Langzeitnachsorge- und Transitionssprechstunde

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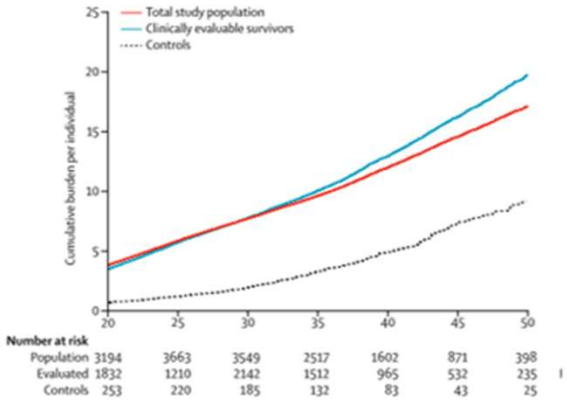
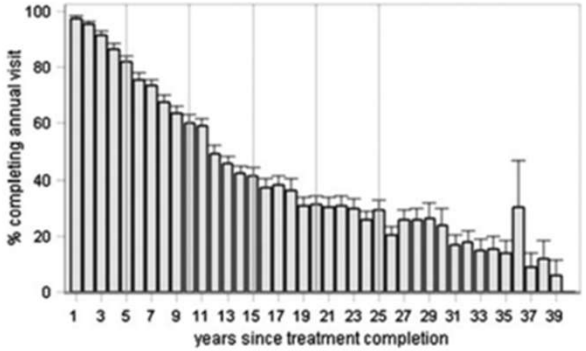
Langzeitnachsorge und Transition



Cumulative burden of chronic health conditions (CTCAE 1-5)

VS



Loss to follow-up care after transition

→ Importance of Transition (purposeful movement from pediatric to adult care)

Bhakta et al, Lancet, 2017
Rokitka et al, J Adolesc Young Adult, 2017

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Transition - allgemein

- process of moving from one setting to another

- a developmental phase

- leaving the «comfort zone» and encountering the unknown

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Transition - Definition

- progressing from active cancer treatment to follow-up care
- purposeful movement from pediatric to adult care

Purposeful

- Preparation (survivor, family, physicians)
- Adequate time point

Movement

- Process / not abrupt
- Individualizes pace

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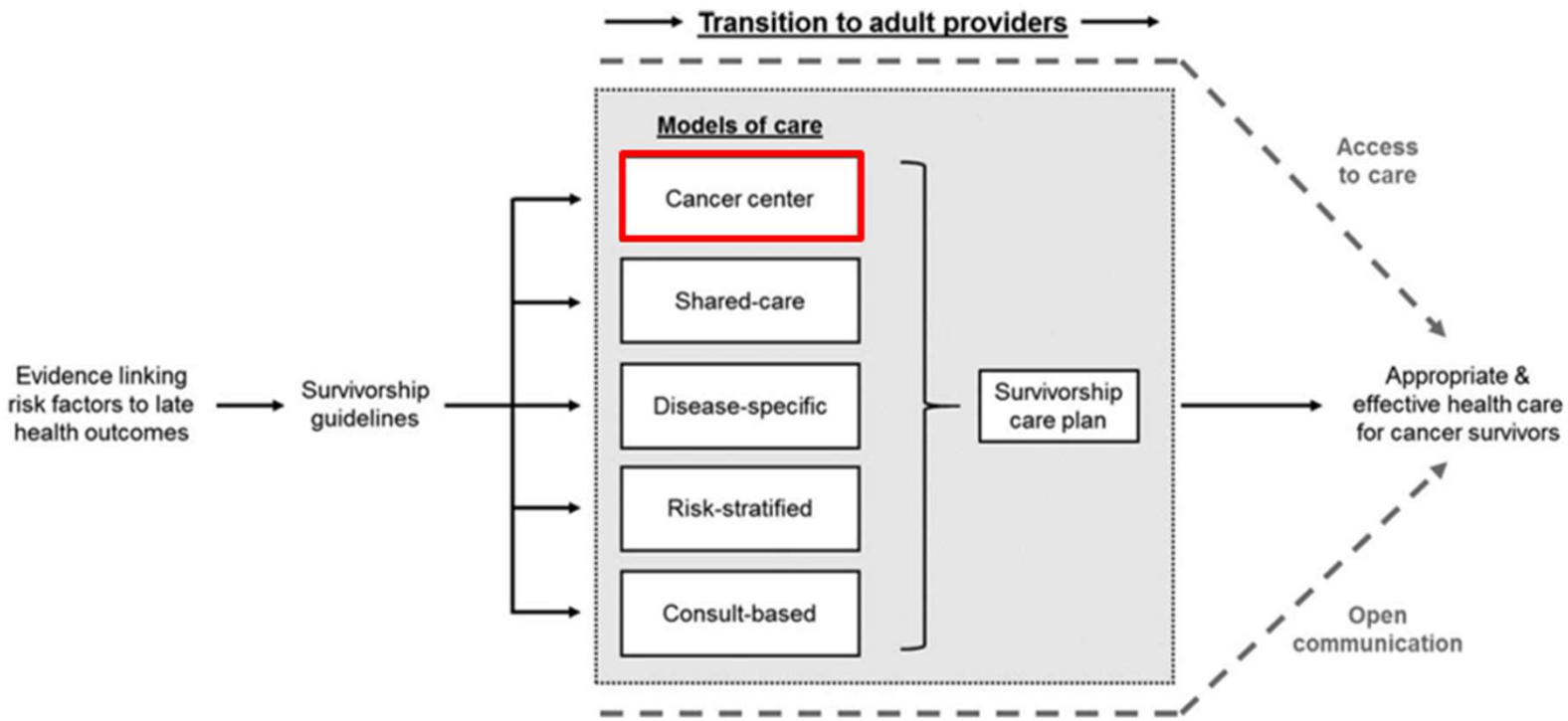
Transitionsmodelle



