RESOURCES, ACHIEVEMENTS, AND GOALS

HERO 2016

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Which is the role of technologies?

TECHNOLOGIES SUPPORTING PATIENTS / SURVIVORS



Problems

TECHNOLOGIES SUPPORTING PATIENTS / SURVIVORS

Late effects of paediatric cancer treatments

- Neurocognitive
- Psychosocial
- Others



Late effects of paediatric cancer treatments

- Neurocognitive
 - Executive function
 - Attention
 - Memory
 - Learning deficit (math and reading)
 - Diminished intelligence quotient
 - Behavioral changes



Chow, E. J., Anderson, L., Baker, K. S., Bhatia, S., Guilcher, G. M. T., Huang, J. T., ... Castellino, S. M. (2016). Late Effects Surveillance Recommendations among Survivors of Childhood Hematopoietic Cell Transplantation: A Children's Oncology Group Report. Biology of Blood and Marrow Transplantation : Journal of the American Society for Blood and Marrow Transplantation. doi:10.1016/j.bbmt.2016.01.023

Late effects of paediatric cancer treatments

- Psychosocial
 - Social withdrawal
 - Educational problems
 - Employment
 - Dependent living
 - Mental disorders (depression, anxiety, post-traumatic stress, suicidal ideation)



Bitsko, M. J., Cohen, D., Dillon, R., Harvey, J., Krull, K., & Klosky, J. L. (2016). **Psychosocial Late Effects in Pediatric Cancer Survivors: A Report From the Children's Oncology Group**. Journal of Clinical Oncology, 63(1), 337–343. http://doi.org/10.1002/pbc

de Ruiter, M. A., Schouten-van Meeteren, A. Y. N., van Vuurden, D. G., Maurice-Stam, H., Gidding, C., Beek, L. R., et al. (2016). **Psychosocial profile of pediatric brain tumor** *survivors with neurocognitive complaints*. Quality of Life Research : An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation, 25(2), 435–46. doi:10.1007/s11136-015-1091-7

Late effects of paediatric cancer treatments

- Psychosocial
 - Assess the psychosocial needs and program preferences
 - 111 patients
 - 12-25 ages (AYA)
 - 52.4% females
 - 70% on treatment
 - 20.40 months off treatment



Barakat, L. P., Galtieri, L. R., Szalda, D., & Schwartz, L. A. (2016). Assessing the psychosocial needs and program preferences of adolescents and young adults with cancer. Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer, 24(2), 823–32. doi:10.1007/s00520-015-2849-8

Late effects of paediatric cancer treatments

• Psychosocial

		1 BILL
Challenge	%	636 -
Being in the hospital/undergoing medical procedures	27.5	<u>r</u> en
Being treated differently (being baby-ed, bullying, extra attention)	27.5	
Physical effects of treatment	24.8	
Not being able to work/job difficulties (finding a job, keeping a job)	23.9	Analyze
Missing friends	17.4	
Lack of physical activity/giving up physical activity (sports)	16.5	
Feeling at a different point in life than peers/not having a "normal" life	16.5	

Problems

Barakat, L. P., Galtieri, L. R., Szalda, D., & Schwartz, L. A. (2016). Assessing the psychosocial needs and program preferences of adolescents and young adults with cancer. Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer, 24(2), 823–32. doi:10.1007/s00520-015-2849-8

Late effects of paediatric cancer treatments

• Psychosocial

		1 Paller V
Challenge	%	
Trying to plan for the future/feeling as if life is "on hold"	14.7	<u>Cor</u>
Losing autonomy/need for independence	12.8	
School attendance / home schooling / needing to quit school	12.8	
Keeping up with schoolwork	12.8	
Hair loss/body image/confidence	9.2	- analyze
Feeling sick or fatigued in general	9.2	
Trying to keep a positive attitude / Being stressed out	9.2	

Problems

Barakat, L. P., Galtieri, L. R., Szalda, D., & Schwartz, L. A. (2016). Assessing the psychosocial needs and program preferences of adolescents and young adults with cancer. Supportive Care in Cancer : Official Journal of the Multinational Association of Supportive Care in Cancer, 24(2), 823–32. doi:10.1007/s00520-015-2849-8

