



lost in transition

becoming an adult with a chronic disease: an example from pediatric oncology

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Transition of care is defined as the

“purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.” blum 1993

Transition is a **process** starting in early adolescence and ending with the actual **transfer** of the patient to adult-centred care.

Ideal age → 16-20 berg kelly 2011

Transition has become a major public health concern

→ improved survival

Average survival for a child with cystic fibrosis

*In 1970 → **7 years***

*In 2000 → **40 years***

5 year survival in childhood cancer

*In 1970 → **40%***

*In 2010 → **80 %***

MAIN OBJECTIVE/CHALLENGE

Work at the **systems level** to develop a health care continuum for youth with special health care needs.

What is the situation in pediatric oncology?

- Most patients need lifelong follow up care because of their elevated risk for developing physical late effects
- No systematic transition is offered (no national program)
- Very challenging because patients are usually healthy → high risk to loose patients to follow up
- No study assessed transition in this population

Aims

We aimed to describe:

1. The follow up status of childhood cancer survivors
 - by age group
 - by risk for late-effects (low, middle, high) Wallace 2001
2. Where they were transferred to (if transferred)
3. The characteristics of survivors who were transferred or in pediatric follow up compared to survivors who were discharged

Methods

Transition after Childhood Cancer Study (TaCC)

- Systematic chart review in 9 clinics
- The study includes childhood cancer survivors
 - registered in the **Swiss Childhood Cancer Registry**
 - survived ≥ 5 years
 - <16 years at diagnosis
 - diagnosed between 1976-2005
 - aged ≥ 16 at study



Methods

Outcome of interest

Follow up status

Transfer: transferred from pediatric oncology to adult-oriented care

Discharge: no longer in follow-up in pediatric oncology and not receiving official follow-up care (i.e. no indication for transfer was found in the medical records)

Pediatric follow up: being in follow up in pediatric oncology

Results I

Study Population

Total charts retrieved and reviewed: 501

Age at study:

mean=27.1 years; SD=6.3

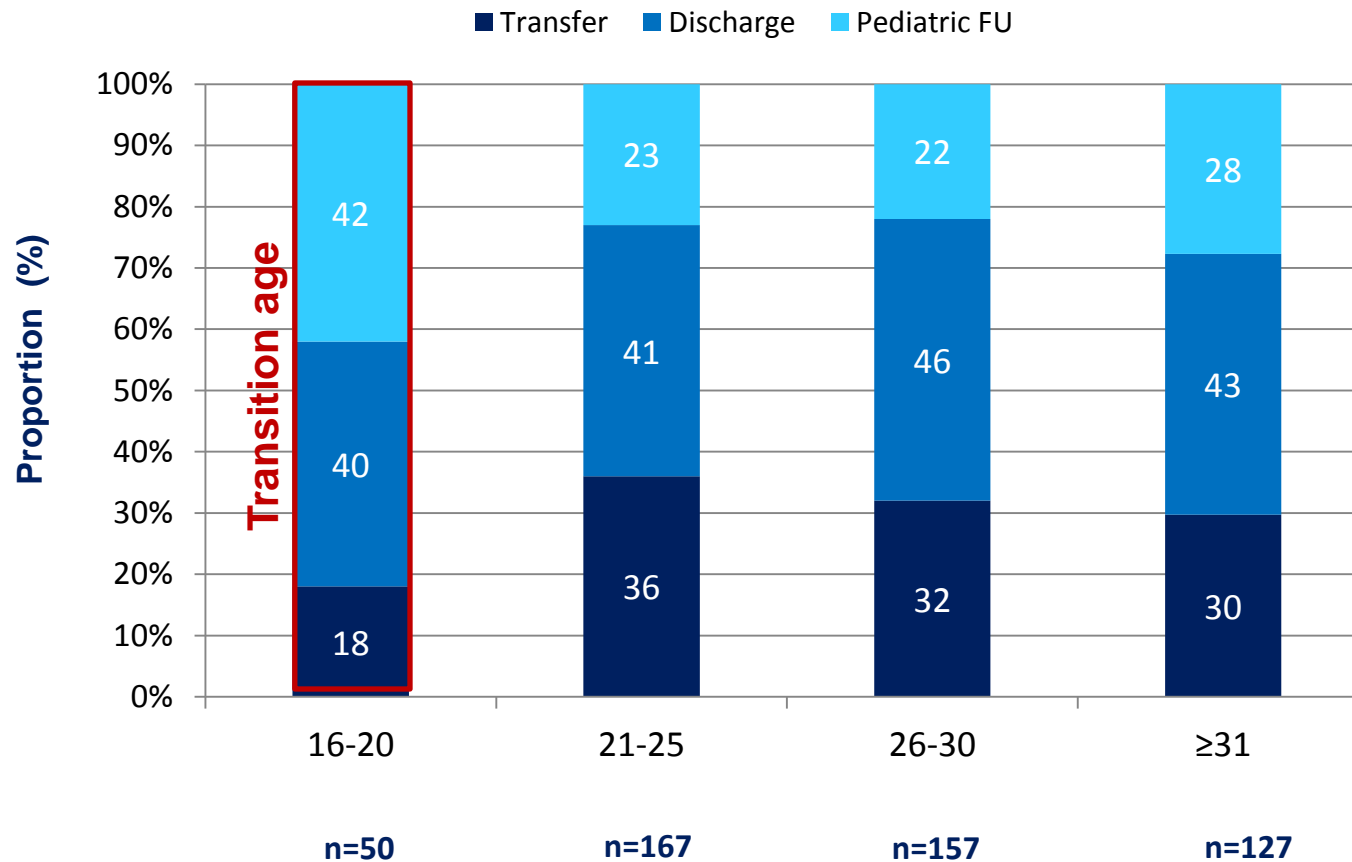
range=16.9-48.1 years

Time since diagnosis:

mean=18.9 years; SD=6.9

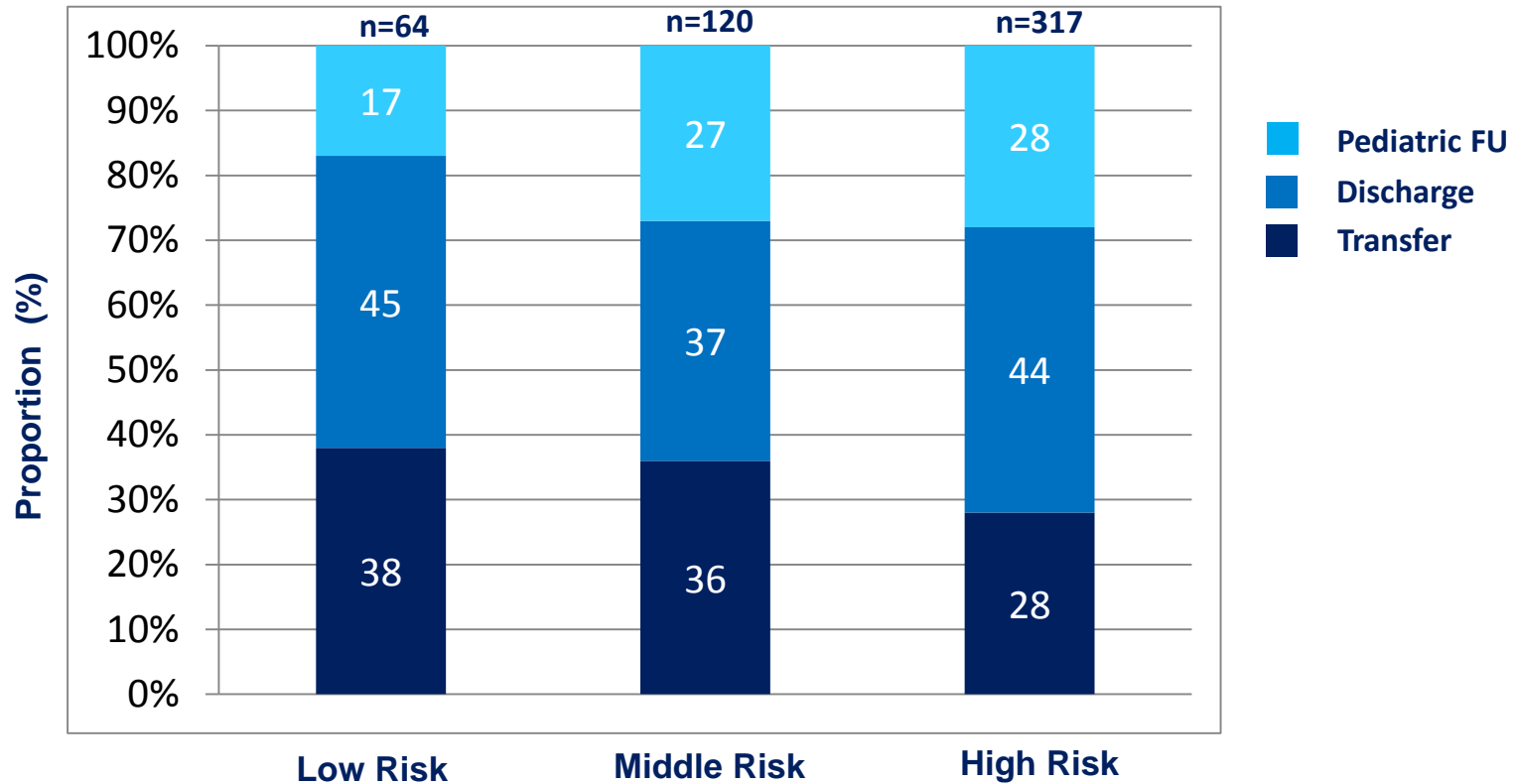
Results II

Follow up status by age group



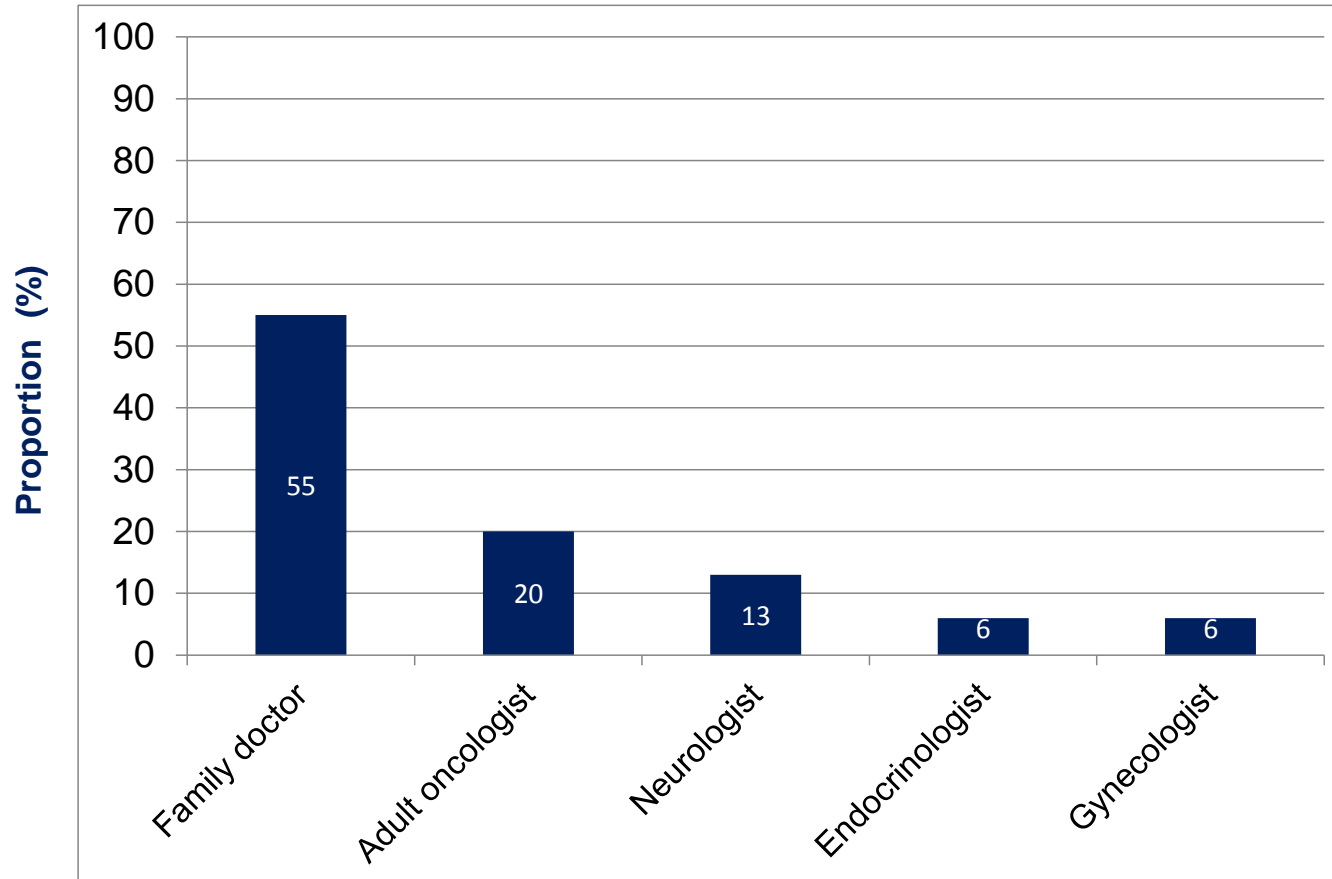
Results III

Follow up status by risk for late effect



Results IV

Transfer destinations



Results V

Characteristics of survivors «Transferred» or «In follow up» compared to «Discharged»

Multivariable multinomial logistic regression

	RR Fu	95%CI	RR Tr	95% CI	p-value
Gender					0.007
Male	1		1		
Female	1.9	1.2-3.2	1.8	1.2-2.8	
Radiotherapy					0.012
None	1		1		
Cranio-spinal	2.3	1.1-4.4	2.8	0.5-5.1	
Body/Limbs	1.4	0.7-3.1	1.2	0.9-3.6	
Type of clinic					<0.001
>30 cases/year	1		1		
<30 cases/year	0.09	0.05-0.2	0.4	0.2-0.8	

Not associated: age, diagnosis, surgery, chemotherapy, relapse

RR= Relative Risk

Summary

- Around 1 in 4 survivors is still in pediatric care even in adult age
- Many are discharged without further referral (both younger and older)
- There is no apparent consideration of the risk for late effects
→ 44% of the high risk group are discharged
- Most common transfer destination → family doctors
- Compared to discharged survivors, those in follow up and transferred were more likely female, received radiotherapy and from larger clinics

Conclusions

- Transition does not seem to be offered systematically
- Patients' age & risk for late effects not considered
- Many survivors are discharged and potentially lost to follow up

→ Early, risk oriented and systematic transition:

no over/undertreatment

no loss to follow up

prevent/early detect late effects

→ Improvement quality of survivorship

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Thank you!

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