human hero

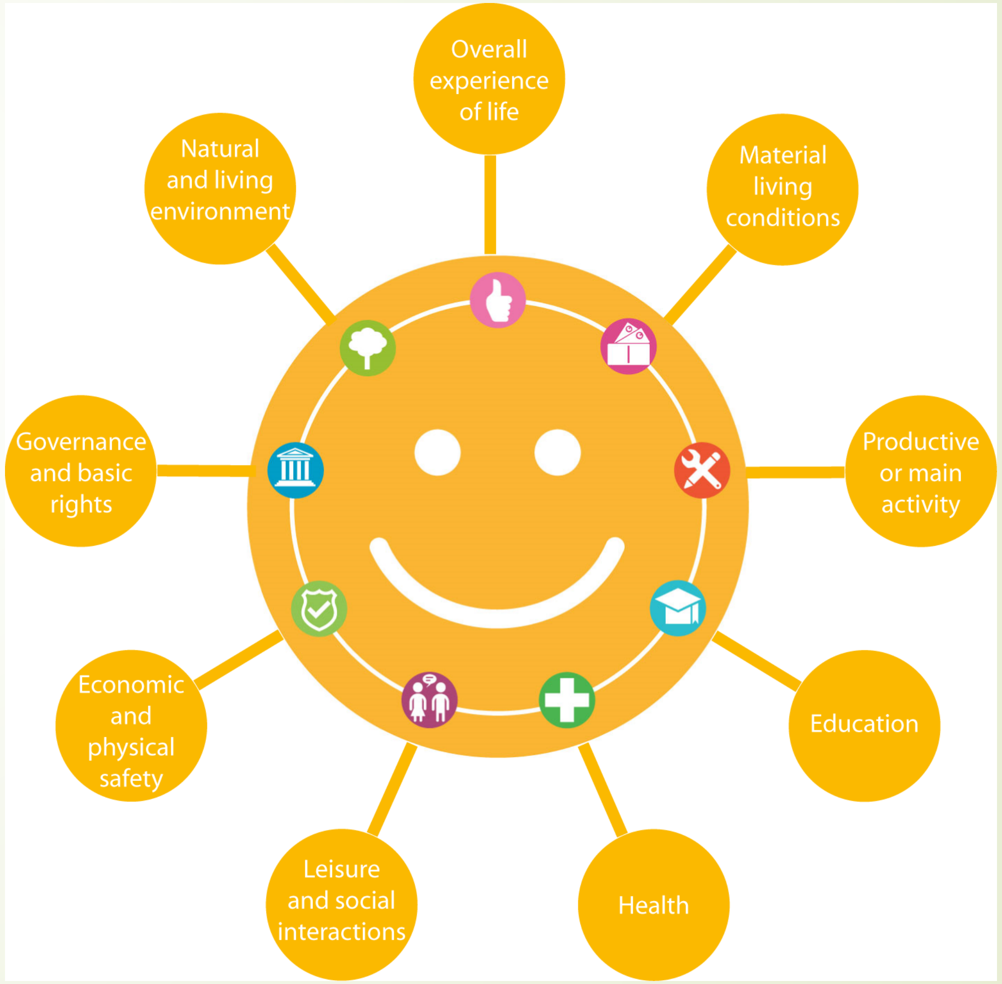
evaluation & rehabilitation after oncology

CALIDAD DE VIDA

CARLOTA CALVO
SEVILLA 2016

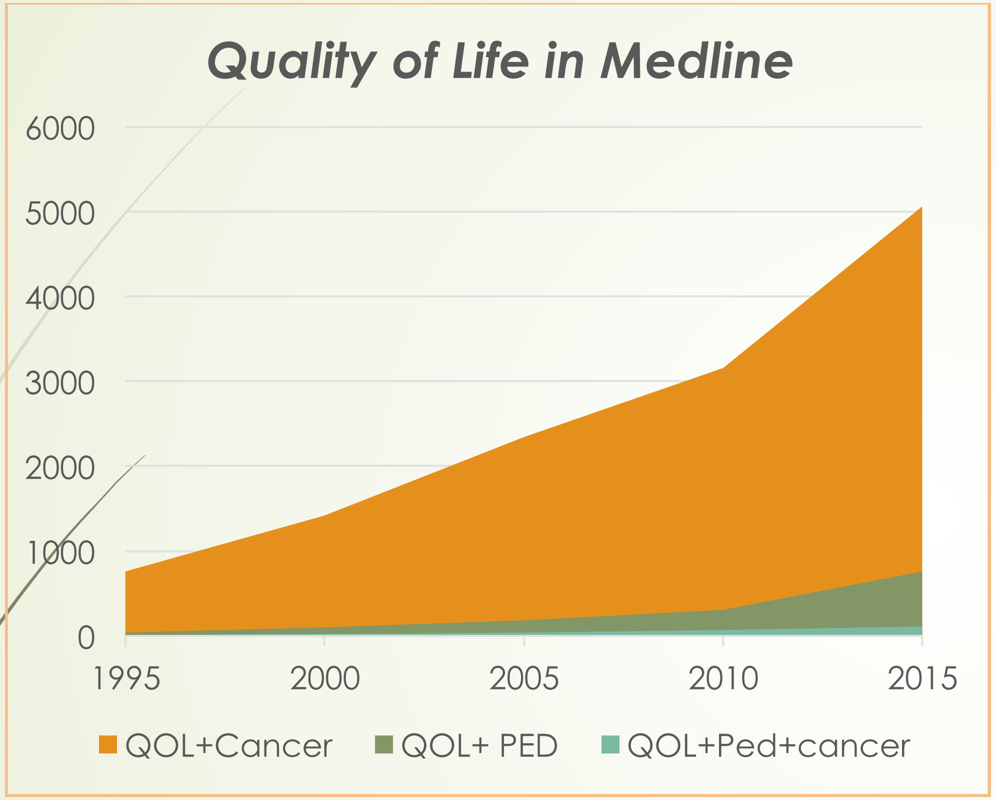
QUALITY OF LIFE

Quality of life (QOL) is a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life. Although health is one of the important domains of overall quality of life, there are other domains as well—for instance, jobs, housing, schools, the neighbourhood. Aspects of culture, values, and spirituality are also key domains of overall quality of life that add to the complexity of its measurement.



human hero evaluation & rehabilitation after oncology

QUALITY OF LIFE


Quality of Life in Medline


APPLIED RESEARCH IN
Quality of Life
The Official Journal of the International Society for Quality of Life Studies
Springer


Quality of Life Research
Springer


Health and Quality of Life Outcomes
BioMed Central

	QOL	QOL+Cancer	QOL+PED	QOL+Ped+Cancer
1995	3195	943	45	14
2005	10734	2344	184	42
… 2015	285148	61301	6094	1273

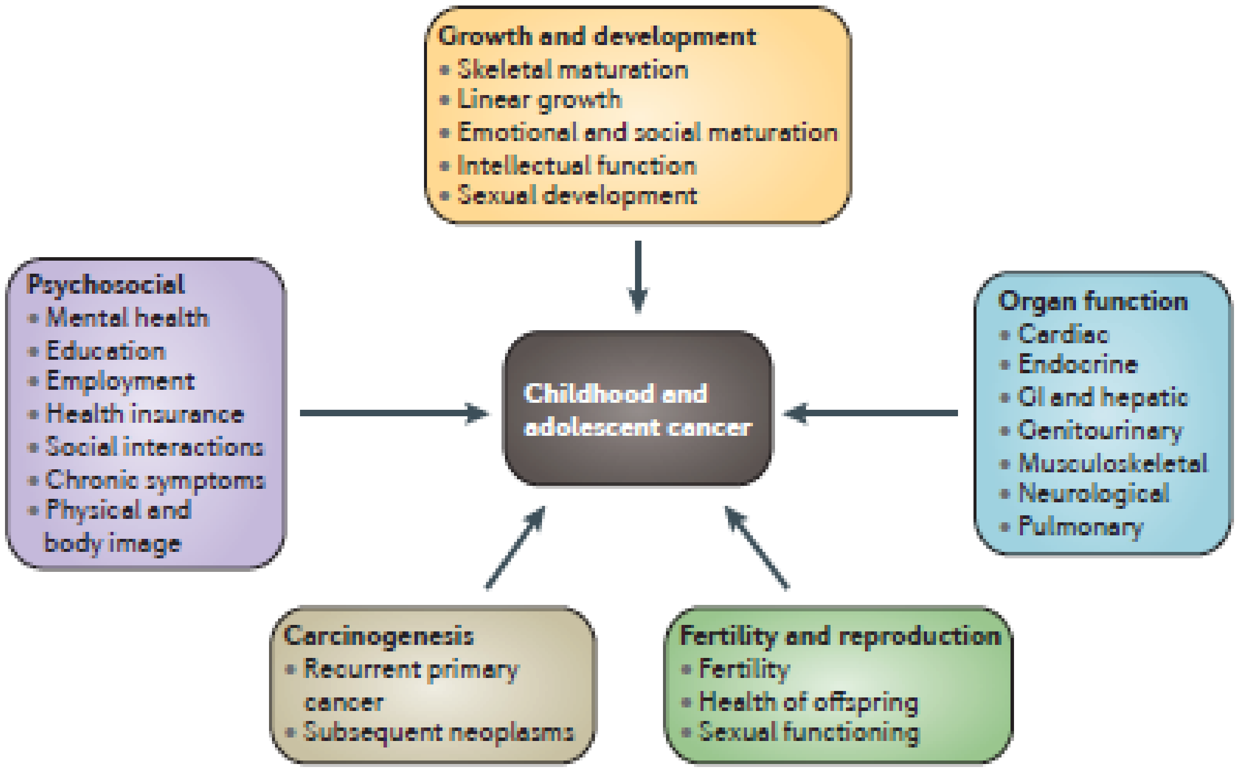
THE ERICE STATEMENT

The long-term goal of the cure and care of the child with cáncer is that he/she become a resilent, fully functioning, autonomous adult with an optimal health-related quality of life, accepted in the society at the same level of his/her age peers.

Erice (Sicily) 2006
EJC 2007;43:1778-1780


Leisure
Health & Safety
Work & Community Options
Personal Control
Choices & Decision Making
Rights
Community Inclusion
Relationships
Organizational Structure
Human Resources
Rights of Individuals
Health & Safety

QUALITY OF LIFE



Growth and development
- Skeletal maturation
- Linear growth
- Emotional and social maturation
- Intellectual function
- Sexual development

Psychosocial
- Mental health
- Education
- Employment
- Health insurance
- Social interactions
- Chronic symptoms
- Physical and body image

Childhood and adolescent cancer

Organ function
- Cardiac
- Endocrine
- GI and hepatic
- Genitourinary
- Musculoskeletal
- Neurological
- Pulmonary

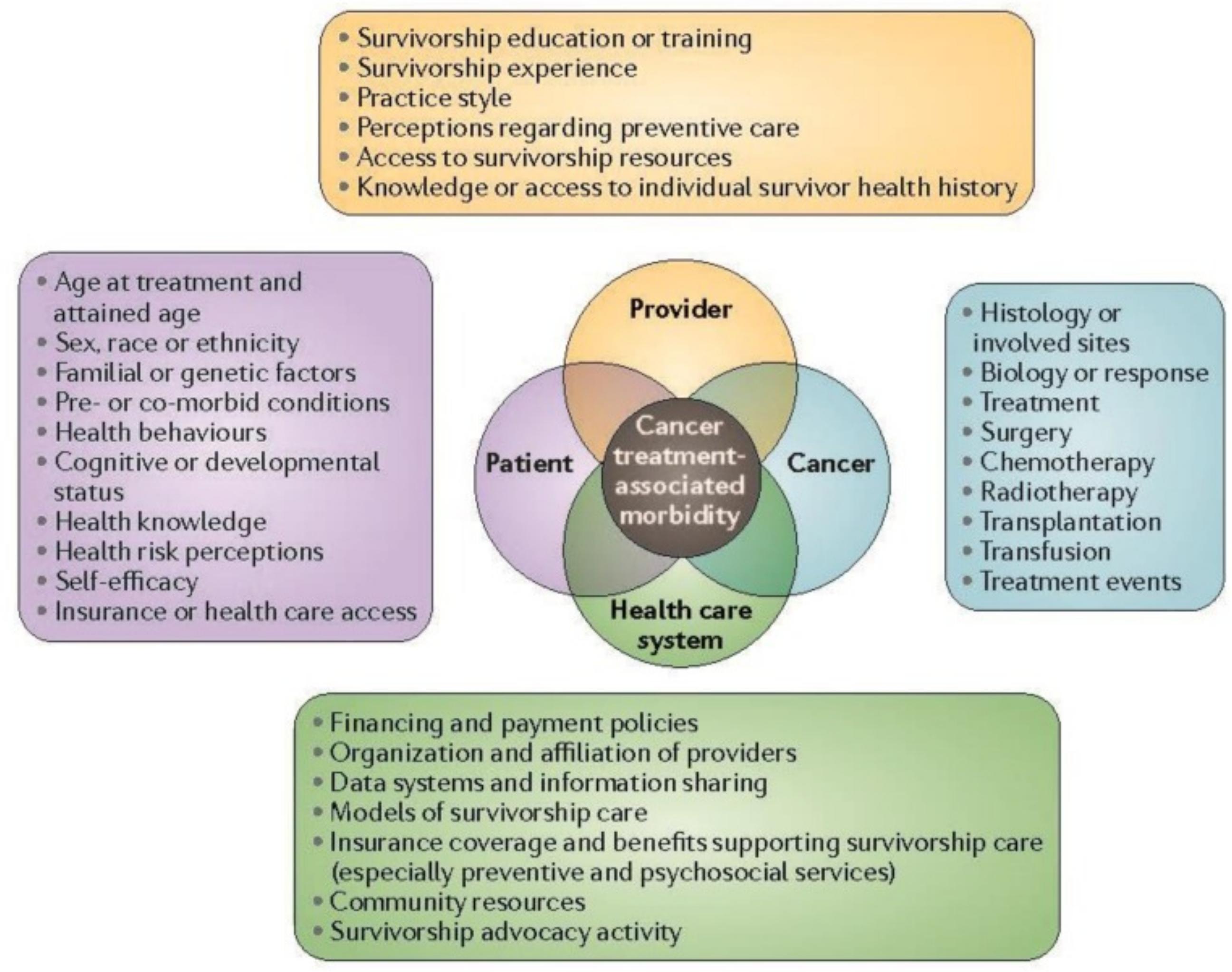
Carcinogenesis
- Recurrent primary cancer
- Subsequent neoplasms

Fertility and reproduction
- Fertility
- Health of offspring
- Sexual functioning

Figure 2 | **Range of health-related and quality-of-life outcomes among long-term survivors of childhood and adolescent cancers.** This figure shows some of the issues that are faced by survivors of childhood and adolescent cancers. GI, gastrointestinal.