Dixon et al, CA Cancer J Clin, 2018

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Transition - players

Survivor

Parents

Pediatric oncology

Adult providers

Oncologist, Hemtologist
Family physician

Med. specialists

Cardiologist
Endocrinologist
Etc.

Other specialists

Social worker

Individualized

Well informed

Local possibilities

Communication

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Transition – barriers and facilitators

1. CCSs' self-management skills (incl. knowledge, education, and empowerment)
2. Social environment (incl. family, friends, and peers)
3. CCSs' personal feelings and emotions
4. Pediatric setting
5. Adult setting
6. Financial issues and insurance
7. Communication
8. Structural circumstances (incl. organization of transition)

Otth et al, Journal of Cancer Survivorship, 2020

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Erfolgreiche Transition

… some barriers are targetable

… some facilitators have to be strengthened

TRANSITION TOOLS

- Prepare Survivors for transition
- Explore knowledge gaps
- Explore fears / uncertainties

- *Structured transition*
- *Prepare parents*
- *Education of adult physicians*

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Transition tools

First author, year, country	
Bashore, 2016, USA [19]	Transition workbook - method of preparing survivors to transition to adult care
Klassen, 2014, Canada [20]	Transition scales - development and evaluation of cancer worry scale, self-management skills scale, expectations scale
Klassen, 2014, Canada [21]	Transition-Q - development and validation of self-management skill scale for adolescents with chronic health conditions (further development of scale developed for childhood cancer patients)
Schwartz, 2011, USA [22]	SMART - development of SMART model - social-ecological model of readiness for transition to adult-oriented care for adolescents and adults with chronic health conditions
Schwartz, 2013, USA [23]	SMART - further validate SMART for survivors of childhood cancer
Schwartz, 2017, USA [24]	Transition Readiness Inventory (TRI) Item Pool - development and validation of TRI Item Pool based on SMART

Otth et al, Journal of Cancer Survivorship, 2020

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Transition Q

	Nie	Manchmal	Immer
1. Ich beantworte die Fragen des Arztes oder der Pflege.	0	1	2
2. Ich helfe mit, Entscheidungen zu meiner Gesundheit zu treffen.	0	1	2
3. Ich bin für die Einnahme meiner Medikamente verantwortlich.	0	1	2
4. Ich spreche mit meinem Arzt oder der Pflege über meine Sorgen zu meiner Gesundheit.	0	1	2
5. Wenn ich eine Frage zu meiner Gesundheit habe, suche ich nach einer Antwort.	0	1	2
6. Ich spreche mit Leuten über meinen Gesundheitszustand, wenn ich muss.	0	1	2
7. Ich stelle dem Arzt oder der Pflege Fragen.	0	1	2
8. Ich spreche selbst mit dem Arzt anstelle meiner Eltern.	0	1	2
9. Ich kann auf Nachfrage meine Krankheitsgeschichte zusammenfassen.	0	1	2
10. Ich kontaktiere einen Arzt, wenn ich ihn brauche.	0	1	2
11. Ich sehe bei meinen Terminen den Arzt oder die Pflege alleine.	0	1	2
12. Ich löse meine Rezepte selbstständig ein, wenn ich Medikamente brauche.	0	1	2
13. Ich gehe alleine zu meinen Arztterminen.	0	1	2
14. Ich vereinbare meine Arzttermine selbständig.	0	1	2

