

Young Carers and Education in Germany

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Outline

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Background

Young Carers in Germany:

- awareness and policy response to young carers are preliminary (Leu & Becker, 2016)
 - little awareness of the phenomenon in public, research or practice
 - few specialized services and specific interventions for young carers and their families but other services may be applicable
- 5% young carers between 12 and 17 years (Lux & Eggert, 2017)
- children and adolescents as carers: experience and construction of familial care (Metzing, 2007)
 - little is known about young carers' situation in their education in Germany (Kaiser & Schulze, 2014; 2015)

The Study: Young Carers and Education in Germany

PhD project, supervised by Prof. Dr. Gisela C. Schulze (Oldenburg, Germany) and Prof. FH Dr. iur. Agnes Leu (Zurich, Switzerland)

Aims

- getting an insight into the situation of young carers in school
- identifying barriers and facilitating factors in school from different perspectives (young carers, parents, teachers)
- evaluating and developing possibilities of support in school context

The Study: Young Carers and Education in Germany

Theoretical Background: Field Theory of Lewin (Lewin, 1946) and Person-Environment-Analysis (Schulze, 2002)

Participants

n= 9 (adolescent) **young carers** (13-16 years), **MACA-YC18*** score **11 and higher**: moderate amount of caring activities (scale: 0-36)

n= 8 of their **parents**

n= 5 of their **teachers**

using a **broad concept of care**

period of recruiting participants: November 2015-2016

*Manual for Measure of Caring Activities and Outcomes for Children and Young People (Joseph, Becker, Becker, et al., 2009)

The Study: Young Carers and Education in Germany

Method: semi-structured, problem-centred interview (Witzel, 1985)

- guideline builds on international research results (Cluver et al., 2012; Dearden & Becker 2002; 2004; Eley, 2004; Hunt et al., 2005; Metzging, 2007; Moore et al., 2006; 2009; Nagl-Cupal et al., 2012; Sempik & Becker, 2013; Smyth et al., 2011) but leaves openness for subjective perceptions

Main topics (adapted for the different participants):

- (1) familial situation,
- (2) situation in school,
- (3) communication and interaction** and
- (4) recommendations for support

Analysis: qualitative content analysis (Mayring 2015)

Findings: Communication of illness, disability and care responsibilities: **Young Carers**

- range of the **type**, **content** and **trigger** of communication about their situation with teachers and their peers

"Yes, I adressed that [the situation] at the beginning of the year because the teachers wanted to point out to the other students that we are in a school where there are children with disabilities. For example, they mentioned that the elevator is only for the disabled. They also asked who has sibilings. After the class I went to my teacher Mrs. X. I told her the situation and said that I wanted to share that in front of the class"

(Sarah, female YC, 13 years old; in Kaiser 2017, p. 155)

- communication with teachers and peers after addressing topic of disability in class

Findings: Communication of illness, disability and care responsibilities: **Young Carers**

“Well, they [the other students] didn’t know about my grandma. Yes, they knew about my mother since she sometimes came to school and they asked about it. Except about my grandma ... yes I told them [later; about my grandma] but it was OK (...)”

(Jonas, male YC, 14 years old; in Kaiser 2017)

“They [my classmates] know because I have to go with my parents to the parent conference day. Yes; that is how they noticed (...)”

(Johannes, male YC, 15 years old; in Kaiser 2017)

- communication of - *visible* - physical condition after peers see relatives,
- talking about illness/ disability after public discussion and raised awareness – (e.g. campaign: ALS Ice Bucket Challenge)

Findings: Communication of illness, disability and care responsibilities: **Young Carers**

- Daniela's mother has a mental illness and mentions her backaches during the interview. Daniela (D) replies to whether she has talked to her classmates about her mother's illness:

„D: They asked what is going on with my mother, or something like that because she didn't come to the parent conference day. I answered: Yes, my mother is ill so she can't come.

I: Do you tell them about your mother or do you just say that she is ill?