Robinson L et al. Nature Reviews/Cancer 2014;14:61-70

QUALITY OF LIFE



- Survivorship education or training
- Survivorship experience
- Practice style
- Perceptions regarding preventive care
- Access to survivorship resources
- Knowledge or access to individual survivor health history

- Age at treatment and attained age
- Sex, race or ethnicity
- Familial or genetic factors
- Pre- or co-morbid conditions
- Health behaviours
- Cognitive or developmental status
- Health knowledge
- Health risk perceptions
- Self-efficacy
- Insurance or health care access

- Histology or involved sites
- Biology or response
- Treatment
- Surgery
- Chemotherapy
- Radiotherapy
- Transplantation
- Transfusion
- Treatment events

- Financing and payment policies
- Organization and affiliation of providers
- Data systems and information sharing
- Models of survivorship care
- Insurance coverage and benefits supporting survivorship care (especially preventive and psychosocial services)
- Community resources
- Survivorship advocacy activity

Inter-relationships. This figure shows patient-, cancer-, health care system- and provider-related issues that affect cancer treatment-associated morbidity among the long-term survivors of childhood and adolescent cancer

Robinson L et al. Nature Reviews/Cancer 2014;14:61-70

QUALITY OF LIFE OF CHILDHOOD AND ADOLESCENTS WITH CANCER

QUESTIONS:

- What are mesuring:
  - Physical funtioning
  - Psychological functioning
  - Social functioning
  - Symptoms and late effects

- When:
  - Diagnosis
  - End of treatment
  - Relapse
  - Progression
  - End of life
  - Survivorship (early or late)

QUALITY OF LIFE OF CHILDHOOD AND ADOLESCENTS WITH CANCER

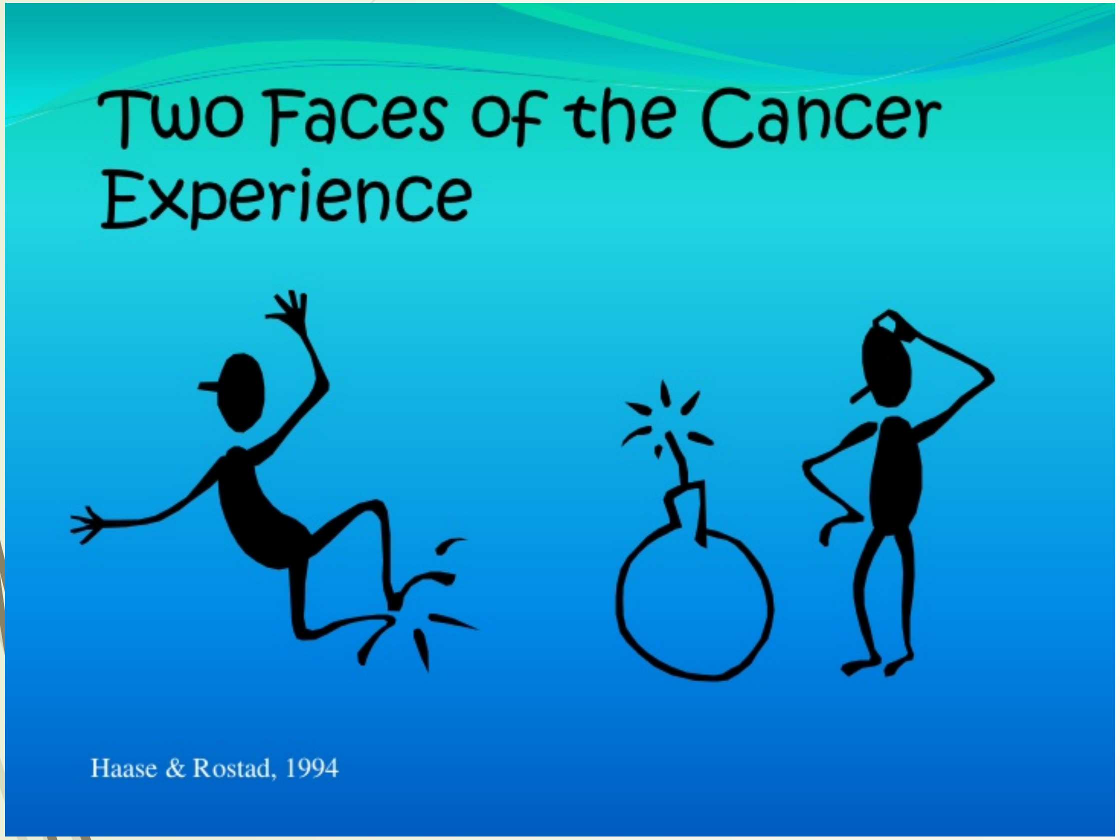
QUESTIONS:

- To whom:
    - parents
    - professionals
    - subjects

- how:
    - Generic instruments
    - Cancer specific instruments
    - Interviews
    - Cross sectional or longitudinal studies

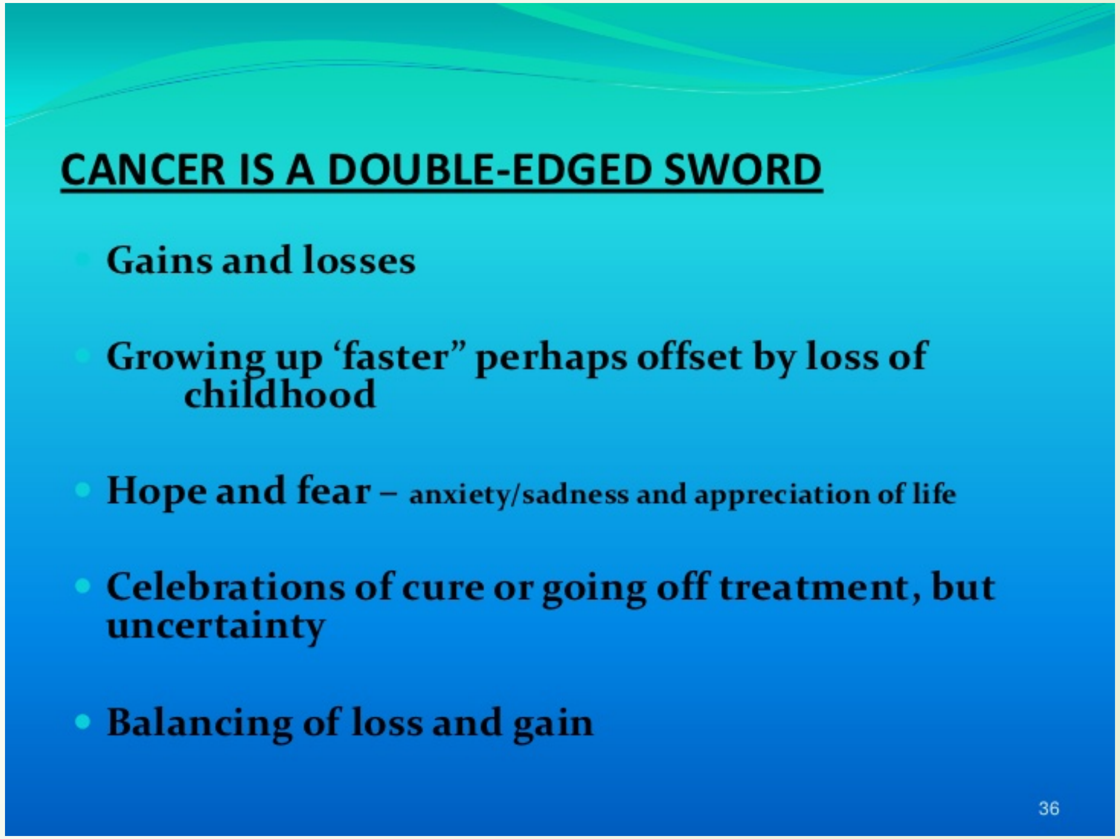
- Related to:
    - Type of tumour
    - Type of treatment
    - Specific population

Psychosocial Outcomes of sharing a diagnosis of cancer with a pediatric patient



Two Faces of the Cancer Experience

Haase & Rostad, 1994



CANCER IS A DOUBLE-EDGED SWORD

- Gains and losses
- Growing up 'faster" perhaps offset by loss of childhood
- Hope and fear – anxiety/sadness and appreciation of life
- Celebrations of cure or going off treatment, but uncertainty
- Balancing of loss and gain

Psychosocial Outcomes of sharing a diagnosis of cancer with a pediatric patient

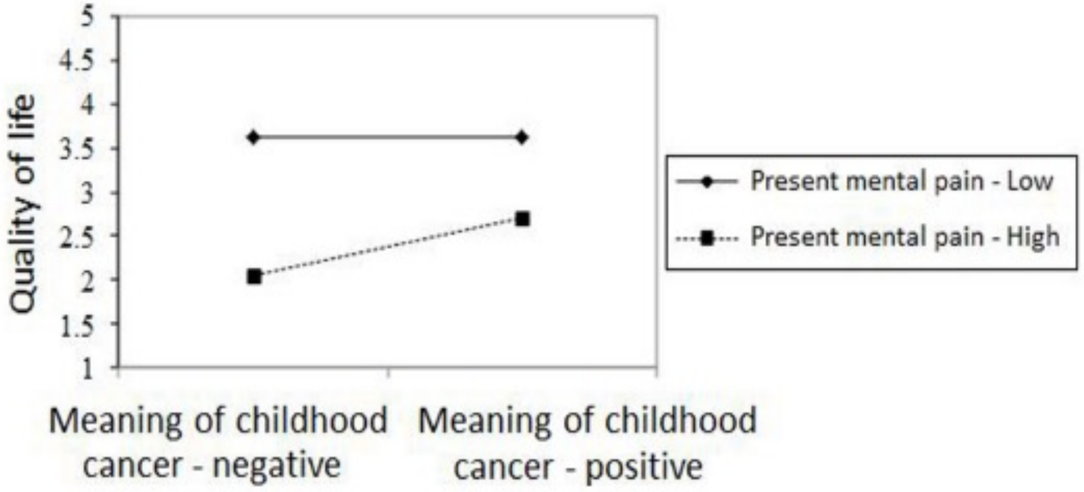
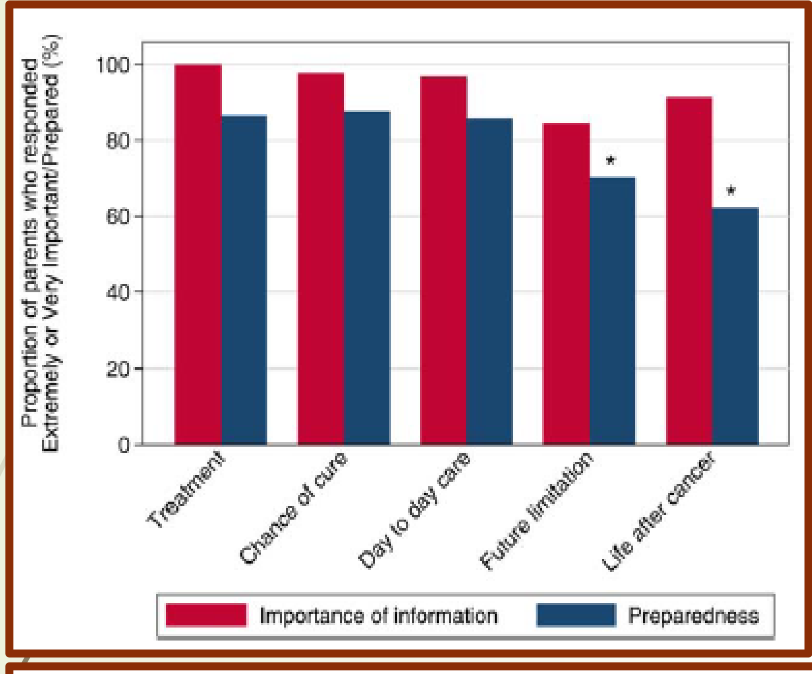


FIGURE 4 | The relationship between meaning of cancer in childhood and quality of life in respondents with high/low present mental pain.

In the group diagnosed at a younger age, those who had received “good information” were found to have better quality of life, lower mental pain, and higher mental pain tolerance than did those in the same group (diagnosed at a younger age) who received “not good information.” By contrast, in the group diagnosed during adolescence, those who had received “not good information” scored higher on these measures than did their counterparts who had received “good information.”

Raz H et al. Frontiers in Pediatrics 2016 ;4: art 70

QUALITY OF LIFE. INFORMATION AND COMMUNICATION



Parents and physicians underestimated children's risks of the late effects of cancer therapy. Given the discrepancy between parent expectations of late effects and children's experiences of late effects, it is not surprising that parents felt unprepared for their child's life after cancer treatment.

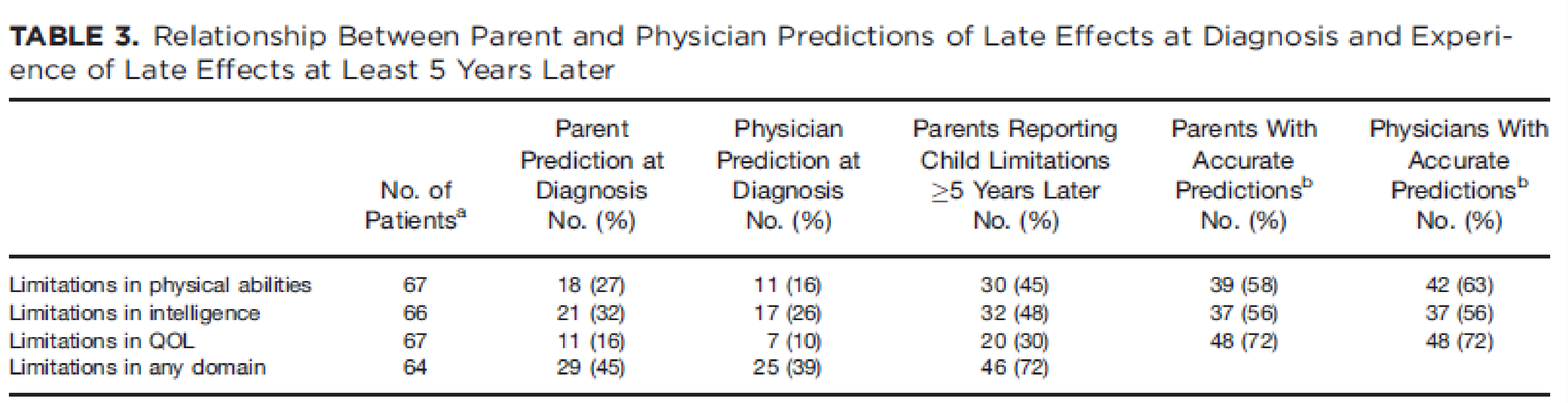
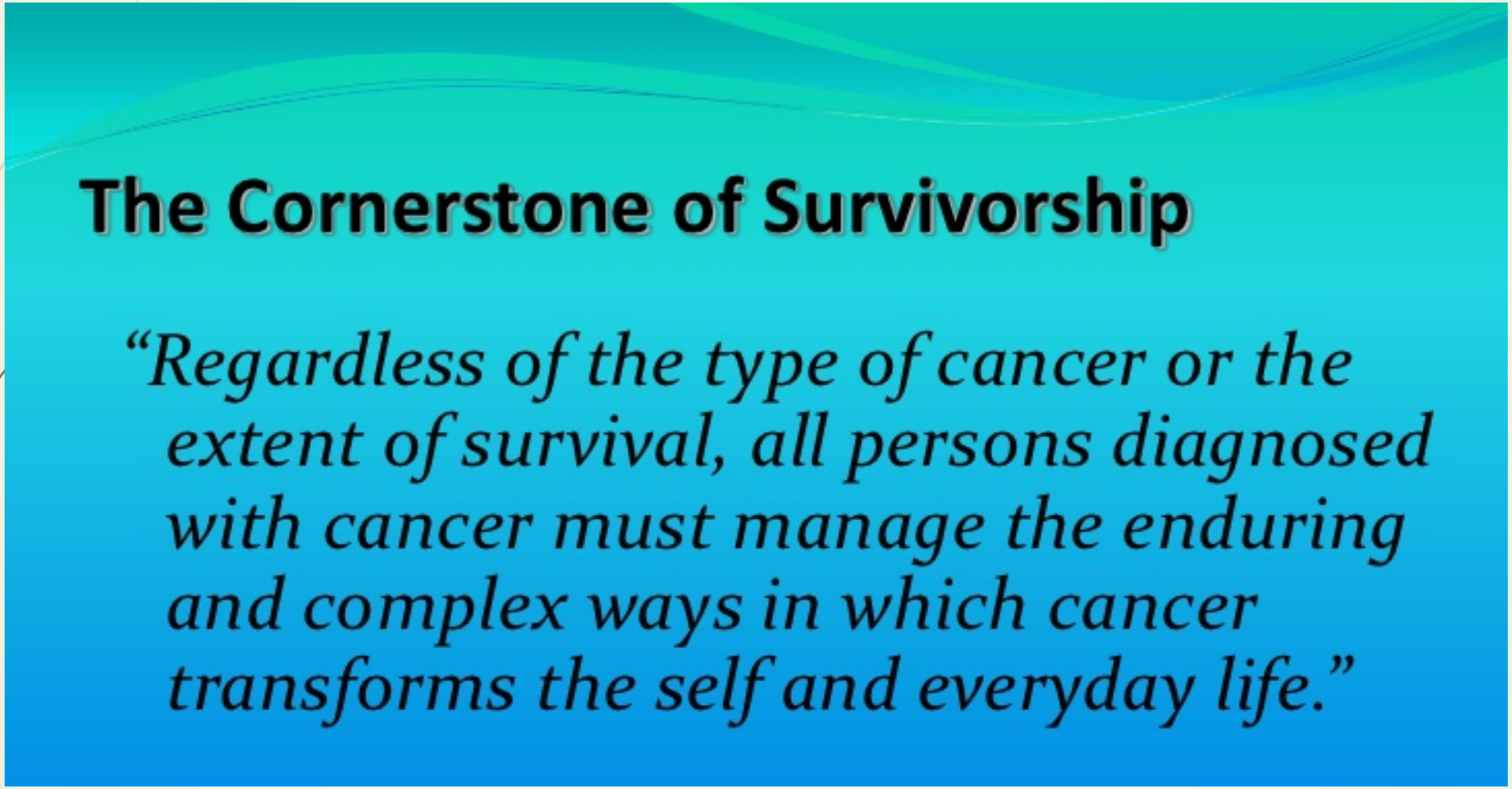