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Modell KSA

- St. Jude's Survivorship Care Plan

  (nur lokal in elektronischer KG abgelegt, kein Algorithmus hinterlegt – sehr individuell)
- Guidelines: COG, IGHG und neueste Papers
- Alter: ab 16 Jahre, individuell nach Patientenwunsch
- Stabile Remission für drei Jahre

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Modell KSA – adulte Partner

- Hämatologie
- Onkologie
- Neuroonkologie
- Nephrologie (Wilms – Einzelniere)
- Endokrinologie
- Kardiologie
- Gastroenterologie

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Modell KSA - timeline

- Mindestens 2 gemeinsame Sprechstunden
- Kinderspital
- Erwachsenenspital
- Alles auf dem KSA Campus

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Konzept Transitionssprechstunde KSA

- Start im Januar 2018
- Konsultation 60 Minuten
- Abgabe und Besprechen der Therapiezusammenfassung und Nachsorgeempfehlungen (wird durch Kinderonkologie erstellt)
- Blut/Urinuntersuchung und Röntgen oder Ultraschall am gleichen Tag
- aufwendigere Bildgebung (z.B. MRI, CT) einige Tage vor Sprechstunde
- Spezialuntersuchungen (Echokardiographie, Audiometrie) werden separat durch uns angemeldet – aktuell organisatorisch nicht möglich, alles an einem Tag zu kombinieren

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Konzept Transitionssprechstunde KSA

- gemeinsame Sprechstunde Kinder- und Erwachsenen-Hämatologie/Onkologie
- ausführliche Anamnese und allgemeine Untersuchung
- Gespräch über Nachsorge/Spätfolgen und Abgabe Therapiezusammenfassung
- Vermessung (z.B. Gewicht, Blutdruck) und Blutentnahme
- Planung der weiteren Spezialuntersuchungen:
  - Knochendichtemessung
  - Fertilitätssprechstunde etc.
- nach der Sprechstunde: Konsultations-Bericht an Hausarzt

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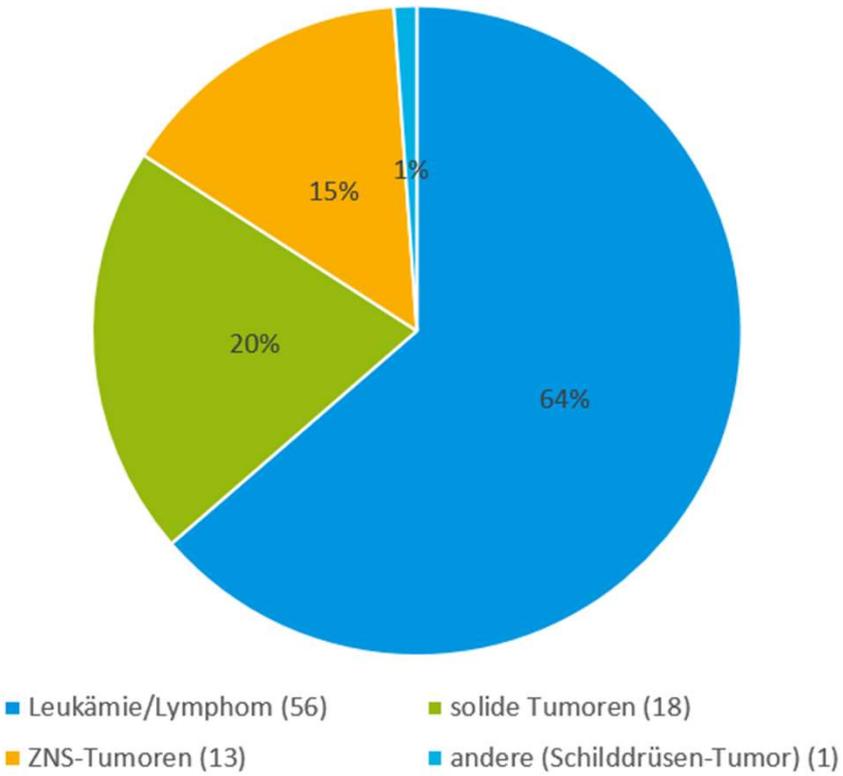
Zahlen Pilotphase Transitionssprechstunde KSA

- 88 Patienten



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Zahlen Pilotphase Transitionssprechstunde KSA