Late effects of paediatric cancer treatments

- Others
 - Metabolic syndrome
 - Adiposity
 - Dyslipidemia
 - Glucose intolerance
 - Hypertension
 - Obesity
 - Diabetes
 - Cardiac toxicity



Kero, A. E., Madanat-Harjuoja, L. M., Järvelä, L. S., Malila, N., Matomäki, J., & Lähteenmäki, P. M. (2016). Health conditions associated with metabolic syndrome after cancer at a young age: A nationwide register-based study. Cancer Epidemiology, 41, 42–49. doi:10.1016/j.canep.2016.01.009

Clement, S. C. C., Schoot, R. A. A., Slater, O., Chisholm, J. C. C., Abela, C., Balm, A. J. M. J. M., ... Merks, J. H. M. H. M. (2016). Endocrine disorders among long-term survivors of childhood head and neck rhabdomyosarcoma. European Journal of Cancer, 54, 1–10. http://doi.org/10.1016/j.ejca.2015.10.064

Late effects of paediatric cancer treatments

- Others
 - Musculoskeletal
 - Low bone mineral density
 - necrosis
 - Hip and knee joints
 - Sleep disturbances



Chow, E. J., Anderson, L., Baker, K. S., Bhatia, S., Guilcher, G. M. T., Huang, J. T., ... Castellino, S. M. (2016). Late Effects Surveillance Recommendations among Survivors of Childhood Hematopoietic Cell Transplantation: A Children's Oncology Group Report. Biology of Blood and Marrow Transplantation : Journal of the American Society for Blood and Marrow Transplantation. doi:10.1016/j.bbmt.2016.01.023

Summary

- Wide variety of effects
- Cognitive and/or physical
- Different intensity
- Different ages
- Different treatments and duration
- Different symptoms
- Different contexts



HIGH DIVERSITY OF SURVIVORS WITH DIFFERENT NEEDS, SKILLS, CAPABILITIES AND PREFERENCES -> PERSONALIZATION AND CUSTOMIZATION

Technological Resources

TECHNOLOGIES SUPPORTING PATIENTS / SURVIVORS

Apps Review

Grey Literature Review

Scientific Literature Review

Apps Review

TECHNOLOGICAL RESOURCES

TECHNOLOGIES SUPPORTING PATIENTS / SURVIVORS

Methodology:

• Azar et al. 2013

Purpose:

Analyse apps to ameliorate late effects childhood cancer treatments

Google Play

Keywords:

- Pediatric, child
- Cancer, oncolog*
- Cognitive, memory, attention, late effect, depression, anxiety, stress, mental

Azar, K. M. J., Lesser, L. I., Laing, B. Y., Stephens, J., Aurora, M. S., Burke, L. E., & Palaniappan, L. P. (2013). Mobile Applications for Weight Management. American Journal of Preventive Medicine, 45(5), 583–589. http://doi.org/10.1016/j.amepre.2013.07.005

Inclusion Criteria:

- Focused on childhood cancer survivors
- For survivors
- Neurocognitive training / evaluation
- Mental Health therapies
- Apps with GUI in Spanish or English

Exclusion Criteria:

- For relatives or health professionals
- Not focused on late effect
- Not related to targeted interventions
- Others languages than Spanish or English

Results: 23 apps Google Play (Android)





Cerpen Islami Leng Galih_Studio

Results: 23 apps Google Play (Android) – Not relevant!!



