

***Promise, pitfalls and progress
of on-line cognitive behavioural therapy:
Lessons learned from a paediatric
oncology unit***



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Accettato il 13 dicembre 2020]

Abstract

A cancer diagnosis during child and adolescent years fundamentally disrupts normal development, and can result in several adverse mental health sequelae. Cognitive-behavioural therapy has proven efficacy in addressing a range of psychological issues relevant to paediatric and adolescent oncology, including depression and different forms of anxiety. However, numerous barriers hinder many patients and families from being able to access specialised clinical psychology services, tailored to the unique psychosocial considerations of paediatric oncology. To address this gap in evidence-based clinical service-provision, our paediatric psycho-oncology research unit has developed several CBT-based interventions tailored to the needs of children and adolescents with cancer and their families. In this commentary, we provide an overview of our clinical-research program, examining how on-line CBT-based programs are feasible, acceptable, safe, and promising models of support for this patient population. We also examine some of the limitations or pitfalls involved in delivering on-line, CBT-based programs, including how we have navigated the ethical management of challenging, clinically-concerning events within our trials. Finally, we examine several future potential applications to extend the impact of on-line, CBT-based interventions to several other

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Quaderni di Psicoterapia Cognitiva (ISSN 1127-6347, ISSNe 2281-6046), n. 47/2020

Doi: 10.3280/qpc47-2020oa11207

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currently unmet needs in paediatric oncology. Drawing from several of our CBT-aligned, health-behaviour-focused intervention programs, we propose that on-line CBT holds significant potential in supporting the health behaviours and quality of life of young people and their families, both during and after cancer treatment. The future impact of on-line CBT-based interventions will rely upon clinicians and researchers effectively collaborating to effectively evaluate – and implement – these programs in real-world settings.

Key words: cognitive-behavioural therapy, on-line interventions, paediatric oncology, adolescents, health behaviours.

Sommario

Promesse, insidie e progressi della terapia cognitivo-comportamentale on-line: lezioni apprese da un'unità di oncologia pediatrica

Una diagnosi di cancro durante l'infanzia e l'adolescenza interrompe fundamentalmente il normale sviluppo e può provocare diverse conseguenze negative per la salute mentale. La terapia cognitivo-comportamentale si è dimostrata efficace nell'affrontare una serie di problemi psicologici rilevanti in oncologia pediatrica e adolescenziale, tra cui la depressione e diverse forme di ansia. Tuttavia, numerose barriere impediscono a molti pazienti e famiglie di poter accedere a servizi di psicologia clinica specializzati, costruiti sulle condizioni psicosociali specifiche dell'oncologia pediatrica. Per colmare questa lacuna nella disponibilità di servizi clinici basati sulle evidenze, la nostra unità di ricerca di psiconcologia pediatrica ha sviluppato diversi interventi basati sulla CBT su misura per le esigenze di bambini e adolescenti con cancro e delle loro famiglie. In questo contributo, forniamo una panoramica del nostro programma di ricerca clinica, esaminando come i programmi basati sulla CBT on-line siano modelli di supporto fattibili, accettabili, sicuri e promettenti per questa popolazione di pazienti. Esaminiamo anche alcuni dei limiti o delle criticità che caratterizzano i programmi on-line basati sulla CBT, incluso il modo in cui abbiamo affrontato la gestione etica di eventi critici e clinicamente rilevanti all'interno dei nostri studi. Infine, esaminiamo diverse potenziali applicazioni future per estendere l'impatto degli interventi on-line basati sulla CBT a molte altre esigenze attualmente non soddisfatte in oncologia pediatrica. Attingendo da molti dei nostri programmi di intervento incentrati sul comportamento e sulla salute, allineati alla CBT, sosteniamo che la CBT on-line abbia un potenziale significativo nel supportare i comportamenti sanitari e la qualità della vita dei giovani e delle loro famiglie, sia durante che dopo il trattamento del cancro. L'impatto futuro degli interventi basati sulla CBT on-line dipenderà dalla collaborazione effettiva tra medici e ricercatori per valutare e implementare efficacemente questi programmi in contesti reali.

Parole chiave: terapia cognitivo-comportamentale, interventi on-line, oncologia pediatrica, adolescenti, comportamenti di salute.

