

# Children's At Home: A social media website for peer support during transition for parents of adolescent cancer survivors

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### Objectives

The primary objective of this study was to pilot-test in Switzerland the feasibility of Children's At Home (C@H), an online social media website built to provide peer support to parents of adolescent cancer survivors in order to facilitate the psychosocial process of transition towards autonomy.

Secondary objectives were (1) To connect parents who share an illness experience, but have heretofore felt isolated and alone; (2) To encourage and support the development of an online community of shared cancer experience; (3) To crowdsource challenges, problem-solving and strategies, struggles, and triumphs.

The hypothesis we wanted to explore was the following: By bringing peer support to *parents of adolescent cancer survivors* at times of transition, it will improve their well-being, reduce their anxiety and worries, reduce their presumed isolation and enhance their handing over of responsibilities of their child's health to their child (to enhance child's autonomy); which, in turn, can have a positive impact on their child's autonomy acquisition and transition process.

### Methods

#### Children's At Home (C@H):

C@H is based on the fundamentals of the Video Intervention/Prevention Assessment (VIA) methodology developed to learn about the illness experiences of adolescents living with a chronic condition and their parents from patients and parents themselves. VIA collects data in the form of patient-generated visual narratives, personal "video-diaries" of living with a medical condition. VIA has been used in various populations (asthma, cystic fibrosis, sickle cell disease, etc.) and has shown to empower those who use it by sharing their stories and articulating what they think and feel to an audience who is eager to listen and understand. Children's At Home (C@H) takes VIA a step further by having participants share their visual narratives on a social media website.

Feasibility of C@H has been tested in a pilot study with parents of adolescents with Neurofibromatosis Type 1 (NF1) [23]. Results from the feasibility study showed: (1) Success in terms of breaking isolation and sharing experience; (2) Success in the design using an online tool with videos which bring strengths that cannot be rendered in writing. This pilot-study was conducted during Akre's fellowship at the Center on Media and Child Health of the Boston Children's Hospital/Harvard School of Public Health (MA, USA). Before applying it in Switzerland and measuring effectiveness on outcomes such as parents' well-being, parents' or adolescent self-efficacy or shared-management, the objective of this study was to pilot-test C@H in the Swiss context.

#### The intervention:

We built a new website using *WordPress* based on/largely inspired by the US-based C@H website created in Boston. We gave the project (and website) a new French title, namely "à suivre". For confidentiality and security reasons, videos were not directly stored on the website but on a University-based data platform called BSCW accessible through unique username and password assigned to each participant enrolled in the project. Participants could go on the website and see dummy pictures of the videos. When clicking on the videos to watch them, they had to connect to BSCW with their username and password given to them in order to view the videos. As long as they did not disconnect, they could watch all the videos they wanted; but if they left the website, they had to reconnect.

#### Recruitment:

Recruitment took place at the Pediatric oncology unit of the Centre Hospitalier Universitaire Vaudois (CHUV) in Lausanne.

Eligibility criteria were parents of survivors aged 13+ years and >2 years after end of treatment

In collaboration with Prof. Maja Beck Popovic, head of the pediatric oncology unit, her team extracted a list of 141 patients corresponding to the inclusion criteria. A letter of invitation to take part in the project co-signed by Prof. Maja Beck Popovic and Dr Christina Akre (CA) was sent by post to all the parents of the patients. A total of 156 letters were sent because parents who were known not to be living together were each sent a letter. The letter explained the project and invited them to contact CA by email, telephone or by returning the letter by post with their name on it if they did wish or did not wish to participate or else (by a given date) CA would contact them by phone.

A total of 15 envelopes had an invalid address, and 43 actively declined participation. When given, main reasons for active refusal were: the child is in good health now and does not want to revive bad memories, too much time has passed since the cancer, does not speak French well enough, and cancer was not a problem as it was diagnosed in an early stage. Two parents wrote an email to express interest in the project.

CA contacted 30 parents by the phone randomly selecting them from the list. After talking with them on the phone and explaining the project, 11 agreed to participate (all mothers) and 16 refused. Main reasons for refusal were: child does not live at home anymore, child in cancer relapse, does not feel comfortable to make videos, difficulty to talk about a hurtful subject, child does not want to hear about the illness anymore, family is leaving the country, lack of time, and not comfortable in French.

#### Participants:

Out of the 11 recruited parents, 2 dropped out after doing the phone interview: one because she did not have a good computer access and was using her son's email address, and the second because she felt too stressed and depressed. Final sample consisted of 9 mothers.

#### Interviews:

Baseline semi-structured interviews were done on the phone with the participants and lasted about 30 minutes.

