée à la santé permet de développer des interventions préventives visant à réduire les séquelles négatives des traitements, à augmenter l'ajustement et à développer des interventions spécifiques à la fin des traitements comme des groupes de thérapie ou soutien (Kremer et al., 2013; Zebrack et Chesler, 2002). L'évaluation cible les patients ayant besoin de support additionnel et permet de faire des références vers les services appropriés. Il a été démontré que suite à l'évaluation et l'intervention, les jeunes survivants de cancer s'adaptent plus aisément à la survivance et rapportent un meilleur niveau de qualité de vie liée à la santé (Kazak et al., 2004).

Dans le contexte médical, la qualité de vie liée à la santé de l'enfant est mesurée par le biais de questionnaires autorapportés évaluant la perspective subjective (Davis et al., 2006; Soulas et Brédart, 2012). Toutefois, certaines circonstances, telles que lorsque les enfants sont trop jeunes, fatigués ou ont trop de séquelles pour s'autoévaluer, ne permettent pas l'obtention d'une auto-évaluation précise et valide (Eiser et Morse, 2001; Pickard et Knight 2005). En effet, des complications comme les difficultés neurocognitives et la détresse peuvent influencer la capacité de l'enfant à bien saisir les implications de sa maladie et à reconnaitre les aspects problématiques de manière juste (Mertens et al., 2014). Alors, il est nécessaire d'avoir recours à évaluation par proxy parental, les parents étant considéré comme des observateurs bien informés sur le statut de santé de leur enfant (Pickard et Knight, 2005; Varni, Limbers et Burwinkle, 2007). Lorsqu'une auto-évaluation est possible et disponible, le proxy parental n'est pas conseillé (Varni et al., 2007). En lieu, la méthode multi-informant qui emploie conjointement les évaluations parentales et autorapportées est privilégiée pour dresser le portrait de la qualité de vie liée à la santé de l'enfant (De Los Reyes et Kazak, 2005; Pickard et Knight, 2005). Cette méthode amasse une plus grande quantité de renseignements sur l'enfant (De Los Reyes et Kazak, 2005; Pickard et Knight, 2005).

La méthode multi-informants souligne l'importance d'utiliser plusieurs sources d'informations pour évaluer la qualité de vie liée à la santé de l'enfant. Cependant, cette méthode pose aussi un dilemme puisque les évaluations parentales et autorapportées ne concordent pas. Il apparait donc que les parents et les enfants ne sont pas en accord en ce qui a trait à la description de la qualité de vie liée à la santé de l'enfant. En oncologie pédiatrique, des écarts entre les évaluations des parents et celles des enfants sont fréquemment rapportés, mais les résultats hétérogènes ne laissent pas place à une interprétation globale. Deux procédés statistiques distincts peuvent être employés afin de comparer les évaluations parents-enfants, soit les corrélations ou

les différences de moyennes standardisées (Hirsch, Keller, Albohn-Kuhne, Krones et Donner-Banzhoff, 2011). D'une part, certaines études rapportent des degrés d'associations parents-enfants modérés ou grands (*r* ou ICC > 0.5) en oncologie pédiatrique (Chaudhry et Siddiqui, 2012; Hamidah et al., 2011). D'autre part, certaines études auprès de la même population indiquent des degrés d'accord parents-enfants faibles (*r* ou ICC < 0.3) (Scarpelli et al., 2008; Yeung et al., 2013). De façon analogue, des investigations révèlent que les parents, comparativement aux enfants, surestiment la qualité de vie liée à la santé de leur enfant (Roddenberry et Renk, 2008; Varni, Burwinkle, Katz, Meeske et Dickinson, 2002). À l'inverse, d'autres données empiriques établissent que les parents sous-estiment la qualité de vie de leur enfant atteint de cancer (Kuhlthau et al., 2012; Penn et al., 2009).

Bien qu'elles soient explicitement recensées, peu d'attention scientifique a été accordée à la signification clinique des différences entre les évaluations parentales et autorapportées de la qualité de vie liée à la santé de l'enfant en oncologie. Les modérateurs associés aux différences entre les évaluations parentales et autorapportées de la qualité de vie sont cruciaux, car les différences entre les évaluations sont reliées à de faibles niveaux d'ajustements et des problématiques comportementales et émotionnelles (De Los Reyes, 2011). Ainsi, une meilleure compréhension des modérateurs permettrait d'améliorer les procédés d'évaluation de la qualité de vie liée à la santé, de mieux planifier les traitements et d'assurer des soins de suivi adaptés aux besoins des patients (Eiser & Varni, 2013). Diverses hypothèses modératrices qui expliqueraient les différences sont recensées dans la littérature pédiatrique. Notamment, il est suggéré que les caractéristiques des parents et des enfants, soit l'âge, le sexe et le statut socioéconomique, seraient reliées aux écarts. À ces effets, les jeunes enfants ont un comportement plus facile à observer et tendent à être plus proches de leurs parents que les adolescents (Achenbach et al.,

1987). De même, la communication entre les adolescents et les parents peut diminuer à l'adolescence (Finkenaeur, Frinjs, Engels Rugtget et Kerhoff, 2005). Une autre explication reconnue est que la détresse parentale influencerait la capacité du parent à évaluer la qualité de vie liée à la santé de l'enfant en biaisant négativement l'évaluation (Abate et al., 2018; De Los Reyes et Kazdin, 2005; Krain et Kendall, 2000). Par ailleurs, il est également proposé que les attitudes culturelles, telle que la proximité familiale, influenceraient l'identification des difficultés des enfants au sein des familles (Fung & Lau, 2010). Tous ces facteurs demeurent toutefois peu étudiés en oncologie pédiatrique et n'y sont pas explicités clairement (Cremeens, Eiser et Blades, 2006).

En somme, la variabilité des données disponibles sur les évaluations parentales et autorapportées et les facteurs explicatifs des écarts parents enfants ne permet aucune conclusion quant à l'utilisation clinique des évaluations parents-enfants. L'absence d'un article synthétique à ce sujet dans la littérature en oncologie pédiatrique est un manque important, spécialement en considérant l'importance de la qualité de vie liée à la santé dans la prise en charge médicale des patients. Cela souligne la nécessité de conduire une investigation quantitative systématique approfondie des accords et différences entre les évaluations des parents et des enfants sur la qualité de vie liée à la santé de l'enfant atteint d'un cancer. À notre connaissance, il n'y a pas de revue de littérature ni de méta-analyse qui compare ces évaluations.

L'étude actuelle

La présente étude est une revue de la littérature et méta-analyse systématique qui compare les évaluations parentales et autorapportées sur la qualité de vie liée à la santé de tout au long de la trajectoire du cancer. Cette étude est la première à utiliser la méta-analyse pour synthétiser les écarts parents-enfants sur les domaines global, physique et psychologique de la qualité de vie liée

à la santé. Elle est aussi la première à identifier et à recenser quantitativement les modérateurs des écarts des écarts parents-enfants.

Les objectifs et hypothèses de recherche

L'étude actuelle comporte trois objectifs et hypothèses de recherche principaux. Le premier objectif de cette étude est de déterminer l'ampleur des niveaux d'accord (corrélations) entre les évaluations parentales et autorapportées de la qualité de vie liée à la santé de l'enfant sur les domaines global, physique et psychologique. À des fins d'interprétation, les indices corrélationnels seront considérés faibles lorsqu'inférieurs à 0.40, modérés entre 0.40 et 0.59, bons entre 0.60 et 0.74, et excellents lorsque plus grands que 0.75 (Landis et Koch, 1977). Nous proposons les hypothèses de recherche qui suivent :

1. Les niveaux d'accord entre évaluations parentales et autorapportées pour les domaines global et physique seront modérés. Le niveau d'accord sur le domaine psychologique sera faible.
2. Le niveau d'accord parents-enfants sera plus grand pour les domaines global et physique en comparaison au domaine psychologique.

Le deuxième objectif de cette étude est de déterminer l'ampleur de la taille des différences (tailles d'effets) entre les évaluations parentales et autorapportées de qualité de vie liée à la santé de l'enfant sur les domaines global, physique et psychologique. Afin d'interpréter les différences, les tailles d'effets seront considérées de magnitude faible lorsqu'inférieures ou égales à 0.30, de magnitude moyenne entre 0.40 et 0.70, et de magnitude élevée lorsque supérieures à 0.8 (Cohen, 1988). Nous émettons les hypothèses de recherche suivantes :

1. Les différences entre les évaluations parentales et autorapportées pour les domaines global et physique seront de magnitude moyenne. Les différences pour le domaine psychologique seront de magnitude élevée.
2. La taille des différences entre les évaluations parents-enfants pour les domaines global et physique sera inférieure à la taille des différences pour le domaine psychologique.

Le troisième objectif de cette étude est d'identifier les modérateurs des niveaux d'accord (corrélations) et des différences (tailles d'effets) entre les évaluations parentales et autorapportées de la qualité de vie liée à la santé de l'enfant pour les domaines global, physique et psychologique. Les modérateurs ont été choisis selon leur utilisation dans les études en oncologie pédiatrique et selon des raisons théoriques. Les modérateurs seront examinés au niveau des caractéristiques des participants (statut clinique, âge de l'enfant, culture) et des caractéristiques des études (instrument, cotes de qualité). Nous anticipons ces hypothèses de recherche :

1. Un statut clinique « en traitement » et un âge plus élevé chez l'enfant seront associés à de plus faibles niveaux d'accord parents-enfants et de plus grandes différences parents-enfants.
2. Aucunes hypothèses ne sont envisagées pour la culture, les instruments de mesure et les cotes de qualité étant donné l'absence d'études synthétiques sur le sujet.

Chapitre 2. Article

Parental and children ratings of child overall, physical and psychological health-related quality of life in pediatric oncology: a meta-analysis

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Introduction

Childhood cancer is a life-threatening disorder that seriously alters the child's physical, psychological, cognitive and social health, as well as their family's integrity. Medical advances in the domain of oncology have led to the ability to cure pediatric cancer and in increased survival rates which now range between 80 and 90 % (Phillips & al., 2015; Steliarova-Foucher & al., 2017; Ward, Kohler, & Jemal, 2014). Psychosocial research on pediatric chronic illnesses accentuated a noncategorical approach where similarities in physical symptoms and psychological consequences are clustered rather than the segregated characteristics of particular diagnoses, therefore allowing for comparisons across cancer types (Silva & al., 2019; Stein & Jessop, 1989; Stein & Silver, 1999).

Children undergoing treatment for cancer face pain and procedural distress, in addition to treatment side effects such as nausea and fatigue (Bryant, 2003; Hewitt, Weiner, & Simone, 2003). Moreover, childhood cancer treatments can generate serious complications that appear during hospitalisation or years after the end of treatment (Eiser, 2004). A large percentage of childhood cancer survivors develop physical and psychological sequelae that have negative impacts on their health-related quality of life and that create additional burdens on the health system (Castellano-Tejedor, Perez-Campdepadros, Capdevila, & Blasco-Blasco, 2016; Robison & Hudson, 2014; Zebrack & al., 2004).

The main treatment goal is to improve the adaptive functioning and enhance the quality of life of children with cancer (Knops & al., 2012; National Cancer Care Network, 2014). To achieve complete health care along the cancer trajectory, international guidelines recommend comprehensive assessments and intervention programs (Hjorth & al., 2011; Landier & al., 2004). The primary assessment target in pediatric oncology is health-related quality of life (Landier, Wallace, & Hudson, 2006). Regular assessments of health-related quality of life are essential as

they serve to detect any disturbances occurring in patients due to their disease process or treatment therapy which then allows for appropriate interventions (Soulas & Brédart, 2012; Zebrack & Chesler, 2002).

Health-related quality of life is a multidimensional concept that captures the subjective impression of well-being and distress related to one's health condition (World Health Organization Quality of Life Assessment, 1999). The concept is composed of physical, psychological social and cognitive dimensions (Ferrans, Zerwic, Wilbur & Larson, 2005). While the most frequently reported dimension is the physical one, it is recognized that the psychological domain is equally important in children and adolescent health-related quality of life (Bottomley, 2002; Vetsch & al., 2018; Wallander & Varni, 1999). Across the cancer trajectory, children's health-related quality of life finds itself compromised.

The most frequent form of systematic assessment of health-related quality of life is conducted by using self-report (Davis & al., 2006). Self-report in pediatric patients may prove difficult to obtain or deemed unreliable. This is particularly the case when children are too young, tired or present many cancer sequelae (De Los Reyes & Kazdin, 2005; Eiser & Morse, 2001; Pickard & Knight, 2005). Specifically, children undergoing cancer treatment or survivors can develop neurocognitive difficulties that impair the accuracy of their self-reports (Abate & al., 2018). Moreover, common side effects in survivors like fatigue, executive function deficits and concentration difficulties can impact negatively the skills necessary to form an accurate report of the self and to realistically judge the implications of the disease (Butler & Haser, 2006; Jacola & &., 2016; Mertens & al., 2014).

In such cases, common practice is to refer to the perspective of another information like a parent or medical professional (Pickard & Knight, 2005). In paediatrics, parents are considered

observers of their children and are therefore likely to be well informed about them (Pickard & Knight, 2005). Under these conditions, the use of a parental proxy is recommended (Varni, Limbers, & Burwinkle, 2007). However, proxy is generally not recommended as a substitute for child assessment when the child is able to do a self-assessment (Varni & al., 2007). In this case, the multi-informant method is preferred (Pickard & Knight, 2005). Both parent and child assessments are used to paint a picture of the child's quality of life (De Los Reyes & Kazak, 2005; De Los Reyes & Kazdin, 2004). This is used to gather more information about the child and to better identify his or her issues (De Los Reyes & Kazak, 2005; De Los Reyes & Kazdin, 2004; Pickard & Knight, 2005).

The multi-informant method refers to the importance of using the different sources of information together. However, the literature has repeatedly demonstrated the existence of discrepancies between parent and child assessments. Individual studies in pediatric oncology examining parent-child agreement have found conflicting patterns of results. Interrater agreement on specific quality of life domains between parent and child assessments is consistently documented, but the results are heterogeneous and difficult to interpret. For example, some studies report moderate to high correlations (r or CCI > 0.5) between parents and children on the overall quality of life of children with cancer (Chaudhry & Siddiqui, 2012; Hamidah & al., 2011; Scarpelli & al., 2008; Yeung & al., 2013). However, other studies with the same population indicate that parent-child agreement on quality of life is low (r or CCI < 0.4) (Banks, Barrowman, & Klaassen, 2008; De Bolle, De Clercq, De Fruyt, & Benoit, 2008) (De Clercq, De Fruyt, Koot, & Benoit, 2004; Hinds & al., 2009; Matziou & al., 2008).

Similarly, when discrepancies between parents' and children's reports about health-related quality of life have been investigated, many studies show that parents, compared to their child with

cancer, overestimate their child's quality of life (Hamidah & al., 2011; Roddenberry & Renk, 2008; Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002). However, some studies have found that parents underestimate their child's quality of life (Kuhlthau & al., 2012; Norris, Moules, Pelletier, & Culos-Reed, 2010; Penn & al., 2009).

Rating differences between informants have been considered in different ways. It has been suggested that these differences may be related to methodology (Eiser & Morse, 2001). Also, variables proper to the participants or the study can impact agreement and have different moderating utilities. Accordingly, an emphasis on factors that explain gaps between raters has been stressed (Cremeens, Eiser, & Blades, 2006b). Studies examining interrater agreement have suggested that child's age, child and parent's sex, socio-economic status, parental distress and culture were explanatory factors (Abate & al., 2018; Achenbach, McConaughy, & Howell, 1987; D'Agostino & Zebrack, 2011; De Los Reyes & Kazdin, 2006; Felder-Puig & al., 2004; Fung & Lau, 2010; Upton, Lawford, & Eiser, 2008). In addition, it is suggested that health-related quality of life dimension is associated with the parent-child gap. Literature reviews on child quality of life have confirmed the presence of greater parent-child agreement ($r > 0.5$) in the physical domain and weaker agreement in the psychological domain ($r < 0.3$) (Eiser & Morse, 2001; Upton & al., 2008). Yet, these factors remain poorly studied in pediatric oncology and, in addition, have not been clearly identified by empirical evidence (Cremeens, Eiser, & Blades, 2006a). The relation of these variables with the prominent dimensions of health-related quality of life underscores the importance of obtaining as accurate a measure as possible and identifying factors associated with divergent reports by parents and children.

Present study

To our knowledge, there is no meta-analysis comparing parent and child assessments of quality of life of children across the cancer trajectory. Given the importance of quality of life assessment in childhood cancer management, the absence of a review article constitutes a significant gap in the literature. Indeed, the variability of available data does not allow any conclusions to be drawn, such an investigation would then make it possible to set clinical standards of agreement and be clinically knowledgeable about the factors associated with agreement between parents and children. A review article could help improve the procedures for evaluating the quality of life of children with cancer and consequently ensure appropriate follow-up care by leading to better detection of the patient's condition and a more accurate interpretation of the differences between parental and self-reported quality of life assessments.

The main objectives of the current meta-analysis were to : 1) determine overall effect sizes (correlations) for agreement between child and parent ratings on the three main domains of health-related quality of life : Overall, Physical, Psychological ; 2) estimate the overall effect sizes (mean differences) for difference in child and parent ratings on the three domains; and 3) to explore possible moderators of child-parent agreement and differences on each of the three domains. Moderators are examined both at the participant level (clinical status, children age, culture) and at the study level (instrument, quality ratings). They were selected based on their use in individual oncology studies of parent-child agreement and discrepancies about child health-related quality of life and for theoretical reasons.

