CAREER COUNSELLING FOR CHILDHOOD CANCER SURVIVORS: EXECUTIVE SUMMARY OF THE RESEARCH

Authors:
Carmen Fernández-Morante & Beatriz Cebreiro López (Dirs.)
Carmen Fernández de la Iglesia, Carol Jean Gillanders,
Santiago García Vázquez, Isabel Porto Golpe.

Contributors:
Anelia Dimitrova, Simona Karaivanova,
Sabine Karner, Olga Mineva, Jennifer Ziegler,
Holger Bienzle, Maria José Rodriguez Malmierca,
Luisa Basset Salom.

Leading partner organisation: University of Santiago de Compostela

Full report published by the University of Santiago Press Service (in process)

This project has been funded with support from the European Commission. This document reflects the views only of the author, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

TABLE OF CONTENTS

1. Issue and Research objectives

In the field of Education Sciences, and in particular hospital pedagogy, multiple educational innovation initiatives have been developed to facilitate the training during the illness and convalescence of school-age children and adults, and even the development of e-learning systems for inpatient (Bienzle, H. et al, 2008)[1].

Therefore there are multiple interesting resources and innovative educational experiences, but very few outstanding in-depth research projects that reveal the full complexity of needs and educational experiences of children with cancer during and after illness.

In other words, there is a gap in educational research that blocks the visibility to this reality and the research-based identification of the needs, problems and challenges that these children, young people and their families face. Further research in this specific area would also define the areas of intervention and improvement that the authorities should respond to with their educational, occupational, economic and social policies among others. The current research, part of the Create Your Future project, aims to respond to this challenge.

Taking into account the above considerations and trying to effectively answer them, we formulated the following **research problem**:

"To know the needs and challenges European childhood cancer survivors are facing once they overcome the disease, and in particular, when they retake their educational process and face their professional future"

The problem culminated in the following **general objectives** that served us to guide the study design and data collection instruments

1. To know to what extent the diagnosis of disease, recovery process and medical treatment could affect the experience of these childhood cancer survivors and their **school performance**.
2. To analyze to what extent the disease conditions the childhood cancer survivors´s **social life, relationships, personal attitudes and self image**. All of them are crucial aspects in the educational process and personal growth.
3. To analyze how the disease affects the **vision of their professional future** and their access to the world of work - barriers experienced, needs and strengths.
4. To discover the point of view of a childhood cancer survivor regarding his/her professional future, learning needs and educational and vocational guidance.

---

[1] This is for instance the case of the European e-hospital Project, previously developed by some of the participant partners in "Create Your Future" (Die Berater, USC and CESGA) and from whose website the handbook and the research report can be downloaded (http://www.ehospital-project.net/downloads.htm)

2. Methodology and phases of the study

To find answers to the objectives outlined above , we developed a descriptive research by using the method of survey which is one of the methods most commonly used in educational research. In this case, we developed and used two complementary instruments for data collection: the questionnaire and semi-structured interview conducted with survivors of childhood cancer from four European countries (Spain, Austria, Bulgaria and Greece).

3. Data collection instruments

As already mentioned above, we designed two instruments that are included in the research study publication to obtain research data:

1. Create Your Future questionnaire on the difficulties, needs and challenges of Childhood Cancer Survivors after their treatment and on their way back to education and work.
2. Create Your Future In-depth interview protocol

4. Study sample

Population: young childhood cancer survivors from four participating countries: Austria, Bulgaria, Spain and Greece.

Sample:

		Frequency	Percent	Valid percent	Sum percent
Valid	Austria	*77*	*21,7*	*21,7*	*21,7*
	Bulgaria	*97*	*27,3*	*27,3*	*49,0*
	Greece	*70*	*19,7*	*19,7*	*68,7*
	Spain	*111*	*31,3*	*31,3*	*100,0*
	Total	*355*	*100,0*	*100,0*	

Distribution per country of the quantitative study actual sample (Questionnaire)

		Frequency	Percent	Valid percent	Sum percent
Valid	Austria	*7*	*27*	*27*	*27*
	Bulgaria	6	*23*	*23*	*50*
	Greece	5	*19,2*	*19,2*	*69,2*
	Spain	8	*30,8*	*30,8*	*100,0*

	Total	***26***	***100,0***	***100,0***	

Distribution per country of the qualitative study actual sample (Interview)

5. Conclusions

Key findings of the study around objective 1: To know to what extent the diagnosis of disease and the recovery process and medical treatment could affect the experience of these childhood cancer survivors and their school performance.

5.1 Educational experience during the treatment and reincorporation into school.

Main ideas that the study reveals:

- The importance of maintaining the link with the school, the teachers and peers during treatment.
- The existence of difficulties to attend class regularly because of the illness and how it involves recurrent absences from school.
- A need for special attention at the moment of reincorporation to the school (teachers and psychologists)
- The impact of the disease and the difficulties in social relations and social dynamics that take place in school.
- The direct impact of the disease and treatment processes of learning and school performance (difficulty keeping pace during school and after treatment and learning problems resulting from side effects of treatment or long-term effects).