TABLE 3. Relationship Between Parent and Physician Predictions of Late Effects at Diagnosis and Experience of Late Effects at Least 5 Years Later

	No. of Patients[a]	Parent Prediction at Diagnosis No. (%)	Physician Prediction at Diagnosis No. (%)	Parents Reporting Child Limitations ≥5 Years Later No. (%)	Parents With Accurate Predictions[b] No. (%)	Physicians With Accurate Predictions[b] No. (%)
Limitations in physical abilities	67	18 (27)	11 (16)	30 (45)	39 (58)	42 (63)
Limitations in intelligence	66	21 (32)	17 (26)	32 (48)	37 (56)	37 (56)
Limitations in QOL	67	11 (16)	7 (10)	20 (30)	48 (72)	48 (72)
Limitations in any domain	64	29 (45)	25 (39)	46 (72)		

Greenzang KA et al.
Cancer 2016;
122(16):2587-2594

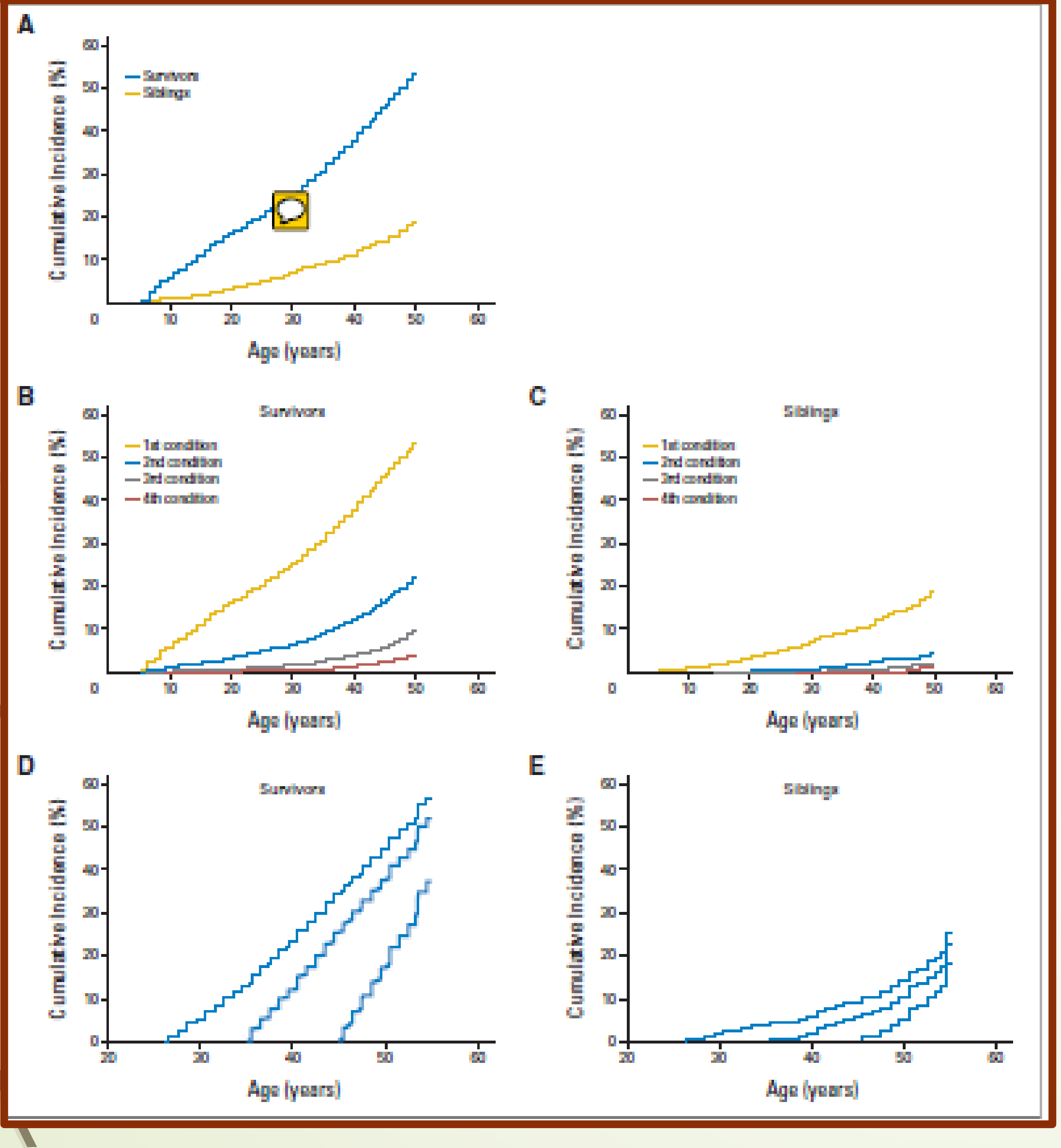
QUALITY OF LIFE. INFORMATION AND COMMUNICATION



The Cornerstone of Survivorship

“Regardless of the type of cancer or the extent of survival, all persons diagnosed with cancer must manage the enduring and complex ways in which cancer transforms the self and everyday life.”

QUALITITY OF LIFE. AGING



Risk for morbidity and mortality continues across the life span for cancer survivors and actually increases beyond age 35 years when compared with a population of siblings. By age 50 years, more than half of survivors have experienced a severe, disabling, or life-threatening event, including death. These data raise concerns for acceleration of the aging process in this population.

Armstrong GT et al. JCO 2014;32:1218-1227

QUALITY OF LIFE. AGING

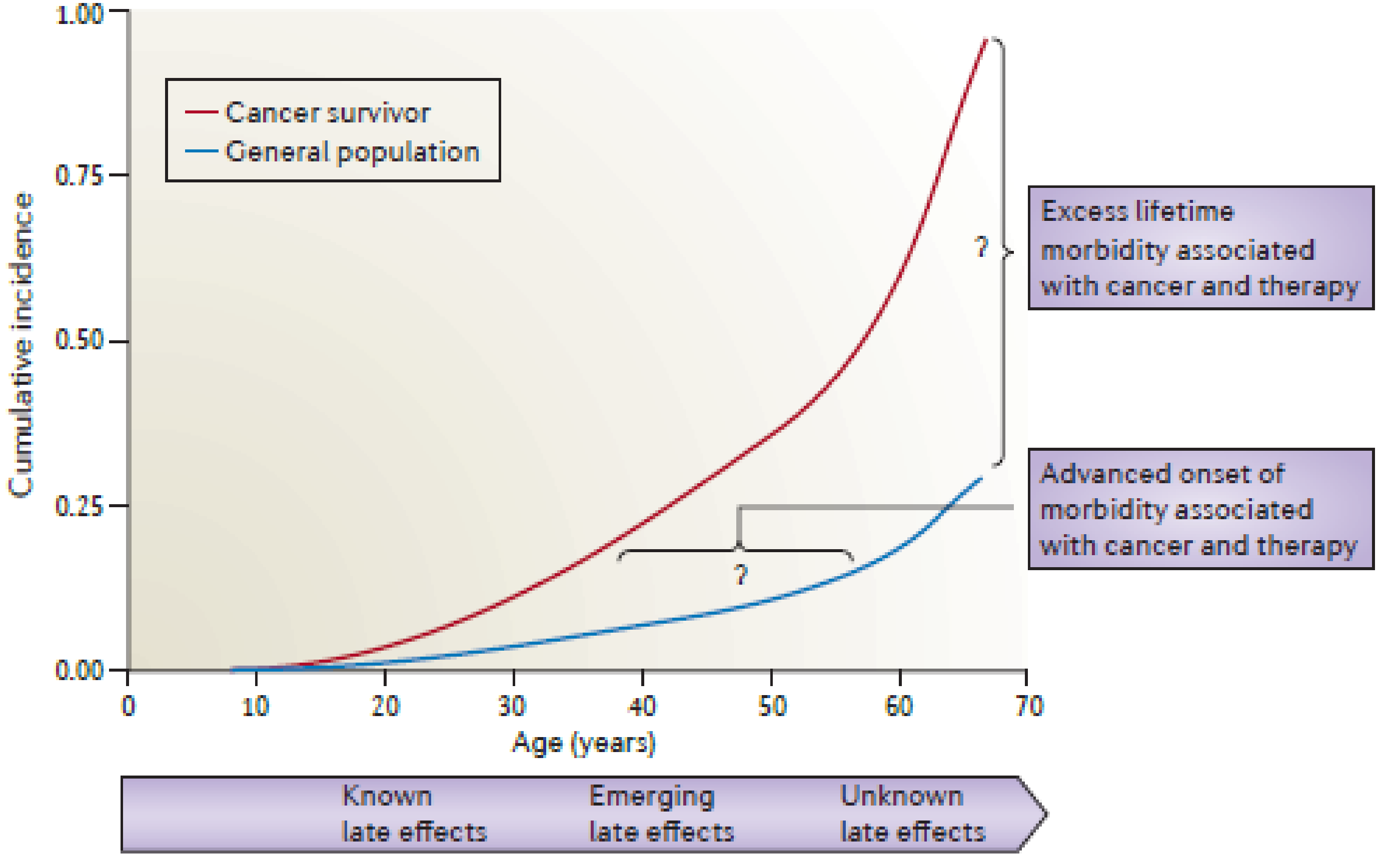
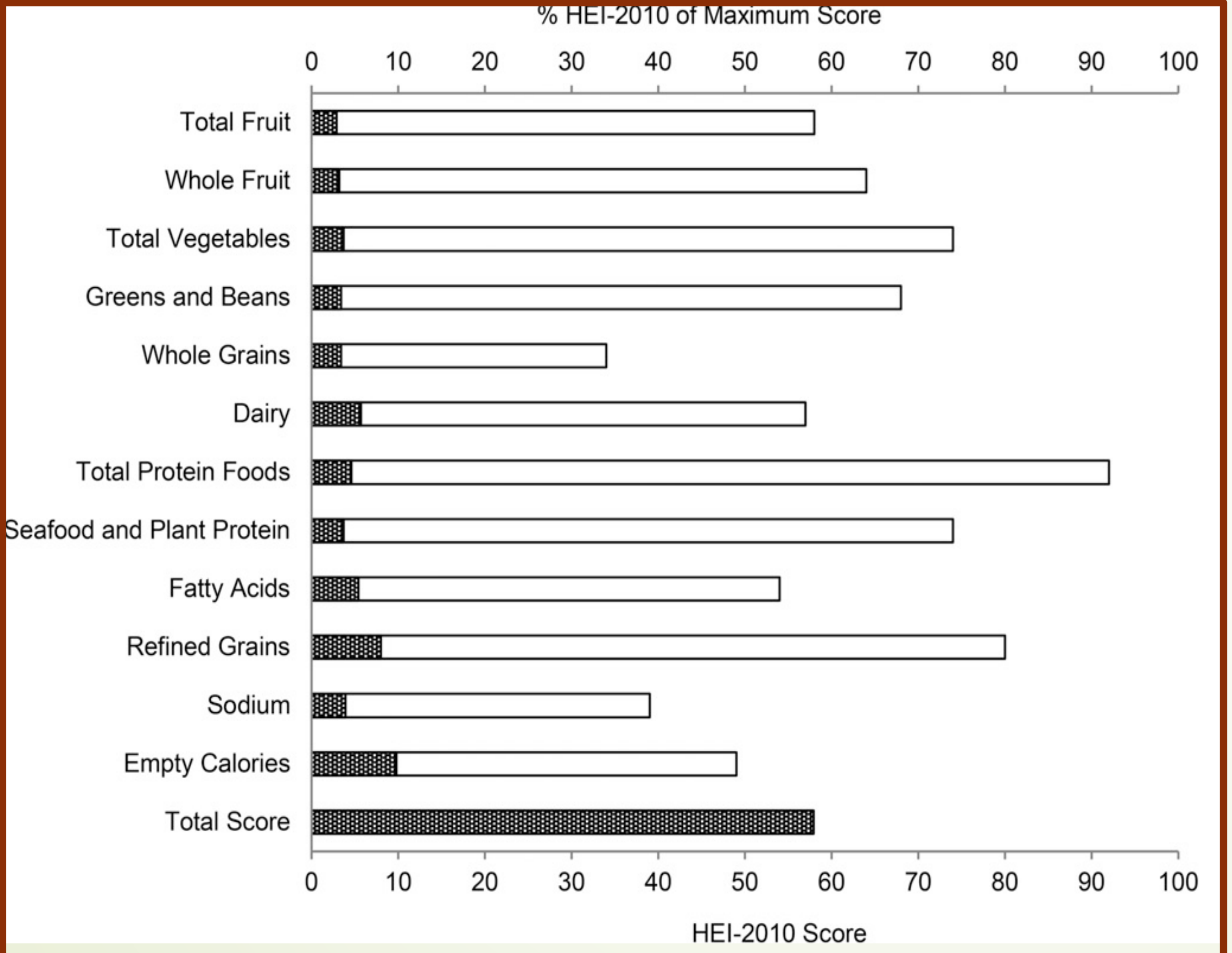


Figure 4 | A theoretical framework. This figure shows the gaps in knowledge regarding the long-term outcomes among ageing childhood and adolescent cancer survivors.