Methods

Overview

The Preferred Reported Items for Systematic reviews and Meta-Analysis (PRISMA) statement was used to conduct our study (Supplemental Material 1) (PRISMA, 2015). The meta-analysis was also performed according to the following PICO question: Population – children under 19 years old diagnosed with cancer; Intervention – treated for cancer (in treatment, in remission or survivors); Comparison - self-report versus parental report on child's status; Outcomes - overall health-related quality of life, physical quality of life and psychological quality of life (Liberati & al., 2019). The study was also listed and described on PROSPERO, the prospective international systematic reviews registry (number CRD42016026672) on January 12th 2016 before being conducted.

Search Strategy

The search strategy, available in supplementary material (Supplemental Material 2), of databases PubMed (NLM), Ovid Medline, Ovid All EBM Reviews, Ovid Embase, Ovid PsychINFO and EBSCO CINAHL was elaborated by the authors and a librarian of Sainte-Justine University Health Center. The following keyword domain search terms were used: "quality of life", "cancer", "pediatric" and "parent" (see Supplemental Material 2). The bibliographic search was modelled after the approach of systematic bibliographic research. Reference lists of the selected studies were revised in the event of identifying additional eligible texts. Further, researchers of the Pediatric Psychology Society (APA div 54) were contacted to retrieve unpublished texts or documents (case studies, pilot studies, theses, etc.) on the subject in order to collect the grey literature.

Inclusion Criteria

Articles were eligible for the meta-analysis if they met specific criteria for types of studies, participants, comparisons, statistical procedures, outcomes and instruments. Solely quantitative studies written in English were considered for inclusion. Eligibility criteria for participants were samples of children under the age of 19 who were being or had been treated for a pediatric cancer. Survivors of childhood cancer under the age of 19 were included based on the definition of each study. Children could be at any stage of the cancer diagnosis. Included cancer diagnoses were defined as any types of cancers, ranging from the most commons such as leukemia and brain and central nervous system tumors to lymphomas and other forms of the disease. Samples with participants aged 19 and over were excluded because of differences in treatment and follow-up care procedures and because parental proxy implies child custody and a proximity in delivery of care. The outcomes needed to target any of the three main dimensions of the health-related quality of life concept: overall quality of life, physical quality of life and psychological quality of life (Martin & Peretti, 2004). All eligible studies had to utilize a reliable and valid instrument to evaluate health-related quality of life and yield a quantitative score on the dimensions considered. The instrument needed to be administered to both child and at least one parent. Parents were defined as the main caregiver of the child at the time of the assessment, whether a mother, father or another important figure in the children's lives. To ensure the presence of parent-child comparisons in the eligible articles, titles, abstracts or study objectives needed to report a direct comparison between child and parent evaluations. We included studies reporting data on either on agreement or association (r) or differences (g) between the children and parents' evaluation given that effect sizes are analyzed separately. Studies had to report enough data for the calculation of (r) or (g) to be permitted.

Study Selection

Following the search in February 2019, articles were imported into the EndNote X8 bibliographic software (see Flowchart in Figure 1). Duplicates were removed and two independent reviewers (CA and ED) verified the titles and summaries of all references to account for their relevance. Full texts of potentially eligible studies were obtained and read to establish their eligibility. Reviewers then compared their selection process to identify dissimilarities. Any dissimilarities were resolved through verification and discussion.

The search strategy identified 3 089 articles (Figure 1). Of those, 1 947 (63 %) were excluded based on the title and abstract. Of the resulting 1 145 (37 %) full texts assessed for eligibility, 419 (36.6 %) did not meet participants inclusion criteria, 578 (50.5 %) did not compare parent and children ratings, 67 (5.6 %) did not measure health-related quality of life and 64 (5.6 %) were excluded because they were case reports, reviews, dissertations, abstracts, posters or books. In final, the sample for this meta-analysis comprised 20 articles (1.7 %).

The number of independent effect sizes examining parental and child agreement and varied with the domain of health-related quality of life examined. Fewer studies reported agreement for overall health-related quality of life while many studies reported agreement for physical and psychological quality of life (Figure 1).

As shown in Figure 1, it is apparent that the numbers of study effect sizes varied greatly: fewer studies reported on discrepancies for the overall domain of health-related quality of life, whereas more studies reported on discrepancies between parental and child ratings for psychological and physical health-related quality of life.

Data collection

Two authors (CA and AH) extracted data from the articles into an extraction spreadsheet inspired from the Template for Cochrane Reviews (Cochrane Consumers & Communication Review Group, 2016). Both extraction forms were compared in order to ascertain the accuracy of the data collection. If the information was discordant, the authors clarified the extracted data by returning to the original article. The following data was extracted for every article: authors; year of publication; type of study; methods, study design, procedures, eligibility criteria; participants, characteristics, number of included participants, response rates; instruments used; and outcomes, quantitative results for the child and parent groups. In case summary quantitative results were not available to yield estimates of association or difference for the entire sample, we converted descriptive data into the desirable format by using the pooled correlations, means and standard deviations (Higgins, Thompson, Deeks, & Altman, 2003; Silva & al., 2019).

Some studies used the same groups of participants several times, in which case they were counted as one group for analysis and the first time point available was selected to compute estimates. In instances when some statistical data were missing and the desirable format could not be computed, the corresponding author was contacted by email (Figure 1).

Quality Assessment

All included studies were assessed to identify risk of bias and methodological quality. Two independent evaluators (AH and CB) performed these assessments using the STROBE checklist for observational cross-sectional studies (Supplemental Material 3). They received an informative document on the checklist. They were trained and supervised by the lead author to discuss the process. Items from the checklist were coded from the title and abstract, the introduction, the

methods, results, discussion and other supplementary information. Studies were given up to 22 points based on the presence or absence of each item. Studies obtaining 0-7 points were classified as "low quality", those with 8-14 as "average", and those with 15-22 as "high". Reviewers compared their assessments of the quality of the articles and the differences were resolved by returning to the original articles and reaching a consensus.

Statistical Analyses

All analyses were performed with the software Comprehensive Meta-Analysis, Version 3. Six separate meta-analyses were conducted [3 quality of life outcomes (overall, physical, psychological) x 2 indices of agreement (correlations, mean differences)]. The number of studies included in each meta-analysis, presented in the flow chart (Figure 1), varied according to the information available. For studies reporting a correlation between child and parent, a weighted combined correlation was calculated. We transformed the correlations of each study in Fisher's z-value according to the method of Hedge and Olkin (1985). Effect size < 0.40 indicated poor agreement, between 0.40-0.59 fair agreement, between 0.60-0.74 good agreement and ≥ 0.75 excellent agreement (Landis & Koch, 1977). For studies reporting mean differences between groups of children and their parents, we calculated the aggregated size of the differences with a combined weighted effect size (Hedge's *g*). To obtain the Hedge's g, we used the means and standard deviations. The means of the parental proxy were subtracted from the means of child self-reports. A negative effect size indicated that parents reported a higher quality of life than children. The absolute value of Hedge's *g* was also examined for cases where the child-parent differences were not statistically significant. This allowed specifying if children and parents did exhibit significant evaluations but a difference of zero was achieved due to a lack of consistency in reports.

Effect sizes of values < 0.3 correspond to small differences in sizes, between 0.3 and 0.5 to medium differences in size and > 0.6 to large differences (Fritz, Morris, & Richler, 2012).

The random allocation model was used for the meta-analyses (Cooper & al., 2009). It assumes that studies are not equivalent to one another because of variance and possible sampling errors (Cooper, Hedge, & Valentine, 2009). The use of this model suggests that there are variations in the effect sizes of the studies (Hedge & Olkin, 1985). Consequently, we tested the presence of heterogeneity between studies using the Q statistic with a statistical significance threshold of $p<0.10$ (Cooper & al., 2009, International University of the North Carolina Evidence-based Practice Center, 2010). For more information on the level of heterogeneity present, we also used the I^2 statistic (Cooper et al., 2009). We interpreted it in the manner of Higgins et al. (2003) who suggested that an I^2 of 25% is low heterogeneity, and levels of 50% and 75% correspond respectively to moderate and high heterogeneity (Higgins et al., 2003). In addition, we calculated the confidence (95% CI) intervals of the aggregated estimates. Confidence intervals accurately identified the extent of results (IntHout, Ioannidis, Rovers, & Goeman, 2016).

Moderators of the parent-child agreement were investigated through categorical testing with mixed effects (Borenstein, Higgins & Rothstein, 2009). The objective was to investigate the relationship between moderating variables and the combined estimates for the outcomes considered. Informant characteristics (clinical status, children age, culture) were the moderators selected based on their use in included studies in addition to study characteristics (instrument, quality ratings of studies). To ensure that the necessary power was reached to detect significant differences between variables, we performed moderator analyses only when at least four studies reported the actual moderator variables.

We also measured publication bias using the Fail-Safe *N* method (Cooper & al., 2009; Rosenthal, 1991). Results were interpreted according to Rosenthal (1991) who suggested that the Fail-safe *N* needed to be bigger than $5k + 10$ where *k* represents the number of studies included in analyses.

Results

Study sample and characteristics

Summaries of the 20 included studies are presented in Table 1. The demographic characteristics of the studies are available in Table 2. The reviewed studies comprised 2 093 children aged 2 to 18 years old and 2 108 parents. Eleven studies involved both mothers and fathers (11/20, 55%) and the others (9/20, 45%) did not report parental sex (Table 2). All disease groups of children were mixed cancer and tumors.

Short than half the studies (9/20, 45%) gave estimates for the three aspects: physical, psychological and overall HRQoL. Three articles (3/20, 15%) only reported overall health-related quality of life estimates and only one study solely reported physical health-related quality of life (1/20, 5%) (Table 1). Seven studies (7/20, 35%) provided estimates for the physical and psychological domains (Table 1).

A large portion of the included studies originated from American-European countries (16/20, 80%) and the others from Asian ones (4/20, 20%) (Table 2). Five studies (5/20, 25%) recruited children while they were receiving treatment for cancer, nineteen studies (11/20, 55%) included mixed samples during and after cancer treatment and twelve studies (4/20, 20%) studied included only survivors of childhood cancer (Table 1).

The most frequently used instrument to evaluate health-related quality of life was the PedsQL^{TM} (10/20, 50%) (Varni, Seid & Kurtin, 2001). Five studies utilized the Child Health Questionnaire (CHQ) (5/20, 25%) (Landgraf, Abetz & Ware, 1996) and two the Quality of Life for Cancer Children (QLCC) (2/20, 10%) (Yeh, Hung & Chao, 2004) (Table 1). The remaining studies used the Kidscreen-52 (1/20, 5%) (Ravens-SIeberer, Gosch, Rajmil, DIpl, Bruil & al., 2008) the Pediatric Oncology Quality of Life Scale (POQOLS) (1/20, 5%) (Goodwin, Bogss & Graham-Pole, 1994) and the Pediatric Functional Assessment of Cancer Therapy (PedsFAct) (Yoo, K, Cella, Shin & Ra, 2011) (1/20, 5%) (Table 1). These instruments are composed of parental and children versions. Both include likert scaled questions assessing frequency of physical, emotional, social and cognitive functioning with items such as "Has your child been limited in doing things that take a lot of energy like riding a bike or running?" (CHQ) or "I worry about what will happen." (PedsQL^{TM}). Instruments also measure worry, communication, schooling and daily activities.

Quality Assessment

The detailed description of the quality assessment by presence or absence of criteria of the included studies is available in Supplemental Table 1. In the final quality categorization, five studies received a low rating (25 %), seven an average quality rating (35%) and eight a high quality rating (40%) (Supplemental Table 2). As shown in Figure 2, the explanations for average and lower quality ratings were situated mostly in the methods and results sections. Indeed, the main reasons for these ratings were no description of efforts to address lack of bias, limited or no reporting of descriptive data such as parents' demographic information and no explanation on how missing data was managed.

Agreement of parental and children ratings of child health-related quality of life

Mean composite effect size (r)

Forest plots presenting the computation of mean weighted *r* effect sizes for parent-child agreement on ratings of overall, physical and psychological health-related quality of life are displayed in Figure 3 showing that effect sizes ranged from 0.14 to 0.86 across studies and health-related quality of life domains. We computed *r* weighted effect sizes of 0.65 (good), 0.64 (good) and 0.55 (fair) for the overall, physical and psychological domains respectively.

Moderators of agreement for overall health-related quality of life (r)

The sum model for agreement about overall quality of life was explored to determine the homogeneity of effect sizes in the samples. We found that parent-child effect sizes, QT (df = 9) = 46.50, $p < .001$, were heterogeneous. Thus, we used categorical model testing to examine if the potential moderator categories could account for variations in the magnitude of effect sizes. All the results from the categorical model testing for overall quality of life are presented in Table 3.

When exploring the heterogeneity across studies, we found significant factors associated with levels of parent-child agreement from between-class effects (see Table 3 a for detailed account of moderators). Specifically, parent-child agreement was higher for dyads where self-report was performed by children aged 5 to 12 in comparison to dyads using self-reports of adolescents aged 13 to 18 years old. Further, the mean parent-child agreement for overall health-related quality of life was significantly lower for the PedsQL^{TM} than for other instruments. We were unable to assess whether the same pattern held for CHQ, Kidscreen-52, and PedsFACT, due to a lack of power because no effect sizes were available for these instruments. Moreover, parent-child agreement for overall health-related quality of life differed according to the quality assessment of the included

studies. Studies with low or average quality ratings had significantly smaller levels of parent-child agreement. Additionally, dyads with families living in American-European cultures we more likely to detect significant smaller parent-child agreement levels on the overall dimension than dyads of families living in Asian cultures (z= -6.19, $p < 0.05$). Similarly, parent-child agreement was more likely to be smaller in the "mixed samples" category, that is studies with samples of participants composed of children in-treatment and survivors of childhood cancer. Parent-child agreement was also more likely to be larger for samples constituted only of survivors (z= 4.72, p<0.001).

Moderators of agreement for physical health-related quality of life (r)

The overall model for agreement about physical quality of life of children along the cancer continuum was examined to identify the homogeneity of the sample's effect sizes. We determined that parent-child effect sizes were not homogeneous as QT (df = 13) = 170.10, $p < .001$. Consequently, categorical model testing permitted the exploration of the potential moderator categories that could explain variations in effect sizes' magnitudes. Physical health quality of life results from the categorical model testing are presented in Table 4. There were no significant differences between parents and children in the agreement between ratings on physical quality of life across age of self-report.

The examination of between-class effects to explore the homogeneity yielded significant differences in parent-child agreement for physical health-related of life (see Table 4 for a detailed account of moderators). More particularly, agreement levels between parents and children were more likely lower for studies using the PedsQL^{TM} in comparison to other instruments. It was not possible to measure if a similar pattern held true for POQOLS, Kidscreen-52, and PedsFACT, given they had no effect sizes thus no power. Also, studies with low and average quality ratings had lower levels of parent-child agreement than studies with high quality ratings (z = 4.88, $p <$

0.001). Furthermore, higher agreement between parent and children were found in studies where families lived in Asian countries versus for families living in American-European countries *(z* = 4.27 , $p < 0.05$). Plus, a clinical status in which children were currently receiving treatment for childhood cancer was associated with stronger parent-child agreement levels on physical health-related quality of life (survivors: $z = 6.31$, $p < 0.001$; mixed: $z = 6.02$, $p < 0.001$).

Moderators of agreement for psychological health-related quality of life (r)

The overall model for agreement about psychological health-related quality of life was explored to determine the heterogeneity of effect sizes in the samples. We established that parent-child effect sizes, QT (df = 13) = 126.15, $p < .001$, were heterogeneous. Therefore, we used categorical model testing to examine the possible categories of moderators that could account for variations in the magnitude of effect sizes. Table 5 presents the results of the testing for psychological health-related quality of life.

Our analysis of heterogeneity with between-class effects demonstrated significant differences in parental and children agreement between studies for the psychological domain (see Table 5 for a detailed account of moderators). We showed that parent-child agreement was higher for study samples of younger children in contrast to study samples of adolescents. Also, parent-child agreement was significantly higher for the PedsQL^{TM} compared to other instruments. We were unable to assess if the same pattern held for POQOLS, Kidscreen-52, and PedsFACT since no effect sizes and power were available for these instruments. Alike, higher agreement levels were found for studies with children currently in treatment for childhood cancer while lower agreement levels were found for studies with survivors ($z = 6.01$, $p < 0.001$) and mixed treatment category samples ($z = 9.75$, $p < 0.001$).

Discrepancies between parental and child ratings of child health-related quality of life

Mean composite effect sizes (g)

The results of the computation of the mean weighted *g* effect sizes for parental and child ratings of overall physical and psychological health-related quality of life are shown in Figure 4. Individual effect sizes (*g)* for discrepancies between parental and child ratings ranged from 0.02 to 1.89 across individual studies.

When combining studies on the overall quality of life, the weighted *g* domain was not significant ($g = 0.26$, $p < 0.07$). We found higher discrepancies between parental and children ratings of physical health-related quality of life ($g = 0.22$, 95 %, CI 0.05 to 0.39) and of psychological health-related quality of life ($g = 0.50$, 95 %, CI 0.01 to 0.99). The physical and psychological domain's mean weighted combined effect sizes were respectively classified as small and medium differences in parental and children ratings.

Moderators of discrepancies in ratings of overall health-related quality of life (Hedge's g)

We explored the sum model for discrepancies about overall quality of life to determine the homogeneity of effect sizes in the samples. We found that parent-child effect sizes, Qt (df=15) = 331.83, $p < 0.001$, were heterogeneous. Thus, we used categorical model testing to examine if the potential moderator categories could account for variations in the magnitude of effect sizes. Results of the categorical model testing for overall quality of life are presented in Table 3. There were no significant differences between parental and children ratings according to child age.