- 50 ♂, 38 ♀
- Alter: 18 – 48 Jahre, Durchschnitt: 24 Jahre
- die Mehrheit transitioniert innerhalb von 2 Sprechstunden (1. Sprechstunde Haus 9, 2. Sprechstunde Haus 40)
- bisher sehr positive Rückmeldungen von Patienten und Familien

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Transitionssprechstunde KSA – learning points

- Aufgebot
- Sozialanamnese
- Noxen – Rauchstopp
- Rolle von Eltern
- AYA Patienten

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ACCS (**A**ftercare of **c**hildhood **c**ancer **s**urvivors in Switzerland) Projekt

Long-term follow-up care after transition can continue as…

- joint clinics (pediatric and adult) in a cancer center ← Clinic A
- visits in adult oncology and hematology (hospital) ← Clinic B
- family physician with specialists outside of cancer center ← Clinic C

} ACCS

krebsforschung schweiz
recherche suisse contre le cancer
ricerca svizzera contro il cancro
swiss cancer research

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ACCS Projekt

Design

- Multicenter, prospective, questionnaire-based, cross-sectional and longitudinal
- Questionnaire: 1) General information, 2) Cancer knowledge, 3) Cancer Worry Scale, 4) Self-management Skill Scale, 5) Expectation Scale, 6) Current follow-up situation

Participants

- 5-year CCSs aged >16 years at recruitment
- transitioned to adult care between 2014 and 2021
  1) Survivors transitioned before start of study (cross-sectional)
  2) Survivors transitioned after start of study (longitudinal)

Denzler et al, JMIR, 2020.
Klassen et al, Child: care, health and development, 2015.
Klassen et al, Health expectations, 2015

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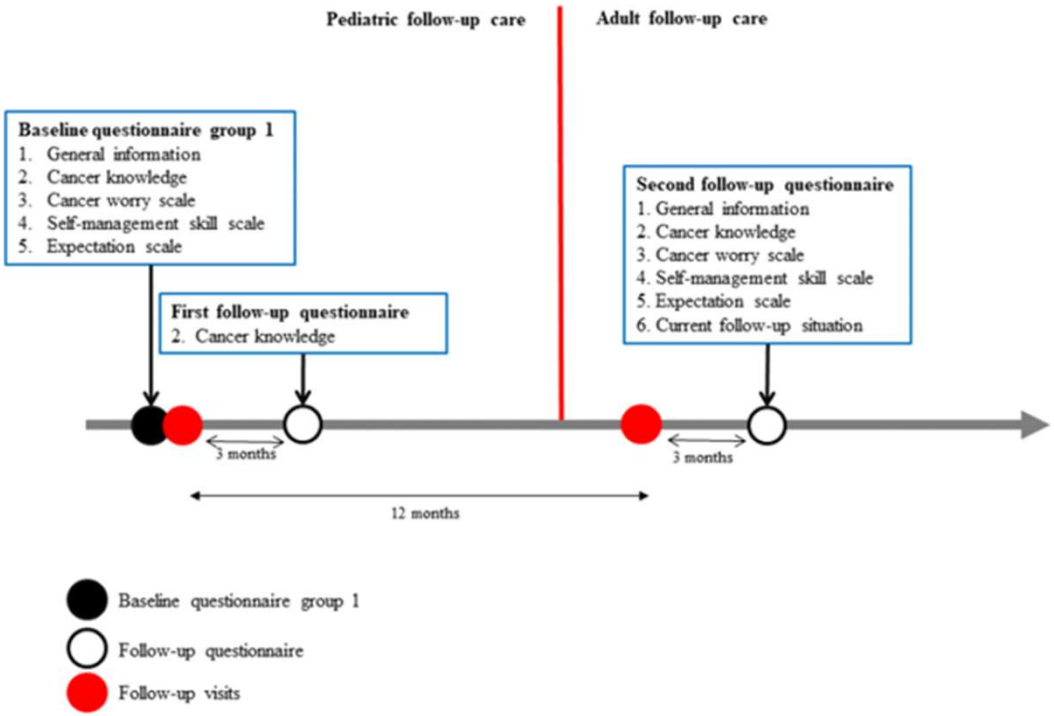
ACCS: Survivors vor Transition