Acknowledgements: The Behavioural Sciences Unit is proudly supported by the Kids with Cancer Foundation, by the Kids Cancer Alliance, as well as a Cancer Council New South Wales Program Grant (PG16-02) with the support of the Estate of the Late Harry McPaul. The *Recapture Life* study is co-funded by a *beyond blue* and Cancer Australia project

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grant (ID: 1022868), a Early Career seed funding grant from the Sydney Partnership for Health Research and Enterprise (SPHERE) Cancer Clinical Academic Group, as well as the Medical Research Future Fund. It was also endorsed by the Psycho-Oncology Cooperative Research Group (PoCoG), Australia. The *Cascade* study was funded by Cancer Australia (APP1065428). The *CATNAP* study was funded by the Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG), and the Kids Cancer Alliance. The *Re-engage* study is funded by the Kids' Cancer Project and the Kids Cancer Alliance. The *Reboot* study is funded by The Kids Cancer Project. Ursula Sansom-Daly is supported by an Early Career Fellowship from the Cancer Institute of New South Wales (ID: 14/ECF/1-11) and an Early Career Fellowship from the National Health and Medical Research Council of Australia (APP1111800). Christina Signorelli is supported by the Kids Cancer Alliance. Claire Wakefield is supported by a Career Development Fellowship from the National Health and Medical Research Council of Australia (APP1143767).

A cancer diagnosis for a child, adolescent or young adult fundamentally disrupts their normal development (Patterson *et al.*, 2012). Young people affected by cancer and their families face the realistic prospect of toxic treatments, unpleasant and painful side-effects, and the possibility that they may not survive. Psychological distress is a common, normative response in this context. For some young people and their families, however, their psychological distress is severe, chronic, and impairs their capacity to engage in (or return to) relatively normal functioning (Michel *et al.*, 2020; Brinkman *et al.*, 2018). Depending on what is measured, and how, clinically-significant distress has been reported to occur in up to 27.4% children (Patel *et al.*, 2020), 56.5% of adolescents and young adults (Sansom-Daly and Wakefield, 2013), and 46.2% of parents (Pierce *et al.*, 2017) at various points across the cancer trajectory. Greater parent distress is also associated with greater distress for the child with cancer (Bakula *et al.*, 2019). In addition to the period following diagnosis, the completion of active cancer treatment appears to be a time of risk, when distress can again spike for some young people and parents (Sansom-Daly and Wakefield, 2013; Wakefield *et al.*, 2011). Evidence-based treatments are needed to address this mental health burden.

The efficacy of cognitive-behavioural therapy (CBT) in treating depression and anxiety in children (Arnberg and Öst, 2014; Cartwright-Hatton *et al.*, 2004), adolescents and young adults (Cartwright-Hatton *et al.*, 2004; Compton *et al.*, 2004), and adults is well established (Cooper *et al.*, 2017). CBT also appears to be a gold-standard therapeutic approach for preventing the development of mental health disorders. Among adolescents with sub-clinical distress, CBT-based programs typically achieve at least moderate sized effects in preventing the development of anxiety and depression (Butler *et al.*, 2006). Among adults, CBT-based programs are effective in preventing the onset of 22% of cases of depression (Cuijpers *et al.*, 2008).

When tailored to health-related concerns, skills-based interventions such as CBT appear efficacious in addressing the distress of adolescents and young adults living with serious and chronic illnesses, including cancer (Sansom-Daly *et al.*, 2012). Face-to-face CBT has also been shown to reduce distress in parents with a child with cancer (Meyler *et al.*, 2010).

The efficacy of CBT in treating distress in the paediatric oncology setting is reliant upon young people and families being able to access it. Access to specialist psychological support within the hospital-setting appears variable at best, and sub-optimal at worst, relative to the published standards of psychosocial care in paediatric oncology (Jones *et al.*, 2018). Although patients and families may desire psychosocial support (Long *et al.*, 2018), ease of access, time burden and cost are critical considerations. Patients and parents describe multiple barriers to accessing support including competing demands on their time and energy, difficulty scheduling around other commitments, transportation difficulties and cost (Wakefield *et al.*, 2012; Robertson *et al.*, 2019) For families who live outside of major cities, access to specialised psychological support may be limited or even unavailable close to home (AIHW, 2019). On-line therapy may overcome some of the barriers faced by young oncology patients and their families by increasing access to specialised support while minimising logistical demands. Group-based on-line therapy also has the powerful potential to connect individuals with similar experiences across large geographical distances (Sansom-Daly *et al.*, 2019).