When exploring heterogeneity across studies, we found significant factors associated with levels of parent-child discrepancies from between-class effects (see Table 3 a for detailed account of moderators). Precisely, discrepancies between parents and children were significantly lower on

the PedsQL™ than on other instruments. No similar assessments were performed for CHQ, Kidscreen-52, and POQOLS since effect sizes were not available for these instruments and analyses could not be powered. Further, parents tended to evaluate the overall domain as worse in studies of low and average quality in comparison to studies of high quality ($z = 13.36$, $p < 0.001$). More, parent-child dyads in Asian cultures were more likely to report smaller discrepancies compared to dyads from American-European cultures. This finding implied that while all parents considered their child to have worse overall health-related quality of life, parents from American-European cultures considered their child's health-related quality of life to be lower. In addition, bigger parent-child discrepancies were noted for studies comprised only of childhood cancer survivors suggesting that parent reported lower scores for survivors. Post hoc contrast exposed that mean differences in sizes were greater for the "survivors" category as compared to the "mixed" category ($z = 20.34$, $p < 0.001$), but not significantly different than for the "in treatment" category ($z = 1.26$, NS).

Moderators of discrepancies in ratings of physical health-related quality of life (Hedge's g)

The overall model for discrepancies about physical quality of life of children along the cancer continuum was examined to identify the homogeneity of the sample's effect sizes. It was determined that parent-child effect sizes were not homogeneous as Qt (df=15) = 331.83, $p < 0.001$. Consequently, categorical model testing permitted the exploration of the potential moderator categories that could explain variations effect sizes' magnitudes. Physical health-related quality of life results from the categorical model testing are presented in Table 4. No significant differences in parent-child discrepancies were found across instruments.

By examining between-class effects to explore the homogeneity, we noted significant differences in parent-child agreement for physical health-related of life (see Table 4 for a detailed

account of moderators). Precisely, discrepancies between parents and children were higher for children aged 5 to 12 years old in comparison to adolescents aged from 13 to 18 years old. This suggests that parents tend to rate overall health-related quality of life at a lower level for children than when rating overall health-related quality of life for adolescents. Also, studies with low and average ratings tended to yield lower discrepancies compared to studies with high quality ratings that tend to yield higher discrepancies between parental and children evaluations ($z = 6.91$, $p < 0.001$). In a similar manner, studies originating from American-European countries found more discrepancies between parental and children ratings compared to studies from Asian countries. To add, higher parent-child discrepancies appeared in studies with children receiving treatment for childhood to cancer compared to studies with mixed samples of children ($z = 20.05$, $p < 0.001$).

Moderators of discrepancies in ratings of psychological health-related quality of life (Hedge's g)

The overall model for discrepancies about psychological health-related quality of life was explored to determine the heterogeneity of effect sizes in the samples. It was found that parent-child effect sizes, QT (df = 14) = 685.51, $p < .001$, were heterogeneous. Therefore, categorical model testing was used to examine the possible categories of moderators that could account for variations in the magnitude of effect sizes. Table 5 presents the results of the testing for psychological health-related quality of life. Discrepancies between parental and children ratings did not differ between studies according to the child's age.

Our analysis of heterogeneity with between-class effects demonstrated significant differences in parental and children agreement between studies for the psychological domain (see Table 5 for a detailed account of moderators). We found that parent-child discrepancies were higher for the PedsQL^{TM} compared to other instruments. We were unable to assess whether the same

pattern held for POQOLS, because a lack of power due to the absence of effect sizes for this instrument. Besides, higher discrepancies between parental and children ratings were noted for studies with low or average quality assessments. This suggests that parents rated their child's psychological health-related quality of life as worse when studies had poorer quality assessments. Likewise, parent and child dyads in American-European countries were more likely to report higher discrepancies as compared to dyads in Asian countries. Such a finding indicated that parents in the "American-European" category evaluated their child's quality of life as lesser. Additionally, higher parent-child differences were found for studies composed of children receiving treatment for cancer.

Discussion

In our quantitative review, 20 included studies reported parental and children ratings of one or more dimensions of child health-related quality of life. This review is the first meta-analysis comparing interrater studies in pediatric oncology. Separate meta-analyses (*r* and Hedge's *g*) were calculated for the main health-related quality of life dimensions (Overall, Physical and Psychological). As a central contribution, we ascertained fair to good levels of parent-child agreement and low to moderate differences between parental and children ratings. We found parental ratings of child health-related quality of life to be somewhat lower than children self-reports. These levels of agreement and discrepancies between parents and children on health-related quality of life are consistent with past reviews and meta-analysis of parent-child dyads on clinical conditions (Achenbach & al., 1987; De Los Reyes & Kazak, 2005).

Large heterogeneity in all types of analyses within the pool of studies also yielded evocative patterns. Categorical testing of potential moderators for both effect sizes was also performed to examine associations between parental and children ratings. Two classes of moderators found

significant differences: informant characteristics (child age, clinical status, culture) and study characteristics (instruments and quality ratings).

Parents and children agreement on ratings of child health-related quality of life

In regards to agreement on ratings of all three domains of health-related quality of life, parent-child dyads showed similar perspectives with levels of agreement ranging from moderate to high. Nonetheless, parents and children were more likely to have higher levels of agreement on the overall and physical domains of health-related quality of life than on the psychological domain. It is possible that the higher agreement levels obtained on the overall health-related quality of life can be accounted for by a reduction in measurement error due to the larger number of scale items included in scoring the domain.

Our findings are similar to those reported by other meta-analytic studies comparing parents and children ratings on clinical conditions, such as the ones conducted by Achenbach & al. (1987) and De Los Reyes & al. (2005). As well, in those studies, levels of parent-child agreement differed according to the nature of the characteristic examined. Indeed, higher agreement is usually found when characteristics are observable or external. It may be due, in part, to the differences in how visible one construct is while the other is less observable (Eiser & Morse, 2001). The overall domain of health-related quality of life encompasses all constructs, the physical domain emphasizes discernable physical symptoms and the psychological domain highlights less perceptible, more internalized, signs like fear and distress. It may also be that agreement differs not by the construct but according to the importance of the domain relative to the stage of the cancer trajectory (Upton & al., 2008; Varni & al., 2003). For example, physical health-related quality of life is vital at the beginning of the cancer trajectory, when the child is first receiving cancer

treatment. Therefore, parent-child agreement may be higher for the physical aspect as a result of a higher focus put on this dimension in the context of cancer.

Notably, the moderate and high levels of dyadic agreement found in our study are higher than those obtained in similar meta-analyses of agreement on clinical conditions (Achenbach & al., 1987; De Los Reyes & Kazak, 2005). Greater agreement in pediatric illness was commonly reported relative to controlled norms with greater agreement between parent and children being attributed to the necessity of having enhanced communication for health and intervention purposes (Graham, Stevenson, & Flynn, 1997; Theunissen & al., 1998; Walker & Heflinger, 1998).

Parents and children discrepancies on ratings of child health-related quality of life

As regards to discrepancies on ratings of health-related quality of life, parent-child dyads presented low to moderate differences in sizes. When calculated with a discrepancy effect size, results of the present meta-analysis varied across domains of health-related quality of life. For overall health-related quality of life, the directional difference in size between parent and children was not significant. Considerable variability across studies (broad confidence intervals for most individual studies) insinuated that studies could have cancelled each other out in the calculation of an aggregated weighted mean. Due to high across study variability, no significant pattern emerged regarding whether one informant overreported or underreported relative to the other for overall health-related quality of life.

Concerning physical health-related quality of life, the finding of small parent-child discrepancy indicated that parents report lower levels of child physical health-related quality of life as compared to children. The same pattern was noted for parent-child discrepancies on psychological health-related quality of life, with a moderate difference in size. Our results are

consistent with past studies that have consistently found less favourable reports or more concerned renderings of children functional limitations and psychological status by parents evaluation (Achenbach & al., 1987; De Los Reyes & Kazdin, 2005; Duhig, Renk, Epstein, & Phares, 2000). This pattern may be due to parents overreporting the difficulties of their children. One possible explanation is that parents hold strong beliefs about the impact of cancer (Kazak & al., 2004; McCubbin, Balling, Possin, Frierdich, & Bryne, 2002). As parents vary in sensitivity and tolerance to their children's health concern, the amount of knowledge they possess and share, as well as and the nature of their beliefs about cancer, leads them to view more negative consequences on the child's status in comparison to other raters (Kazak & al., 2004; Kazak & al., 1998). Another plausible explanation is that parents' own levels of distress favour the reporting of lower child quality of life (Abate & al., 2018; Krain & Kendall, 2000; Richters, 1992). The literature repeatedly highlighted that parents of children with cancer present higher levels of psychological distress, depression and anxiety and constant fear of recurrence, even years after the end of treatment, which can bias parental ratings of their child (Ljungman & al., 2015; Sultan & al. 2015; Vrijmoet-Wiersma & al., 2008).

Regarding the notable discrepancies between parental and child ratings on the physical and psychological domains of health-related quality, another way to interpret the results is that it is children who underestimate or underreport their quality of life in contrast to parents. On the one hand, the "response shift" states that children may misjudge their limitations and symptoms believing that they are an undeniable and normative part of their cancer experience and may not fully understand cancer repercussions. As time passes, children perceive their conditions to reflect normative health-related quality of life (Adler, 2008; Sprangers & Schwartz, 2008). On the other hand, children also tend to evaluate their symptoms in favourable light or to deny their existence

and importance, a phenomenon understood as a desire for children to return to normalcy (Miedema, Hamilton, & Easley, 2007; Woodgate, 2006). Children striving to go back to their old life or to resembles their healthy peers could explain why they rate their health-related quality of life more favourably than their parents. This phenomenon may also reflect the self-serving bias which suggests that individuals have favourable perceptions of themselves or overestimate their abilities (Myers, 2010).

The forest plots expressed heterogeneity and pictured that some studies do not find the pattern of parents rating worse child health-related quality of life. Instead, few studies steadily conveyed that parents reported better evaluation of their child's overall, physical and psychological health-related quality of life than the children reported themselves. An explanation is that children can sometimes try to shield their parents by keeping important and distressing information from them, leading parents to report better their health-related quality of life (Metcalfe, Coad, Plumridge, Gill, & Farndon, 2008).

Consistent with the observation made on agreement levels, we found that discrepancies were larger in the psychological than the physical domain (Achenbach & al., 1987; Duhig & al., 2000; Korelitz & Garber, 2016).

Moderators of parent-child agreement and discrepancies

Categorical subgroup analyses showed that instrument, quality ratings of studies, country, children's age at self-report and clinical status were moderators explaining heterogeneity across studies. The results differed depending on the health-related quality of life domain being measured and on the method used to examine agreement and discrepancies (*r* or Hedge's *g*).

Culture

The most robust moderator across all dimensions of health-related quality of life was culture. Our findings highlight that parent-child agreement was stronger and that fewer discrepancies between ratings were reported for Asian cultures while levels of agreement were lower and that more dyadic discrepancies were reported for American-European cultures. This indicated that the pattern of agreement and discrepancy varied according to the culture but it is also plausible that socioeconomic status or ethnicity rather than culture accounted for these relations. It should be considered that this effect was noted in mixed samples in which culture was inferred based on the geographical location. It could also be that participants identify with another culture. The cancer experience may be moulded by the cultural disparities in family functioning, socialization and attitudes contributing to perceiving and evaluating health-related quality of life differently (Eiser & Morse, 2001). The child's capability to assimilate the social and cultural norms transmitted by parents can support or hinder their quality of life evaluation (Eiser & Morse, 2001). Some studies have found that Asian parents tend to be stricter, less warn and more orientated towards collectivism and interdependence, and that American-European parents tend to be lenient, warmer and focus on individualistic and independent orientations (Kim & Wong, 2002; Mousavi, Low, & Hashim, 2016). In light of these results, specific attention should be given to the cultural distribution of each sample, regardless of country of origin, to determine the disparity in ratings that could be accounted for by this moderator. In this regard, familial and cultural factors proved to be relevant but have only been assessed in the minority of studies included in our sample. Similarly, Vestch (2018) stressed the need to include moderators similar in nature to be further tested in prospective studies.

Clinical Status

Another important moderator across health-related quality of life dimensions and method was the child's clinical status. Levels of agreement between parental and children ratings on the physical and psychological domain was higher for studies composed solely of children actively receiving treatment for childhood cancer. Larger parent-child discrepancies were noted for survivors of childhood cancer for all three domains of health-related quality of life and psychological domain. Clinical status is closely related to the child's health status, that is when children are on treatment, their condition is more labile and necessitates close monitoring. The necessity to closely pay attention to the child's health-related quality of life during treatment may explain why agreement is higher at that stage of the cancer diagnosis (Adler, 2008). In opposite, children off-treatment and survivors have stable and chronic health-condition that are only monitored punctually (Landier, 2006). Possibly, less attention is devoted to the monitoring of their health-related quality of life by parents. Such mechanisms suggest that parent-child agreement and discrepancies are related to child symptoms at different stages of treatment and therefore stress the need to clearly define the study participants' cancer trajectory.

Children Age at Self-report

There was significantly higher parent-child agreement regarding overall and psychological health-related quality of life for younger children and lower agreement for adolescents, a finding consistent with Achenbach's (1987) meta-analysis. Health-related quality of life of younger children may be most easily observable as parents spend knowingly more time with younger children providing opportunities to gather more information on their status (Dishion & McMahon, 1998; Dubas & Gerris, 2002). In parallel, information on adolescent health-related quality of life may be harder to acquire as parent-adolescent relationships are characterized by strained

communication which can be further disrupted by uncertainty about the future, lack of autonomy and increased parental dependency (Ehrlich, Richards, Lejuez & Cassidy, 2016; Habermas & Bluck, 2000; Van Dijk & al., 2014; Finkenaeur, Frinjs, Rugtget & Kerhoff, 2005; Phillips-Salimi, Robb, Dossey & Haase, 2014). Noteworthy, there were higher parent-child discrepancies regarding physical health-related quality of life in younger children, suggesting that parent report worse physical limitations than the young child themselves. Even though the same moderators have emerged as significant, different pattern of results were found when examining agreement and when examining discrepancies. These may be a consequence of the different underlying questions that each method posed but also in part to the small number of effect sizes available and resulting low power (Duhig & al., 2000). It must be stressed that an age categorization is feasible only if studies examining the association between child age at self-report and parent discrepancies are consistent in their methods to determine and define age periods for childhood and adolescence. Methodological consistency across future studies will enable larger comparisons and yield analyses with stronger power.

Instruments

Regarding instruments, studies using the PedsQL™ reported higher levels of agreement between parental and children ratings of psychological health-related quality of life in comparison to other instruments. It must be considered that the extent of agreement or discrepancies may be more dependent on the domains comprised in each instrument or the items found in specific instruments. Interpretations are further complicated given the variability in the content of each instrument's domain and composition. Most studies used the PedsQL™ in which the majority of items concern things that children can accomplish rather than what they think or what they're feelings (Upton & al., 2008). As such, if subjective psychological symptoms are evaluated through

observable and concrete statements, parent-child agreement is expected to be higher. It must also be taken into account that proxy and self-report versions of an instrument are not all mirrored. In some instruments, the CHQ for example, the parent and adolescents questionnaires differ in wording and length, which could justify the lower levels of agreement between parents and children on the psychological domain. Besides, studies using the PedsQL^{TM} reported higher levels of parent-child discrepancies on the overall and psychological domains of health-related quality of life compared to other instruments. These results suggest that, independent of the construct measured, some instruments might be less sensitive to detecting agreement and differences in ratings of child health-related quality of life. Differences across instruments may also be due to the variance in the conceptualization of health-related quality of life the distribution of content in the instruments and to the validity of the proxy ratings (Davis & al., 2006; Wallander & Varni, 1999).

Quality Ratings

Regarding quality ratings, we found that the category of rating plays a role in both levels of agreement and differences in sizes between parents and children for overall and physical health-related quality of life and in parent-child discrepancies for the psychological domain. Studies with "higher" quality ratings were consistently associated with higher levels of parent-child agreement and consistently associated with larger levels of parent-child discrepancies. These findings suggest that studies with better methodological quality ratings capture best the variability accounted individually and as a group by parents and children in ratings of child health-related quality of life. One possibility is that quality ratings reflect some other methodological considerations like method of data collection or statistical strategies employed. It has been recommended that measures of parent-child agreement are superior and provide better estimates of agreement which may be reflected in the poor levels obtained by low and average quality studies (Peat & Barton, 2005).

Similarly, it has been hypothesized that the method of data collection such as the completion of health-related quality of life at home or at the hospital could be related to levels of agreement between parents and children (Upton & al., 2008).

Limitations

We should recognize the limitations of the present review. Firstly, we cannot discard a possible selection bias as we solely included studies where parental and children ratings were statistically compared and where the presence of interrater comparisons was clearly stated and provided enough statistical information to be computed. Moreover, individual study results were cross-sectional limiting the interpretation of agreement and discrepancies across the cancer trajectory. Although heterogeneity was addressed by examining the participants' and study characteristics' with subgroup categorical analyses, studies did not provide all information that could have served to examine categorical associations. Consequently, only children's age, clinical status, instrument, quality rating and country were analyzed as moderators of parent-child agreement and discrepancies. Different moderators could have given valuable information but could not be studied in the present work due to lack of power, such as parental stress, socioeconomic status and child and parental sex. In a similar manner, publication bias was not calculated in each meta-analyses because of the risk of low power and false positives results with the statistical procedure employed when fewer than ten studies are included (Rosenthal, 1991; Silva & al., 2019). Further, we partly relied on the demographic information provided by authors to categorize moderators of included studies. Subsequently, some operational criteria for categorization were not consistent across the studies included in the meta-analysis. For example, some studies defined survivors as children finishing treatment and others considered survivors as children whose treatment ended for five years or more. Each individual's study definition was used

which implies the extent of the associations may be more a reflection of the resulting classification of this sample than of a distinct category. This issue is an echo of the broader survivorship classification problem that exists in the oncology literature. At last, condensing research data into a single parameter as done in meta-analyses can lead to loss of data or supplementary heterogeneity that meaningfully influences interpretation (Rosenthal, 1991).