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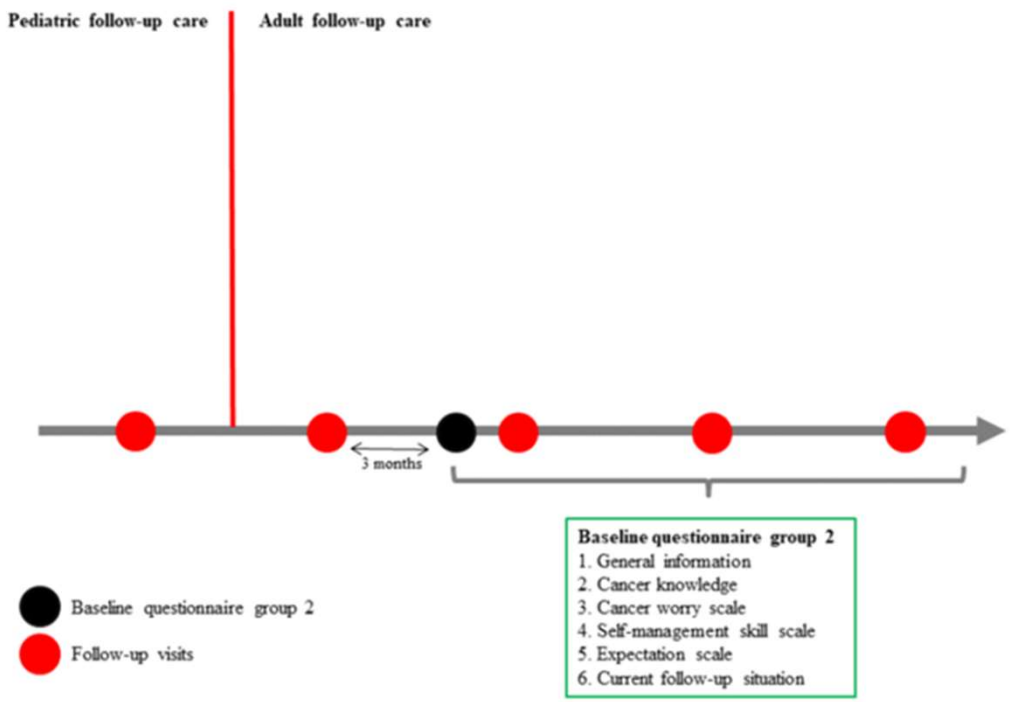
ACCS: Survivors nach Transition



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ACCS: erste Resultate

	Clinic A	Clinic B	Total
Number of participants, n (%)	37 (65)	20 (35)	57 (100)
Time point			
- any time	20 (35)	20 (35)	40 (70)
- 15 months	17 (30)	0	17 (30)
Sex			
- female	22 (39)	12 (21)	34 (60)
Age at diagnosis [years], Median (IQR)	8 (4 – 13)	14 (5 – 16)	9 (4 – 14)
Age at survey [years], Median (IQR)	24 (21-27)	22 (20 – 25)	23 (21 – 27)
Type of cancer (reported by physician)			
- Leukemia	15	6	21 (37)
- Lymphoma	7	2	9 (16)
- CNS tumors	3	1	5 (9)
- Ewing sarcoma	4	1	5 (9)
- Other	8	10	18 (30)

Otth M, Denzler S, Diesch-Furlanetto T and Scheinemann K (2022) Cancer knowledge and health-consciousness in childhood cancer survivors following transition into adult care—results from the ACCS project. *Front. Oncol.* 12:946281. doi: 10.3389/fonc.2022.946281