Promises: What we have learned

Building on our research that highlighted adolescents' unique challenges returning to "normal life" after cancer treatment completion (Wakefield *et al.*, 2011), we developed a tailored, on-line CBT-based program called *Recapture Life* ("Resilience and Coping for young people to live well following cancer") (Sansom-Daly *et al.*, 2012). Across six weekly, group-based sessions delivered by a trained healthcare professional using on-line videoconferencing, *Recapture Life* aims to support adolescents' and young adults' development of adaptive coping skills in the early survivorship period. Rather than focusing solely on young people already demonstrating clinically-significant distress, *Recapture Life* takes a secondary-prevention approach; targeting the recognised time of increased psychosocial risk following treatment completion. In a Phase-II randomised-trial we demonstrated the acceptability, feasibility, and safety of *Recapture Life* (Sansom-Daly *et al.*, 2019). Participants

reported strong therapeutic alliance with the psychologist facilitating the program, and positive perceptions of the group cohesion within the on-line model (McGill *et al.*, 2017). Participants also reported having developed important CBT-based skills to support their resilience in survivorship (Sansom-Daly *et al.*, 2019). Table 1 outlines the key content and skills focus of each session.

Similarly, we have conducted several studies (Wakefield *et al.*, 2011, Wakefield *et al.*, 2014; Wakefield *et al.*, 2012; Robertson *et al.*, 2019; McLoone *et al.*, 2011) to identify the support needs of parents with a child with cancer and used this evidence-base to inform development of a manualised, on-line, group CBT intervention for parents called *Cascade* (Wakefield *et al.*, 2015). *Cascade* aims to improve quality of life in families of young cancer survivors. The program consists of four 90-minute group sessions and an individual booster session. Pilot results showed that *Cascade* was feasible and acceptable (Wakefield *et al.*, 2016). We then conducted an RCT, comparing *Cascade* to an attention control (videoconferencing peer-support group) and a waitlist control (manuscript under preparation) to determine benefit on parents' health-related quality of life, mental health, and CBT skill-use and competence.

Pitfalls: Navigating and overcoming challenges in clinical practice

Safety

Numerous challenges can arise in the clinical delivery of CBT-based interventions in paediatric oncology. For both young people and family members, skills-based psychological therapies such as CBT necessitate examination of distressing thoughts and feelings (Hofmann *et al.*, 2012). While this is a natural part of the therapeutic process, heightened emotional distress raises important safety concerns. In the context of group-based therapies, management of individuals' expression of distress is an important consideration for the emotional wellbeing of the whole group. Additionally, safety protocols for on-line therapies must be tailored to ensure that remotely-managed safety screening and distress management is timely. Some guidance exists to support best-practice in managing these kinds of safety concerns within on-line mental health interventions (Sansom-Daly *et al.*, 2016). We have also detailed our own approach to this with adolescent/young adult cancer survivors participating in *Recapture Life* (Sansom-Daly *et al.*, 2015). Across the *Recapture Life* study trajectory, all detected instances of clinically-concerning increases in participant distress were able to be further assessed

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by a clinical psychologist within 48 hours, with no actual risks to safety/wellbeing evident upon further assessment (Sansom-Daly *et al.*, 2015).

Expanding access

Fundamental questions relating to access, uptake and dissemination of CBT programs in paediatric oncology remain. In Australia, hospital-based clinical psychologists with expertise in paediatric, adolescent or young adult oncology are rare; most paediatric oncology centres have just one such position, often part-time in nature. National data also highlight that 80% of clinical psychologists practice in metropolitan city centres (AIHW, 2019). The disparities of access to clinical psychologists, particularly with cancer expertise, poses significant challenges to the ability to scale-up intervention models such as *Recapture Life* and *Cascade*.

In the hospital context, studies have shown that it is possible to train non-psychologist healthcare professionals (e.g. nurses) to effectively deliver CBT-based interventions in adult oncology (Moorey *et al.*, 2009). In the outpatient and community settings, partnerships with community-based cancer support organisations – many of whom have counselling teams and telephone support “helplines” embedded within their services – may offer similar opportunities to expand access to cancer-specific on-line CBT programs. However, evidence is lacking to prove how well this works in practice, or how in-demand these services are in the “real world”. There is also little knowledge regarding whether equity of access can be achieved for rural/remote communities, families with poor Internet access, or culturally and linguistically diverse populations.

To fill these knowledge gaps, we are conducting community-based Implementation-Effectiveness Hybrid Type 2 trials for *Recapture Life* and *Cascade*. To ensure long-term sustainability, we are training counselling teams within our partner community organisations to deliver the interventions. Our model of implementation also allows community organisations to tailor the interventions based on their expertise, experience, and workflow. As such, we will investigate intervention uptake and effectiveness in community settings, as well as the success of delivering the interventions via a range of health professionals including clinical psychologists, social workers, and counsellors. We are also implementing *Recapture Life* across two countries, and *Cascade* across four countries. Using a rigorous process of cultural and linguistic adaptation, we will assess the value of the interventions across cultures.