Robinson L et al. Nature Reviews/Cancer 2014;14:61-70

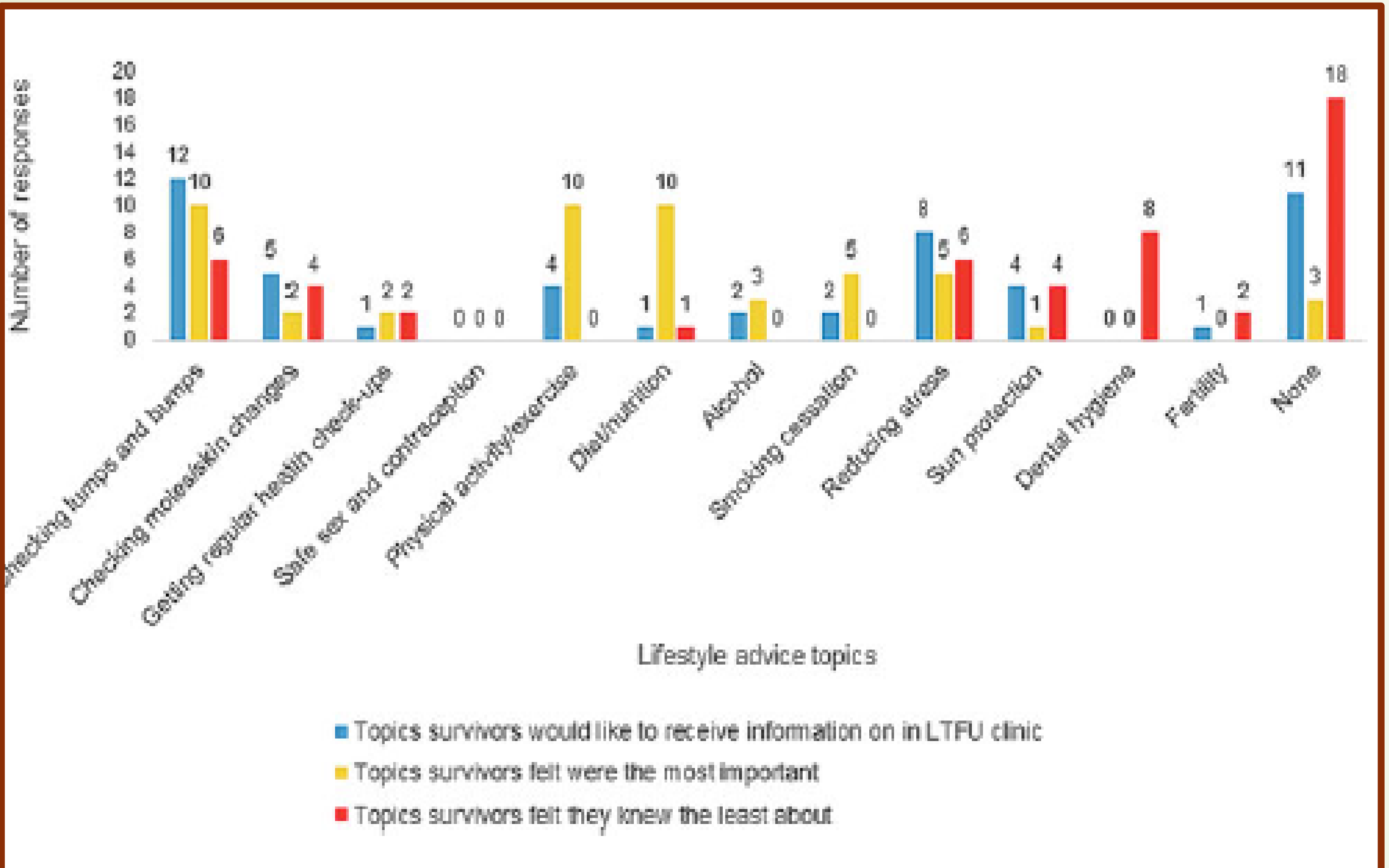
QUALITY OF LIFE. NUTRITION



Nutrition plays an important role in chronic disease prevention. Evidence of poor dietary intake in childhood cancer survivors calls for actions to be taken to incorporate nutrition support as an integral part of cancer care for survivors and families. The early onset of chronic health conditions in childhood cancer survivors reinforces the need for dietary interventions early in survivorship care to avoid long-term morbidity in this vulnerable population.

Zhang FF et al. J Nutr 2016 doi 103945

HEALTH PROMOTION AND LIFESTYLE ADVICE

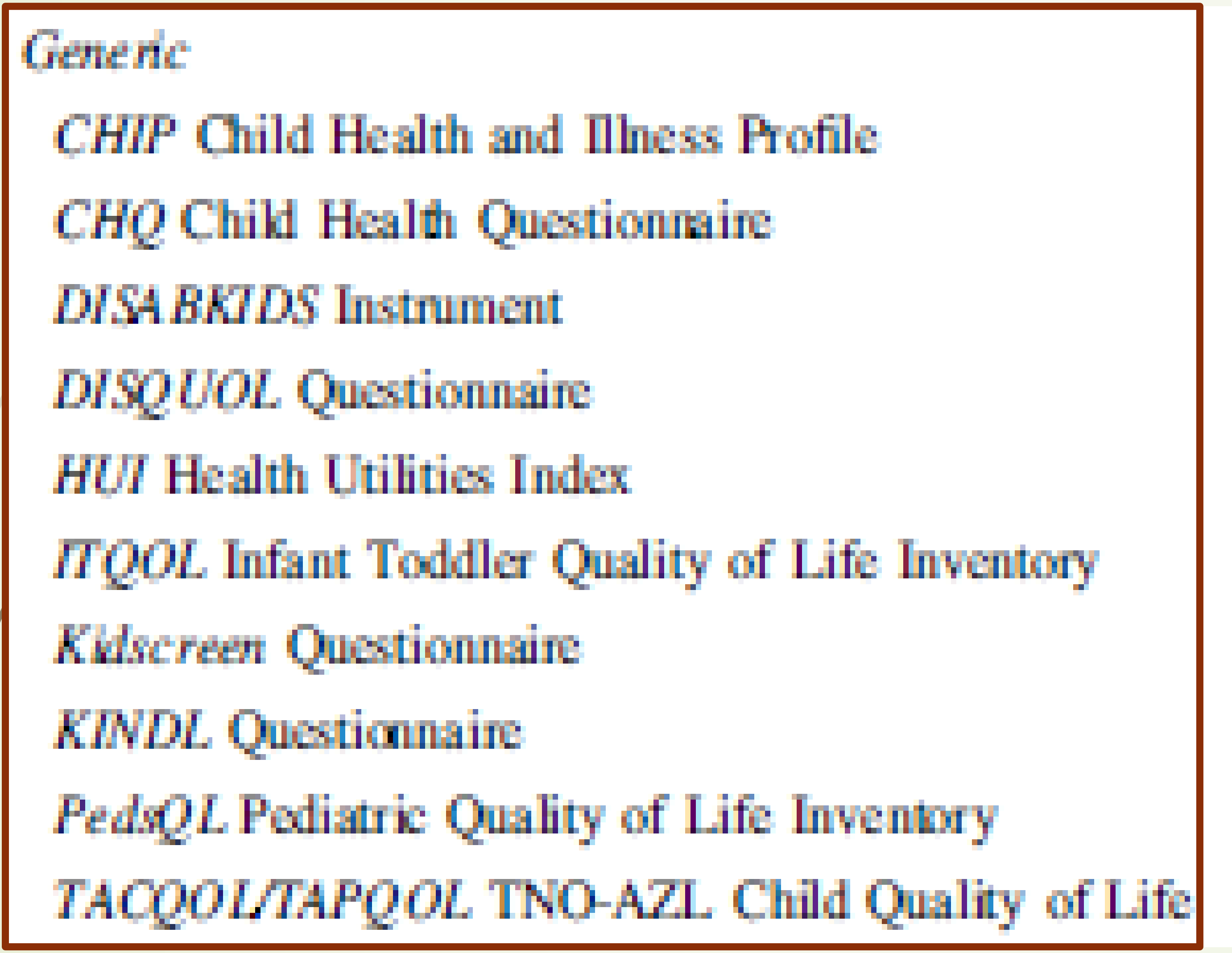


1. Survivors’ views on lifestyle advice topics.

Health promotion and lifestyle advice is now generally considered to be a vital part of medical care of CCS. However, no guidelines currently give recommendations for how best to communicate this information to CCS to aid sustainable adoption of positive health behaviors by these patients.

Mayes J et al. Ped Hematol Oncol 2016;33(6):359-370

HOW TO MESURE THE QUALITY OF LIFE OF CHILDHOOD CANCER SURVIVORS



Generic

- *CHIP* Child Health and Illness Profile
- *CHQ* Child Health Questionnaire
- *DISABKIDS* Instrument
- *DISQUOL* Questionnaire
- *HUI* Health Utilities Index
- *ITQOL* Infant Toddler Quality of Life Inventory
- *Kidscreen* Questionnaire
- *KINDL* Questionnaire
- *PedsQL* Pediatric Quality of Life Inventory
- *TACQOL/TAPQOL* TNO-AZL Child Quality of Life

The assessment of quality of life (QOL) is key within pediatric oncology and requires a clearly defined construct of QOL.

Our research highlights important problems with content validity of existing PRO scales, indicating that the tools we have to date have limited utility in research and clinical practice.

Anthony SJ et al. Qual Life Res 2016 DOI 10.1007/s 11136-016-1393-4

HOW TO MESURE THE QUALITY OF LIFE OF CHILDHOOD CANCER SURVIVORS

PRO instruments

Cancer-specific

AQOL Adolescent Quality of Life Questionnaire

MMQL Minneapolis-Manchester Quality of Life Instrument

MPQOLQ Miami Pediatric Quality of Life Questionnaire

PEDQOL Quality of Life in Children and Adolescents with Cancer

Peds-FACT-Brs Pediatric Functional Assessment of Cancer Therapy Childhood Brain Tumor Survivor

PedsQL Brain Pediatric Quality of Life Inventory—Brain Tumor Module

PedsQL Cancer Pediatric Quality of Life Inventory—Cancer Module

POQOLS Pediatric Oncology Quality of Life Scale

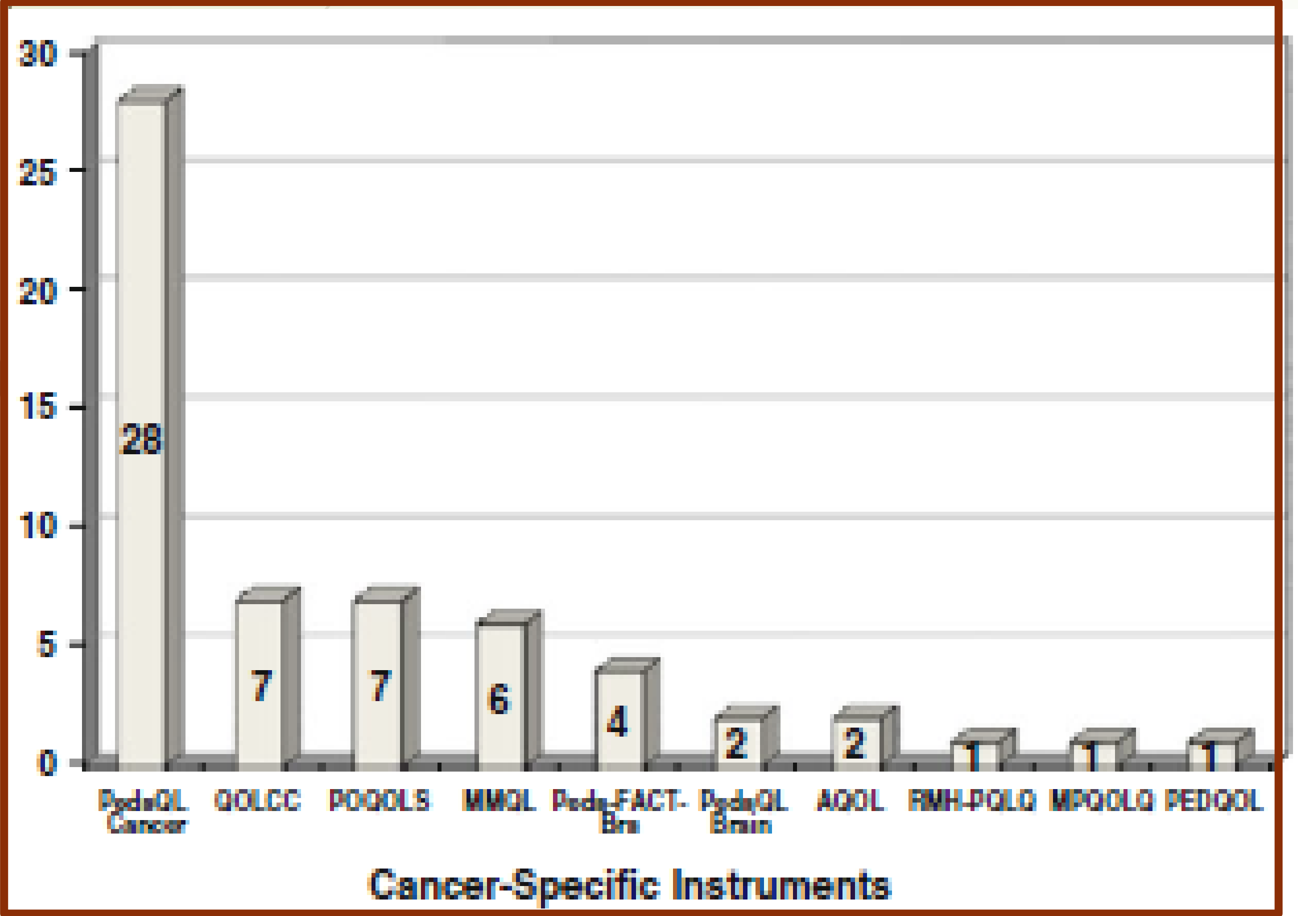
QOLCC Quality of Life for Cancer Children

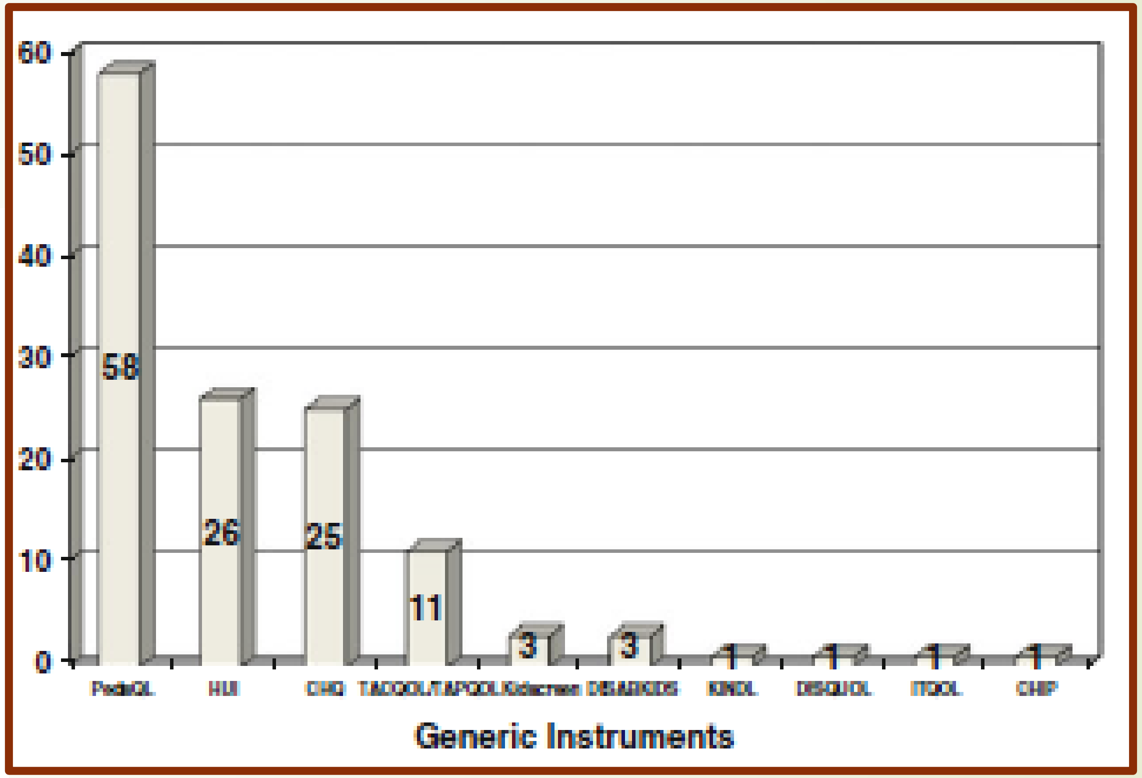
RMH-PQLQ Royal Marsden Hospital Pediatric Oncology Quality of Life Questionnaire

Measuring health status and QOL is important for understanding the impact of cancer in the lives of children. Inconsistencies in definitions or conceptual understanding of QOL have led to confusion about how to select or use instruments designed to measure this multidimensional concept.