Strengths, Clinical Implication and Future Directions

This meta-analysis can also be considered in light of its strengths. First, this is the first meta-analysis to synthesize parental and children agreement and discrepancies on child health-related quality of life anywhere along the cancer trajectory and to describe its moderators. Second, the quantitative review was conducted according to the PRISMA guidelines and utilized a broad search strategy. Third, the literature search comprised ways to integrate the grey literature. Fourth, the non-categorical approach of our study permitted to extend the ecological validity of our study and to generalize findings to multiple cancer diagnosis and to patients at any stages of the disease. Fifth, the main outcome of analysis is health-related quality of life which constitutes the main focus and goal of treatment in oncology. Sixth, the included studies represent a diverse pool of countries and languages hereby enhancing the cultural generalizability of the current results. Last, the moderator variables were chosen both according to the literature and according to published studies and thereof offer a rendering of the empirical activity in this area.

Our study has clinically meaningful implications for treatment planning and delivery of care in pediatric oncology. The data established aggregated mean levels of agreement and differences between ratings of parents and children on health-related quality of life. The pooled estimates could be considered as minimally important differences between ratings and hence be used as a regular constituent of care by clinicians to assess whether further investigations into the

nature of parent-child differences are necessary before planning treatment (Eiser & Varni, 2013). Findings also certified a general direction of the relation between differences in parental and children ratings where parent reported worse child health-related quality of life than children. Parent-child discrepancies are associated with poor adjustment and behavioural and emotional difficulties in prospective studies (De Los Reyes, 2011; Guion, Mrug, & Windle, 2009). Openly addressing discrepancies in the context of targeted treatment may help families in their relationship and prevent the development of further health-related problems. Together, the results further indicated that the levels of parent-child agreement and discrepancies vary by domain, child clinical status, child age, family culture, instrument and quality assessment. Thus, they exemplified that differences between parents and their children on health-related quality of life are more than operational noise and instead represent relevant information about the relationship existing within the families of children with cancer.

The findings denote the importance of considering ways to maximize the validity of ratings. For future studies comparing parental and children evaluations of child health-related quality of life, it is suggested that researchers incorporate more descriptive characteristics in their articles as well as other important data to facilitate study. Demographic data needs to be reported in a more thorough manner in order to better understand participants characteristics and determine potential moderators of parent-child agreement and discrepancies. As an example, it was noted that parental gender distribution was not always indicated thus exposing the tendency to consider the mother as the main parent proxy. Prospective studies could put more emphasis could be put in the role of fathers as proxy raters. Researchers should also consider that family variable and parental characteristics constitute probable moderators related to parent-child agreement and discrepancies on health-related quality of life. It is crucial to study other moderators like parental distress which

were not examined directly in our meta-analysis. In addition, more exhaustive statistical information (i.e. means, standard deviations and correlations) should be provided to enable the calculate of basic measures of dyadic agreement and discrepancies. Studies should also make sure to compute both levels of agreement and differences in sizes between ratings given that different pattern of results can emerge and that it is the recommended statistical practice to examine dyadic agreement (Lewsey, 2006). At least, it appears important to keep in mind that it is ideal to gather information of multiple informants when assessing the health-related quality of life of a child with cancer. While variability is present between parents and children, the gathering of multiple sources of information will likely lead to a better assessment and mostly better understanding of the child's health-related quality of life. Thus, instruments that measure health-related quality of life should be selected on the basis that they were developed to measure both parental and children perspectives.

Conclusion

This meta-analysis supports fair to good levels of parent-child agreement on the three domains of health-related quality of life. It also highlights the presence of discrepancies between parental and child ratings of health-related quality of life to a small degree for the physical domain and to a larger degree in the psychological domain. Higher agreement between parents and children was associated with younger child age, families situated in Asian cultures, children actively receiving treatment for childhood cancer and studies with higher quality assessments. In sum, these finding provide a better understanding of agreement and discrepancies when evaluating the health-related quality of life of children with cancer. As well, they support the value of understanding the factors that moderate agreement and discrepancies between the perspectives of parents and children when planning assessments and interventions.

Table 1 Characteristics of studies included in the meta-analyses

Study (year)	Country of publication	N	Age range (mean)	Male (%)	HRQOL measures	HRQOL outcomes	Data available for effect size	Characteristics available for moderation analyses
Anu & al. (2017)	Nepal	37 children 43 parents	2-18	72	PedsQL™	Overall Physical Psychological	M,C M,C M,C	
Chang & al. (2004)	USA	141	7-18	65	QOLCC	Overall Physical Psychological	M, C M, C M, C	Child age
De Bolle & al. (2008)	Belgium	37	6.3-16.8	49	PedsQL™	Overall Physical Psychological	M, C M, C M, C	
De Clerq & al. (2004)	Belgium	67	8-14	57	PedsQL™	Overall Physical Psychological	C M M	
Jurbergs & al. (2008)	USA	199	7-18	52	CHQ	Physical Psychological	M M	Adaptative style
Levi & al. (1999)	USA	27	8-18	52	CHQ	Physical	M	
Matziou & al. (2008)	Greece	149	12-18	62	PedsQL™	Overall Physical Psychological	M, C M, C M, C	On/Off treatment Parent age Child age Sociodemographics
Parsons & al. (2012)	USA	222	13-18	55	PedsQL™	Overall Physical Psychological	M, C M, C M, C	Child age Treatment intensity
Penn & al. (2009)	England	35	2-17	51	PedsQL™	Overall	M	

Table 1 (continued)

Study (year)	Country	N	Age range (mean)	Male (%)	HRQOL measures	HRQOL outcomes	Analyses	Moderator
Roddenberry& al. (2008)	USA	18	5-18	NA	POQOLS	Overall	C,M	
Russell & al. (2006)	USA	199	7-18	54	CHQ	Physical Psychological	M, C M, C	On/Off treatment
Sato & al. (2013)	Japan	134	5-18	55	PedsQL™	Overall	M	On/Off treatment Child and parent distress Sociodemographics
Sawyer & al. (1999)	Australia	70	10-18	53	CHQ	Physical Psychological	M, C M, C	On/Off treatment
Schulte & al. (2016)	Canada	51	6-18	49	PedsQL™	Overall Physical Psychological	M, C M, C M, C	
Speyer & al. (2009)	France	28	6-18	63	CHQ	Physical Psychological	M, C M,C	On/Off treatment
Vance & al. (2001)	England	27 children 36 parents	6-12	56	PedsQL™	Overall Physical Psychological	M M M	
Van Dijck & al. (2007)	Netherlands	65	8-18	52	Kidscreen-52	Physical Psychological	M, C M,C	Age of children
Yagci-Kupeli & al. (2012)	Turkey	302	8-18	58	PedsQL™	Physical Psychological	M, C M, C	
Yeh & al. (2005)	Taiwan	126	7-18	64	QOLCC	Physical Psychological	M, C M, C	On/Off treatment
Yoo & al. (2010)	Korea	351	7-18	50	PedsFACT	Overall Physical Psychological	M, C M, C M, C	Child Age Parental sex

Note. M : means ; C : correlations

Table 2. Demographic characteristics of studies included in the meta-analysis

Study (year)	Parental sex (% female)	Clinical Status	Culture	Quality rating	Socioeconomic status (available)	Mean child age (years old)	Mean parental age (years old)	Mean time since diagnosis (months)
Anu & al. (2017)	62	Mixed	Asian	Average	No	11.34	N/A Range : 22 to 56	Range : 2-84
Chang & al. (2004)	N/A	Mixed	Asian	Average	Yes	11.78	Mothers : 38.95 Fathers : 42.40	N/A
De Bolle & al. (2008)	N/A	Receiving treatment	American-European	Average	No	11.4	N/A	N/A
De Clerq & al. (2004)	N/A	Survivors	American-European	Low	No	10.4	N/A	92.4 Range : 36-156
Jurbergs & al. (2008)	90.7	Mixed	American-European	Low	Yes	12.32	N/A	Range : 1-60+
Levi & al. (1999)	85	Receiving treatment	American-European	High	No	13.31	Both parents : 41.17	Range : 3-36+
Matziou & al. (2008)	N/A	Receiving treatment	American-European	Low	No	12.08	Mothers : 36.87 Fathers : 41.65	N/A
Parsons & al. (2012)	N/A	Receiving treatment	American-European	Average	No	11.6	N/A	N/A
Penn & al. (2009)	N/A	Receiving treatment	American-European	Low	No	9.1	N/A	1.8 Range : 0.8-16.4

Table 2 (continued)

Study (year)	Parental sex (% female)	Clinical Status	Culture	Quality rating	Socioeconomic status (available)	Mean child age (years old)	Mean parental age (years old)	Mean time since diagnosis (months)
Roddenberry& al. (2008)	N/A	mixed	American-European	High	No	13.7	N/A	38 Range : 4-112
Russell & al. (2006)	90.7	mixed	American-European	Average	Yes	12.38	N/A	Range : 1-60+
Sato & al. (2013)	94	mixed	Asian	High	Yes	Median : 11	N/A	Median : 37
Sawyer & al. (1999)	N/A	mixed	American-European	High	Yes	13.6	N/A	57.6
Schulte & al. (2016)	86	survivors	American-European	High	Yes	13.30	Mothers : 43.56 Fathers : 45.33	83.28
Speyer & al. (2009)	82.5	mixed	American-European	Average	No	13.6	N/A	16.9
Vance & al. (2001)	80.5	mixed	American-European	High	No	89.92	Both parents : 34.06	N/A
Van Dijck & al. (2007)	N/A	survivors	American-European	High	No	12.7	Both parents : 43.63	N/A
Yagci-Kupeli & al. (2012)	42.8	mixed	Asian	Low	No	Median : 13	Median both parents : 40	Range : 1-60+
Yeh & al. (2005)	83	mixed	Asian	Average	No	11.69	Mothers : 39.03 Fathers : 43	5.47 Range : 0.96-33.96
Yoo & al. (2010)	90.5	survivors	Asian	High	No	12.85	Mothers : 41.40 Fathers : 44.21	N/A

Table 3 Categorical analysis for *r* and *g* effect sizes of overall health-related quality of life

Variable/Category	Between classes effects (Qb)	No of effect sizes	N Child/parent	Mean weighted g	95 %CI Lower	95% CI Upper	Within class (Qw)
r effect sizes							
Cancer trajectory	13.71**						
In treatment		2	186	0.70	0.61	0.76	0.01
Mixed		4	357	0.57	0.50	0.64	8.02*
Survivors		4	581	0.72	0.67	0.75	24.67***
Self-report age	7.12**						
Children (5-12)		2	248	0.79	0.74	0.84	9.76**
Adolescents (13-18)		2	244	0.69	0.61	0.75	0.68
Instrument	3.36						
PedsQL™		6	443	0.63	0.57	0.69	21.25***
Others		4	681	0.70	0.65	0.73	21.89**
Quality rating	19.96**						
Others		6	622	0.60	0.55	0.65	21.21**
High		4	502	0.71	0.71	0.78	5.33
Country	7.16***						
Western		5	469	0.61	0.0.56	0.67	21.95**
Eastern		4	655	0.78	0.67	0.74	21.95***
g effect sizes							
Cancer trajectory	44.73***						
In treatment		2	61/70	0.53	0.18	0.88	0.22
Mixed		6	612/629	-0.03	-0.14	0.09	36.59***
Survivors		3	402/254	0.60	0.45	0.76	10.67***
Self-report age	1.48						
Children (5-12)		2	244/262	0.02	-0.15	0.20	2.19
Adolescents (13-18)		2	248/267	-0.13	-0.30	0.05s	12.17*
Instrument	79.31*						
PedsQL™		7	430/447	0.30	0.17	0.43	12.87*
Others		4		0.14	0.02	0.27	76.11***
Quality rating	29.65*						
Others		3	636/662	0.04	-0.07	0.15	54,59***
High		3	439/291	0.55	0.40	0.71	7.96**
Country	7.22**						
Western		6	288/306	0.39	0.23	0.55	9.67
Eastern		5	787/647	0.13	0.02	0.24	75.23***

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table 4 Categorical analysis for *r* and *g* effect sizes of physical health-related quality of life

Variable/Category	Between classes effects (Qb)	No of effect sizes	N Child/parent	Mean weighted g	95% CI Lower	95 %CI Upper	Within class (Qw)
r effect sizes							
Cancer trajectory	44.23***						
In treatment		3	273	0.84	0.80	0.87	12.31**
Mixed		7	628	0.64	0.59	0.69	24.06***
Survivors		4	769	0.68	0.59	0.68	89.51***
Self-report age	3.49						
Children (5-12)		2	248	0.78	0.73	0.86	5.71*
Adolescents (13-18)		2	244	0.71	0.64	0.77	21.14**
Instrument	8.44*						
PedsQL™		8	755	0.64	0.59	0.68	131.82***
Other		6	915	0.71	0.68	0.74	29.84***
Quality rating	18.82***						
Other		11	1 231	0.64	0.61	0.68	136.72***
High		3	439	0.77	0.72	0.82	14.56***
Country	14.32***						
Western		10	1 015	0.64	0.60	0.67	28.65***
Eastern		4	655	0.74	0.70	0.77	127.13***
g effect sizes							
Cancer trajectory	37.93***						
In treatment		3	64/64	0.32	0.20	0.45	4.96
Mixed		8	949/964	0.05	-0.06	0.12	37.41***
Survivors		5	793/647	0.46	0.35	0.58	251.53***
Self-report age	5.94*						
Children (5-12)		3	248/267	0.67	0.51	0.82	68.65***
Adolescents (13-18)		3	244/262	0.41	0.28	0.55	75.07***
Instrument	0.43						
PedsQL™		8	799/806	0.23	0.15	0.31	10.25
Others		7	942/804	0.19	0.09	0.29	79.30
Quality rating	29.67*						
Others		11	1275/1292	0.15	0.07	0.20	293.41*
High		4	466/318	0.61	0.46	0.75	2.02
Country	4.21*						
Western		12	1151/1162	0.27	0.00	0.20	254.18*
Eastern		4	655/513	0.13	0.00	0.01	73.44*

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table 5 Categorical analysis for *r* and *g* effect sizes of psychological health-related quality of life

Variable/Category	Between classes effects (Qb)	No of effect sizess	N child/parentChild/parent	Mean weighted *g*	95 %CI Lower	95 %CI Upper	Within class (Qw)
r effect sizes							
Cancer trajectory	50.78***						
In treatment		3	408	0.72	0.66	0.76	51.06***
Mixed		7	622	0.41	0.34	0.48	7.03
Survivors		4	769	0.54	0.49	0.59	17.31***
Child age	134.60***						
Children (5-12)		3	248	-0.52	-0.61	-0.43	144.89**
Adolescents (13-18)		3	244	0.44	0.33	0.54	1.20
Instrument	10.56**						
PedsQL™		8	884	0.60	0.56	0.64	96.89**
Others		6	915	0.49	0.44	0.54	18.71***
Quality rating	4.21						
Others		11	1 360	0.53	0.49	0.57	121.21***
High		3	439	0.59	0.53	0.65	2.58
Country	2.93						
Western		10	1 144	0.57	0.53	0.61	108.24***
Eastern		4	655	0.51	0.45	0.56	14.98**
g effect sizes							
Cancer trajectory	25.87**						
In treatment		2	37/37	0.69	0.59	0.83	1.26
Mixed		8	949/964	0.26	0.16	0.36	639.73***
Survivors		5	793/646	0.31	0.18	0.43	18.64***
Child age	2.89						
Children (5-12)		3	244/262	0.09	-0.06	0.24	41.33***
Adolescents (13-18)		3	248/267	0.27	0.13	0.40	36.09***
Instrument	126.34***						
PedsQL™		7	772/779	0.67	0.58	0.75	529.59***
Others		7	942/803	-0.08	-0.18	0.01	25.43***
Quality rating	9.63**						
Others		11	1191/1207	0.37	0.30	0.44	669.39**
High		3	439/291	0.11	-0.04	0.25	2.35
Country	102.76*						
Western		11	1124/1134	0.55	0.48	0.63	576.73***
Eastern		4	655/513	-0.32	-0.47	-0.17	5.98

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Figure 1 Literature screening process flow chart

