Appendix S1. Supplemental Methods

After the 2-stage article screening process identified 36 articles for inclusion, concepts were configured into theories in 2 subsequent stages, as described below. Throughout this process, recommendations for theory development were applied[1]: attention was paid to the relationships among variables and clear definitions of concepts.

The primary goal of the first stage was to identify and record the chief reason for changes in HRQOL among children and/or parents. Information was extracted from each article: study design, primary outcome, secondary outcome(s), key predictors, covariates, whose HRQOL was evaluated (children and/or parents), direction of change in HRQOL (improvement, decline, no change), key findings, age and disease of affected children, and notes on any other relevant information.

Two key concepts emerged from the first stage. Improvements in HRQOL were seen when participants engaged in interventions that shifted their focus away from the health condition and when participants were involved in educational interventions. This was particularly evident among studies that reported improvements in HRQOL among children with obesity whose weight stayed the same or even increased.[2,3]

In the second stage, the primary goal was to understand the mechanisms that led to improved HRQOL following interventions based on the concepts identified during the first round. Each intervention was reevaluated and a table was made of study characteristics: group-based vs solo, commonalities among participants (eg, shared culture, ethnicity, or language), participants (ie, parents, children, or both), setting where the intervention was administered (eg, health care vs non–health care), and the country where the intervention was administered.

On completion of the table, concept definitions were compared across studies. There was generally strong agreement on definitions, but variability in the depth to which the theoretical frameworks or conceptual models associated were described. For example, a study provided a definition of hope, referring to the Snyder hope theory, and used a validated hope scale, whereas another stated that there "was an increase in hope" among participants without defining hope or providing further details.[5,6]

Separate concept maps[4] were drawn for self-concept interventions and knowledge interventions. For self-concept, there appeared to be links between HRQOL and interventions that shifted participants' focus away from their health conditions and to new roles (eg, cooking lessons for children with obesity). This observation led to an exploration of the broader theoretical literature about self-concept and the creation of a more detailed self-concept concept map. Similarities between self-concept and HRQOL were identified (eg, congruence between perceived self and ideal self yields high HRQOL, and congruence between self-image and ideal self yields a healthy self-concept). These findings ultimately led to the self-concept theory.

For knowledge, 2 distinct clusters of concepts were identified on the concept map, including a cluster of concepts about worry, uncertainty, parental anxiety, fear, and anticipatory guidance. Further evaluation of these concepts led to the Mishel uncertainty in illness theory, which says that disease-specific information may improve HRQOL among people who live with diseases with heterogeneous outcomes.[4] Both the Mishel uncertainty in illness theory and the concept map for anticipatory guidance revealed similar associations between improved HRQOL from improved understanding and reduced worry, fear, and anxiety. These findings ultimately led to the theory that the HRQOL of children with MS and their parents may improve when they are provided with information about how MS may manifest and affect their lives.

With further evaluation, the authors felt that "knowledge" was a more appropriate term for the theory related to education or information because the goal of these studies was for families to actually understand and apply the information received.

The second distinct cluster included social connections, peer support or acceptance, conflict resolution, communication, and psychosocial family risk, all of which relate to connections with other people. Review of the concept maps revealed a relationship between improved HRQOL and increased knowledge, improved communication, and improved social connections. These observations led to the knowledge theory related to enhanced communication and social connections.

After configuring the self-concept and knowledge theories, concept maps were drawn and evaluated for hope, goal setting, problem-solving, self-efficacy, locus of control, goal attainment experience, motivational interviews, perceived vulnerability, and coping skills. It became clear that many of the concepts cited as associated with improvements in HRQOL overlapped with the core concepts of the Snyder hope theory. The hope theory presented for this study includes the Snyder hope theory with extension to the additional concepts identified in this review.

In summary, this configurative review was carried through iterative stages by a single author. The first stage involved identification of themes among the primary concepts cited for improvements in HRQOL. The second stage involved the creation of concept maps and the configuration of concept maps to ultimately generate theories. Findings from this review should be considered in light of the limitation that it was performed by a single author. Attempts to overcome this limitation included extensive documentation of methods, observations, findings, and decisions.

Appendix S2. Qualitative Interview Topic Guide

The interviewees were invited to describe:

1) reactions to previous findings;
2) reactions to theories;
3) overlap between theories and usual care;
4) how they ascertain HRQOL among children with MS and their parents;
5) barriers to providing psychosocial care to children with MS and their parents.

Table S1. Details of Included Studies

Study	Design	Disease	Participants	Age of Children, y	Location
Grano et al[1]	Mediator	ARM	Mothers	6-15	Italy
Chini et al[2]	Longitudinal (PI)	Asthma	Children	5-12	Italy
Seid et al[3]	RCT	Asthma	Parents & children	2-14	US
Flores et al[4]	RCT	Asthma	Parents & children	2-18	US
Baron Nelson et al[5]	Longitudinal (PI)	Brain tumor	Parents	< 21	US
Barrera et al[6]	Longitudinal (PI)	Brain tumor survivors	Children	8-18	Canada
Racine et al[7]	Buffer	Cancer	Parents & children	6-17	Canada
Santos* et al[8]	Mediators	Cancer	Parents & children	8-20	Portugal
Sigurdardottir et al[9]	Longitudinal (PI)	Cancer	Parents & children	5-18	Iceland
Huang et al[10]	Mediator	Cancer survivors	Parents	8-23	US
Brosig et al[11]	Longitudinal (PI)	Cardiology	Children	2.7-17	US
Minooei et al[12]	RCT	Chronic renal failure	Parents & children	8-12	Iran
Hsieh et al[13]	Longitudinal (PI), comparison group	Developmental delays	Parents & children	18-36 months	Taiwan

