ME WE young carers

THE ME-WE MODEL

A co-created and scientifically tested support programme for adolescent young carers

Country focus: UK

CARERS TRUST

UNIVERSITY OF SUSSEX

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement n° 754702

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Linnaeus University (lead partner)	Sweden	Linnæus University
Eurocarers	Belgium	EURO CARERS European Association Working for Carers
University of Sussex	United Kingdom	US UNIVERSITY OF SUSSEX
Carers Trust	United Kingdom	CARERS TRUST
Kalaidos University of Applied Sciences	Switzerland	Kalaidos University of Applied Sciences Switzerland The University for Professionals.
The Netherlands Institute for Social Research	The Netherlands	The Netherlands Institute for Social Research
The national Centre of Expertise for Long-term Care in the Netherlands (Vilans)	The Netherlands	Vilans
Anziani e non solo	Italy	ANS Anziani e non solo società cooperativa sociale
National Institute of Health and Science on Ageing (INRCA)	Italy	INRCA
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Introduction

Young carers are children and young people who provide care, help, or support to a family member, friend, or some other closely related person, with a disability, long-term illness, infirmity, substance dependency problems, or other health-related conditions. Young carers who have extensive care responsibilities are at a considerably higher risk of suffering from psychological illness and social exclusion compared to other children.

The goal of the H2020 ME-WE project - Psychosocial Support for Promoting Mental Health and Well-being among Adolescent Young Carers in Europe - is to strengthen the resilience of AYCs, improve their mental health and well-being, and mitigate the negative influences of psychosocial and environmental factors. The project developed with steer from young carers and former young carers an **innovative framework of primary prevention interventions that have been tested and adapted in six European countries** (Italy, Netherlands, Slovenia, Sweden, Switzerland, United Kingdom) at different stages of awareness and development of policy and services for AYCs. The project aims to evaluate what works and provide evidence-based actions at national, European and international levels.

Adolescent young carers (AYCs) are those in the age group 15-17 years. They are in a transitional phase, from childhood to adulthood. They deserve a special attention, as navigating growing up and all the challenges that life throws at them, while caring for someone, can be overwhelming.

Background

Across Europe, there is a varied level of responses and awareness level to this phenomenon by professionals, policy-makers, and academics. Researchers have deemed the **UK** to be a country at an **advanced level of supportive practice development, research, and policy** (Leu & Becker, 2017). Scholarly research on young carers has been underway since the early 1990s. There are **hundreds of dedicated young carers support services**, called "young carers projects" in England and to a lesser extent across the other three nations in the UK. Strides have also been made in recent years for young carers in England, through the passage of the Care Act 2014 and the Children's and Families Act 2014 which first-time legal right to young carers to receive an assessment if need is demonstrated and right to access formal support. Despite these advances made in social care, policy, research, young carers -and in particular adolescent young carers- had yet to receive a primary preventive intervention specifically designed with their needs in mind. Hence, **the ME-WE Model was ground-breaking.**

Purpose

The aim of this Brief is to provide an overview of the main results from a study that evaluated the ME-WE intervention programme in the United Kingdom.

The ME-WE intervention programme

The ME-WE Model consists of a psychosocial intervention and a mobile app for young carers.

Both have been co-designed with young carers and professionals, as they were discussed in the framework of the Blended Learning Networks (a heterogenous group of people who share common interest(s) and contribute with some form of expert knowledge to the community by creating a learning network that meets regularly) in earlier stages of the ME-WE project.

The ME-WE psychoeducational intervention is an adapted form of the DNA-V model (Hayes and Ciarrochi, 2015). The latter is used in educational and clinical contexts to help adolescents to manage their emotions, to find solutions to daily problems, to connect with their own values, to reach a level of awareness and vitality and to develop positive relationships with friends and family. The model is focussed on the development of a strong sense of oneself and gives adolescents the confidence they require to make the transition towards adulthood.