Anthony SJ et al. Qual Life Res 2016 DOI 10.1007 /s 11136-016-1393-4

HOW TO MESURE THE QUALITY OF LIFE OF CHILDHOOD CANCER SURVIVORS





Anthony SJ Qual Life Res 2014;23(3):771-779

HOW TO MESURE THE QUALITY OF LIFE OF CHILDHOOD CANCER SURVIVORS

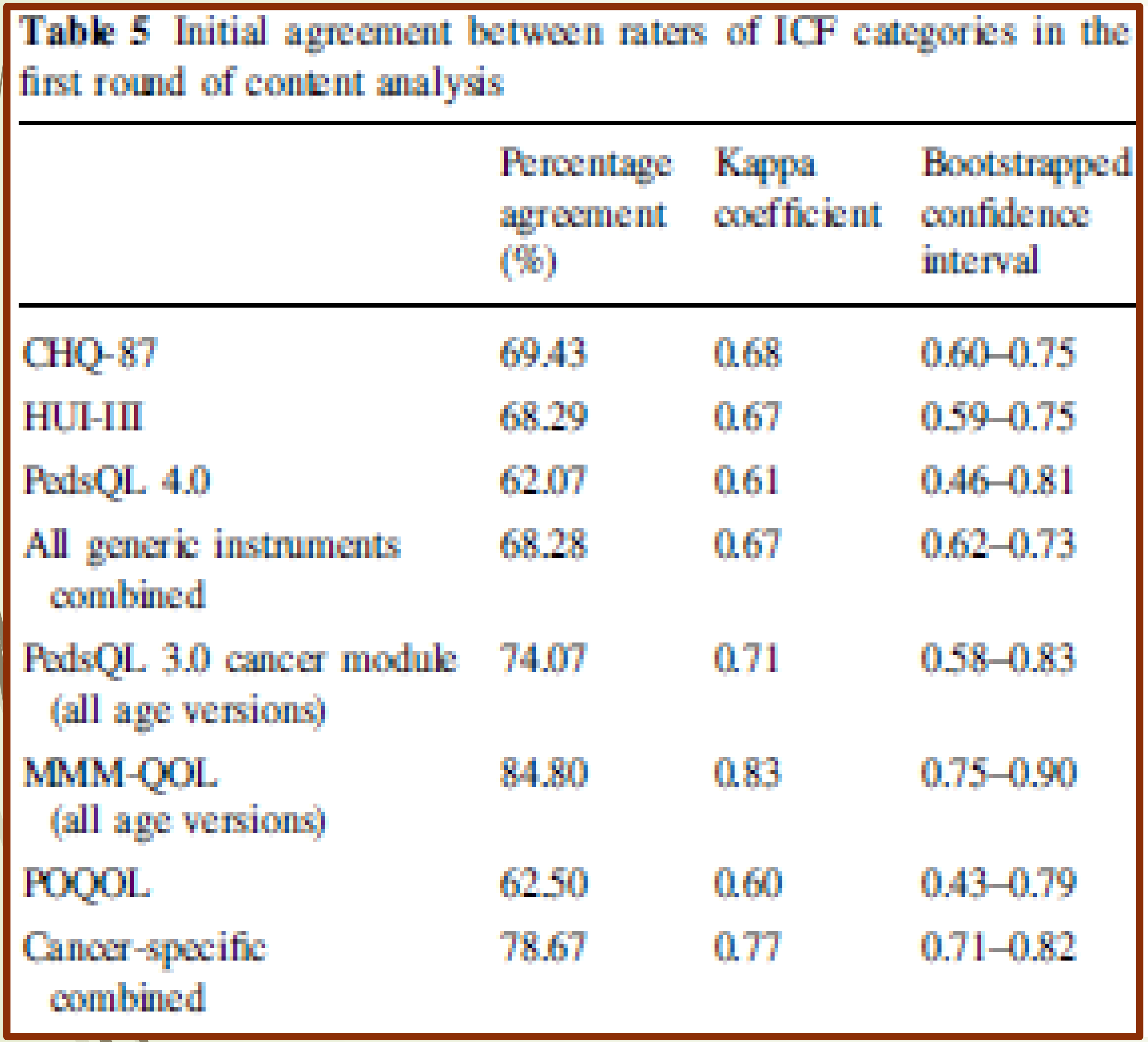


Table 5 Initial agreement between raters of ICF categories in the first round of content analysis

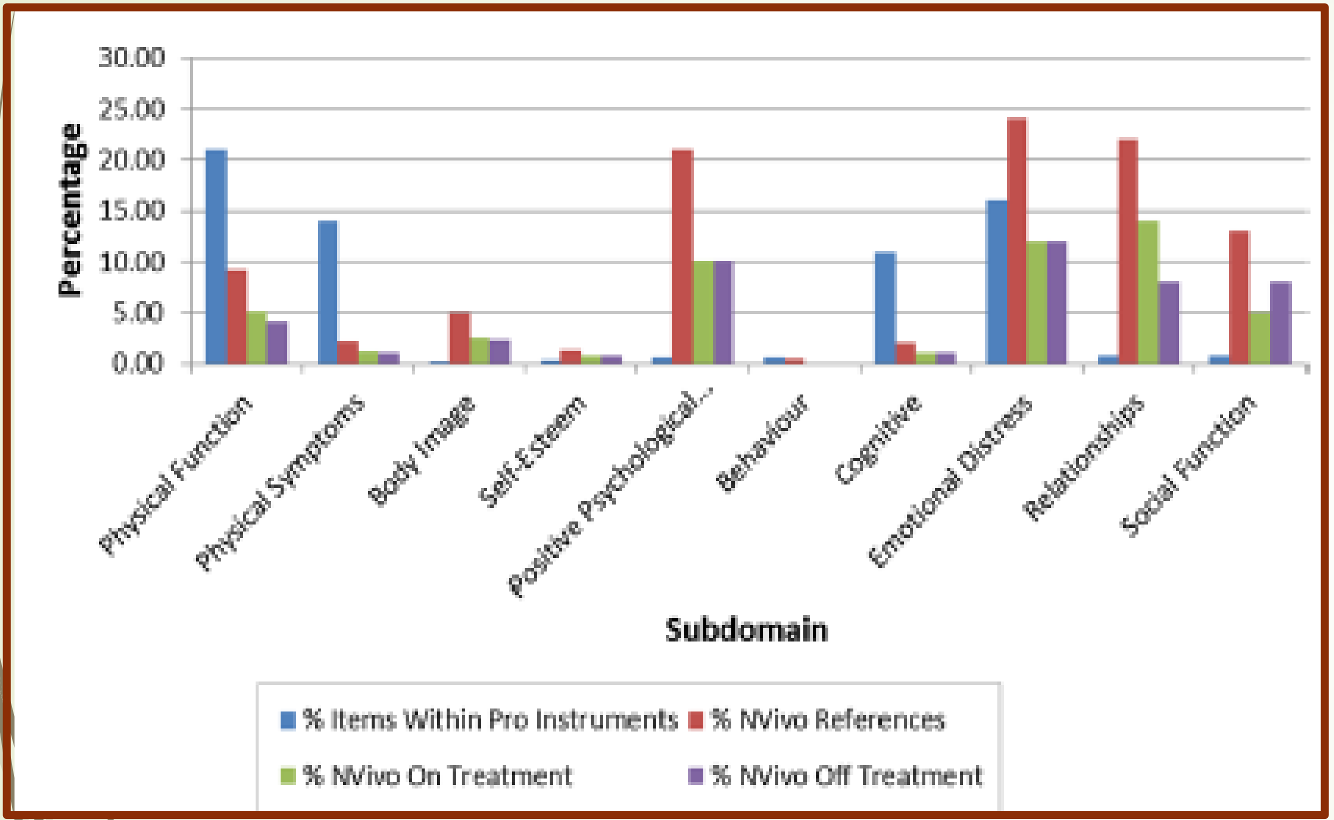
	Percentage agreement (%)	Kappa coefficient	Bootstrapped confidence interval
CHQ-87	69.43	0.68	0.60–0.75
HUI-III	68.29	0.67	0.59–0.75
PedsQL 4.0	62.07	0.61	0.46–0.81
All generic instruments combined	68.28	0.67	0.62–0.73
PedsQL 3.0 cancer module (all age versions)	74.07	0.71	0.58–0.83
MMM-QOL (all age versions)	84.80	0.83	0.75–0.90
POQOL	62.50	0.60	0.43–0.79
Cancer-specific combined	78.67	0.77	0.71–0.82

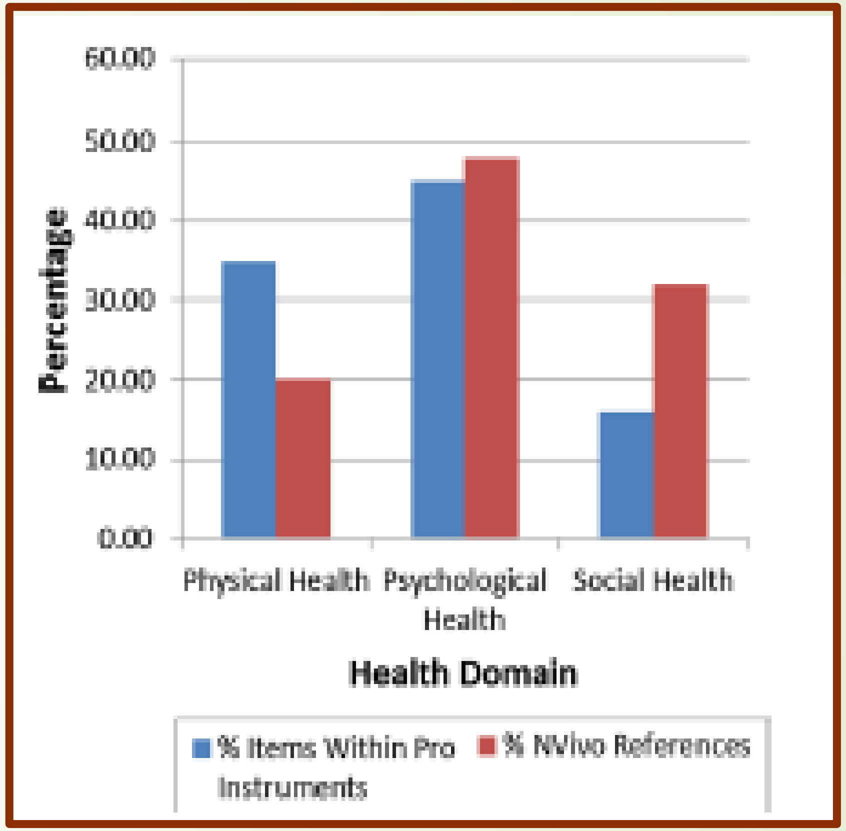
The ICF-CY is a uniform terminology, and classification system developed by the WHO that can classify biopsychosocial health content found in health status and QOL instruments

Our analysis of commonly used generic and cancer specific instruments in childhood cancer research showed that the popular measures used to assess QOL reflect a variety of health and health-related domains but consistently use a health status approach as opposed to a QOL approach.

Fayed N et al. Qual Life Res 2011 20:1247-1258

HOW TO MESURE THE QUALITY OF LIFE OF CHILDHOOD CANCER SURVIVORS

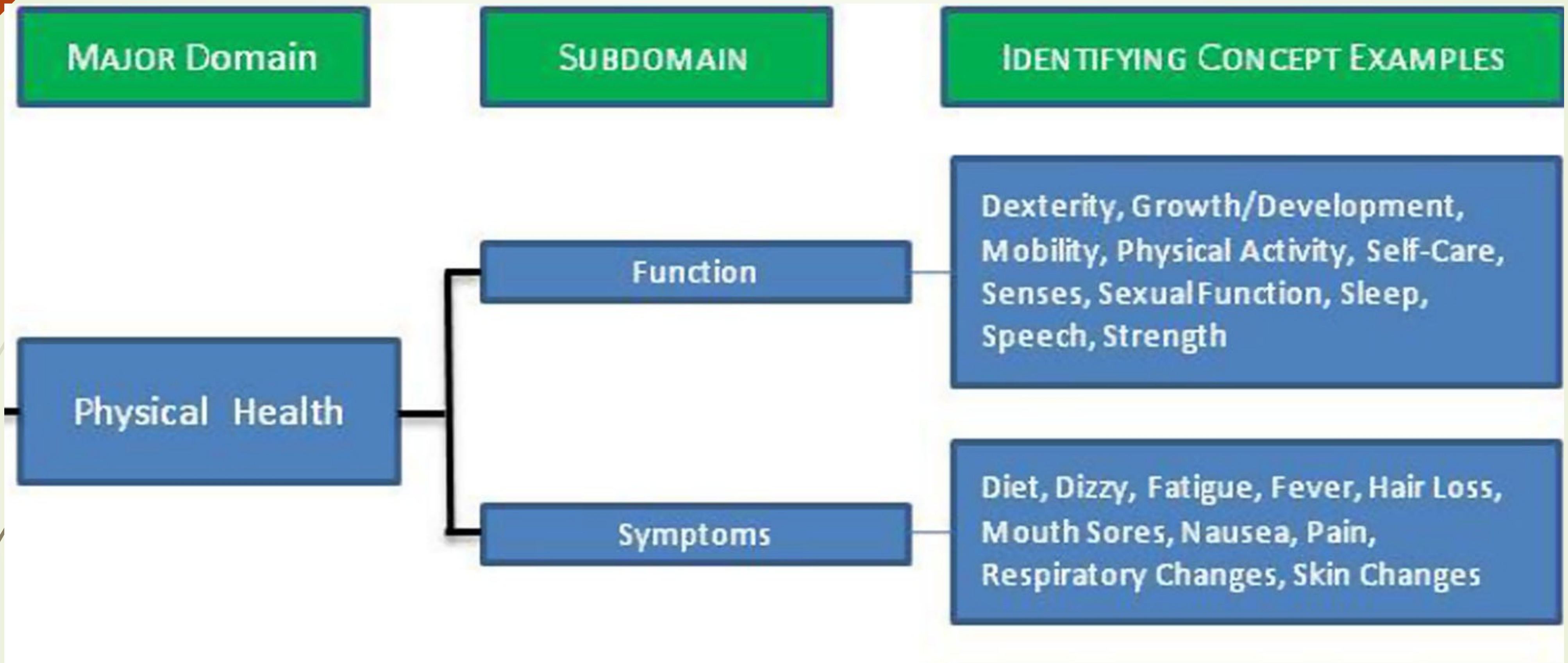




Childhood cancer is a complex, multi-layered process of difficulty, adjustment and growth. Our findings suggest that existing PRO instruments contain content that does not reflect the QOL experiences and perspectives of childhood cancer patients and survivors.

