Young Carers and Young Adult Carers in Switzerland: Strategic Approach and First Findings

2nd International Young Carers Conference in Malmö, Sweden 29-31 May 2017

Prof. Dr. Agnes Leu
Marianne Frech, PhD candidate SNSF
Outline

1. Careum Research
2. Strategic Approach
3. Research Programme «Young Carers»
4. First Research Findings
5. Questions & Discussion
Careum Research
Research Orientation along the Lifespan
Careum Research
Team Young Carers

2nd International Young Carers Conference in Malmö, Sweden May 29-31 2017
Research Programme «Young Carers»
Strategic Approach

Research

Start Young Carers Research in Switzerland: May 2014
Development Research Programme

Politics

«This report does not suggest any actions for children of minor age who look after their ill parents. This issue goes beyond the scope of political commission» (p. 10).
Research Programme «Young Carers»
Strategic Approach

Postulate by National Council Member Schmid-Federer: May 2015
«Don’t exclude caring children»

Federal Council Statement: September 2015
He will pay particular attention to the specific needs of the YC, so there is no need for a further report. The Federal Council recommends rejecting the postulate.

Newspaper Report NZZ: April 2016
Family care by minors - the hard lot of caring children
Research Programme «Young Carers»
Strategic Approach

Personal Letter of the Federal Councillor: June 2016
Support Program CTI Plus (Commission for Technology and Innovation):
Research funding – development of practical basic principles also for YC

First Swiss TV contribution on Young Carers: August 2016
http://www.srf.ch/play/tvpopupvideoplayer?id=efb6ef2f-5f0b-485c-adc0-35ed878e3d0d#/t=96.086
Research Programme «Young Carers» Strategic Approach

Federal Office of Public Health (FOPH): February 2017
Development plan for caring relatives 2017-2020: Call for submission of research proposals

End of Project Conference Young Carers in Switzerland: March 2017
Presentation of Ebnet Results
Head of national health policy section (FOPH): «We learned from you!»

Research Programme «Young Carers»
Strategic Approach

Definition of YC in Switzerland currently
(Becker, S., 2000, p. 378)
Research Programme «Young Carers»
Strategic Approach

What is the significance for Switzerland?

<table>
<thead>
<tr>
<th>Children and young adults up to 25 years</th>
<th>YC &amp; YAC 2%</th>
<th>YC &amp; YAC 4%</th>
<th>YC &amp; YAC 5%</th>
</tr>
</thead>
<tbody>
<tr>
<td>2’280’451</td>
<td>45’609</td>
<td>91’218</td>
<td>114’022</td>
</tr>
</tbody>
</table>

Figures of the Federal Statistical Office Switzerland, 2015
https://www.bfs.admin.ch/bfs/de/home/statistiken/bevoelkerung.assetdetail.80423.html
| Research Programme «Young Carers»  
<table>
<thead>
<tr>
<th>Ongoing Subprojects (SP)</th>
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</table>

### Research Programme Young Carers in Switzerland

<table>
<thead>
<tr>
<th></th>
<th>EBNET Foundation</th>
<th>SNSF (Swiss National Science Foundation)</th>
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</table>
| **SP 1 (2014)**      | Young Carers &  
|                      | Young Adult     
|                      | Carers in       
|                      | Switzerland     |
| **SP 2 (2015)**      | Awareness of    
|                      | professionals   
|                      | from health care,  
|                      | education and   
|                      | social services |
| **SP 3 (2016)**      | Awareness of    
|                      | professionals from  
|                      | health care, social  
|                      | services and   
|                      | education (N=1’000) |
| **SP 4 (2017)**      | Pupils (aged 9 to  
|                      | 16) in schools, representative sample |
| **SP 5 (2018)**      | Young Carers &  
|                      | Young Adult      
|                      | Carers and affected  
|                      | family member(s) |

<table>
<thead>
<tr>
<th></th>
<th>5 cantons</th>
<th>5 cantons</th>
<th>Swiss wide</th>
<th>Swiss wide</th>
<th>Swiss wide</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>50 interviews</strong></td>
<td>30 interviews</td>
<td>5 focus groups</td>
<td>online survey</td>
<td>online survey</td>
<td>40 interviews</td>
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<tr>
<td></td>
<td>qualitative</td>
<td>quantitative</td>
<td></td>
<td></td>
<td>qualitative</td>
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</tbody>
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- **11th International Young Carers Conference in Malmö, Sweden May 29-31 2017**
Research Programme «Young Carers»
Quo vadimus?