Progress: Future opportunities to extend on-line CBT in paediatric oncology

Survivors' health behaviours

Given that the risk of treatment-related late effects may be exacerbated by poor health behaviours (Oeffinger *et al.*, 2006), it is vital that childhood cancer survivors adopt a healthy lifestyle. Adhering to physical activity and dietary guidelines has significant benefits to survivors (e.g. reduced mortality), compared to those whose diet and exercise behaviours fall below guideline standards (Smith *et al.*, 2014; Scott *et al.*, 2018). The incorporation of CBT elements to enhance the effectiveness of health behaviour interventions holds promise; for example, behavioural therapy has been used to effectively reduce picky eating in children (Dahlsgaard *et al.*, 2019).

A major challenge to supporting behaviour change in younger survivors is that general community-based diet and exercise interventions rarely address children's cancer-specific challenges, such as the development of taste aversions to certain foods or picky eating behaviours (e.g., avoidance of vegetables) among some children after cancer treatment (Cohen *et al.*, 2014). Similarly, physical limitations such as amputation, fatigue, and cardiac risk, are often not considered in local community exercise settings. Given the relative rarity of childhood cancer and the lack of specialist cancer knowledge held by local gymnasiums and out-of-the-box dietary programs, tailored programs may not be feasible to offer on a local basis. On-line CBT programs that can be delivered to survivors anywhere, provide evidence-based tools and strategies to effectively address the myriad physical and cognitive barriers that survivors face in maintaining health behaviours (Hobbis and Sutton, 2005).

However, there is a dearth of evidence directly supporting the effectiveness of CBT in encouraging health behaviour change generally. By targeting the modification of unhelpful beliefs that perpetuate poor health behaviours and strengthening or creating adaptive ones, it may be possible to create lasting change. Used in combination with practical support to overcome common barriers to creating sustainable health behaviour changes, CBT may be effective for a range of healthy changes including exercise, weight management, smoking cessation, and reduced alcohol consumption (Hobbis and Sutton, 2005). A common criticism of CBT use in health behaviour interventions is that its primary purpose is to support the execution of already-intended behaviours, not to create the intentions (Fishbein and Ajzen, 2005). Whilst CBT alone may not be effective in creating new intentions, many survivors already express a desire for positive lifestyle changes (Badr *et al.*, 2013).

Table 1 – Overview of CBT programs developed by the Behavioural Sciences Unit

Program name	Clinical objective	Client group	Number/length of sessions	Format	Mode of delivery	Key clinical content
Recapture Life(31)	Improved QoL	AYA's who have completed cancer treatment	6 x 60 minute sessions	Group (2-5 participants)	Video conference	<ul style="list-style-type: none"> • Psycho-education • Behavioural activation • The ABC model • Awareness of unhelpful thinking • Strategies for managing thoughts • Skills for enhancing social support • Goal setting and problem solving
Cascade(35)	Improved QoL	Parents of children (<18 years) who have completed cancer treatment	4 x 90 minute sessions	Group (2-5 participants)	Video conference	<ul style="list-style-type: none"> • Psycho-education • The ABC model • Awareness of unhelpful thinking • Strategies for managing thoughts • Skills for enhancing social support • Relapse prevention

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Program name	Clinical objective	Client group	Number/length of sessions	Format	Mode of delivery	Key clinical content
Catnap (59)	Improved sleep quantity and quality, reduced distress	Parents of children (<18 years) with cancer who are staying overnight in hospital	1 x 30-45 minute session	Individual	Face to face	<ul style="list-style-type: none"> • Psychoeducation focused on sleep and thinking • Awareness of unhelpful thinking including rumination and worry • Strategies for managing unhelpful thinking • Sleep hygiene • Relaxation • Understanding burnout • Self-care strategies
<i>CBT-aligned programs</i>						
Re-engage (60)	Improved health-related self-efficacy, QoL, health behaviours	Adult survivors of childhood cancer or parents of young survivors (<18 years)	2 x 30-60 minute sessions	Individual	Telephone or video conference	<ul style="list-style-type: none"> • Education about risk of treatment-related health conditions • Recommendations for screening and specialist care • Recommendations for health behaviours and lifestyle advice • Discussion about overcoming barriers to accessing care