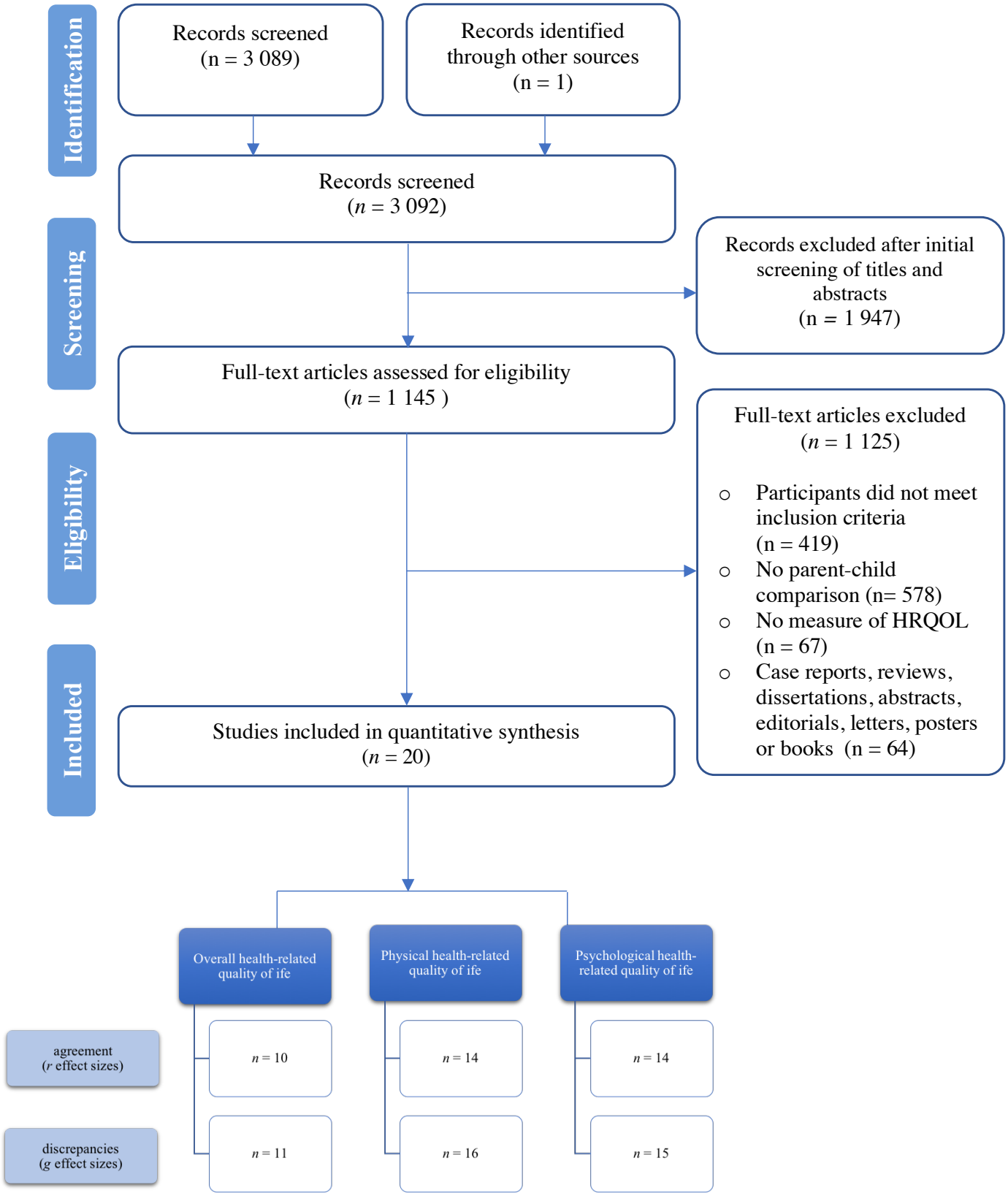


Figure 2 Bias by domain from the STROBE statement

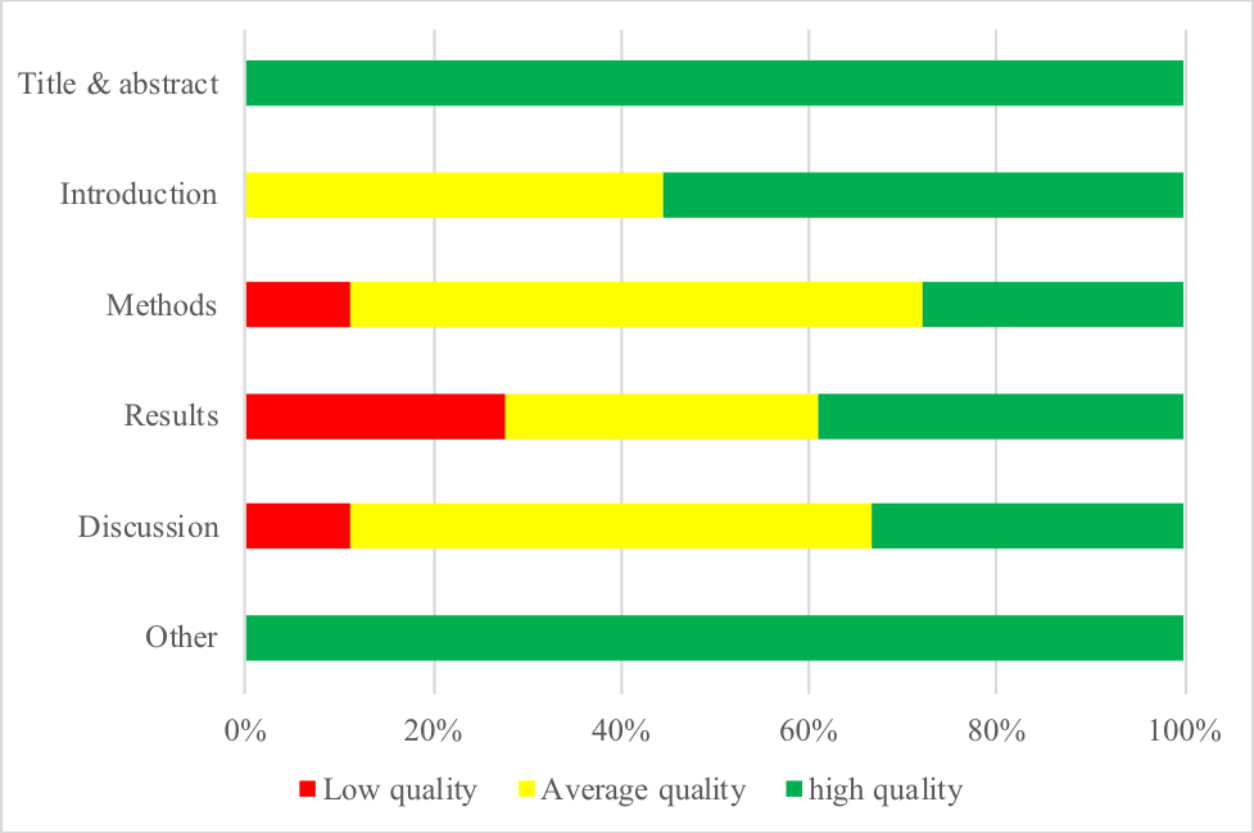
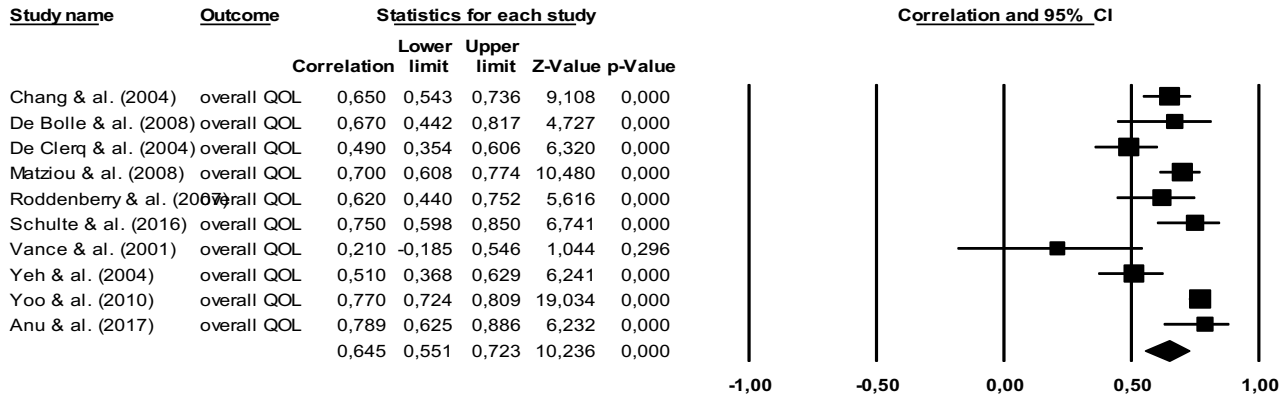


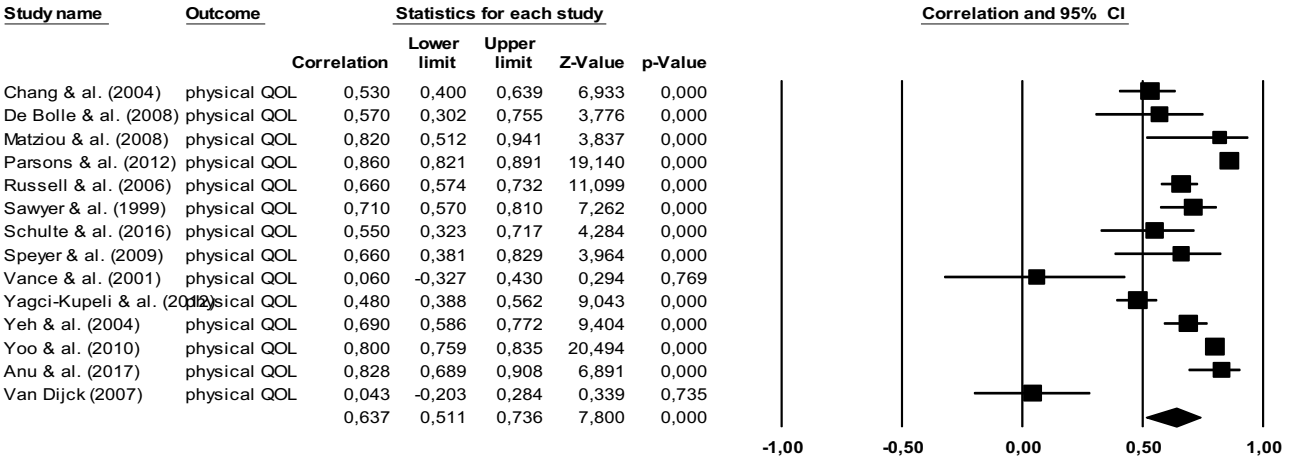
Figure 3 Forest plots for random effect meta-analyses of parent-child agreement for (1) overall health-related quality of life, (2) physical health-related quality of life and (3) psychological health-related quality of life

1) Parent-child agreement for overall health-related quality of life



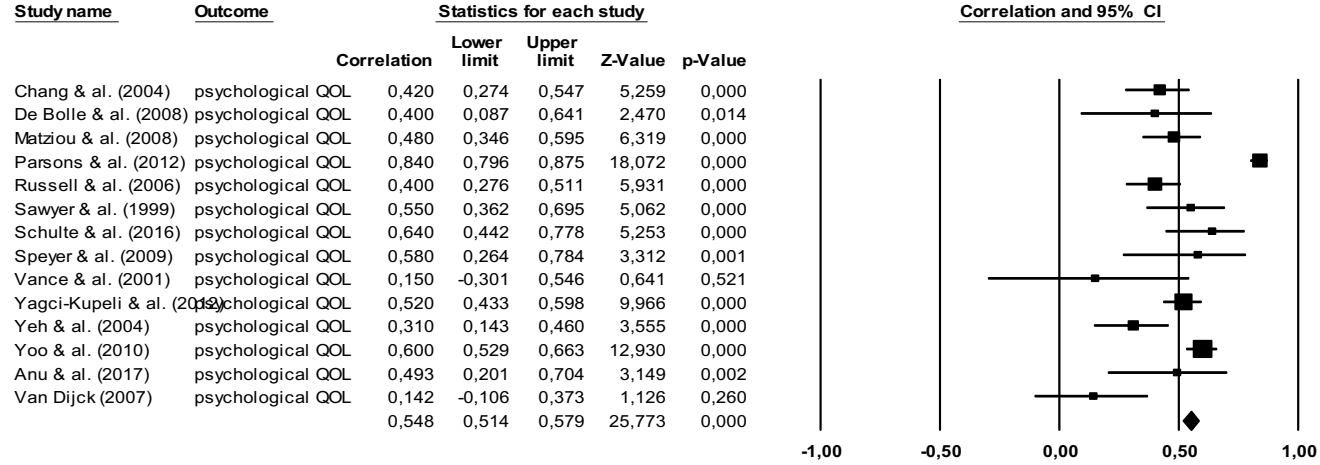
Study name	Outcome	Correlation	Lower limit	Upper limit	Z-Value	p-Value
Chang & al. (2004)	overall QOL	0,650	0,543	0,736	9,108	0,000
De Bolle & al. (2008)	overall QOL	0,670	0,442	0,817	4,727	0,000
De Clerq & al. (2004)	overall QOL	0,490	0,354	0,606	6,320	0,000
Matziou & al. (2008)	overall QOL	0,700	0,608	0,774	10,480	0,000
Roddenberry & al. (2007)	overall QOL	0,620	0,440	0,752	5,616	0,000
Schulte & al. (2016)	overall QOL	0,750	0,598	0,850	6,741	0,000
Vance & al. (2001)	overall QOL	0,210	-0,185	0,546	1,044	0,296
Yeh & al. (2004)	overall QOL	0,510	0,368	0,629	6,241	0,000
Yoo & al. (2010)	overall QOL	0,770	0,724	0,809	19,034	0,000
Anu & al. (2017)	overall QOL	0,789	0,625	0,886	6,232	0,000
		0,645	0,551	0,723	10,236	0,000

2) Parent-child agreement for physical health-related quality of life



Study name	Outcome	Correlation	Lower limit	Upper limit	Z-Value	p-Value
Chang & al. (2004)	physical QOL	0,530	0,400	0,639	6,933	0,000
De Bolle & al. (2008)	physical QOL	0,570	0,302	0,755	3,776	0,000
Matziou & al. (2008)	physical QOL	0,820	0,512	0,941	3,837	0,000
Parsons & al. (2012)	physical QOL	0,860	0,821	0,891	19,140	0,000
Russell & al. (2006)	physical QOL	0,660	0,574	0,732	11,099	0,000
Sawyer & al. (1999)	physical QOL	0,710	0,570	0,810	7,262	0,000
Schulte & al. (2016)	physical QOL	0,550	0,323	0,717	4,284	0,000
Speyer & al. (2009)	physical QOL	0,660	0,381	0,829	3,964	0,000
Vance & al. (2001)	physical QOL	0,060	-0,327	0,430	0,294	0,769
Yagci-Kupeli & al. (2012)	physical QOL	0,480	0,388	0,562	9,043	0,000
Yeh & al. (2004)	physical QOL	0,690	0,586	0,772	9,404	0,000
Yoo & al. (2010)	physical QOL	0,800	0,759	0,835	20,494	0,000
Anu & al. (2017)	physical QOL	0,828	0,689	0,908	6,891	0,000
Van Dijck (2007)	physical QOL	0,043	-0,203	0,284	0,339	0,735
		0,637	0,511	0,736	7,800	0,000

3) Parent-child agreement for psychological health-related quality of life

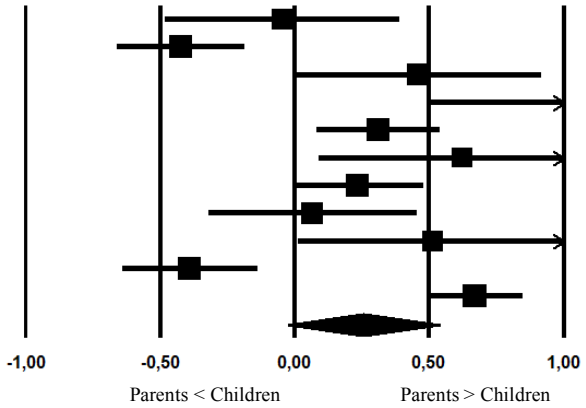


Study name	Outcome	Correlation	Lower limit	Upper limit	Z-Value	p-Value
Chang & al. (2004)	psychological QOL	0,420	0,274	0,547	5,259	0,000
De Bolle & al. (2008)	psychological QOL	0,400	0,087	0,641	2,470	0,014
Matziou & al. (2008)	psychological QOL	0,480	0,346	0,595	6,319	0,000
Parsons & al. (2012)	psychological QOL	0,840	0,796	0,875	18,072	0,000
Russell & al. (2006)	psychological QOL	0,400	0,276	0,511	5,931	0,000
Sawyer & al. (1999)	psychological QOL	0,550	0,362	0,695	5,062	0,000
Schulte & al. (2016)	psychological QOL	0,640	0,442	0,778	5,253	0,000
Speyer & al. (2009)	psychological QOL	0,580	0,264	0,784	3,312	0,001
Vance & al. (2001)	psychological QOL	0,150	-0,301	0,546	0,641	0,521
Yagci-Kupeli & al. (2012)	psychological QOL	0,520	0,433	0,598	9,966	0,000
Yeh & al. (2004)	psychological QOL	0,310	0,143	0,460	3,555	0,000
Yoo & al. (2010)	psychological QOL	0,600	0,529	0,663	12,930	0,000
Anu & al. (2017)	psychological QOL	0,493	0,201	0,704	3,149	0,002
Van Dijck (2007)	psychological QOL	0,142	-0,106	0,373	1,126	0,260
		0,548	0,514	0,579	25,773	0,000

Figure 4 Forest plots for random effect meta-analyses of parent-child discrepancies for (1) overall health-related quality of life, (2) physical health-related quality of life and (3) psychological health-related quality of life

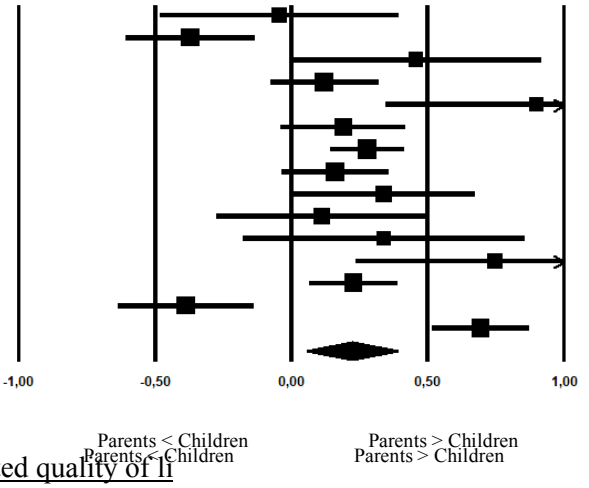
1) Parent-child differences in means for overall health-related quality of life