#### Procedures:

After doing the interview, participants received by post: a mini-tripod and smartphone adaptor to make videos and a paper giving a few instructions on how to create a video and upload it to the project coordinator and some prompt suggestions of what they could discuss in the videos. They were also sent a secure connection (unique username and password created for each participant) a University-based platform called BSCW where CA build a specific folder where participants can upload there videos. After viewing the videos and anonymizing them if necessary, CA saved them in another folder where they could be viewed by all participants who went on the website and were given authorization to connect to the videos.

### **Results**

#### Baseline interviews:

Interviews put forward several interesting aspects.

First, parents rarely were in contact with other parents of adolescent cancer survivors. Many were very active in exchanging with other parents at diagnosis and during cancer treatment mainly through patient associations, but usually not after end of treatment. However, many new challenges came up after end of treatment and in particular when reaching adolescence and parents reported to no longer be in contact with anyone anymore to discuss these challenges.

Second, parents' main expectations when participating in C@H were: 1) to be able to compare with other parents and see if the difficulties they were going through were normal, and 2) to see how other parents who have same-age children and who went through similar experiences do in everyday life.

Third, parents reported that new challenges appeared recently when their child reached adolescent age, problems that did not exist in childhood (for example: depression, suicide attempts), or difficulties with siblings who were often left aside during the difficult years of fighting cancer.

Fourth, parents also highlighted that they want to help other parents by sharing their experience, as a way of giving back something for what they had received in the past, being thankful for their child's survival.

Fifth, some parents reported that they cannot talk about the past cancer in their family and especially not with their child who had the cancer because the illness is part of the past and has become a taboo subject. Therefore, exchanging with other parents on this platform is a way to get relief from this and be able to talk about it.

#### Visual narratives and website functioning:

Only 5 visual narratives were posted by participants. Main subjects covered were a general presentation of family history around the illness and difficulties of dealing with this past burden for child and/or parents.

### **Discussion**

Feasibility was an important issue in this pilot study. Indeed, when the project was developed, the original plan was to easily translate the Boston Children's Hospital (BCH) website in French on *Drupal* for usage here in Switzerland. Therefore, a lot of work with the IT from the University of Lausanne to find a way to do this and a lot of talk was also done with BCH in terms of our rights to reproduce their website that belongs to them. Finally,

we decided to build a completely new website on *WordPress* and use BSCW as the best way to have participants send or upload videos in a secure way. However, this made it very complicated first for the participants – as it demanded to be technology-savvy to go through the process – and second for the research manager – as it was a very time-consuming and fastidious functioning. This discouraged to a large degree both the participants and the research manager.

Given these results and technical and feasibility difficulties, solutions were searched for and CA received new funding from the Swiss National Science Foundation (SNSF) for a two-year project to test the effectiveness of C@H with a non-categorical approach to chronic conditions. Most important, included in the budget was the funding to develop a secure mobile application. This App has now been developed and enables participants to create their visual narratives on their phone and upload them directly on the secure (password-protected) App. This research is being conducted at the moment and we look forward to have new results in terms of effectiveness of the intervention. All participants in this C@H project for parents of cancer survivors have of course been invited to be transferred to participate in the new App.

Regarding recruitment in this project, it needs to be noted that there was a high number of spontaneous refusal to participate in the project (N=43, 31%<sup>1</sup>) and of refusals to participate after talking on the phone (16/30, 53%). Given the main reasons for refusal in either way (spontaneous or on the phone), it appears that running this project among parents of cancer survivors is much different than doing it among a population of patients with chronic conditions (as was tested previously with parents of adolescents with Neurofibromatosis Type 1). For many parents, cancer appears as disease from the past and they want it to stay that way and not necessarily bring up to the present bad memories of suffering. On the contrary, for parents of adolescents with chronic conditions, the condition is lived out at the moment and brings in new challenges when adolescence adds up to the chronic condition and reach times of transition (pediatric to adult care but also personal and professional transitions or those linked to adolescence, i.e. puberty). Thus, this intervention might appear as more useful for parents of adolescents with a concurrent chronic condition, rather than for those with a past severe illness.

## **Conclusion**

To conclude, although this intervention as it was developed here was technically difficult which put into question its feasibility, it brought a great deal of thoughts and suggestions for the development of the App and the new project funded by the SNSF. Therefore, we can conclude that it fulfilled its objective of testing feasibility in Switzerland in the CHUV-UNIL setting and brings important insights for a future project.

After testing efficacy of the intervention, we hope that in the future, it can become part of a wider ongoing transition program for parents of adolescents with chronic conditions and their families.

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<sup>1</sup> This percentage is the one of the total list of letters that were sent out and that arrived at designated address (excluding the 15 envelopes that came back for invalid address).