D: (laughs) No, about the backache, yes. I have often mentioned that. But, they don't have any problem with that.“

(Daniela, female YC, 15 years old; in Kaiser 2017, p. 153)

→ communication only of non-stigmatized illnesses in school

Findings: Communication of illness, disability and care responsibilities: **Parents**

- diverse **situations, extent, intentions** and **types** of communication between parents and teachers

"This is our situation. As you can see, it's not quite working for our children. This is normal because they are in school half of the day. Of course, teachers need to know why he [my son] is like that. I told them. I think this is better" (father, ≤ 50 y.; in Kaiser 2017, p. 152)

"(...) [in secondary schools] nobody is interested" (mother, ≤ 50 y., in Kaiser 2017, p. 152)

- parents state the need for teachers to know about the situation of YC to react appropriately but they report different (positive and negative) reactions
- problem: privacy and open communication *for* their children

Findings: Communication of illness, disability and care responsibilities: **Teachers**

- diverse **moments** when they learned about the situation, sometimes **insufficient communication between teachers, different reactions**

"Certainly. I think parents are afraid that their child will be looked at differently and, indeed, it is really difficult. The child does not want that either. The effect will occur according to the motto: 'It is all very difficult for you. It will be good if you do half of the tasks'. This cannot be the right thing to do. Moreover, I think the child, or I mean the student, won't feel appreciated." (female teacher, ≤ 30 y., in Kaiser 2017, p. 177)

- good intended reactions

Findings: Communication of illness, disability and care responsibilities: **Teachers**

„I wouldn't say we treat him differently. But, maybe you are more cautious or you consider it somehow... yes, automatically, without thinking about it“
(female teacher, ≤ 40 y., in Kaiser 2017, p. 149)

- teachers see a risk in treating students differently but 4 out of 5 teachers say they reacted more indulgently
- exchange of the students' situations between teachers seems difficult: between primary and secondary school and also in secondary school

Findings: Different Perceptions

- concerning single cases (*young carers-parents-teachers*): some participants have divergent perceptions on the same phenomena or situations but the grading, positive or negative, is similar (Kaiser, 2017, p. 242ff.)
- main discrepancies in perception is related to:
 - type of illness or disability
 - amount of caring responsibilities
 - **bullying in school** (Kaiser, 2017, p. 242ff.)

Findings: Different Perceptions

Daniela is being bullied by her classmates. She blames her behaviour and outer appearance, and:

„Yes, I don't care what they say, how they insult my mother or something like that. Because I can't understand that. Of course I protect my mother, she is my life. She really means something to me...“

(Daniela, female YC, 15 years old; in Kaiser 2017, p. 146)

„I don't tell her. I don't want her to become more anxious. I haven't told her the incidents.“ (Daniela, female YC, 15 years old; in Kaiser 2017, p. 160)

„Yes, she didn't want to go to school because of the bullying, she... it was a new experience for her, she was helpless (...). But now, not anymore!“

(her mother, ≤ 50, in Kaiser, 2017, p. 139)

Conclusion

- anti-disability culture in school (Moore 2005) prevents young carers (and families) from openly communicating illness, disability and care → fear of bullying or being treated differently are common topics in the study

(Kaiser 2017)