Study name	Outcome	Hedges's g	Standard error	Variance	Lower limit	Upper limit	Z-Value	p-Value
Anu & al. (2017)	overall	-0,045	0,222	0,049	-0,480	0,390	-0,202	0,840
Chang & al. (2005)	overall	-0,423	0,120	0,014	-0,658	-0,187	-3,519	0,000
De Bolle & al. (2008)	overall	0,459	0,233	0,054	0,002	0,916	1,967	0,049
De Clerq & al. (2005)	overall	1,109	0,308	0,095	0,505	1,712	3,601	0,000
Matziou & al. (2009)	overall	0,311	0,116	0,014	0,083	0,539	2,677	0,007
Penn & al. (2009)	overall	0,625	0,271	0,073	0,094	1,156	2,307	0,021
Sato & al. (2013)	overall	0,237	0,123	0,015	-0,003	0,478	1,934	0,053
Schulte & al. (2016)	overall	0,068	0,197	0,039	-0,317	0,454		
Vance & al. (2001)	overall	0,516	0,256	0,065	0,015	1,017	63	
Yeh & al. (2005)	overall	-0,388	0,127	0,016	-0,637	-0,140		
Yoo & al. (2010)	overall	0,672	0,090	0,008	0,495	0,849	7,436	0,000
		0,256	0,144	0,021	-0,027	0,539	1,774	0,076



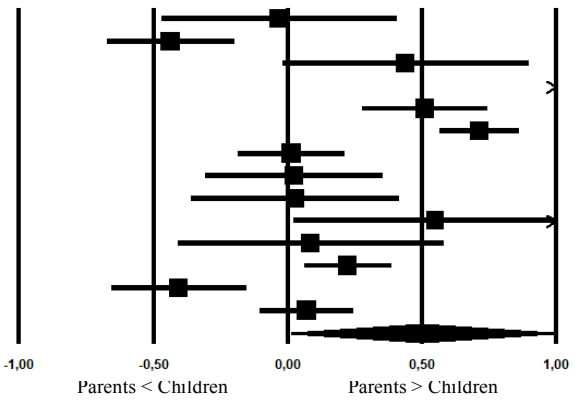
2) Parent-child differences in means for physical health-related quality of life

Study name	Outcome	Hedges's g	Standard error	Variance	Lower limit	Upper limit	Z-Value	p-Value
Anu & al. (2017)	physical	-0,042	0,222	0,049	-0,478	0,393	-0,190	0,849
Chang & al. (2005)	physical	-0,368	0,120	0,014	-0,603	-0,133	-3,073	0,002
De Bolle & al. (2008)	physical	0,459	0,233	0,054	0,002	0,916	1,967	0,049
Jurbers & al. (2008)	physical	0,123	0,100	0,010	-0,073	0,319	1,230	0,219
Levi & al. (1999)	physical	0,901	0,282	0,079	0,348	1,453	3,195	0,001
Matziou & al. (2009)	physical	0,192	0,116	0,013	-0,035	0,419	1,659	0,097
Parsons & al. (2012)	physical	0,279	0,068	0,005	0,145	0,413	4,091	0,000
Russell & al. (2006)	physical	0,162	0,100	0,010	-0,034	0,359	1,617	0,106
Sawyer & al. (1999)	physical	0,340	0,169	0,029	0,009	0,672	2,011	0,044
Schulte & al. (2016)	physical	0,113	0,197	0,039	-0,273	0,498	0,572	0,567
Speyer & al. (2009)	physical	0,342	0,263	0,069	-0,174	0,858	1,298	0,194
Vance & al. (2001)	physical	0,749	0,260	0,068	0,239	1,259	2,879	0,004
Yagci-Kupeli & al. (2012)	physical	0,230	0,082	0,007	0,069	0,391	2,803	0,005
Yeh & al. (2005)	physical	-0,385	0,127	0,016	-0,633	-0,136	-3,035	0,002
Yoo & al. (2010)	physical	0,696	0,091	0,008	0,518	0,873	7,687	0,000
		0,223	0,085	0,007	0,055	0,390	2,607	0,009



3) Parent-child differences in means for psychological health-related quality of li

Study name	Outcome	Hedges's g	Standard error	Variance	Lower limit	Upper limit	Z-Value	p-Value
Anu & al. (2017)	psychological	-0,031	0,222	0,049	-0,466	0,404	-0,140	0,889
Chang & al. (2005)	psychological	-0,434	0,120	0,014	-0,670	-0,199	-3,613	0,000
De Bolle & al. (2008)	psychological	0,440	0,233	0,054	-0,017	0,896	1,888	0,059
Jurbers & al. (2008)	psychological	5,312	0,213	0,045	4,895	5,729	24,976	0,000
Matziou & al. (2009)	psychological	0,512	0,117	0,014	0,282	0,742	4,361	0,000
Parsons & al. (2012)	psychological	0,714	0,075	0,006	0,567	0,861	9,526	0,000
Russell & al. (2006)	psychological	0,015	0,100	0,010	-0,181	0,211	0,150	0,881
Sawyer & al. (1999)	psychological	0,025	0,168	0,028	-0,305	0,354	0,147	0,883
Schulte & al. (2016)	psychological	0,029	0,197	0,039	-0,356	0,414	0,147	0,883
Speyer & al. (2009)	psychological	0,551	0,269	0,072	0,024	1,077	2,050	0,040
Vance & al. (2001)	psychological	0,086	0,252	0,063	-0,407	0,579	0,343	0,731
Yagci-Kupeli & al. (2012)	psychological	0,225	0,082	0,007	0,064	0,385	2,739	0,006
Yeh & al. (2005)	psychological	-0,404	0,127	0,016	-0,653	-0,155	-3,184	0,001
Yoo & al. (2010)	psychological	0,072	0,088	0,008	-0,100	0,245	0,820	0,412
		0,500	0,248	0,062	0,014	0,986	2,016	0,044



Note. A positive Hedge's *g* represented a higher parent mean than children mean (worse parent-reported health-related quality of life).

Supplemental Table 1 Presence or absence of STROBE statement criteria for studies included in the meta-analysis

	STROBE statement item number																						
	Title and abstract	**Introduction**		**Methods**									**Results**					**Discussion**				**Other**	**Total /22**
Study (year)	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**19**	**20**	**21**	**22**	
Anu & al. (2017	x	x	x	x			x	x		x	x		x	x		xx		x	x	x	xx		17
Chang & al. (2004)	x	x	x	x	x			x		x	x		x		x	x	x	x	x	x		x	16
De Bolle & al. (2008)	x	x		x	x	x		x	x	x	x				x	x	x	x	x	x	x	x	19
De Clerq & al. (2004)	x	x	x	x		x		x		x	x				x	x	x		x	x	x		14
Jurbergs & al. (2008)	x	x	x	x		x	x	x		x	x				x	x	x		x	x	x		16
Levi & al. (1999)	x	x	x	x	x	x	x	x		x	x		x		x	x	x	x	x	x	x	x	19
Matziou & al. (2008)	x	x		x			x	x	x	x	x				x	x	x	x	x	x	x		15
Parsons & al. (2012)	x	x	x	x				x	x	x	x	x		x	x	x	x	x		x	x	x	17
Penn & al. (2009)	x	x		x	x			x	x	x	x				x	x	x	x		x		x	14
Roddenberry& al. (2008)	x	x	x	x			x	x	x	x	x		x	x	x	x	x		x	x	x	x	18
Russell & al. (2006)	x	x		x		x	x	x	x	x	x			x	x	x	x		x	x	x	x	17
Sato & al. (2013)	x	x	x	x	x	x	x	x		x	x	x	x		x	x	x	x	x	x	x	x	16
Sawyer & al. (1999)	x	x		x	x		x	x	x	x	x			x	x	x	x		x	x	x	x	17
Schulte & al. (2016)	x	x	x	x	x	x	x	x		x	x		x		x	x	x	x	x	x	x	x	19
Speyer & al. (2009)	x	x		x	x			x	x	x	x				x	x	x		x	x	x	x	16
Vance & al. (2001)	x	x	x	x			x	x	x	x	x		x		x	x	x	x	x	x	x	x	18
Van Dijck & al. (2007)	x	x		x		x	x	x		x	x			x		x		x	x	x		x	18
Yagci-Kupeli & al. (2012)	x	x		x	x	x	x	x		x	x	x			x	x	x	x	x	x			16
Yeh & al. (2005)	x	x		x		x	x	x		x	x				x	x	x		x	x		x	17
Yoo & al. (2010)	x	x	x	x	x		x	x	x	x	x			x	x	x	x		x	x	x	x	19
Total/20	18	18	12	18	10	10	12	18	11	18	18	3	6	5	18	18	18	11	16	18	14	14	

Note. An empty box is indicative of the absence of the strobe statement item number that should be reported in individual studies : 1) title and abstract 2) background/rational 3) objectives 4) study design 5) setting 6) participants 7) variables 8) data source/measurement 9) bias 10) study size 11) quantitative variables 12) statistical methods 13) participants 14) descriptive data 15) outcome dame 16) main results 17) other analyses 18) key results 19) limitations 20) interpretation 21) generalisability and 22) funding. Explicit recommendations for the Strobe statement item criteria by item number are available in Supplementary Material 2.

Supplemental table 2 Quality rating by STROBE statement categories for articles included in the meta-analysis

	STROBE statement categories						
Study (year)	**Title and abstract**	**Introduction**	**Methods**	**Results**	**Discussion**	**Other**	**Total**
Anu & al. (2017)	●	●	●	●	●	●	●
Chang & al. (2004)	●	●	●	●	●	●	●
De Bolle & al. (2008)	●	●	●	●	●	●	●
De Clerq & al. (2004)	●	●	●	●	●	●	●
Jurbergs & al. (2008)	●	●	●	●	●	●	●
Levi & al. (1999)	●	●	●	●	●	●	●
Matziou & al. (2008)	●	●	●		●	●	●
Parsons & al. (2012)	●	●	●	●	●	●	●
Penn & al. (2009)	●	●	●	●	●	●	●
Roddenberry& al. (2008)	●	●	●	●	●	●	●
Russell & al. (2006)	●	●	●	●	●	●	●
Sato & al. (2013)	●	●	●	●	●	●	●
Sawyer & al. (1999)	●	●	●	●	●	●	●
Schulte & al. (2016)	●	●	●	●	●	●	●
Speyer & al. (2009)	●	●	●	●	●	●	●
Vance & al. (2001)	●	●	●	●	●	●	●
Van Dijck & al. (2007)	●	●	●	●	●	●	●
Yagci-Kupeli & al. (2012)	●	●	●	●	●	●	●
Yeh & al. (2005)	●	●	●	●	●	●	●
Yoo & al. (2010)	●	●	●	●	●	●	●

● low quality ● average quality ● high quality

Supplemental material 1 PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	**5**
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	**Before pagination**
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	**4**
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	**5-6**
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	**6**
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	**6-7**
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	**7**
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	**7-8**
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	**8**
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	**7-8**
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	**9**
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	**8**
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	**9**

Supplemental material 1 (Continued) PRISMA Checklist

Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	**9**
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	**9-10**
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	**9-10**
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	**10**
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	**Table 1**
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	**11, Figure 2 Supp T 2, 3**
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	**11 to 18**
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	**11 to 18**
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	**11 to 18**
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	**11 to 18**
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	**19-25**
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	**26**
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	**27**
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	**28**

Supplemental Material 2 Search strategy by database

1. PubMed

1	Quality of life	Quality of life[MH] OR life quality[TIAB] OR quality of life[TIAB] OR qol[TIAB] OR "Cancer Therapy-Childhood Brain Tumor Survivors questionnaire"[TIAB] OR "pedsFACT-BrS"[TIAB] OR Child health questionnaire[TIAB] OR CHQ*[TIAB] OR "Child Health and Illness Profile"[TIAB] OR CHIP*[TIAB] OR DISABKID*[TIAB] OR DCGM*[TIAB] OR HRQoL*[TIAB] OR HRQL*[TIAB] OR EQ-5D*[TIAB] OR SF-6D*[TIAB] OR Kidscreen*[TIAB] OR KINDL*[TIAB] OR Health Utility Index Mark[TIAB] OR HUI*[TIAB] OR ILK*[TIAB] OR PedsQL*[TIAB] OR life quality[OT] OR quality of life[OT] OR qol[OT] OR "Cancer Therapy-Childhood Brain Tumor Survivors questionnaire"[OT] OR "pedsFACT-BrS"[OT] OR Child health questionnaire[OT] OR CHQ*[OT] OR "Child Health and Illness Profile"[OT] OR CHIP*[OT] OR DISABKID*[OT] OR DCGM*[OT] OR HRQoL*[OT] OR HRQL*[OT] OR EQ-5D*[OT] OR SF-6D*[OT] OR Kidscreen*[OT] OR KINDL*[OT] OR Health Utility Index Mark[OT] OR HUI*[OT] OR ILK*[OT] OR PedsQL*[OT]
2	Cancer	Neoplasms[MH] OR Medical Oncology[MH] OR Radiotherapy[MH] OR "Oncology Service, Hospital"[MH] OR Oncology Nursing[MH] OR Integrative Oncology[MH] OR Cancer Pain[MH] OR Cancer Care Facilities[MH] OR adenocarcinoma*[TIAB] OR adenomatous[TIAB] OR polypos*[TIAB] OR gardner syndrome*[TIAB] OR gardners syndrome*[TIAB] OR "gardner's syndrome"[TIAB] OR "gardner's syndromes"[TIAB] OR anaplasia*[TIAB] OR astrocytoma*[TIAB] OR carcinoid*[TIAB] OR carcinogene*[TIAB] OR carcinoma*[TIAB] OR choriocarcinoma*[TIAB] OR cancer*[TIAB] OR chemotherap*[TIAB] OR craniopharyngioma*[TIAB] OR ependymoma*[TIAB] OR hepatocarcinoma*[TIAB] OR hematoonco*[TIAB] OR hemato onco*[TIAB] OR hematolo*[TIAB] OR histiocytoma*[TIAB] OR hodgkin*[TIAB] OR leukemi*[TIAB] OR leukaemi*[TIAB] OR leucocythaemia*[TIAB] OR leucocythemia*[TIAB] OR lymphoma*[TIAB] OR erythroleukem*[TIAB] OR erythroleukaem*[TIAB] OR glioma*[TIAB] OR glioblastoma*[TIAB] OR medulloblastoma*[TIAB] OR nephroblastoma*[TIAB] OR neuroblastoma*[TIAB] OR pleuropulmonary blastoma*[TIAB] OR retinoblastoma*[TIAB] OR pineoblastoma*[TIAB] OR macroglobulinemi*[TIAB] OR macroglobulinaemi*[TIAB] OR malignan*[TIAB] OR melanoma*[TIAB] OR meningioma*[TIAB] OR mesothelioma*[TIAB] OR metasta*[TIAB] OR "mycosis fungoides"[TIAB] OR myelodysplastic[TIAB] OR myeloma*[TIAB] OR myeloproliferative[TIAB] OR neoplasia*[TIAB] OR neoplasm*[TIAB] OR neoplastic*[TIAB] OR oncolog*[TIAB] OR oncogene*[TIAB] OR psychooncolog*[TIAB] OR phacomatos*[TIAB] OR pheochromocytoma*[TIAB] OR radiotherap*[TIAB] OR sarcoma*[TIAB] OR carcinosarcoma*[TIAB] OR fibrosarcoma*[TIAB] OR osteosarcoma*[TIAB] OR chondrosarcoma*[TIAB] OR lymphosarcoma*[TIAB] OR osteosarcoma*[TIAB] OR rhabdomyosarcoma*[TIAB] OR "sezary syndrome"[TIAB] OR tumor*[TIAB] OR tumour*[TIAB] OR thymoma*[TIAB] OR adenocarcinoma*[OT] OR adenomatous[OT] OR polypos*[OT] OR gardner syndrome*[OT] OR gardners syndrome*[OT] OR "gardner's syndrome"[OT] OR "gardner's syndromes"[OT] OR anaplasia*[OT] OR astrocytoma*[OT] OR carcinoid*[OT] OR carcinogene*[OT] OR carcinoma*[OT] OR choriocarcinoma*[OT] OR cancer*[OT] OR chemotherap*[OT] OR craniopharyngioma*[OT] OR ependymoma*[OT] OR hepatocarcinoma*[OT] OR hematoonco*[OT] OR hemato onco*[OT] OR hematolo*[OT] OR histiocytoma*[OT] OR hodgkin*[OT] OR leukemi*[OT] OR leukaemi*[OT] OR leucocythaemia*[OT] OR leucocythemia*[OT] OR lymphoma*[OT] OR erythroleukem*[OT] OR erythroleukaem*[OT] OR glioma*[OT] OR glioblastoma*[OT] OR medulloblastoma*[OT] OR nephroblastoma*[OT] OR neuroblastoma*[OT] OR pleuropulmonary blastoma*[OT] OR retinoblastoma*[OT] OR pineoblastoma*[OT] OR macroglobulinemi*[OT] OR macroglobulinaemi*[OT] OR malignan*[OT] OR melanoma*[OT] OR meningioma*[OT] OR mesothelioma*[OT] OR metasta*[OT] OR "mycosis fungoides"[OT] OR myelodysplastic[OT] OR myeloma*[OT] OR myeloproliferative[OT] OR neoplasia*[OT] OR neoplasm*[OT] OR neoplastic*[OT] OR oncolog*[OT] OR oncogene*[OT] OR psychooncolog*[OT] OR phacomatos*[OT] OR pheochromocytoma*[OT] OR radiotherap*[OT] OR sarcoma*[OT] OR carcinosarcoma*[OT] OR fibrosarcoma*[OT] OR osteosarcoma*[OT] OR