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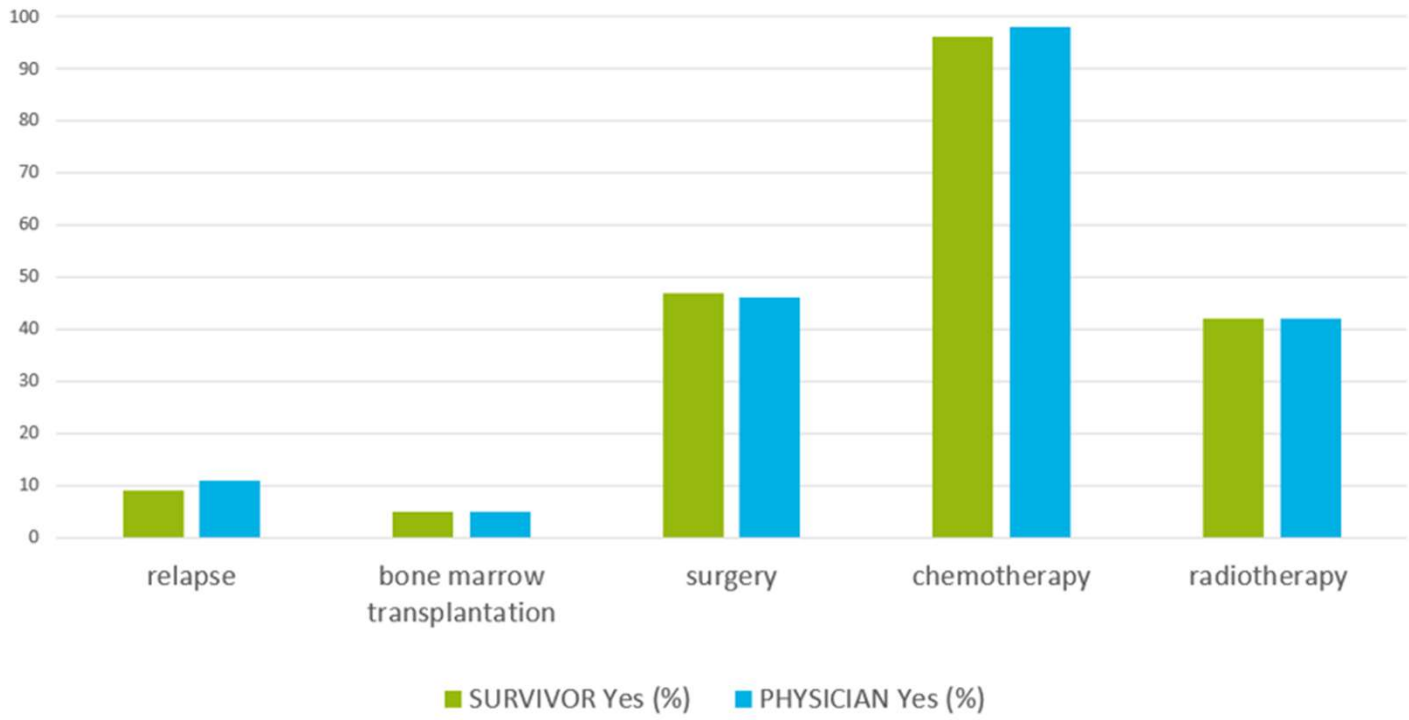
Fragebogen: Cancer knowledge



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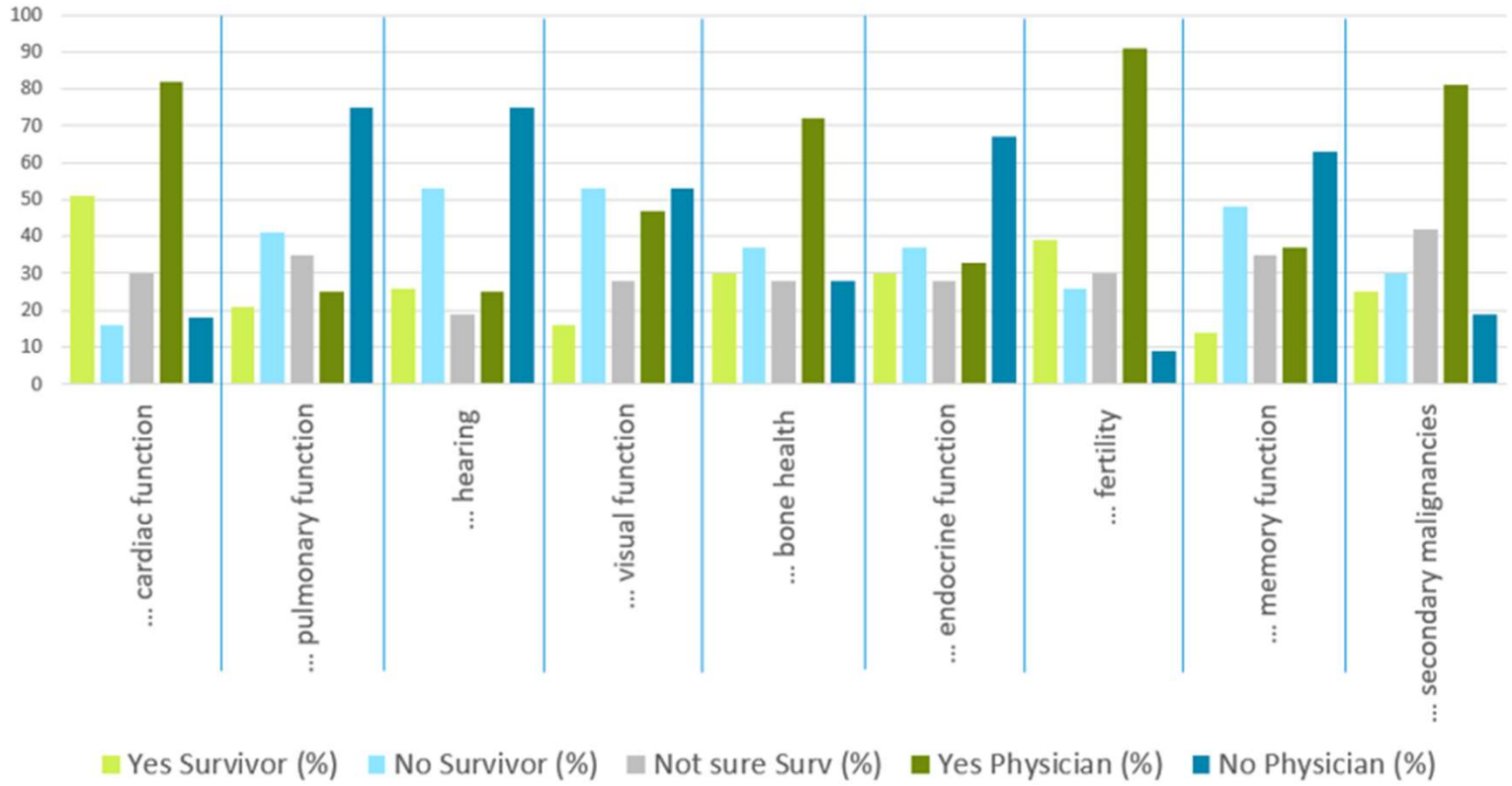
Fragebogen: Cancer knowledge