Anthony SJ et al. Qual Life Res 2016 DOI 10.1007/s 11136-016-1393-4

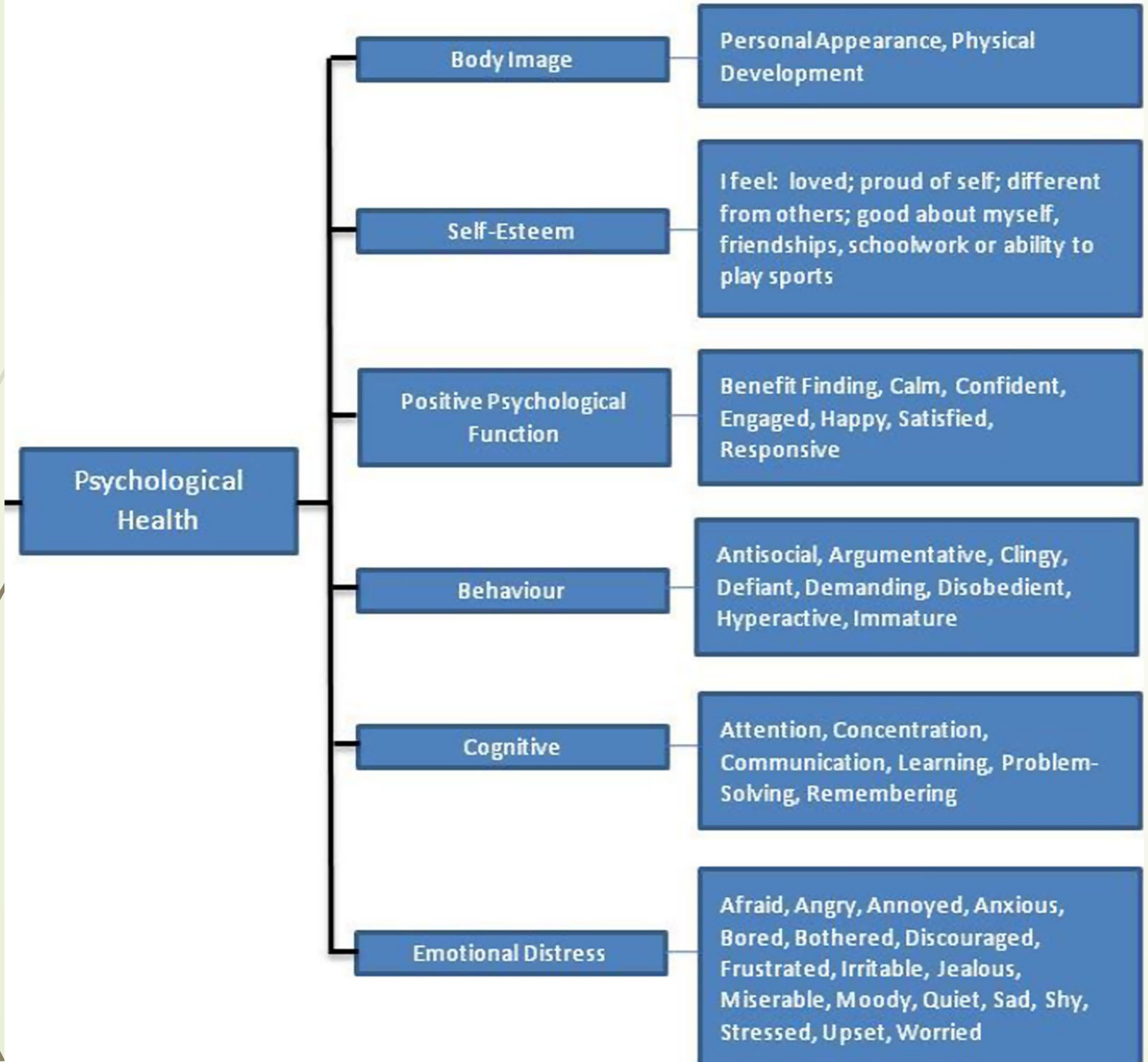
HOW TO MESURE THE QUALITY OF LIFE OF CHILDHOOD CANCER SURVIVORS



A comprehensive conceptual framework provides the necessary foundation for the development of theoretical models and the progression toward interventional studies aimed at improving the QOL for children with cancer and childhood cancer survivors.

Anthony SJ et al. Qual Life Res 2014 23(3):771-779

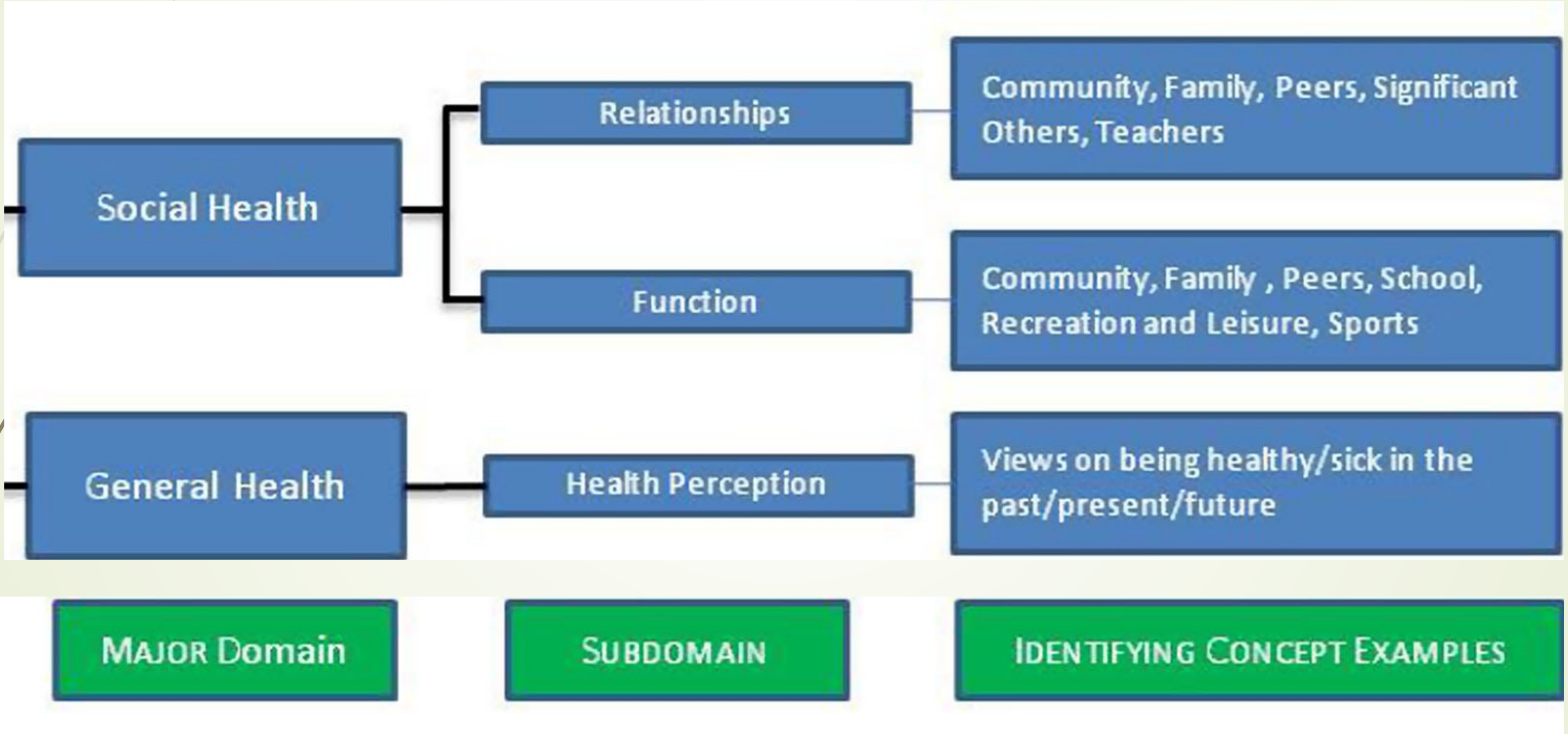
HOW TO MESURE THE QUALITY OF LIFE OF CHILDHOOD CANCER SURVIVORS



MAJOR DOMAIN	SUBDOMAIN	IDENTIFYING CONCEPT EXAMPLES
Psychological Health	Body Image	Personal Appearance, Physical Development
	Self-Esteem	I feel: loved; proud of self; different from others; good about myself, friendships, schoolwork or ability to play sports
	Positive Psychological Function	Benefit Finding, Calm, Confident, Engaged, Happy, Satisfied, Responsive
	Behaviour	Antisocial, Argumentative, Clingy, Defiant, Demanding, Disobedient, Hyperactive, Immature
	Cognitive	Attention, Concentration, Communication, Learning, Problem-Solving, Remembering
	Emotional Distress	Afraid, Angry, Annoyed, Anxious, Bored, Bothered, Discouraged, Frustrated, Irritable, Jealous, Miserable, Moody, Quiet, Sad, Shy, Stressed, Upset, Worried

Anthony SJ et al. Qual Life Res 2014 23(3):771-779

HOW TO MESURE THE QUALITY OF LIFE OF CHILDHOOD CANCER SURVIVORS



Social Health

Relationships

Community, Family, Peers, Significant Others, Teachers

Function

Community, Family , Peers, School, Recreation and Leisure, Sports

General Health

Health Perception

Views on being healthy/sick in the past/present/future

Major Domain

Subdomain

Identifying Concept Examples

Anthony SJ et al. Qual Life Res 2014 23(3):771-779

QUALITY OF LIFE EVALUATION

Report of 30 studies about QOL done in the USA

Despite the heterogeneity in study procedures and the methodological shortcomings the results suggest the following:

● Physical functioning

1. The majority of survivors reported they were in apparently good health, with the exception of bone tumour survivors, who were more likely to perceive their health as fair or poor.
2. Some studies mentioned fatigue as a residual effect of treatment.

● Psychological functioning

1. Most long-term survivors functioned well psychologically and did not have significantly more emotional problems than controls.(mood disturbances, tension, anger, confusion and anxiety).

Support Care Cancer (2002) 10:579–600
DOI 10.1007/s00520-002-0388-6

REVIEW ARTICLE

N.E. Langeveld
H. Stam
M.A. Grootenhuis
B.F. Last

Quality of life in young adult survivors of childhood cancer

QUALITY OF LIFE EVALUATION

- Social functioning

1. Survivors of CNS tumours and survivors of ALL seemed to be at risk for educational deficits.

2. The majority of survivors old enough to be in the workforce were employed.

3. Survivors seem to stay at home longer after reaching adulthood and leave home at an older age than their controls.

4. There is a lower prevalence of marriage among survivors, particularly in male survivors with a diagnosis of CNS tumours.

5. The percentage of survivors with children seems lower.

Support Care Cancer (2002) 10:579–600
DOI 10.1007/s00520-002-0388-6

REVIEW ARTICLE

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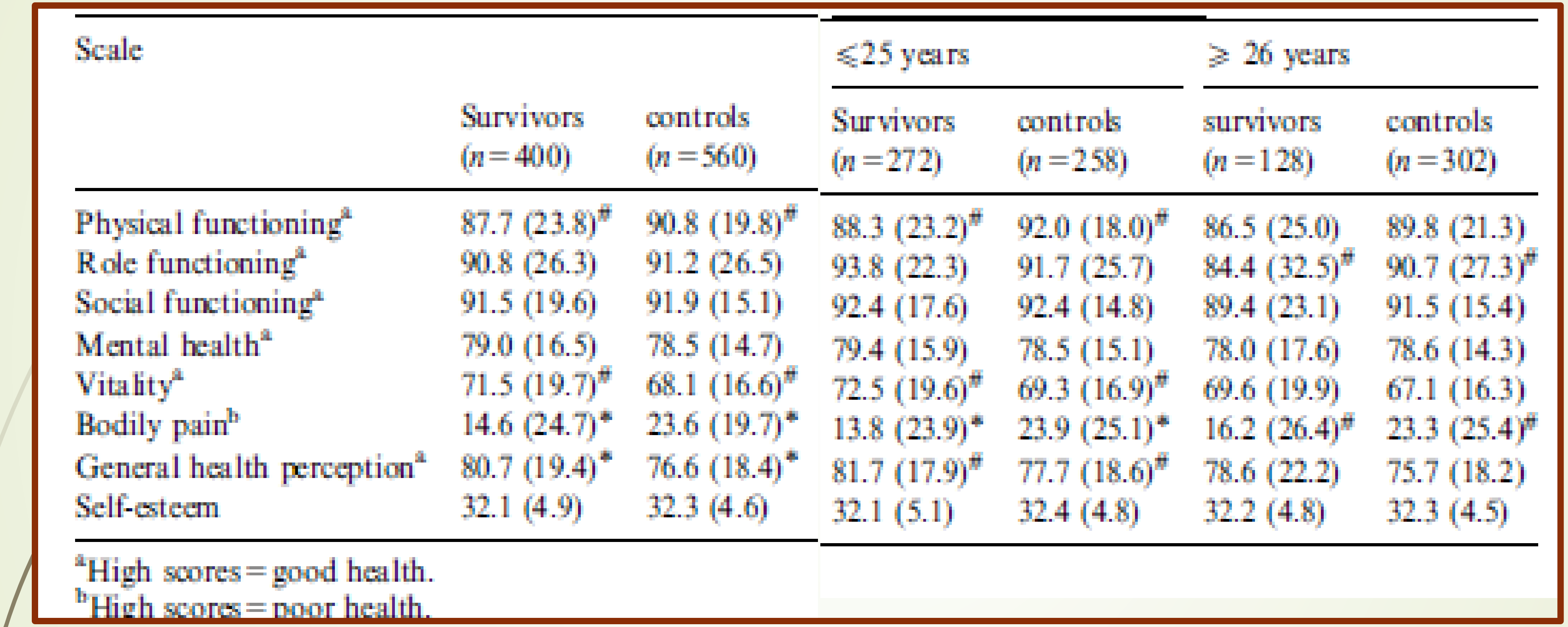
QUALITY OF LIFE EVALUATION



Scale	Survivors ($n=400$)	controls ($n=560$)	≤25 years Survivors ($n=272$)	≤25 years controls ($n=258$)	≥ 26 years survivors ($n=128$)	≥ 26 years controls ($n=302$)
Physical functioning[a]	87.7 (23.8)$^{\#}$	90.8 (19.8)$^{\#}$	88.3 (23.2)$^{\#}$	92.0 (18.0)$^{\#}$	86.5 (25.0)	89.8 (21.3)
Role functioning[a]	90.8 (26.3)	91.2 (26.5)	93.8 (22.3)	91.7 (25.7)	84.4 (32.5)$^{\#}$	90.7 (27.3)$^{\#}$
Social functioning[a]	91.5 (19.6)	91.9 (15.1)	92.4 (17.6)	92.4 (14.8)	89.4 (23.1)	91.5 (15.4)
Mental health[a]	79.0 (16.5)	78.5 (14.7)	79.4 (15.9)	78.5 (15.1)	78.0 (17.6)	78.6 (14.3)
Vitality[a]	71.5 (19.7)$^{\#}$	68.1 (16.6)$^{\#}$	72.5 (19.6)$^{\#}$	69.3 (16.9)$^{\#}$	69.6 (19.9)	67.1 (16.3)
Bodily pain[b]	14.6 (24.7)*	23.6 (19.7)*	13.8 (23.9)*	23.9 (25.1)*	16.2 (26.4)$^{\#}$	23.3 (25.4)$^{\#}$
General health perception[a]	80.7 (19.4)*	76.6 (18.4)*	81.7 (17.9)$^{\#}$	77.7 (18.6)$^{\#}$	78.6 (22.2)	75.7 (18.2)
Self-esteem	32.1 (4.9)	32.3 (4.6)	32.1 (5.1)	32.4 (4.8)	32.2 (4.8)	32.3 (4.5)

[a] High scores = good health.
[b] High scores = poor health.