Supplemental Material 2 Search strategy by database

		chondrosarcoma*[OT] OR lymphosarcoma*[OT] OR osteosarcoma*[OT] OR rhabdomyosarcoma*[OT] OR "sezary syndrome"[OT] OR tumor*[OT] OR tumour*[OT] OR thymoma*[OT]
3	Pediatric AND parent	(Infant[MH] OR Child[MH] OR Adolescent[MH] OR Intensive Care, Neonatal[MH] OR Intensive Care Units, Neonatal[MH] OR Intensive Care Units, Pediatric[MH] OR Hospitals, Pediatric[MH] OR Neonatology[MH] OR Neonatal Nursing[MH] OR Nurses, Pediatric[MH] OR Nurseries[MH] OR Perinatology[MH] OR Perinatal Care[MH] OR Pediatrics[MH] OR Pediatricians[MH] OR Child, Hospitalized[MH] OR Child, Institutionalized[MH] OR Adolescent, Hospitalized[MH] OR Adolescent, Institutionalized[MH] OR newborn*[TIAB] OR new born*[TIAB] OR babie*[TIAB] OR baby*[TIAB] OR infant*[TIAB] OR infancy[TIAB] OR toddler*[TIAB] OR preschool*[TIAB] OR pre school*[TIAB] OR child[TIAB] OR child'[TIAB] OR childs[TIAB] OR child's[TIAB] OR children*[TIAB] OR childhood*[TIAB] OR kid[TIAB] OR kid'[TIAB] OR kids[TIAB] OR kid's[TIAB] OR boy[TIAB] OR boy'[TIAB] OR boys[TIAB] OR boy's[TIAB] OR girl[TIAB] OR girl'[TIAB] OR girls[TIAB] OR girl's[TIAB] OR schoolchild*[TIAB] OR juvenil*[TIAB] OR preadolescen*[TIAB] OR youth*[TIAB] OR adolescen*[TIAB] OR teen[TIAB] OR teen'[TIAB] OR teens[TIAB] OR teen's[TIAB] OR teenage*[TIAB] OR puber[TIAB] OR puber'[TIAB] OR pubers[TIAB] OR puber's[TIAB] OR pubert*[TIAB] OR pubescen*[TIAB] OR high school*[TIAB] OR highschool*[TIAB] OR secondary school*[TIAB] OR paediatric*[TIAB] OR pediatric*[TIAB] OR PICU*[TIAB] OR neonat*[TIAB] OR neo nat*[TIAB] OR NICU*[TIAB] OR nursery[TIAB] OR nurserie*[TIAB] OR peri natal*[TIAB] OR perinat*[TIAB] OR post natal*[TIAB] OR postnat*[TIAB] OR puericult*[TIAB] OR newborn*[OT] OR new born*[OT] OR babie*[OT] OR baby*[OT] OR infant*[OT] OR infancy[OT] OR toddler*[OT] OR preschool*[OT] OR pre school*[OT] OR child[OT] OR child'[OT] OR childs[OT] OR child's[OT] OR children*[OT] OR childhood*[OT] OR kid[OT] OR kid'[OT] OR kids[OT] OR kid's[OT] OR boy[OT] OR boy'[OT] OR boys[OT] OR boy's[OT] OR girl[OT] OR girl'[OT] OR girls[OT] OR girl's[OT] OR schoolchild*[OT] OR juvenil*[OT] OR preadolescen*[OT] OR youth*[OT] OR adolescen*[OT] OR teen[OT] OR teen'[OT] OR teens[OT] OR teen's[OT] OR teenage*[OT] OR puber[OT] OR puber'[OT] OR pubers[OT] OR puber's[OT] OR pubert*[OT] OR pubescen*[OT] OR high school*[OT] OR highschool*[OT] OR secondary school*[OT] OR paediatric*[OT] OR pediatric*[OT] OR PICU*[OT] OR neonat*[OT] OR neo nat*[OT] OR NICU*[OT] OR nursery[OT] OR nurserie*[OT] OR peri natal*[OT] OR perinat*[OT] OR post natal*[OT] OR postnat*[OT] OR puericult*[OT]) **AND** (Parents[MH:NOEXP] OR Fathers[MH] OR Mothers[MH] OR Caregivers[MH] OR parent*[TIAB] OR father*[TIAB] OR paterna*[TIAB] OR mother*[TIAB] OR matern*[TIAB] OR caregive*[TIAB] OR care give*[TIAB] OR carer*[TIAB] OR parent*[OT] OR father*[OT] OR paterna*[OT] OR mother*[OT] OR matern*[OT] OR caregive*[OT] OR care give*[OT] OR carer*[OT])
4	Combination and limitations	(#1 AND #2 AND #3) AND (english[LA] OR french[LA]) 1 232 results

2. Medline (OVID) and 2.2 All EBM Reviews

1	Quality of life	Quality of life/ OR (life quality OR quality of life OR qol OR "Cancer Therapy-Childhood Brain Tumor Survivors questionnaire" OR "pedsFACT-BrS" OR Child health questionnaire OR CHQ* OR "Child Health and Illness Profile" OR CHIP* OR DISABKID* OR DCGM* OR HRQoL* OR HRQL* OR EQ-5D* OR SF-6D* OR Kidscreen* OR KINDL* OR Health Utility Index Mark OR HUI* OR ILK* OR PedsQL*).ti,ab,kf,kw

Supplemental Material 2 (Continued) Search strategy by database

2	Cancer	exp Neoplasms/ OR exp Medical Oncology/ OR exp Radiotherapy/ OR "Oncology Service, Hospital"/ OR Oncology Nursing/ OR Integrative Oncology/ OR Cancer Pain/ OR Cancer Care Facilities/ OR (adenocarcinoma* OR adenomatous OR polypos* OR gardner syndrome* OR gardners syndrome* OR "gardner's syndrome" OR "gardner's syndromes" OR anaplasia* OR astrocytoma* OR carcinoid* OR carcinogene* OR carcinoma* OR choriocarcinoma* OR cancer* OR chemotherap* OR craniopharyngioma* OR ependymoma* OR hepatocarcinoma* OR hematoonco* OR hemato onco* OR hematolo* OR histiocytoma* OR hodgkin* OR leukemi* OR leukaemi* OR leucocythaemia* OR leucocythemia* OR lymphoma* OR erythroleukem* OR erythroleukaem* OR glioma* OR glioblastoma* OR medulloblastoma* OR nephroblastoma* OR neuroblastoma* OR pleuropulmonary blastoma* OR retinoblastoma* OR pineoblastoma* OR macroglobulinemi* OR macroglobulinaemi* OR malignan* OR melanoma* OR meningioma* OR mesothelioma* OR metasta* OR "mycosis fungoides" OR myelodysplastic OR myeloma* OR myeloproliferative OR neoplasia* OR neoplasm* OR neoplastic* OR oncolog* OR oncogene* OR psychooncolog* OR phacomatos* OR pheochromocytoma* OR radiotherap* OR sarcoma* OR carcinosarcoma* OR fibrosarcoma* OR osteosarcoma* OR chondrosarcoma* OR lymphosarcoma* OR osteosarcoma* OR rhabdomyosarcoma* OR "sezary syndrome" OR tumor* OR tumour* OR thymoma*).ti,ab,kf,kw
3	Pediatric AND parent	(exp Infant/ OR exp Child/ OR Adolescent/ OR exp Intensive Care, Neonatal/ OR exp Intensive Care Units, Neonatal/ OR exp Intensive Care Units, Pediatric/ OR exp Hospitals, Pediatric/ OR exp Neonatology/ OR exp Neonatal Nursing/ OR exp Nurses, Pediatric/ OR exp Nurseries/ OR exp Perinatology/ OR exp Perinatal Care/ OR exp Pediatrics/ OR exp Pediatricians/ OR exp Child, Hospitalized/ OR exp Child, Institutionalized/ OR exp Adolescent, Hospitalized/ OR exp Adolescent, Institutionalized/ OR (newborn* OR new born* OR babie* OR baby* OR infant* OR infancy OR toddler* OR preschool* OR pre school* OR child OR child' OR childs OR child's OR children* OR childhood* OR kid OR kid' OR kids OR kid's OR boy OR boy' OR boys OR boy's OR girl OR girl' OR girls OR girl's OR schoolchild* OR juvenil* OR preadolescen* OR youth* OR adolescen* OR teen OR teen' OR teens OR teen's OR teenage* OR puber OR puber' OR pubers OR puber's OR pubert* OR pubescen* OR high school* OR highschool* OR secondary school* OR paediatric* OR pediatric* OR PICU* OR neonat* OR neo nat* OR NICU* OR nursery OR nurserie* OR peri natal* OR perinat* OR post natal* OR postnat* OR puericult*).ti,ab,kf,kw) **AND** (Parents/ OR Fathers/ OR Mothers/ OR Caregivers/ OR (parent* OR father* OR paterna* OR mother* OR matern* OR caregive* OR care give* OR carer*).ti,ab,kf,kw)
4	Combinaison	(1 AND 2 AND 3) AND (english or french).lg Medline: 1 248 results All EBM Reviews: 149 results

3. Embase

1	Quality of life	exp "Quality of life"/ OR (life quality OR quality of life OR qol OR "Cancer Therapy-Childhood Brain Tumor Survivors questionnaire" OR "pedsFACT-BrS" OR Child health questionnaire OR CHQ* OR "Child Health and Illness Profile" OR CHIP* OR DISABKID* OR DCGM* OR HRQoL* OR HRQL* OR EQ-5D* OR SF-6D* OR Kidscreen* OR KINDL* OR Health Utility Index Mark OR HUI* OR ILK* OR PedsQL*).ti,ab,kw
2	Cancer	exp neoplasm/ OR exp oncology/ OR exp radiotherapy/ OR cancer center/ OR exp oncology nursing/ OR cancer pain/ OR (adenocarcinoma* OR adenomatous OR polypos* OR gardner syndrome* OR gardners syndrome* OR "gardner's syndrome" OR "gardner's syndromes" OR anaplasia*

Supplemental Material 2 (Continued) Search strategy by database

		OR astrocytoma* OR carcinoid* OR carcinogene* OR carcinoma* OR choriocarcinoma* OR cancer* OR chemotherap* OR craniopharyngioma* OR ependymoma* OR hepatocarcinoma* OR hematoonco* OR hemato onco* OR hematolo* OR histiocytoma* OR hodgkin* OR leukemi* OR leukaemi* OR leucocythaemia* OR leucocythemia* OR lymphoma* OR erythroleukem* OR erythroleukaem* OR glioma* OR glioblastoma* OR medulloblastoma* OR nephroblastoma* OR neuroblastoma* OR pleuropulmonary blastoma* OR retinoblastoma* OR pineoblastoma* OR macroglobulinemi* OR macroglobulinaemi* OR malignan* OR melanoma* OR meningioma* OR mesothelioma* OR metasta* OR "mycosis fungoides" OR myelodysplastic OR myeloma* OR myeloproliferative OR neoplasia* OR neoplasm* OR neoplastic* OR oncolog* OR oncogene* OR psychooncolog* OR phacomatos* OR pheochromocytoma* OR radiotherap* OR sarcoma* OR carcinosarcoma* OR fibrosarcoma* OR osteosarcoma* OR chondrosarcoma* OR lymphosarcoma* OR osteosarcoma* OR rhabdomyosarcoma* OR "sezary syndrome" OR tumor* OR tumour* OR thymoma*).ti,ab,kw
3	Pediatric AND parent	(exp childhood/ OR juvenile/ OR adolescent/ OR exp child health care OR exp postnatal care/ OR exp pediatrics/ OR exp pediatric nursing/ OR perinatal care/ OR hospitalized adolescent/ OR hospitalized child/ OR exp child care/ OR pediatric hospital/ OR pediatrician/ OR maternity ward/ OR delivery room/ OR (newborn* OR new born* OR babie* OR baby* OR infant* OR infancy OR toddler* OR preschool* OR pre school* OR child OR child' OR childs OR child's OR children* OR childhood* OR kid OR kid' OR kids OR kid's OR boy OR boy' OR boys OR boy's OR girl OR girl' OR girls OR girl's OR schoolchild* OR juvenil* OR preadolescen* OR youth* OR adolescen* OR teen OR teen' OR teens OR teen's OR teenage* OR puber OR puber' OR pubers OR puber's OR pubert* OR pubescen* OR high school* OR highschool* OR secondary school* OR paediatric* OR pediatric* OR PICU* OR neonat* OR neo nat* OR NICU* OR nursery OR nurserie* OR peri natal* OR perinat* OR post natal* OR postnat* OR puericult*).ti,ab,kw) **AND** (parent/ OR father/ OR mother/ OR caregiver/ OR (parent* OR father* OR paterna* OR mother* OR matern* OR caregive* OR care give* OR carer*).ti,ab,kw)
4	Combination and limitations	(1 AND 2 AND 3) AND (english or french).lg 2 373 results

4. PsychINFO

1	Quality of life	"Quality of life"/ OR (life quality OR quality of life OR qol OR "Cancer Therapy-Childhood Brain Tumor Survivors questionnaire" OR "pedsFACT-BrS" OR Child health questionnaire OR CHQ* OR "Child Health and Illness Profile" OR CHIP* OR DISABKID* OR DCGM* OR HRQoL* OR HRQL* OR EQ-5D* OR SF-6D* OR Kidscreen* OR KINDL* OR Health Utility Index Mark OR HUI* OR ILK* OR PedsQL*).ti,ab,id
2	Cancer	exp Neoplasms/ OR Oncology/ OR Radiation Therapy/ OR (adenocarcinoma* OR adenomatous OR polypos* OR gardner syndrome* OR gardners syndrome* OR "gardner's syndrome" OR "gardner's syndromes" OR anaplasia* OR astrocytoma* OR carcinoid* OR carcinogene* OR carcinoma* OR choriocarcinoma* OR cancer* OR chemotherap* OR craniopharyngioma* OR ependymoma* OR hepatocarcinoma* OR hematoonco* OR hemato onco* OR hematolo* OR histiocytoma* OR hodgkin* OR leukemi* OR leukaemi* OR leucocythaemia* OR leucocythemia* OR lymphoma* OR erythroleukem* OR erythroleukaem* OR glioma* OR glioblastoma* OR medulloblastoma* OR nephroblastoma* OR neuroblastoma* OR pleuropulmonary blastoma* OR retinoblastoma* OR pineoblastoma* OR macroglobulinemi* OR macroglobulinaemi* OR malignan* OR melanoma* OR meningioma* OR mesothelioma* OR metasta* OR "mycosis fungoides" OR myelodysplastic OR myeloma* OR

Supplemental Material 2 (Continued) Search strategy by database

		myeloproliferative OR neoplasia* OR neoplasm* OR neoplastic* OR oncolog* OR oncogene* OR psychooncolog* OR phacomatos* OR pheochromocytoma* OR radiotherap* OR sarcoma* OR carcinosarcoma* OR fibrosarcoma* OR osteosarcoma* OR chondrosarcoma* OR lymphosarcoma* OR osteosarcoma* OR rhabdomyosarcoma* OR "sezary syndrome" OR tumor* OR tumour* OR thymoma*).ti,ab,id
3	Pediatric AND parent	((100 OR 120 OR 140 OR 160 OR 180 OR 200).ag OR (newborn* OR new born* OR babie* OR baby* OR infant* OR infancy OR toddler* OR preschool* OR pre school* OR child OR child' OR childs OR child's OR children* OR childhood* OR kid OR kid' OR kids OR kid's OR boy OR boy' OR boys OR boy's OR girl OR girl' OR girls OR girl's OR schoolchild* OR juvenil* OR preadolescen* OR youth* OR adolescen* OR teen OR teen' OR teens OR teen's OR teenage* OR puber OR puber' OR pubers OR puber's OR pubert* OR pubescen* OR high school* OR highschool* OR secondary school* OR paediatric* OR pediatric* OR PICU* OR neonat* OR neo nat* OR NICU* OR nursery OR nurserie* OR peri natal* OR perinat* OR post natal* OR postnat* OR puericult*).ti,ab,id) **AND** (Parents/ OR Fathers/ OR Mothers/ OR Caregivers/ OR (parent* OR father* OR paterna* OR mother* OR matern* OR caregive* OR care give* OR carer*).ti,ab,id)
4	Combination and limitations	(1 AND 2 AND 3) AND (english or french).lg 405 results

5. CINAHL Complete

1	Quality of life	MH("Quality of life" OR Comfort) OR TI(life quality OR quality of life OR qol OR "Cancer Therapy-Childhood Brain Tumor Survivors questionnaire" OR "pedsFACT-BrS" OR Child health questionnaire OR CHQ* OR "Child Health and Illness Profile" OR CHIP* OR DISABKID* OR DCGM* OR HRQoL* OR HRQL* OR EQ-5D* OR SF-6D* OR Kidscreen* OR KINDL* OR Health Utility Index Mark OR HUI* OR ILK* OR PedsQL*) OR AB(life quality OR quality of life OR qol OR "Cancer Therapy-Childhood Brain Tumor Survivors questionnaire" OR "pedsFACT-BrS" OR Child health questionnaire OR CHQ* OR "Child Health and Illness Profile" OR CHIP* OR DISABKID* OR DCGM* OR HRQoL* OR HRQL* OR EQ-5D* OR SF-6D* OR Kidscreen* OR KINDL* OR Health Utility Index Mark OR HUI* OR ILK* OR PedsQL*)
2	Cancer	MH(Neoplasms+ OR Oncology+ OR Radiotherapy+ OR "Oncologic Nursing"+ OR "Oncology Care Units" OR "Oncologic Care" OR Cancer Pain OR "Cancer Care Facilities" OR "Cancer Patients") OR TI(adenocarcinoma* OR adenomatous OR polypos* OR gardner syndrome* OR gardners syndrome* OR "gardner's syndrome" OR "gardner's syndromes" OR anaplasia* OR astrocytoma* OR carcinoid* OR carcinogene* OR carcinoma* OR choriocarcinoma* OR cancer* OR chemotherap* OR craniopharyngioma* OR ependymoma* OR hepatocarcinoma* OR hematoonco* OR hemato onco* OR hematolo* OR histiocytoma* OR hodgkin* OR leukemi* OR leukaemi* OR leucocythaemia* OR leucocythemia* OR lymphoma* OR erythroleukem* OR erythroleukaem* OR glioma* OR glioblastoma* OR medulloblastoma* OR nephroblastoma* OR neuroblastoma* OR pleuropulmonary blastoma* OR retinoblastoma* OR pineoblastoma* OR macroglobulinemi* OR macroglobulinaemi* OR malignan* OR melanoma* OR meningioma* OR mesothelioma* OR metasta* OR "mycosis fungoides" OR myelodysplastic OR myeloma* OR myeloproliferative OR neoplasia* OR neoplasm* OR neoplastic* OR oncolog* OR oncogene* OR psychooncolog* OR phacomatos* OR pheochromocytoma* OR radiotherap* OR sarcoma* OR carcinosarcoma* OR fibrosarcoma* OR osteosarcoma* OR chondrosarcoma* OR lymphosarcoma* OR osteosarcoma* OR rhabdomyosarcoma* OR "sezary syndrome" OR tumor* OR tumour* OR thymoma*) OR