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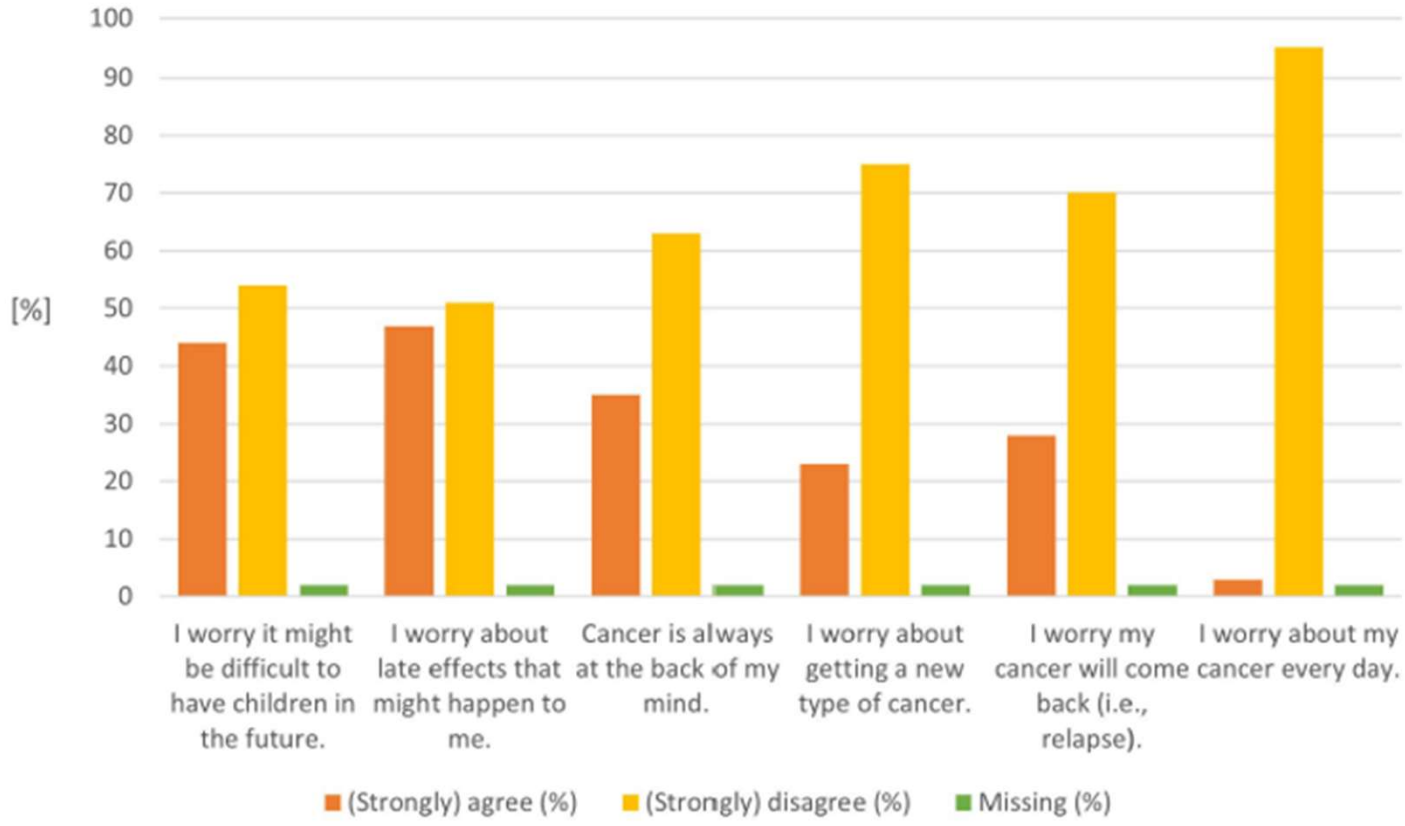
Fragebogen: Cancer worry scale