Second search

Keywords:

- Child, kid
- Cognitive training

Results

- 250 apps
 - 202 free and 48 paying
 - 242 with more than 4 stars
 - All apps are based on mini-games (memory, attention, puzzle, maths, visual acuity, analysis, etc.)
 - Customization is not allowed in most of them.
 - Sincrolab Kids developed in collaboration with neuroscientists from UCM



Grey Literature

TECHNOLOGICAL RESOURCES

TECHNOLOGIES SUPPORTING PATIENTS / SURVIVORS

Integrated cognitive skills

WISC-V (Wechsler Intelligence Scale for Children)

- https://en.wikipedia.org/wiki/Wechsler Intelligence Scale for Children
- <u>http://www.helloq.com/tests/wisc-v.html#</u> (software)

Memory

Benton Visual Retention Test

- https://en.wikipedia.org/wiki/Benton Visual Retention Test
- <u>http://dl.acm.org/citation.cfm?id=1234593</u> ("Design and evaluation of a computerised version of the Benton visual retention test", 2007)

Attention, distractibility and reaction time

CPT-III (Conners Continuous Performance Test 3rd Edition)

- <u>http://www.mhs.com/product.aspx?gr=edu&prod=cpt3&id=overview</u> (computer software)
- <u>http://en.wikipedia.org/wiki/Continuous_performance_task</u>

Visual perception and motor skills

Grooved Pegboard Test

http://link.springer.com/referenceworkentry/10.1007%2F978-0-387-79948-3_187

Higher executive functions

- <u>http://id.loc.gov/authorities/subjects/sh2010012940.html</u>
- <u>https://en.wikipedia.org/wiki/Verbal_fluency_test</u>
- <u>http://en.wikipedia.org/wiki/Delis%E2%80%93Kaplan Executive Function System</u>

Scientific Literature Review

TECHNOLOGICAL RESOURCES

TECHNOLOGIES SUPPORTING PATIENTS / SURVIVORS

Questions:

- Which ICT based interventions have reported positive impact to ameliorate neurocognitive or mental health related late effects of paediatric cancer treatments?
- Which tools have been used to support the evaluation/assessment tests?

MedLine (Pubmed), Science Direct, IEEE Xplore, Chocrane Lib.

Keywords:

- Pediatric, child
- Cancer, oncolog*
- Computer*, m-health, e-health, assistive tech*, serious game, gam*, tech*, software, app*
- Cognitive, memory, attention, late effect, depression, anxiety, stress, mental

Last 10 years

Inclusion Criteria:

- Technology based intervention/training program
- Focused on childhood cancer survivors
- For survivors
- Neurocognitive training / evaluation
- Mental Health therapies
- Papers in Spanish or English

Exclusion Criteria:

- For relatives or health professionals
- Not focused on late effect
- Full paper not available
- Others languages than Spanish or English

Preliminary Results: 2072 (including duplicates)

- Pubmed: 428
- Science Direct: 1607
- IEEE Xplore: 35
- Chocrane Lib: 2
- Papers included: 13
- Training Programs (9)
- Tests (2)
- Management solutions (2)

Computerized Training Programs

SCIENTIFIC LITERATURE REVIEW

Braintrain – Captain's Log (http://www.braintrain.com/)

- Cognitive skills
 - Memory, attention, concentration, listening skills, and self-control in people aged six years and older
- Intervention
 - Home-based 12-week cognitive training program.
 - At least, 50 minutes per week
 - Post intervention and 3 month later assessments. Weekly phone-based check-ins.
 - 33 multilevel, entertaining, game-like "brain training" exercises
- Participants
 - 9 survivors of acute lymphoblastic leukemia and brain tumors with attention and working memory deficits.
- Results
 - Significant increases in working memory and decreases in parent-rated attention problems.

Hardy, K. K., Willard, V. W., & Bonner, M. J. (2011). Computerized cognitive training in survivors of childhood cancer: a pilot study. Journal of Pediatric Oncology Nursing : Official Journal of the Association of Pediatric Oncology Nurses, 28(1), 27–33. http://doi.org/10.1177/1043454210377178

Lumosity (https://www.lumosity.com/)

- Cognitive Skills
 - Executive function (cognitive flexibility, attention and working memory)
- Intervention
 - Home-based online cognitive rehabilitation program
 - An one-arm open trial pilot study
 - 8 week, 40 sessions (5 sessions per week), 20 minutes per session.
- Participants
 - 23 paediatric cancer survivors (7-19 y.o.)
- Results
 - Significantly increased processing speed, cognitive flexibility, verbal and visual declarative memory scores as well as significantly increased pre-frontal cortex activation compared to baseline.