Supplemental Material 2 (Continued) Search strategy by database

		AB(adenocarcinoma* OR adenomatous OR polypos* OR gardner syndrome* OR gardners syndrome* OR "gardner's syndrome" OR "gardner's syndromes" OR anaplasia* OR astrocytoma* OR carcinoid* OR carcinogene* OR carcinoma* OR choriocarcinoma* OR cancer* OR chemotherap* OR craniopharyngioma* OR ependymoma* OR hepatocarcinoma* OR hematoonco* OR hemato onco* OR hematolo* OR histiocytoma* OR hodgkin* OR leukemi* OR leukaemi* OR leucocythaemia* OR leucocythemia* OR lymphoma* OR erythroleukem* OR erythroleukaem* OR glioma* OR glioblastoma* OR medulloblastoma* OR nephroblastoma* OR neuroblastoma* OR pleuropulmonary blastoma* OR retinoblastoma* OR pineoblastoma* OR macroglobulinemi* OR macroglobulinaemi* OR malignan* OR melanoma* OR meningioma* OR mesothelioma* OR metasta* OR "mycosis fungoides" OR myelodysplastic OR myeloma* OR myeloproliferative OR neoplasia* OR neoplasm* OR neoplastic* OR oncolog* OR oncogene* OR psychooncolog* OR phacomatos* OR pheochromocytoma* OR radiotherap* OR sarcoma* OR carcinosarcoma* OR fibrosarcoma* OR osteosarcoma* OR chondrosarcoma* OR lymphosarcoma* OR osteosarcoma* OR rhabdomyosarcoma* OR "sezary syndrome" OR tumor* OR tumour* OR thymoma*)
3	Pediatric AND parent	(MH(Infant+ OR "Infant, Newborn"+ OR Child+ OR Adolescence+ OR "Intensive Care, Neonatal"+ OR "Intensive Care Units, Pediatric"+ OR "Pediatric Units"+ OR "Hospitals, Pediatric" OR Pediatrics+ OR "Pediatric Care"+ OR "Pediatric nursing"+ OR "Pediatric Nurse Practitioners"+ OR "Nurseries, Hospital" OR "Nursing Units" OR "Perinatal Care" OR "Postnatal Care"+ OR "American Academy of Pediatrics") OR TI(newborn* OR new born* OR babie* OR baby* OR infant* OR infancy OR toddler* OR preschool* OR pre school* OR child OR child' OR childs OR child's OR children* OR childhood* OR kid OR kid' OR kids OR kid's OR boy OR boy' OR boys OR boy's OR girl OR girl' OR girls OR girl's OR schoolchild* OR juvenil* OR preadolescen* OR youth* OR adolescen* OR teen OR teen' OR teens OR teen's OR teenage* OR puber OR puber' OR pubers OR puber's OR pubert* OR pubescen* OR high school* OR highschool* OR secondary school* OR paediatric* OR pediatric* OR PICU* OR neonat* OR neo nat* OR NICU* OR nursery OR nurserie* OR peri natal* OR perinat* OR post natal* OR postnat* OR puericult*) OR AB(newborn* OR new born* OR babie* OR baby* OR infant* OR infancy OR toddler* OR preschool* OR pre school* OR child OR child' OR childs OR child's OR children* OR childhood* OR kid OR kid' OR kids OR kid's OR boy OR boy' OR boys OR boy's OR girl OR girl' OR girls OR girl's OR schoolchild* OR juvenil* OR preadolescen* OR youth* OR adolescen* OR teen OR teen' OR teens OR teen's OR teenage* OR puber OR puber' OR pubers OR puber's OR pubert* OR pubescen* OR high school* OR highschool* OR secondary school* OR paediatric* OR pediatric* OR PICU* OR neonat* OR neo nat* OR NICU* OR nursery OR nurserie* OR peri natal* OR perinat* OR post natal* OR postnat* OR puericult*)) AND (MH(Parents OR Fathers OR Mothers OR Caregivers) OR TI(parent* OR father* OR paterna* OR mother* OR matern* OR caregive* OR care give* OR carer*) OR AB(parent* OR father* OR paterna* OR mother* OR matern* OR caregive* OR care give* OR carer*))
4	Combination and limitations	S1 AND S2 AND S3 AND LA(english OR french) 668 results

Supplementary material 3 STROBE Statement

Checklist of items that should be included in reports of cross-sectional studies

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
Outcome data	15*	Report numbers of outcome events or summary measures

Supplementary material 3 (continued)

Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.com

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Chapitre 3. Discussion

Retour sur nos résultats

L'article actuel est une méta-analyse synthétisant 20 études qui examinent les évaluations parentales et autorapportées de la qualité de vie liée à la santé de l'enfant avec un cancer sur un ou plus des domaines global, physique et psychologique. En tant que contribution centrale, cette méta-analyse fournit des estimés agrégés des accords et différences entre les évaluations parentales et autorapportées en oncologie pédiatrique.

D'abord, nous avons constaté que les niveaux d'accord entre les parents et les enfants étaient modérées pour les dimensions globale et physique et faible pour la dimension psychologique. Ces résultats sont concordants autres d'autres méta-analyses de l'accord parent-enfant portant sur des conditions cliniques de l'enfant, comme celles menées par Achenbach, McConaughy, and Howell (1987) et De Los Reyes and Kazdin (2005). En effet, un accord plus élevé est généralement constaté dans la littérature lorsque les domaines observés sont plus objectifs et externes. Cela peut être attribué aux différences entre la visibilité ou l'importance d'un domaine comparativement à un autre dans la trajectoire du cancer (Eiser et Morse, 2001; Upton, Lawford et Eiser, 2008). Alors que domaine physique de la qualité de vie liée à la santé accentue les symptômes discernables et particulièrement importants sur le plan clinique durant les traitements pour le cancer, le domaine psychologique évalue des symptômes moins perceptibles comme la peur et la détresse.

Par la suite, nous avons constaté que les parents sous-rapportent la qualité de vie liée à la santé de leurs enfants. Une explication possible est que les croyances des parents sur l'impact du cancer les mènent à percevoir davantage de conséquences négatives sur la qualité de vie liée à la santé de leur enfant (Kazak et al., 2004; McCubbin, Balling, Possin, Frierdich et Bryne, 2002). Une

autre explication plausible est que le niveau de détresse des parents, singulièrement élevé en oncologie pédiatrique à cause des peurs de la récidive et de la détresse, peut biaiser à la baisse les évaluations parentales (Abate et al., 2018; De Los Reyes et Kazdin, 2005; Sultan, Leclerc, Rondeau, Burns et Abate, 2015). Notablement, ce résultat s'interprète aussi comme étant que les enfants sur-rapportent leur qualité de vie. Effectivement, il se peut que les enfants évaluent leurs symptômes comme étant normatifs et indéniables à l'expérience du cancer, un phénomène appelé « response shift » (Sprangers et Schwartz, 2008). En ajout à cela, il se peut que les enfants évaluent leurs symptômes sous un jour favorable ou les minimalisent, un phénomène perçu comme un désir de retour à la normalité (Miedeman, Hamilton et Easley, 2007).

Enfin, nous avons recensé qu'autant les caractéristiques des participants (âge de l'enfant, état clinique, culture) et les caractéristiques de l'étude (instruments et cotes de qualité) étaient associées aux degrés d'accord et aux différences parents-enfants sur la qualité de vie liée à la santé. L'un de nos résultats les plus intéressants est que la culture asiatique était reliée à un meilleur accord et moins de différences, tandis que la culture américano-européenne était reliée à un plus faible accord et davantage de différences. Il apparaît donc que l'évaluation de la qualité de vie peut être façonnée par les disparités culturelles dans le fonctionnement familial, la socialisation et les attitudes. D'ailleurs, la capacité de l'enfant à assimiler les normes culturelles transmises est soutenue par les parents et peut entraver l'évaluation de sa qualité de vie (Eiser et Morse, 2001). En ce sens, il a été démontré que les parents asiatiques ont tendance à être plus stricts et orientés vers le collectivisme, et que les parents américano-européens ont tendance à être indulgents et orientés sur l'individualisme (Kimg et Wong, 2002; Mousavi, Low et Hashim, 2016). Par ailleurs, nous avons illustré l'intérêt de considérer le statut clinique de l'enfant dans l'évaluation de la qualité de vie liée à la santé, car un accord parents-enfants plus grand pour les enfants en traitement et de

plus grandes différences parents-enfants chez les survivants ont été notés. Sûrement qu'une attention particulière doit être portée à la qualité de vie liée à la santé durant les traitements, car l'état des enfants y est volatile (Eiser, 2004). En contraste, les survivants ont un état de santé stable qui nécessite moins d'attention et de surveillance parentale (Landier, Wallance et Hudson, 2006). Aussi, nous avons réitéré la considération qui doit être attribuée à l'âge de l'enfant lors de l'évaluation de la qualité de vie en démontrant de plus grands niveaux d'accord entre les parents et les enfants comparativement aux parents et adolescents. Certainement, les parents ont plus d'occasions d'obtenir de l'information sur l'état des jeunes enfants, mais moins avec les adolescents, car la communication parents-enfants est perturbée à l'adolescence (Dubas et Gerris, 2002; Ehrlich, Richards, Lejuez et Cassidy, 2016; Van Dijk et al., 2014).

Limites de notre étude

La présente étude porte également des limites qu'il est essentiel d'identifier afin d'interpréter conséquemment les résultats. D'un côté, les résultats font face à des limites qui se retrouvent communément dans les revues et méta-analyses systématiques. Nous ne pouvons pas écarter la possibilité d'un biais de sélection des études, puisque nous avons inclus uniquement celles où les évaluations parentales et autorapportées fournissaient suffisamment d'indices statistiques pour calculer des mesures agrégées. Aussi, le fait de synthétiser les résultats de toutes les études en un seul paramètre peut entraîner une perte de données ou une hétérogénéité supplémentaire qui influence de façon significative les indices abrégés obtenus (Rosenthal, 1991). De même, le biais de publication n'a pas été calculé pour tous les domaines et mesures par manque de puissance, car l'analyse statistique ne peut pas être utilisée avec moins de dix études par méta-analyse (Rosenthal, 1991; Silva et al., 2019). De l'autre côté, les articles scientifiques inclus ont aussi limité notre méta-analyse. Les études incluses étaient transversales, ce qui fait que nous ne

pouvons estimer les niveaux d'accord et les différences qu'à des points fixes et non pas suivre longitudinalement la trajectoire du cancer. De plus, nous nous sommes en partie fiés aux données démographiques fournies par les auteurs pour catégoriser les modérateurs des études incluses. Cela a comme effet que les critères de catégorisation des modérateurs n'étaient pas uniformes dans toutes les études incluses. Par exemple, certaines études ont défini les survivants de cancer comme étant des enfants présentement hors traitement et d'autres comme des enfants dont le traitement a pris fin au minimum cinq ans auparavant. De manière similaire, les études incluses ne prodiguaient pas toutes les informations démographiques qui auraient pu servir à examiner les modérateurs des accords et différences entre les évaluations parents-enfants. Par conséquent, un nombre restreint de modérateurs ont été analysés comme facteurs explicatifs de l'accord et des différences entre les évaluations des parents et des enfants. D'autres modérateurs potentiels n'ont pas été étudiés la présente étude en raison d'un manque de puissance statistique, comme le stress parental, le statut socio-économique et le sexe des enfants et des parents.

Forces de notre étude

Au-delà de ses limites, l'article actuel se doit aussi d'être considéré à la lumière de ses forces. Premièrement, elle fournit les premières données quantitatives synthétiques de l'accord, des différences et des modérateurs entre les évaluations parentales et autorapportées de la qualité de vie liée à la santé de l'enfant tout au long de la trajectoire du cancer. Deuxièmement, les procédés méthodologiques, les statistiques et la rédaction de l'article scientifique ont été effectués conformément aux lignes directrices de PRISMA. Troisièmement, nous avons aussi intégré des moyens pour incorporer la littérature grise à notre recherche documentaire. Quatrièmement, l'utilisation d'une approche non catégorique a permis d'augmenter la validité écologique et de généraliser les résultats à de différents diagnostics de cancer ainsi qu'aux patients se trouvant à

différents stades de la maladie. Cinquièmement, la variable principale d'étude, soit la qualité de vie liée à la santé, représente le principal objectif de traitement et soins en oncologie. Enfin, les variables modératrices ont été choisies à la fois en fonction de la littérature et d'études publiées et offrent un compte rendu de l'activité empirique dans ce domaine.

Pistes de recherches futures

Nos résultats amènent des constats et des réflexions en ce qui a trait à la direction des études prospectives concernant les évaluations parentales et autorapportées de la qualité de vie liée à la santé du patient en oncologie pédiatrique. Pour commencer, il est suggéré que les chercheurs incorporent ou rendent disponible un plus grand nombre de données sur les caractéristiques descriptives de leurs participants pour faciliter l'étude des modérateurs. Pareillement, dans l'étude des modérateurs, les chercheurs devraient prendre en compte les variables familiales et les caractéristiques parentales. Il est crucial d'étendre l'étude des facteurs explicatifs en utilisant le sexe des parents, la détresse parentale et d'autres facteurs familiaux comme modérateurs. En ajout à cela, les études devraient fournir des données statistiques plus exhaustives (c.-à-d. moyennes, écarts-types et corrélations) qui permettent facilement de calculer les mesures d'accord et de différences dyadiques. En terminant, il semble pertinent de souligner que la méthode multi-informant est la manière recommandée de recueillir de l'information sur la qualité de vie liée à la santé de l'enfant. Ainsi, les instruments utilisés par les études, en plus d'être fiables et valides, doivent avoir été construits pour mesurer à la fois la perspective des parents (version proxy) et la perspective des enfants (version autorapportée).

Les implications cliniques

Notre recherche a des implications cliniquement significatives pour la planification des traitements et la délivrance des soins en oncologie pédiatrique. En effet, il a été démontré de façon

longitudinale que les différences parents-enfants entrainent un mauvais ajustement et des difficultés comportementales et émotionnelles chez les enfants (De Los Reyes, 2001; Guion, Mrug et Windle, 2009). Appliqué au domaine de l'oncologie, il devient alors primordial d'investiguer et de mieux comprendre les écarts parents-enfants afin de favoriser l'ajustement à la maladie et de réduire les répercussions potentielles des écarts sur la qualité de vie liée à la santé des enfants. Les données de notre étude ont permis d'établir des moyennes agrégées des accords et des différences entre les évaluations parentales et autorapportées de la qualité de vie liée à la santé de l'enfant. Ces dernières pourraient potentiellement être considérées comme étant les niveaux d'accords et les différences minimales attendus de cette population (Eiser et Varni, 2013). Ce faisant, elles pourraient être utilisées en tant que barème par les cliniciens pour évaluer si des investigations plus poussées sur la nature des différences parents-enfants sont nécessaires avant de planifier le traitement (Eiser et Varni, 2013). Aussi, les données ont permis d'établir la direction générale de la différence entre les évaluations des parents et des enfants en indiquant que les parents rapportent une qualité de vie inférieure aux enfants. Les cliniciens pourraient, dans le cadre d'un traitement adapté, aider les familles présentant de larges différences parents-enfants et prévenir l'apparition de problématiques subséquentes liées à la qualité de vie. Ensemble, nos résultats indiquent en outre que les niveaux d'accord et d'écart entre les parents et les enfants varient selon le domaine, l'état clinique de l'enfant, l'âge, la culture familiale, l'instrument et l'évaluation de la qualité. Ainsi, ils ont démontré que les différences entre les parents et leurs enfants sur la qualité de vie liée à la santé sont plus que des erreurs méthodologiques et représentent plutôt de l'information pertinente sur la relation entre les parents et l'enfant atteint de cancer.

Conclusion

Somme toute, l'étude réalisée dans le cadre de l'essai doctoral portait sur l'analyse synthétique quantitative des niveaux d'accord et différences entre les évaluations parentales et autorapportées de la qualité de vie liée à la santé en oncologie pédiatrique. Les résultats ont démontré des niveaux d'accord modérés pour les domaines globaux et physiques et passables pour le domaine psychologique ; des différences de magnitudes faibles pour le domaine physique et de magnitude moyenne pour le domaine psychologique ; ainsi qu'un plus grand niveau d'accord parents-enfants associé à un plus jeune âge chez les enfants, aux cultures asiatiques, à des enfants recevant actuellement un traitement contre le cancer et à des études de meilleure qualité.

L'évaluation de la qualité de vie liée à la santé fait partie intégrale du suivi médical tout au long de la trajectoire du cancer chez l'enfant. Les ressources, tant en recherche que sur le plan clinique, sont dorénavant dédiées à améliorer et favoriser la qualité de vie des patients durant et après les traitements. Une meilleure connaissance des niveaux d'accord et différences parents-enfants moyennes est utile pour déterminer les situations cliniques où une investigation plus approfondie est nécessaire avant de planifier les traitements. En terminant, il apparaît particulièrement important de connaitre et étudier les facteurs qui modèrent l'accord et les différences entre les perspectives des parents et des enfants sur la qualité de vie liée à la santé de l'enfant pour améliorer la planification et la délivrance des interventions en oncologie pédiatrique.

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