5.2 Educational situation of survivors at the end of treatment.

Main ideas that the study reveals:

- Fortunately quitting school occurs only at a very low percent (1,5%), while most of the survivors normally return to school and the same classroom after the treatment has ended.
- The disease has a direct impact on the academic performance for a significant percentage of childhood cancer survivors (47,1%) (from processes that result in delays even involve repeating a school year, slower rhythms or difficulties associated with long-term effects of treatment to more complex cases which fortunately occur in very low percentages, where as a result of the process, the child drops out of school and the educational process is interrupted).

5.3 Type of educational aids with which childhood cancer survivors counted during treatment.

Main ideas that the study reveals:

- The institutions' educational response with regard to the treatment period and the illness effects includes neither protocols nor specially trained personnel.
- The professional guidance that is offered to this group of people is not defined nor are the counsellors trained to meet their needs and there are no action protocols/official guidelines designed. The most common situation was the lack of professional guidance that can be understood as the invisibility of the needs of this group of people. Even those services that meet the specific needs related to the disability do not take into account long-term illnesses where the illness effects affect the physchological aspects more than the physical ones.
- More than half of survivors did not have available most of the principal aids: Specific support of teachers, peers and other education professionals who can play a crucial role in these cases, Accessibility measures and technological resources which are essential to make more bearable or minimize the usual short and long-term treatment effects, Curricular adaptations that allow flexibility in the educational process and are adapted to the conditions resulting from the disease and medical treatment.
- The two most valuable aids are family support and the support of close friends / environment.
- It is also worth noting that the importance the researched target group attaches to the availability of any recreational activities and entertainment after treatment reaches ...%. This fact underlines the strong impact of the disease process and the treatmentover the young patients, caused by suffering the insecurity, stress and the negative physical experience. in these terms it is important to provide non-formal entertainment and leisure alternative and some degree of disconnection and mental well-being and relaxation, that would encourage the normalization of life in the later stages of treatment.

Key findings of the study around objective 2: To analyze to what extent the disease is conditioning the childhood cancer survivors' social life, their relationships, personal attitudes and their self image.

5.4. Help that survivors received during the treatment

Main ideas that the study reveals:

- Survivors attach great importance to all aid that can help them in the process related to *the* permanence and personal socio-emotional involvement (family support, support from friends), with the support of different professionals (doctors/nurses, psychologist, teachers), with the availability of leisure activities in the hospital and at home and with the access and identification with other equals (other children with oncological diseases).

- The most frequent help the survivors received during the treatment is family support, psychological support, caregivers support (doctors/nurses) and the support from friends.

- Throughout the treatment, survivors received less help in: recreation and entertainment during the convalescence at home, support of the teachers, contact with other children with oncological diseases, leisure activities and entertainment in the hospital.

- The Long-term and social-emotional accompaniment is crucial part of the survivor's emotional support, to convert the recovery process into a common goal and to make the survivor feel accompanied.

- The psychologist is an indispensable professional that is not always available in pediatric oncology units in the public health structure, and that in many cases is being recruited by the associations to alleviate this shortfall in public hospitals.

5.5. Impact of Disease in Survivors' social, personal environment and self-image

Main ideas that the study reveals:

- The critical nature of the family unit in the process of coping with childhood cancer.

- The impact of disease in one of the two heads of households' professional development that usually must devote itself to accompany the minor (sometimes) it involves the loss of work of the mother or the father). The situation is exacerbated and compounded in single-parent families that also are represented in the study.

- The impact of disease in the couple's and with the sibling's relationship. The worry and stress resulting from the impact of the disease on the child and treatment certainly affects the atmosphere and family affective state.

- The necessity of global management (educational, employment and social policy) that also bears in mind the impact on households with children suffering from oncological diseases and that develops measures (labor rights, compensatory measures, educational services) to help minimize this impact and allow these families to focus with all the intensity required in the recovery process of children.

- Although childhood cancer diseases have very strong/significant consequences for the child's life, impact has no irreversible consequences, but it does have some positive learning:
  - Only in a few cases the disease led to the isolation and loss of friends(8,7%).
  - An important group (47%) of survivors recognize that the illness had a strong impact but with time and effort they recovered and maintain satisfactory social life.
  - An important group (44,2%) of survivors claim that childhood cancer hardly altered their self-image, self-esteem, sense of security and attitude towards life and the world of relationships.
  - In general survivors have a very positive image of themselves, highlighting their attitude (brave, entrepreneurial, courageous, optimistic, positive) and their abilities (have self-reliance (security) to be mature, organized, face the real world and do things (they don't like "not doing anything"), try out things.)

5.6. Social view of the illness and cancer survivors

Main ideas that the study reveals:

- The need for the social normalization of the disease as something you get over it and it is part of reality, so that does not entail a social obstacle for children and childhood cancer survivors. Social ignorance of the disease poses serious obstacles to these children to interact.
- There are many prejudices about cancer survivors unknown to society, which include a high capacity for resilience and strength due to premature ripening involved in the recovery process.