The present findings indicate that QL and level of self-esteem in young adult survivors of childhood cancer is not significantly different from their healthy peers. Female gender, age at follow-up, unemployment, years since completion of therapy, severe late effects/health problems and self-esteem could explain variations in QL and worries only to a limited extent.

Langeveld NE et al. Psycho-Oncology 2004;13:867-881

QUALITY OF LIFE EVALUATION

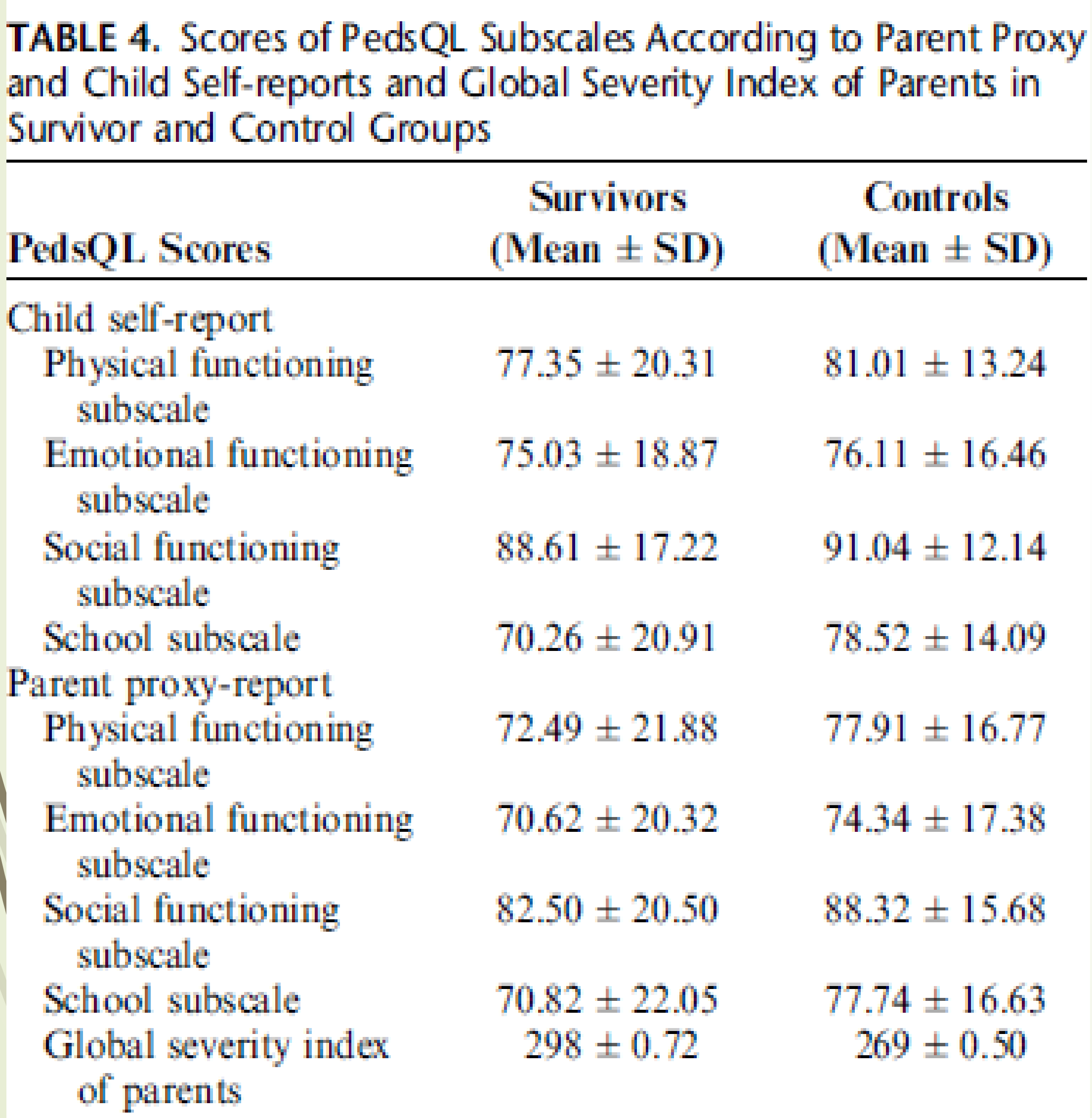


TABLE 4. Scores of PedsQL Subscales According to Parent Proxy and Child Self-reports and Global Severity Index of Parents in Survivor and Control Groups

PedsQL Scores	Survivors (Mean ± SD)	Controls (Mean ± SD)
Child self-report		
Physical functioning subscale	77.35 ± 20.31	81.01 ± 13.24
Emotional functioning subscale	75.03 ± 18.87	76.11 ± 16.46
Social functioning subscale	88.61 ± 17.22	91.04 ± 12.14
School subscale	70.26 ± 20.91	78.52 ± 14.09
Parent proxy-report		
Physical functioning subscale	72.49 ± 21.88	77.91 ± 16.77
Emotional functioning subscale	70.62 ± 20.32	74.34 ± 17.38
Social functioning subscale	82.50 ± 20.50	88.32 ± 15.68
School subscale	70.82 ± 22.05	77.74 ± 16.63
Global severity index of parents	298 ± 0.72	269 ± 0.50

Tumor type is one of the most important factors affecting HRQOL. We found significantly lower scores on the social, physical, and school functioning subscales of CNS tumor survivors than the survivors of other tumours according to child self-reports. Despite all negative effects of cancer and its treatment, survivors seem to have a good overall HRQOL.

Yagci-Küpeli B et al.J Pediatr Hematol Oncol 2012;34:194–199

QUALITY OF LIFE EVALUATION

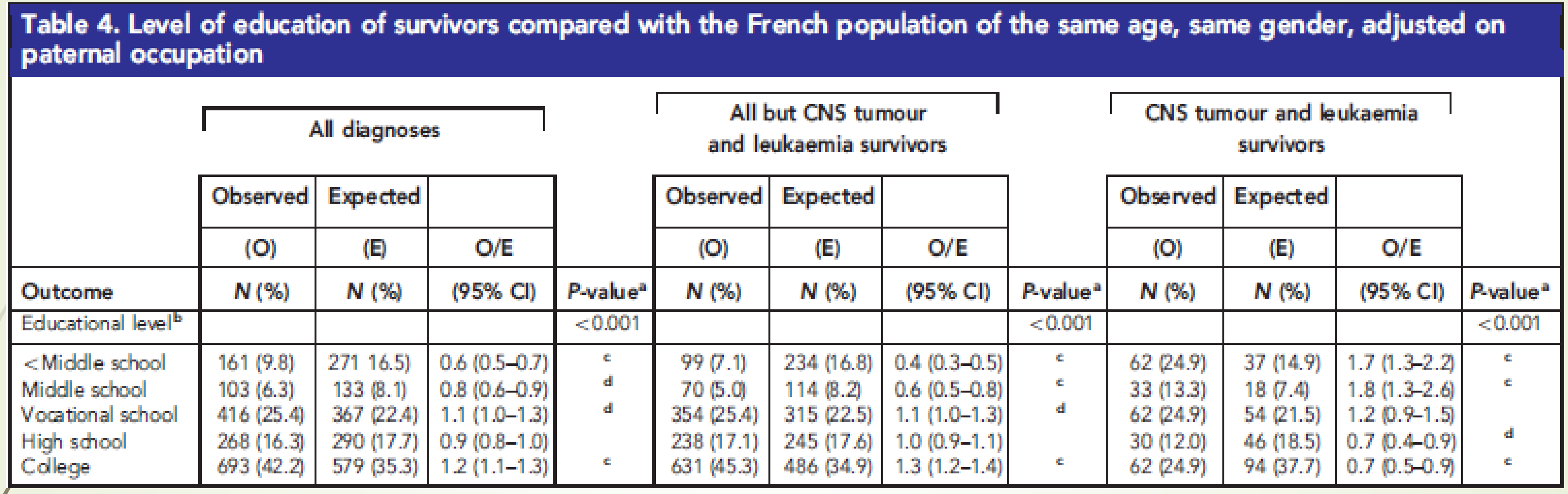


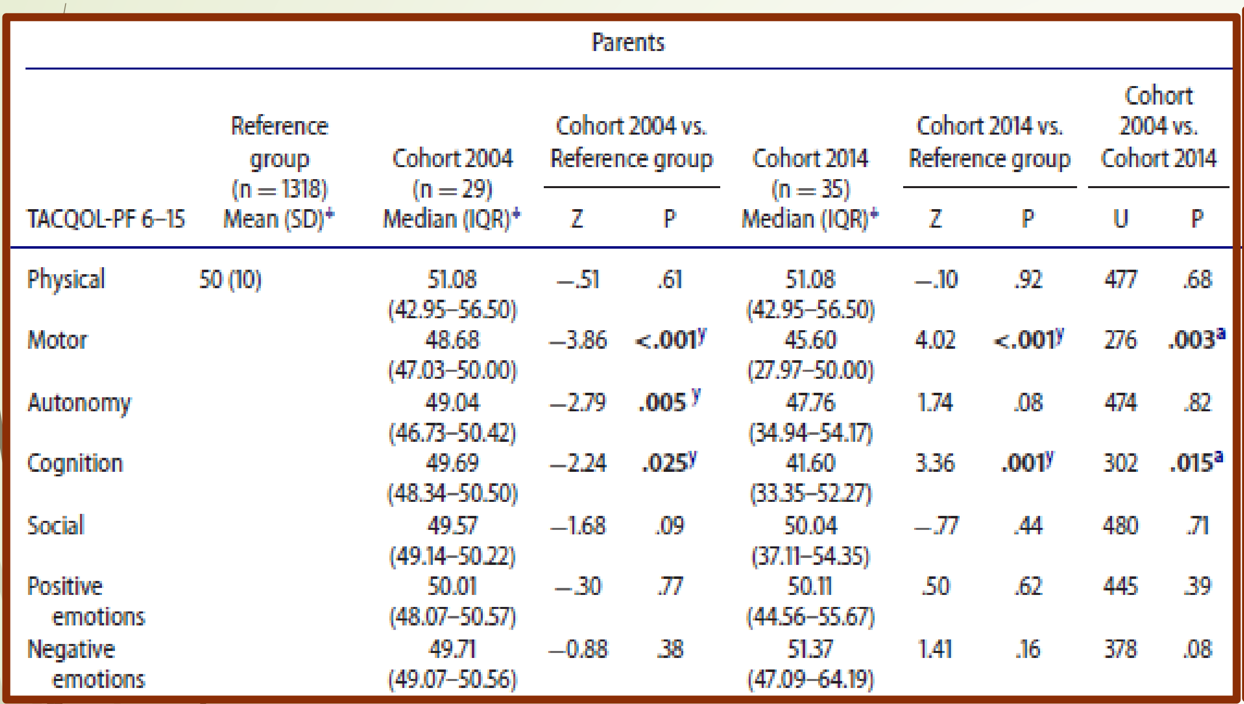
Table 4. Level of education of survivors compared with the French population of the same age, same gender, adjusted on paternal occupation

	All diagnoses				All but CNS tumour and leukaemia survivors				CNS tumour and leukaemia survivors			
	Observed	Expected			Observed	Expected			Observed	Expected		
	(O)	(E)	O/E		(O)	(E)	O/E		(O)	(E)	O/E	
Outcome	*N* (%)	*N* (%)	(95% CI)	*P*-value[a]	*N* (%)	*N* (%)	(95% CI)	*P*-value[a]	*N* (%)	*N* (%)	(95% CI)	*P*-value[a]
Educational level[b]				<0.001				<0.001				<0.001
<Middle school	161 (9.8)	271 16.5)	0.6 (0.5–0.7)	[c]	99 (7.1)	234 (16.8)	0.4 (0.3–0.5)	[c]	62 (24.9)	37 (14.9)	1.7 (1.3–2.2)	[c]
Middle school	103 (6.3)	133 (8.1)	0.8 (0.6–0.9)	[d]	70 (5.0)	114 (8.2)	0.6 (0.5–0.8)	[c]	33 (13.3)	18 (7.4)	1.8 (1.3–2.6)	[c]
Vocational school	416 (25.4)	367 (22.4)	1.1 (1.0–1.3)	[d]	354 (25.4)	315 (22.5)	1.1 (1.0–1.3)	[d]	62 (24.9)	54 (21.5)	1.2 (0.9–1.5)	
High school	268 (16.3)	290 (17.7)	0.9 (0.8–1.0)		238 (17.1)	245 (17.6)	1.0 (0.9–1.1)		30 (12.0)	46 (18.5)	0.7 (0.4–0.9)	[d]
College	693 (42.2)	579 (35.3)	1.2 (1.1–1.3)	[c]	631 (45.3)	486 (34.9)	1.3 (1.2–1.4)	[c]	62 (24.9)	94 (37.7)	0.7 (0.5–0.9)	[c]

Compared with national statistics adjusted on age and sex, we found that most survivors of childhood cancer had a significantly higher educational level and occupational class than expected, even when controlling for their socioeconomic background.
Unemployment and health-related unemployment were higher than expected for CNS tumour survivors, but not for survivors of other diagnoses.

