Technologies supporting patients / survivors

RESOURCES, ACHIEVEMENTS, AND GOALS

HERO 2016

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Universidad de Sevilla
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Which is the role of technologies?

TECHNOLOGIES SUPPORTING PATIENTS / SURVIVORS
Technologies supporting patients / survivors
Problems

TECHNOLOGIES SUPPORTING PATIENTS / SURVIVORS
Technologies supporting patients / survivors

Late effects of paediatric cancer treatments

- Neurocognitive
- Psychosocial
- Others
Technologies supporting patients / survivors

Late effects of paediatric cancer treatments

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

Technologies supporting patients / survivors

Late effects of paediatric cancer treatments

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


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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

Technologies supporting patients/survivors

Late effects of paediatric cancer treatments

- Psychosocial

<table>
<thead>
<tr>
<th>Challenge</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being in the hospital/undergoing medical procedures</td>
<td>27.5</td>
</tr>
<tr>
<td>Being treated differently (being baby-ed, bullying, extra attention)</td>
<td>27.5</td>
</tr>
<tr>
<td>Physical effects of treatment</td>
<td>24.8</td>
</tr>
<tr>
<td>Not being able to work/job difficulties (finding a job, keeping a job)</td>
<td>23.9</td>
</tr>
<tr>
<td>Missing friends</td>
<td>17.4</td>
</tr>
<tr>
<td>Lack of physical activity/giving up physical activity (sports)</td>
<td>16.5</td>
</tr>
<tr>
<td>Feeling at a different point in life than peers/not having a “normal” life</td>
<td>16.5</td>
</tr>
</tbody>
</table>

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Late effects of paediatric cancer treatments

- Psychosocial

<table>
<thead>
<tr>
<th>Challenge</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trying to plan for the future/feeling as if life is “on hold”</td>
<td>14.7</td>
</tr>
<tr>
<td>Losing autonomy/need for independence</td>
<td>12.8</td>
</tr>
<tr>
<td>School attendance / home schooling / needing to quit school</td>
<td>12.8</td>
</tr>
<tr>
<td>Keeping up with schoolwork</td>
<td>12.8</td>
</tr>
<tr>
<td>Hair loss/body image/confidence</td>
<td>9.2</td>
</tr>
<tr>
<td>Feeling sick or fatigued in general</td>
<td>9.2</td>
</tr>
<tr>
<td>Trying to keep a positive attitude / Being stressed out</td>
<td>9.2</td>
</tr>
</tbody>
</table>

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Late effects of paediatric cancer treatments
- Others
  - Metabolic syndrome
    - Adiposity
    - Dyslipidemia
    - Glucose intolerance
  - Hypertension
  - Obesity
  - Diabetes
  - Cardiac toxicity


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Late effects of paediatric cancer treatments

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

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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
Technologies supporting patients / survivors

Apps Review
Grey Literature Review
Scientific Literature Review
Apps Review

TECHNOLOGICAL RESOURCES

TECHNOLOGIES SUPPORTING PATIENTS / SURVIVORS
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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

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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
Technologies supporting patients / survivors

Results: 23 apps Google Play (Android)
Technologies supporting patients / survivors

Results: 23 apps Google Play (Android) – Not relevant!!
Technologies supporting patients / survivors

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
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Integrated cognitive skills

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

Memory

Benton Visual Retention Test
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Attention, distractibility and reaction time

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

Visual perception and motor skills

Grooved Pegboard Test
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Higher executive functions

- http://id.loc.gov/authorities/subjects/sh2010012940.html
Scientific Literature Review

TECHNOLOGICAL RESOURCES
TECHNOLOGIES SUPPORTING PATIENTS / SURVIVORS
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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
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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
Technologies supporting patients / survivors

Preliminary Results: 2072 (including duplicates)
- Pubmed: 428
- Science Direct: 1607
- IEEE Xplore: 35
- Chocran Lib: 2

Papers included: 13
- Training Programs (9)
- Tests (2)
- Management solutions (2)
Computerized Training Programs

SCIENTIFIC LITERATURE REVIEW
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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.

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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.

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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.

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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.

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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.

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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.

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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
  - statistically significant fewer depressive symptoms.
  - no differences in children's anxiety scores.

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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.

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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.

Computerized Tests

SCIENTIFIC LITERATURE REVIEW
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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

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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.

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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.

**References**


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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.

Others interesting reviews

SCIENTIFIC LITERATURE REVIEW
Technologies supporting patients / survivors


Conclusions

TECHNOLOGIES SUPPORTING PATIENTS / SURVIVORS
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- 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
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- 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
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