Kesler, S. R., Lacayo, N. J., & Jo, B. (2012). A pilot study on an online cognitive rehabilitation program for executive function skills in children with cancer-related brain injury. Brain Injury, 25(1), 101–112. http://doi.org/10.3109/02699052.2010.536194.A

Cogmed (http://www.cogmed.com/)

- Cognitive Skills
 - Working memory
- Intervention
 - home-based computerized working memory training program, CogmedRM
 - Two randomized groups (success-adapted computer intervention, and non-adaptive, active control condition)
 - 25 sessions, weekly phone-based coaching support.
 - Pre- and post-intervention
- Participants
 - 20 Survivors of brain tumors or ALL with identified deficits in attention and/or working memory.
- Results
 - Significant post-training improvements in their visual working memory and in parent-rated learning problems.
 - No differences in verbal working memory functioning.

Hardy, K. K., Willard, V. W., Allen, T. M., & Bonner, M. J. (2013). Working memory training in survivors of pediatric cancer: a randomized pilot study. Psycho-Oncology, 22(8), 1856–65. http://doi.org/10.1002/pon.3222

Cogmed (2) (http://www.cogmed.com/)

- Cognitive Skills
 - Working memory, attention, and processing speed.
- Intervention
 - home-based computerized training program
 - Randomized Controlled Trial (RCT)
 - 25 sessions, 30-45 minutes per session, weekly phone-based coaching (5 to 9 weeks)
- Participants
 - 68 survivors of childhood acute lymphoblastic leukemia (ALL) or brain tumor (BT) with identified cognitive deficit
- Results
 - Greater improvement than controls on measures of working memory, attention, and processing speed.
 - Greater reductions in reported executive dysfunction.

Conklin, H. M., Ogg, R. J., Ashford, J. M., Scoggins, M. A., Zou, P., Clark, K. N., ... Zhang, H. (2015). Computerized cognitive training for amelioration of cognitive late effects among childhood cancer survivors: A randomized controlled trial. Journal of Clinical Oncology, 33(33), 3894–3902. http://doi.org/10.1200/JCO.2015.61.6672

Cogmed (3) (http://www.cogmed.com/)

- Cognitive Skills
 - Working memory, attention, processing speed
- Intervention
 - home-based computerized training program
 - RCT. 2 groups (computerized cognitive intervention and waitlist control group)
 - Pre, Post, 6 months post-postintervention
- Participants
 - 68 survivors of childhood acute lymphoblastic leukemia (ALL) or brain tumor (BT) with identified cognitive deficit
- Results
 - working memory and processing speed were unchanged from immediate to 6 months postintervention.
 - group differences on an attention measure did not persist.

Conklin, H. M., Ashford, J. M., Clark, K. N., Martin-Elbahesh, K., Hardy, K. K., Merchant, T. E., ... Zhang, H. (2016). Long-Term Efficacy of Computerized Cognitive Training Among Survivors of Childhood Cancer: A Single-Blind Randomized Controlled Trial. Journal of Pediatric Psychology, 1–12. http://doi.org/10.1093/jpepsy/jsw057

Onco-STEP

- Psychosocial
 - Stress and fears
- Intervention
 - Internet-based psychotherapy
 - "Looking Back": reduce posttraumatic stress symptoms
 - "Looking Ahead": Coping with cancer-related fears of relapse and progression
- Participants
 - Young adult survivors of pediatric cancer
- Results
 - The majority was satisfied and perceived the treatment components as helpful.

Seith DC., Kanevelsrud C, Duran G, Waadt S, and Goldbeck L. Internet-based psychotherapy in young adult survivors of paediatric cancer: feasibility and participants' satisfaction. Cyberpsychol Behav Soc Netw. 2014; 17(9):624-9. doi: 1089/cyber.2014.0066.

Therapeutic game

- Psychosocial
 - Anxiety, depressive symptoms
- Intervention
 - Virtual Reality Computer Game
 - non-equivalent control group pretest-post-test, between-subject design
 - 30 minutes per session, 5 days a week.
- Participants
 - 122 children 8-16 y.o. during treatment (52 in experimental group/ 70 in control group)
- Results
 - $\circ~$ statistically significant fewer depressive symptoms.
 - no differences in children's anxiety scores.