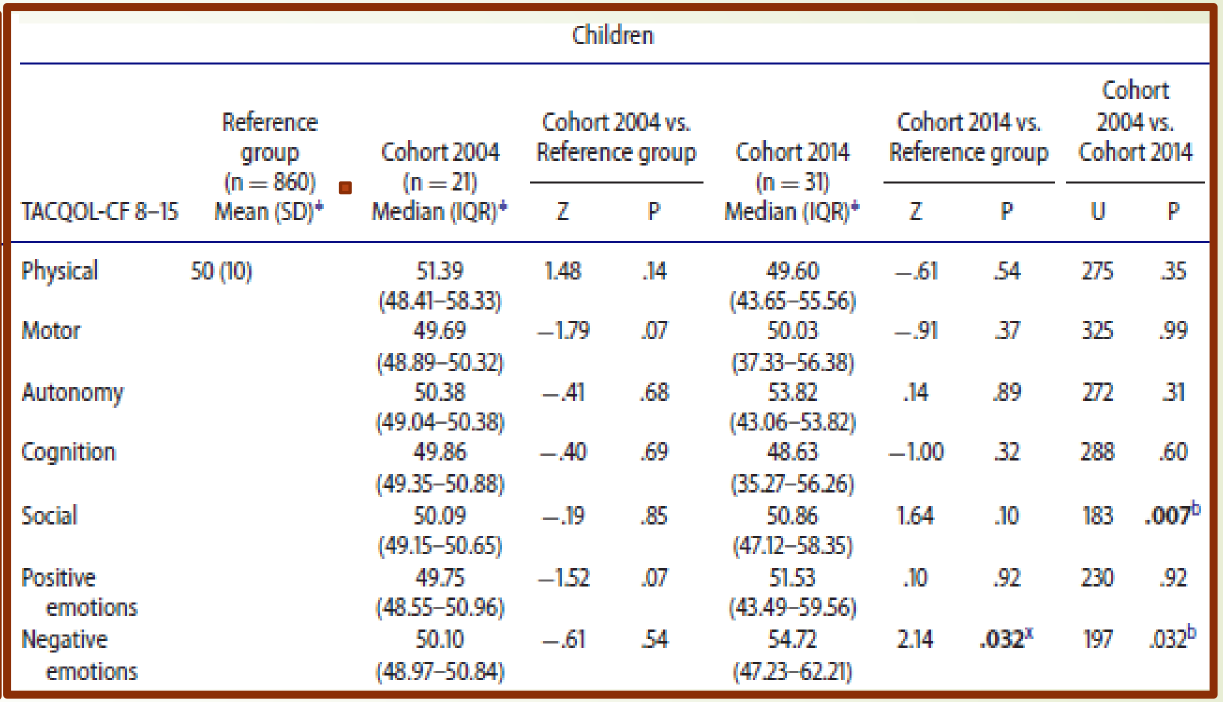
Dumas A et al. Br J Cancer 2016;114:1060-1068

QUALITY OF LIFE EVALUATION



Parents

TACQOL-PF 6–15	Reference group (n = 1318) Mean (SD)[*]	Cohort 2004 (n = 29) Median (IQR)[*]	Cohort 2004 vs. Reference group		Cohort 2014 (n = 35) Median (IQR)[*]	Cohort 2014 vs. Reference group		Cohort 2004 vs. Cohort 2014	
			Z	P		Z	P	U	P
Physical	50 (10)	51.08 (42.95–56.50)	−.51	.61	51.08 (42.95–56.50)	−.10	.92	477	.68
Motor		48.68 (47.03–50.00)	−3.86	**<.001**[y]	45.60 (27.97–50.00)	4.02	**<.001**[y]	276	**.003**[a]
Autonomy		49.04 (46.73–50.42)	−2.79	**.005**[y]	47.76 (34.94–54.17)	1.74	.08	474	.82
Cognition		49.69 (48.34–50.50)	−2.24	**.025**[y]	41.60 (33.35–52.27)	3.36	**.001**[y]	302	**.015**[a]
Social		49.57 (49.14–50.22)	−1.68	.09	50.04 (37.11–54.35)	−.77	.44	480	.71
Positive emotions		50.01 (48.07–50.57)	−.30	.77	50.11 (44.56–55.67)	.50	.62	445	.39
Negative emotions		49.71 (49.07–50.56)	−0.88	.38	51.37 (47.09–64.19)	1.41	.16	378	.08



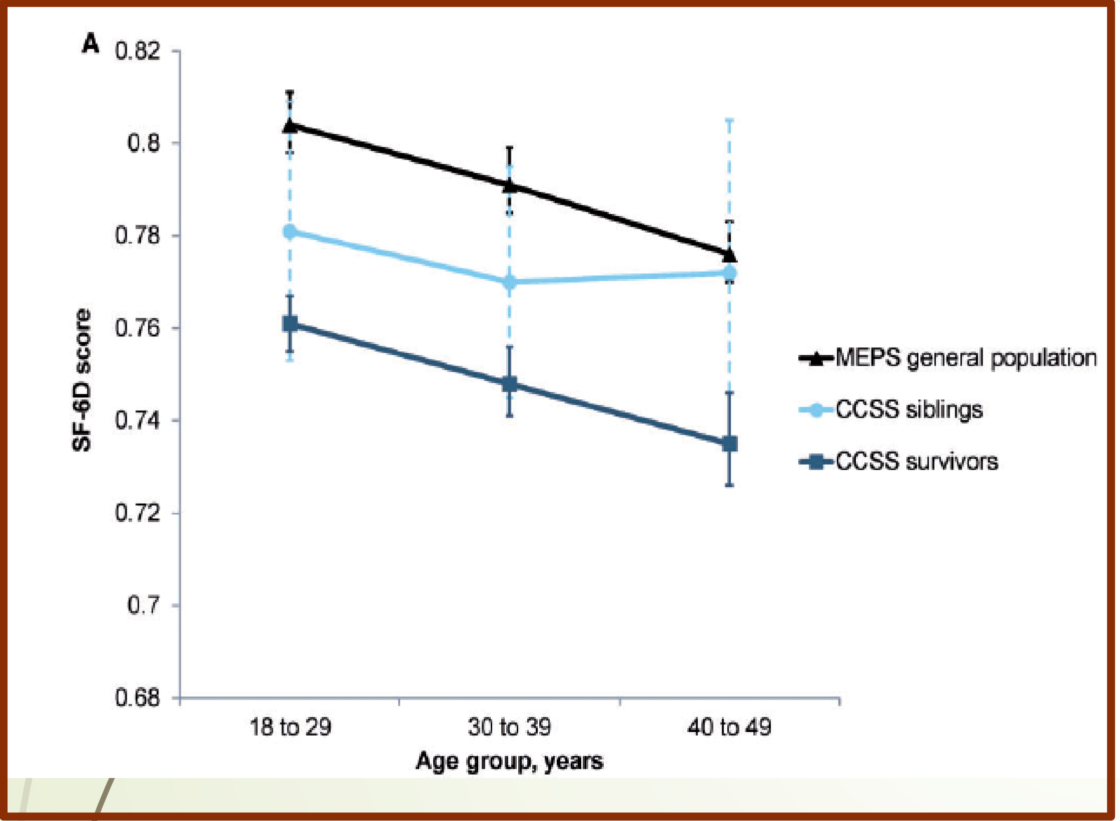
Children

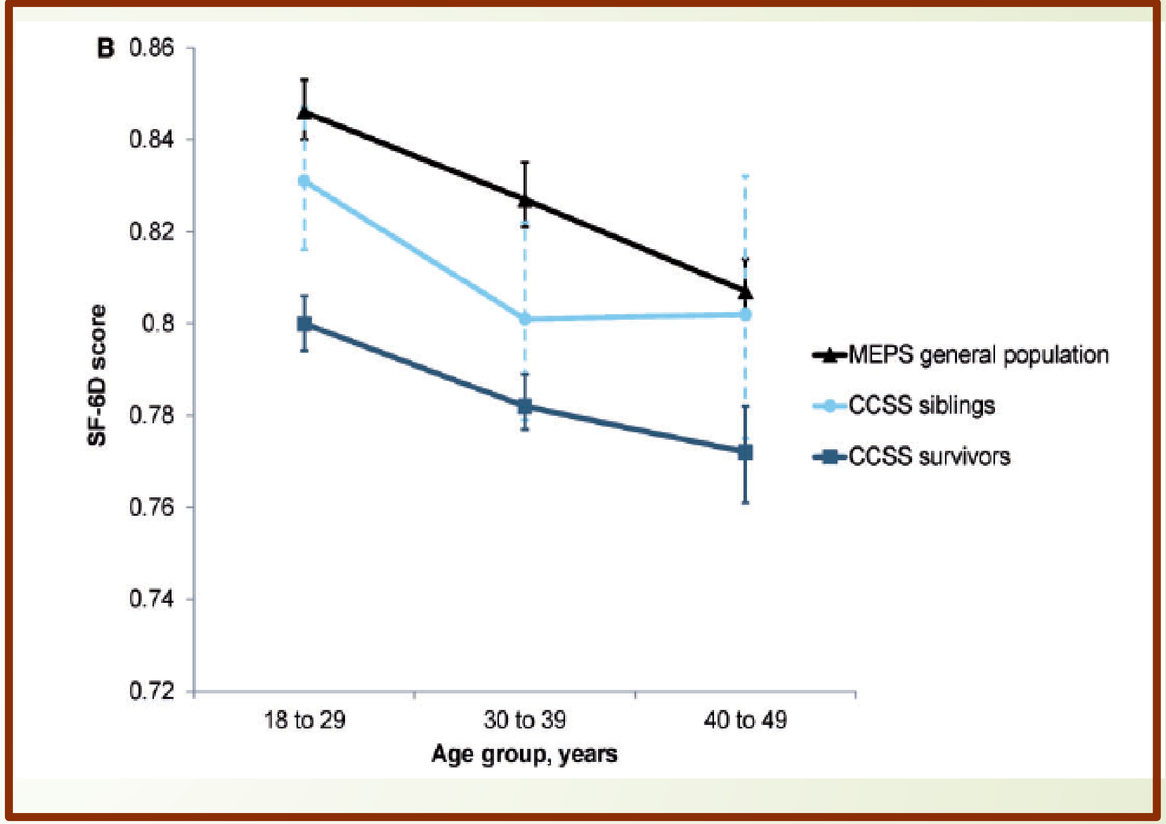
TACQOL-CF 8–15	Reference group (n = 860) Mean (SD)[*]	Cohort 2004 (n = 21) Median (IQR)[*]	Cohort 2004 vs. Reference group		Cohort 2014 (n = 31) Median (IQR)[*]	Cohort 2014 vs. Reference group		Cohort 2004 vs. Cohort 2014	
			Z	P		Z	P	U	P
Physical	50 (10)	51.39 (48.41–58.33)	1.48	.14	49.60 (43.65–55.56)	−.61	.54	275	.35
Motor		49.69 (48.89–50.32)	−1.79	.07	50.03 (37.33–56.38)	−.91	.37	325	.99
Autonomy		50.38 (49.04–50.38)	−.41	.68	53.82 (43.06–53.82)	.14	.89	272	.31
Cognition		49.86 (49.35–50.88)	−.40	.69	48.63 (35.27–56.26)	−1.00	.32	288	.60
Social		50.09 (49.15–50.65)	−.19	.85	50.86 (47.12–58.35)	1.64	.10	183	**.007**[b]
Positive emotions		49.75 (48.55–50.96)	−1.52	.07	51.53 (43.49–59.56)	.10	.92	230	.92
Negative emotions		50.10 (48.97–50.84)	−.61	.54	54.72 (47.23–62.21)	2.14	**.032**[x]	197	.032[b]

The impairments of brain tumor survivors influence quality of life particularly regarding motor, cognitive, and social functioning. Children impeded in their autonomy may develop a delay in their social capacities. This is affirmed by their parents, who reported more social problems. Early detecting of such problems is important, as timely interventions can prevent aggravation of such problems and will enhance the child’s coping capacities.

Dessens AB et al. Ped Hematol Oncol 2016;33(5):282-294

QUALITY OF LIFE EVALUATION





Our findings, which represent the first use of utility scores to illuminate quality-of-life differences among adult survivors of childhood cancer and nonsurvivors, highlight the importance of chronic conditions on health-related quality of life for childhood cancer survivors and provide encouraging results on the impact of the cancer experience on long-term sibling wellbeing.

Yeh JM. JNCI J Natl Cancer Inst (2016) 108(9)

QUALITY OF LIFE EVALUATION

Los adolescentes que han tenido cáncer y en la actualidad se encuentran en remisión manifiestan una calidad de vida satisfactoria y similar a la que se observa en su grupo de referencia de la población general sin historia previa de cáncer

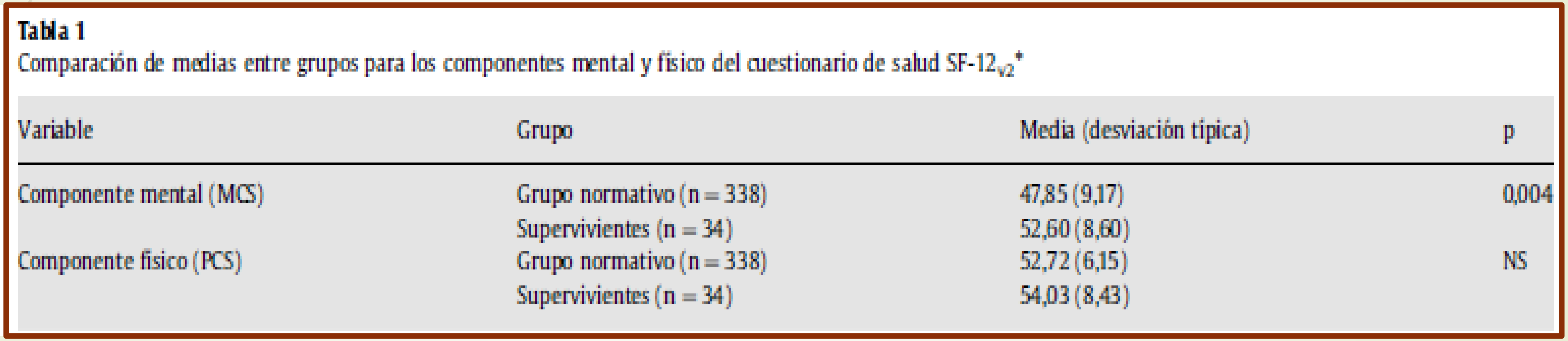


Tabla 1

Comparación de medias entre grupos para los componentes mental y físico del cuestionario de salud SF-12$_{v2}$*

Variable	Grupo	Media (desviación típica)	p
Componente mental (MCS)	Grupo normativo (n = 338)	47,85 (9,17)	0,004
	Supervivientes (n = 34)	52,60 (8,60)	
Componente físico (PCS)	Grupo normativo (n = 338)	52,72 (6,15)	NS
	Supervivientes (n = 34)	54,03 (8,43)	

El SF- 12v 2 es un instrumento de evaluación de calidad de vida en relación con la salud formado por un subconjunto de 12 ıtems del SF-36[7]. La información de estos 12 ítems se utiliza para construir las dimensiones de)componente físico* (PCS) y de)componente mental* (MCS) del SF-12v2,

C. Castellano et al/MedClin(Barc).2009;133(20):783–786

QUALITY OF LIFE . CONCLUSIONS

- We need a consensus definition of QOL .
- We need a new tool to mesure QOL that include all the relevant domains.
- In general terms QOL of childhood cancer survivors is good and no different from their peers.
- There is a role not only for researchers and health care providers but also for survivors and their families, governing bodies and advocacy groups in helping to understand and overcome the barriers that prevent survivors from receiving optimal care to minimize adverse health-related outcomes and to maximize quality-of-life outcomes.


THANK YOU