Study	Design	Disease	Participants	Age of Children, y	Location
Hsieh et al[14]	Longitudinal (PI)	Developmental delays	Parents & children	18-36 months	Taiwan
Joo et al[15]	Longitudinal (PI)	Epilepsy	Parents & children	10-18	South Korea
Knibb et al[16]	Longitudinal (PI)	Food allergy	Children	11-12	UK
Phadnis et al[17]	Longitudinal (PI)	Hemophilia	Parents	2-18	India
Varni et al[18]	Mediator	Inflammatory bowel disease	Children	13-18	US
Rainone et al[19]	Moderator	MS	Children	14-23	Italy
Steele et al[20]	Longitudinal (PI)	Obesity	Parents & children together	7-17	US
Cronk et al[21]	Longitudinal (PI)	Obesity	Parents & children	7-11	US
Quinlan et al[22]	Intervention, longitudinal (weight loss camp)	Obesity	Children	9-18	US
Wallander et al[23]	Mediation	Obesity	Children	10-13	US
Rudolf et al[24]	Longitudinal (PI); qualitative interviews	Obesity	Parents & children	8-16	UK
Freira et al[25]	RCT (parallel design involving 2 groups)	Obesity	Children	14-19	Portugal
Mollerup et al[26]	Longitudinal (PI), quasiexperimental study	Obesity	Parents & children	3-18	Denmark
Pratt et al[27]	Longitudinal correlation	Obesity	Parents & children	8-18	US
Dalton et al[28]	Longitudinal (PI)	Obesity	Caregivers	5-12	US
Daniel et al[29]	RCT, no findings	Sickle cell disease	Parents & children	6-12	US
de Wit et al[30]	RCT	Type 1 diabetes	Children	13-17	Netherlands
Murphy et al[31]	RCT	Type 1 diabetes	Parents & children	12-16	UK

Study	Design	Disease	Participants	Age of Children, y	Location
Laffel et al[32]	RCT	Type 1 diabetes	Parents & children	8-17	US
Jaser et al[33]	RCT	Type 1 diabetes	Children	11-14	US
Grey et al[34]	RCT	Type 1 diabetes	Children	11-14	US
Oriel et al[35]	Longitudinal (PI)	Various	Children	5-18	US
Houtzager et al[36]	Mediator	Community sample	Parents	5-18	Netherlands

ARM, anorectal malformation; MS, multiple sclerosis; PI, program intervention; RCT, randomized controlled trial; UK, United Kingdom; US, United States.

The 36 included articles consisted of 10 RCTs, 18 pre- and post-intervention evaluations, and 8 studies of mediators/moderators or buffers among the following diseases: ARM (n = 1), asthma (n = 3), brain tumors (n = 1), cancer survivors (n = 2), cancer (n = 3), cardiology (n = 1), chronic renal failure (n = 1), developmental delays (n = 2), epilepsy (n = 1), food allergy (n = 1), hemophilia (n = 1), inflammatory bowel disease (n = 1), MS (n = 1), overweight or obesity (n = 9), sickle cell disease (n = 1), type 1 diabetes (n = 5), and multiple diseases (n = 1). One article covered a community-based healthy population. Developmental delays were defined as speech delays with or without cognitive deficits among 18- to 36-month-old children who were on the waitlist for early intervention services. Among the 28 studies that evaluated psychosocial interventions, 15 (54%) involved both parents and children, and 19 (68%) involved interactions between families that were facing the same disease.

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2. Chini L, Iannini R, Chianca M, et al. Happy Air, a successful school-based asthma educational and interventional program for primary school children. *J Asthma*. 2011;48(4):419-426. doi:10.3109/02770903.2011.563808

3. Seid M, Varni JW, Gidwani P, Gelhard LR, Slymen DJ. Problem-solving skills training for vulnerable families of children with persistent asthma: report of a randomized trial on health-related quality of life outcomes. *J Pediatr Psychol*. 2010;35(10):1133-1143. doi:10.1093/jpepsy/jsp133

4. Flores G, Bridon C, Torres S, et al. Improving asthma outcomes in minority children: a randomized, controlled trial of parent mentors. *Pediatrics*. 2009;124(6):1522-1532. doi:10.1542/peds.2009-0230

5. Baron Nelson M, Riley K, Arellano K. Adding a parent to the brain tumor team: evaluating a peer support intervention for parents of children with brain tumors. *J Pediatr Oncol Nurs*. 2018;35(3):218-228. doi:10.1177/1043454218762797

6. Barrera M, Schulte F. A group social skills intervention program for survivors of childhood brain tumors. *J Pediatr Psychol*. 2009;34(10):1108-1118. doi:10.1093/jpepsy/jsp018

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17. Phadnis S, Kar A. The impact of a haemophilia education intervention on the knowledge and health related quality of life of parents of Indian children with haemophilia. *Haemophilia*. 2017;23(1):82-88. doi:10.1111/hae.13070

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