Li, W. H., Chung, J. O., & Ho, E. K. (2011). The effectiveness of therapeutic play, using virtual reality computer games, in promoting the psychological well-being of children hospitalised with cancer. Journal of Clinical Nursing, 20(15–16), 2135–2143. http://doi.org/10.1111/j.1365-2702.2011.03733.x

ShopTalk - Therapeutic game

- Psychosocial
 - Talk about their illness in non-threatening way
- Intervention
 - Distribution at a conference and survey regarding their clinical experience using ShopTalk
- Participants
 - 110 professionals
- Results
 - ShopTalk appears to be a beneficial therapeutic tool in building rapport and identifying and discussing difficult issues with medically ill children.

Wiener, L., Battles, H., Mamalian, C., & Zadeh, S. (2011). ShopTalk: a pilot study of the feasibility and utility of a therapeutic board game for youth living with cancer. Supportive Care in Cancer, 19(7), 1049–1054. JOUR. http://doi.org/http://dx.doi.org/10.1007/s00520-011-1130-z

LIFECommunity

- Psychosocial
 - Depression and self-efficacy
- Intervention
 - Social media and video blog
 - Study how cancer survivors construct their identities and the impact on their psychological health
 - 6 months
- Participants
 - 14 young adult survivors of pediatric cancer
- Results
 - Although pediatric cancer survivors often do not publicly discuss a "cancer survivor identity," they do internalize both positive and negative stereotypes about cancer survivorship.

Song, H., Nam, Y., Gould, J., Sanders, W. S., McLaughlin, M., Fulk, J., ... Ruccione, K. S. (2012). *Cancer Survivor Identity Shared in a Social Media Intervention*. Journal of Pediatric Oncology Nursing, 29(2), 80–91. http://doi.org/10.1177/1043454212438964

Computerized Tests

SCIENTIFIC LITERATURE REVIEW

ImPACT (Immediate Post-Concussion Assessment and Cognitive Testing)

- Measurements
 - Attention, memory and processing speed
- Monitoring recovery
- Participants
 - 24 childhood brain tumor (BT) survivors treated with conformal radiation therapy (mean age= 15.7±1.6; mean age at irradiation= 9.8±2.5)
 - 20 solid tumor (ST) survivors treated without CNS-directed therapy (mean age= 16.2±1.8)
 - 20 healthy siblings (mean age= 15.1± 1.6 years)
- Results
 - The ImPACT test battery demonstrated sensitivity to cognitive late effects experienced by some BT survivors with clinical predictors of performance consistent with the pediatric oncology literature

Conklin, H. M., Ashford, J. M., Di Pinto, M., Vaughan, C. G., Gioia, G. A., Merchant, T. E., ... Wu, S. (2013). Computerized assessment of cognitive late effects among adolescent brain tumor survivors. Journal of Neuro-Oncology, 113(2), 333–40. http://doi.org/10.1007/s11060-013-1123-5

PROMIS (Patient Reported Outcomes Measurement Information System)

- Measurements
 - Symptoms, function, and quality of life during and following treatment for cancer
- Study
 - a cross-sectional study design to establish known-group validity
 - In-person interaction with researchers
- Participants
 - 203 (8-17 y. o.) were administered eight PROMIS pediatric measures
 - Patients undergoing treatments (n = 93) and survivors (n= 107)
- Results
 - Participants in treatment were significantly different (worse) on parent-reported clinical indicators (blood counts, fatigue, and appetite) and on seven self-reported measures (depression, anxiety, peer relationships, pain interference, fatigue, upper extremity function, and mobility) from participants in survivorship.