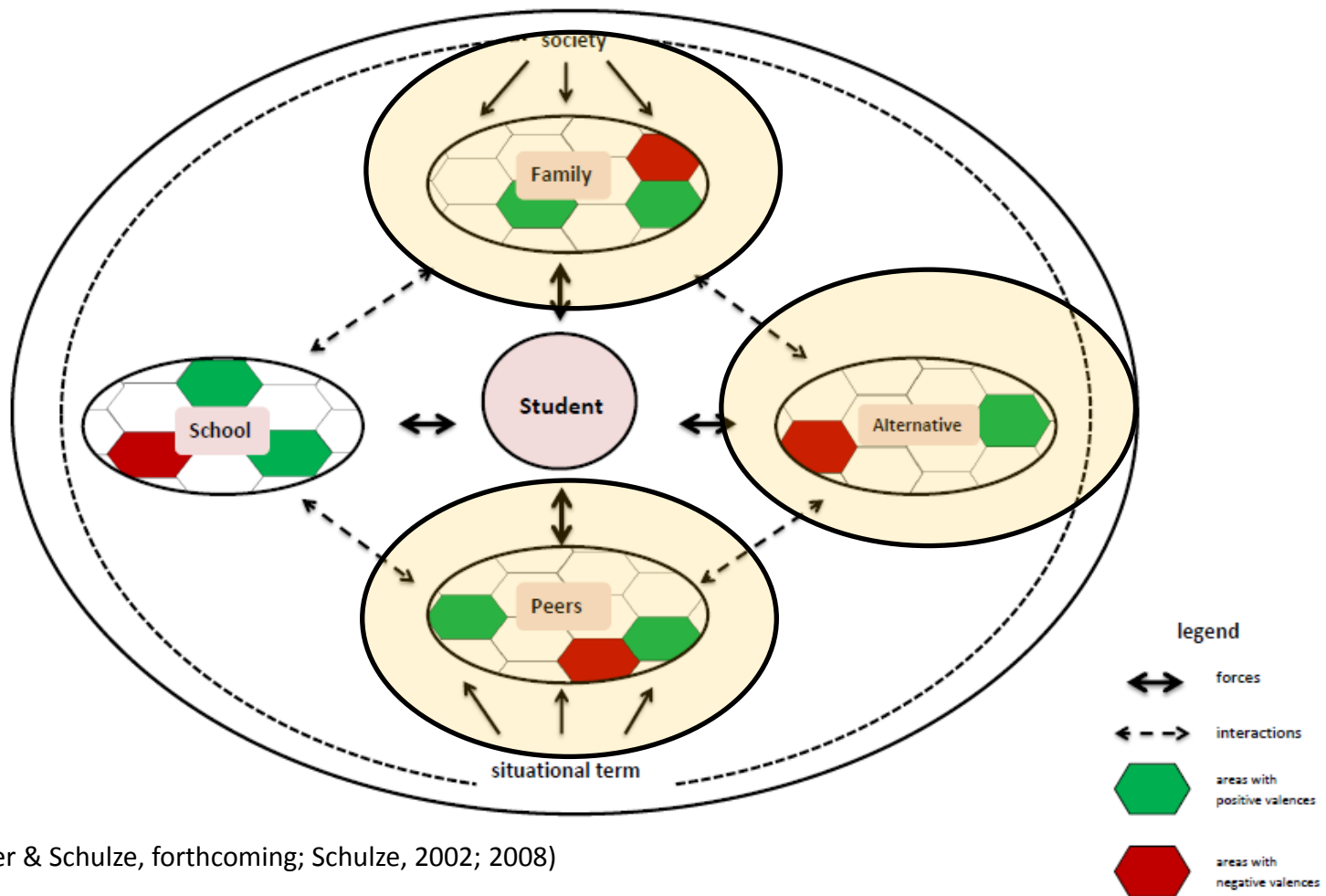
„My mother has an illness, too. I think one should, I don't know, do one day where... The problem is you need confidence in class but few have it (...). I think that is the biggest problem. Many are afraid to say something. There should be a day in which everyone says what's happening to have a closer look at some of the illnesses; that is, to learn what the illness is really about. I think they would understand more and there wouldn't be so much teasing and so on“ (Sarah, female YC, 13 years old; in Kaiser 2017, p. 167)

Conclusion

- concerning communication, there is a difference between socially accepted health conditions and those who have a stigma → school is a place to educate about illness and disability (*successful* inclusion)
- first study to capture young carers', parents' and teachers' perspectives on the situation inside school and family
 - situation in school consistent with international research (school absenteeism, bullying, worries, ...)
 - results give in-depth explanations
 - reveals strategies to support young carers in school

(Kaiser 2017)

Perspectives: The Student's Life Space



Perspectives

- evaluating the perceptions of peers (classmates), siblings and other individuals on the situation of young carers
- quantitative extent of the awareness of professionals working in education, health and social care on young and young adult carers (cooperation of Oldenburg University & Careum Forschung; completed July 2017: Rehder, Vagelpohl & Handelsmann)



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