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Fragebogen: self – management skills

15 Questions about handling and independence for own medical care

Top 3

1. I know the type of medical insurance I have (97% [strongly] agree)
2. I answer a doctor or nurse's questions (94%)
3. I know how to contact a doctor if I need to (94%)

Low 3

1. I prefer it when a doctor speaks to me instead of my parent(s) (67% [strongly] agree)
2. I prefer to see a doctor or nurse without any parent(s) with me (69%)
3. I talk to a doctor or nurse when I have health concerns (74%)

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Fragebogen: expectation scale

12 Questions about structural/ organizational aspects of follow-up care

Top 3

When leaving the children's hospital I expect that…

1. … my after care physician knows my cancer history (97% [strongly] agree)
2. … the visit starts on time (95%)
3. … I can always call my physician in case of questions (92%)

Low 3

When leaving the children's hospital I expect that…

1. …my follow-up care physician team spends a lot of time with me (13% [strongly] agree)
2. … my follow-up care physician becomes like a friend (25%)
3. … my parents can come to the visit (44%)

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ACCS

- Analyse longitudinale Daten
- Neues Zentrum für Hausarztmodell eingeschlossen, Analyse läuft

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«Young Survivors» Registry

- RedCap
- Baseline: survivorship care plan
- FU visits
- Severity of late effects (modified CTCAE) – each annual visit

To cite: Otth M, Drozdov D, Hügli C, *et al.* Young Survivors at KSA: registry for standardised assessment of long-term and late-onset health events in survivors of childhood and adolescent cancer—a study protocol. *BMJ Open* 2021;**11**:e053749. doi:10.1136/bmjopen-2021-053749

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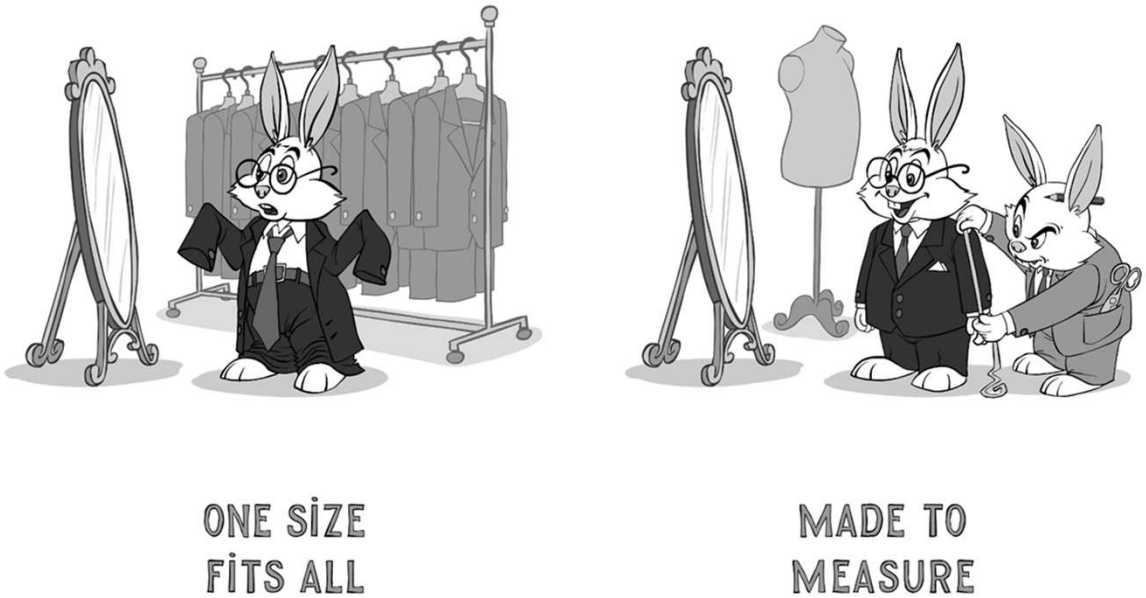
Vielen Dank für die Aufmerksamkeit!



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