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<i>Program name</i>	<i>Clinical objective</i>	<i>Client group</i>	<i>Number/length of sessions</i>	<i>Format</i>	<i>Mode of delivery</i>	<i>Key clinical content</i>
Reboot Kids (61)	Improved dietary intake and quality	Young survivors of childhood cancer and their parents	4 x 30-45-minute web-based modules 4 x 30-45-minute web-based modules	Individual	Online/telephone	<ul style="list-style-type: none"> • Goal setting • Education about the importance of healthy eating for children who have received cancer treatment • Education about age-based national dietary guidelines • Awareness of parent providing of vegetables to children • Strategies for encouraging parent providing of healthy meals and snacks • Strategies for managing picky eating • Discussing parent dietary habits and role-modelling to children

QoL = Quality of Life
AYA = Adolescent and Young Adult

There are few health behaviour programs which are delivered entirely on-line (Cohen *et al.*, 2016; Mizrahi *et al.*, 2017; Pugh *et al.*, 2016). However, new programs are emerging. Our team is currently trialling Reboot Kids, a new on-line parent program to promote healthy eating habits in young cancer survivors. Reboot Kids uses behavioural techniques which align with CBT, to support behaviour change, including goal-setting, self-monitoring/behaviour change diary and a flexible food-exposure paradigm to encourage parents to provide vegetables to young survivors, repeatedly throughout the day (see Table 1) (Touyz *et al.*, 2018). Pilot results indicated that all parents perceived the program to be useful in promoting a healthy diet to their child and increasing their confidence in managing their young survivors' diet. Given the efficacy of health behaviour change to significantly reduce disease in adult cancer survivors, it is surprising that there is such a paucity of on-line programs available for younger cancer survivors. Further research is warranted to investigate whether CBT techniques can be used to improve the effectiveness of current health behaviour change interventions in this at-risk population.

Parents' sleep during treatment

Our team also has experience developing and evaluating CBT interventions for families during treatment. Families often spend extended periods of time at the hospital during treatment and can experience isolation and heightened distress during this time, particularly in the weeks after diagnosis. As such, CBT interventions delivered face-to-face by experienced clinicians who can gauge distress and respond to additional support care needs may be appropriate at this time-point. *CATNAP* (Carers at Night in Paediatrics) is a ward-based tailored sleep intervention for parents of children with cancer (Ellis *et al.*, 2018), grounded in cognitive behavioural therapy for insomnia (CBT-I) (Perlis *et al.*, 2005). A clinical psychologist delivers the intervention on the ward including a one-on-one session, supplemented by a hard copy booklet containing psycho-education about sleep, and cognitive/behavioural strategies to improve sleep and general self-care. Parents described face-to-face sessions with a health-care professional as one of the most helpful aspects of the intervention.

However, in this post-Covid-19 clinical landscape, a hybrid or a fully on-line version of this intervention would increase equitable access for parents who may not be required, or allowed (due to new Covid-19 restrictions) to stay in hospital with their child but are still experiencing sleep difficulties. The efficacy of partly or wholly self-guided CBT-based interventions

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is further supported by promising results from a recent Internet delivered insomnia intervention, which found significant improvements in sleep and quality of life among adolescent and young adult cancer survivors using a fully automated CBT-I program (Zhou and Recklitis, 2020). Translating the psycho-educational information and practical intervention strategies on-line (e.g. by including interactive tasks), may also increase uptake among families, as parents can easily access these resources as needed throughout their child's treatment journey and into survivorship. In addition, in-hospital support is restricted to the availability and capacity of clinicians on the ward, who typically and understandably prioritise the paediatric patients above family members who may also be experiencing difficulties. Providing CBT interventions such as CATNAP on-line may enable parents to access the support when it is most needed, and when they have the energy and motivation to truly engage in the intervention.

Conclusions

Young people affected by cancer and their families are at increased risk of clinically relevant distress and mental health disorders. Evidence indicates that CBT is an acceptable, feasible and effective intervention to treat and prevent anxiety, depression, and insomnia in children impacted by chronic disease. CBT may also enhance the effectiveness of broader health behaviour change interventions that have a non-psychological focus (e.g., healthy eating). On-line CBT delivery may overcome some of the barriers that young people and their families have in accessing it. Despite the potential of on-line CBT, it remains unclear how best to adapt the evidence base to paediatric oncology, or how to implement the on-line delivery of specialised CBT in the real world. Researchers, clinicians and consumers must continue to collaborate so that all families can access the psychological support that they need.

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