Key findings of the study around objective 3: To analyze how the disease affects the vision of their professional future and their access to the world of work. Barriers experienced needs and strengths.

5.7. Attitude to professional future and work

Main ideas that the study reveals:

- Survivors generally show quite or very positive attitude towards a professional future, showing a positive self-image and good levels of personal safety and self-confidence. Although the general tone is positive, results show minority groups (28,5%) presenting significant levels of insecurity about their professional future, doubt of what they would like to professionally become and feelings of inability to carry out a fulltime profession in the future.

- The world of work is very important for their personal development and they build their pathway thinking about their entry into the labour market. Survivors associating professional future with freedom and economic independence allows them to be autonomous and not dependent on their family.
- They are proactive and persistent in the search for work, although they talk about rejection and the increase of difficulties due to the European economic crisis.

5.8. Strengths of the survivors

Main ideas that the study reveals:

- Survivors describe themselves as people who work very hard,show great commitment and are responsible. Personal traits very valuable for any job position can be pointed out: hard-working, on-time, active, tenacious, organized, creative, spares no effort to achieve something, good use of time, overcomes difficulties, has initiative, listens to others, reflects before talking. In general the researched participants believe to be proactive and positive facing difficulties.
- Their respect and correct attitude towards others stand out: Open. Patient. Affective. Social skills. Empathy. Good humour when working
- They have adequate strategies: good team work; listening attentively to people; accepting people as they are and what they say; understanding that the must not think that everything said at work is personal and that the others are also under stress; learning from other.
- They relate training with a better preparation and promotion at work. They make use of all the opportunities to go to language courses or specialized courses
- Willingness to try, experiment and have initiative

5.9. Barriers and needs to enter the labor world

Main ideas that the study reveals:

- The researched survivors demonstrated a feeling of awareness that late effects have influence on their job performance and it worries them that this will restrict their opportunities of finding a job related to their expectations. In some cases they think that these jobs can be less qualified than their expectations or the tasks less interesting and motivating

- They believe that the labour market´s principal barrier is due to prejudice because of the lack of knowledge.
- For them, discrimination is based on society's fear of cancer and its illness effects, and this could also be the reason why sometimes some employers reject them. Also, this could be the reason why employers do not listen to them when they explain that they are not ill and that having needs doesn't mean that they can't work. Indeed, they believe that in their case they are at a disadvantage in comparison with other disabilities that are better known and their needs are better socially understood.
- Another inherent difficulty of the labour market that acts as a barrier is the current working style of the companies that seek productivity without considering the job profile and the stress employees are under

Key findings of the study around objective 4: To know how childhood cancer survivors see themselves about professional future, their learning needs and educational and vocational guidance.

5.10. Attitude towards training, educational and vocational guidance needs and training topics most requested

Main ideas that the study reveals:

- Survivors in general tend to prioritize training and preparation for employment so there is a clear and strong desire and a positive predisposition towards training.
- A minor-but relevant group recognizes gaps in their school educational process as a result of the disease.
- The main training needs that would arise according to the interviewed survivors are related to safety and ergonomics in the workplace, knowledge of the labor market and professions and employment and training opportunities for people with disabilities.
- There is a high interest demonstrated among the researched target group in receiving advice and guidance to know the world of work and define their professional profile.
- The personal skills are conceived currently in Europe as keys for citizenship and active professionals (Key competences) constitute other priorities (communication, empathy, teamwork, leadership, autonomy, self-esteem, self-knowledge and decision-making).
- Educational and vocational guidance services available in the education system do

not meet the specific needs of survivors and counselors lack specific training in this area.

5.11- Measures to enhance the employability/ labour market integration

Main ideas that the study reveals:

- The main relevant measures to enhance employability/ labour market integration for the survivors are: social awareness, return to education programs that allow to obtain a professional qualification for those who have not and incentives for hiring young survivors.

Create Your Future partnership was formed by:

CATRO
Bulgaria
www.catro.com

Association Children with oncohematologic diseases
Bulgaria
www.decaohz.org

Die Berater
Austria
www.dieberater.com

Osterreichische Kinder-Krebs- Hilfe
Austria
www.kinderkrebshilfe.at

CESGA
Spain
www.cesga.es

University of Santiago de Compostela
Spain
www.usc.es/tecnoeduc/

Spanish Federation of childhood cancer parents' organizations
Spain
cancerinfantil.org

SEN/JA (Junior Achievement)
Greece
senja.gr

KYTTARO - The Greek Childhood Cancer Survivors' Association
Greece
www.childhoodcancerinternational.org/kyttaro-greek-survivors-association/

Create your Future - Career Counselling for Childhood Cancer Survivors.
Project Reference 2014-1-BG01-KA204-001721.
createyourfuture-eu.org