Hinds, P. S., Nuss, S. L., Ruccione, K. S., Withycombe, J. S., Jacobs, S., DeLuca, H., ... DeWalt, D. A. (2013). PROMIS Pediatric Measures in Pediatric Oncology: Valid and Clinically Feasible Indicators of Patient-Reported Outcomes. Pediatric Blood & Cancer, 60(1), 402–408. http://doi.org/10.1002/pbc

Management

SCIENTIFIC LITERATURE REVIEW

Aftercare App

- Manage and Minimise the Risk of Late Effects
- information regarding the aftercare and supports a reminder functionality to attend medical visits
- Participants
 - 22 subjects, 13 former patients and 9 relatives.

Kock, A.-K., Kaya, R. S., Müller, C., Andersen, B., Langer, T., & Ingenerf, J. (2015). **Design, implementation, and evaluation of a mobile application for patient empowerment and management of long-term follow-up after childhood cancer**. Klinische Pädiatrie, 227(3), 166–70. http://doi.org/10.1055/s-0035-1548840

Kock, A.-K., Kaya, R., Müller, C., Andersen, B., Langer, T., & Ingenerf, J. (2015). A mobile application to manage and minimise the risk of late effects bv childhood Studies in Health Technology and Informatics, 210. 798-802. Retrieved from caused cancer. http://www.ncbi.nlm.nih.gov/pubmed/25991264

Pain Buddy

- m-Health for pain assessment and intervention in the home setting
- Daily pain and symptom diaries completed by children
- Remote monitoring of symptoms
- Cognitive and behavioural skills training
- Interactive three-dimensional avatars that guide children through the program
- An incentive system to motivate engagement
- Participants
 - 12 children ages 8–18 years undergoing cancer treatment.

Fortier, M. A., Chung, W. W., Martinez, A., Gago-Masague, S., & Sender, L. (2016). Pain buddy: A novel use of m-health in the management of children's cancer pain. Computers in Biology and Medicine, 76, 202–214. http://doi.org/10.1016/j.compbiomed.2016.07.012

Others interesting reviews

SCIENTIFIC LITERATURE REVIEW

Castellino, S. M., Ullrich, N. J., Whelen, M. J., & Lange, B. J. (2014). **Developing interventions for cancer-related cognitive dysfunction in childhood** *cancer survivors*. Journal of the National Cancer Institute, 106(8), dju186. http://doi.org/10.1093/jnci/dju186

Olson, K., & Sands, S. A. (2016). Cognitive training programs for childhood cancer patients and survivors: A critical review and future directions. Child Neuropsychology, 22(5), 509–536. http://doi.org/10.1080/09297049.2015.1049941

Richter, D., Koehler, M., Friedrich, M., Hilgendorf, I., Mehnert, A., & Weißflog, G. (2015). **Psychosocial interventions for adolescents and young adult** *cancer patients: A systematic review and meta-analysis*. Critical Reviews in Oncology/hematology, 95(3), 370–86. http://doi.org/10.1016/j.critrevonc.2015.04.003

Mohr, D. C., Burns, M. N., Schueller, S. M., Clarke, G., & Klinkman, M. (2013). **Behavioral Intervention Technologies: Evidence review and** *recommendations for future research in mental health.* General Hospital Psychiatry, 35(4), 332–338. http://doi.org/10.1016/j.genhosppsych.2013.03.008

Conclusions

TECHNOLOGIES SUPPORTING PATIENTS / SURVIVORS

- There are many mini-games based apps for cognitive training.
- No one of them have been designed for CCSs' specific needs, conditions and preferences
- Computerized neurocognitive programs have reported positive impact in cognitive remediation
- Efficacy of Only 3 computerized cognitive programs for CCS have been demonstrated empirically.
- The variety and intensity of late effects of childhood cancer treatments results in a wide diversity of needs, skills, capabilities and conditions.
- Customizable Assistive technological solutions adapted to their needs and capabilities are required. (High level of personalization)

How?

TECHNOLOGIES SUPPORTING PATIENTS / SURVIVORS

- Multidisciplinary research
- "Survivor research"
- Personalized interventions (Educational, remediation, etc.)
- Ecological momentary interventions
- Assistive Solutions (Adaptation or new development)
- Technological solutions to promote healthy lifestyle (Physical and diet)
- Survivor Centred Design