<table>
<thead>
<tr>
<th>D-A-CH</th>
<th>Horizon 2020</th>
<th>FOPH</th>
<th>EBNET follow up</th>
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<tbody>
<tr>
<td>Young adult carers’ participation in higher education</td>
<td>Psycho-social Support for Promoting Mental Health and Well-being among Adolescent Young Carers in Europe</td>
<td>Carers needs for support and relief over the lifespan</td>
<td>Young Carers &amp; Young Adult Carers: Challenging Transition from Education to Professional Career</td>
</tr>
<tr>
<td>Germany, Austria, Switzerland</td>
<td>International</td>
<td>Swiss wide</td>
<td>Swiss wide</td>
</tr>
<tr>
<td>Under review</td>
<td>Under review</td>
<td>Under review</td>
<td>Under review</td>
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</tbody>
</table>
Research Programme «Young Carers»
Quo vadimus?

Research Programme «Young Carers»
Welcome back to Switzerland!

https://www.atlas.bfs.admin.ch/maps/13/map/mapIdOnly/0_de.html
Research Programme «Young Carers»
Research Challenges: 26 Cantons

https://www.bfs.admin.ch/bfs/de/home/statistiken/regionalstatistik/regionale-portraits-kennzahlen/kantone.html
Research Programme «Young Carers»
Subproject 1

Aims / Methods:

SP 1: Evaluation of the **nature and intensity of care**, the **ways into care**, **socio-economic and demographic circumstances** of caring children, adolescents and young adults and their families

Methods: Interviews (German/French)
Grounded Theory approach

Duration: July 2015 to October 2016

Funding: [http://www.careum.ch/youngcarers-ebnet](http://www.careum.ch/youngcarers-ebnet)
Research Programme «Young Carers»
Selected Findings Subproject 1

YC/YAC are also a reality in Switzerland

- The Swiss research results correspond with results from international research

- Consequences of a missing awareness from and about YC: reduced use of existing services

- YC/YAC are not involved in the decision making process, even though they often take on main responsibility for caring tasks at home.

- New aspect: communication
Communication as a core theme

- YCs and YACs are „information and coordination hub“: time-intensive and stressful!
- Communication hub is experienced as a burden by YC
- Communication versus silence
Research Programme «Young Carers»
Results from Focus Groups (SP 2)
Aims / Methods:

SP 2: Raising awareness among professionals, development of specific tools to support professionals in health and social services (e.g. GPs, A&E departments, protection authorities for children and adults) in their daily work

Methods: five focus groups in German/French qualitative content analysis

Duration: December 2015 to April 2016

Funding: http://www.careum.ch/youngcarers-ebnet
Professionals awareness of YC
- Lacking awareness
- Retrospective recognition
- Patient focused approach

Best practice requirements & needs for achievement
- Existing practice tools for professionals
- Interprofessional network
- Target-oriented support (whole family approach)
- Services (websites, YC support group, school-based case management, …)
Research Programme «Young Carers»
Practice Tools for Professionals

First Priority for Professionals: Checklist

Further Priorities:

- assessment programmes (Pro Infirmis, home care nursing, palliative home care services)
- new curriculum in school/s for nursing and social work (caring relatives)
- absence management (e.g. vocational training)
- websites and brochures

Development in our «Ebnet Follow Up Project»
Questions & Discussion

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http://www.careum.ch/youngcarers

#youngcarersCH
Careum@CareumCH

http://blog.careum.ch/?p=7022
Selected Publications


Complete publication list: http://www.careum.ch/yc/publikationen.
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Thank you for your esteemed attention. It has been a pleasure!