Methodology

RECRUITMENT AND IMPLEMENTATION OF THE ME-WE INTERVENTION

The preliminary step in order to implement the ME-WE intervention consisted in recruiting young people who satisfied the criteria to take part in the study, namely: aged between 15 and 17 and be responsible for the care of family members or other people of significance in their life (inclusion criteria) and not already receiving psychological/mindfulness-based therapy or medications (exclusion criteria).

Those who passed the screening were placed at random in two groups: the first group took part in the intervention programme (intervention group), whilst the other group was placed on a waiting list (control group).

As the intervention took place in England, where dedicated, supportive programmes for young carers (young carers projects) are relatively widespread, the participants in the study were recruited not via schools or NGOs (like in the other project countries), rather via young carers services.

Originally, the ME-WE programme was designed to be delivered face-to-face in schools during the normal school day. The effect of the pandemic necessitated smaller, online groups, which were held in the early evenings.

There were 9 Control groups and 9 Intervention groups, with a total of 74 young carers recruited.

EVALUATING THE EFFECTIVENESS OF THE ME-WE INTERVENTION

In order to evaluate the effectiveness of the intervention, a mixed method evaluation was conducted, including a questionnaire to be filled by young carers who participated in the study (both in the intervention and in the control group) and interviews/online survey to be answered by stakeholders that had been either actively involved or actively supported the development of the intervention, the information, recruitment and/or implementation of the ME-WE intervention.

Evaluation questionnaire AYCs

The questionnaire for AYCs was handed out in three different moments: before the seven-week intervention (T0, baseline), immediately post-intervention for the ME-WE intervention group or after 7 weeks for the waitlist control group (T1), and again at three months' follow-up (T2).
The intervention and control group were compared in terms of the changes (between T0 and T1 and between T0 and T2) observed in a series of outcome variables.

Out of the 74 recruited young carers, 25 filled in all three questionnaires.

Evaluation for stakeholders

In addition to the questionnaire for AYCs, a contextual evaluation was conducted, in order to gain a deeper understanding of success factors and challenges encountered during the recruitment and implementation of the ME-WE intervention in each country. A secondary aim was to explore to what extent the recruitment efforts have contributed to an increased awareness of AYCs' situation among key stakeholders in all six partner countries and to changes in the way they work.

A total of 12 professionals took part in one focus group and eight individual interviews. All of them were facilitators in the UK ME-WE programme and had extensive experience working directly with young carers in their current employment.

The online survey was answered by 14 stakeholders, the majority of whom were from carer support centres/carer organisations and had acted as facilitators of the ME-WE intervention.

Main findings and discussion

THE EXPERIENCE OF ADOLESCENT YOUNG CARERS WHO PARTICIPATED IN THE ME-WE INTERVENTION

The evaluation results clearly demonstrated the psychosocial benefits of the ME-WE programme for UK adolescent young carers. **The ME-WE intervention resulted in a positive impact on the AYCs' observed resilience, health behaviours, and self-harming thoughts and thoughts of harm to others**.

The ME-WE intervention gave some AYCs a new language to discuss their feelings related to their caring role. Others felt that **the intervention gave them a safe space to express their feelings**, however negative they may be, about their caring experience and life in general. Generally, the intervention appeared to aid in emotional regulation.

The majority of the respondents expressed that **participating in the intervention had allowed them to gain a fresh perspective on their caring role and life in general**. Others reported a **higher sense of self-esteem and confidence towards themselves**. Overall, the **changes in their life as a result of the intervention were extremely positive.**

As to the negative side of the intervention, the respondents noted that the subject matter of the intervention was at times triggering for them, or caused them to reconsider, aspects of their caring role that was uncomfortable for them. There was a general consensus that the training sessions were overly long.

In relation to the impact of Covid on AYCs, some AYCs spoke of their mental health during the pandemic and reflected that their mental health had worsened, due to the isolation they experienced. Other AYCs noted that their need for support had increased during the pandemic and they were not in receipt of the support they felt they needed.

The substantial negative effect of the pandemic on the AYCs' mental health needs to be taken into account when interpreting the evaluation data: for instance, poorer observed mental health could easily be attributed to the special context, rather than to the ME-WE intervention, as **one would most certainly expect to see poorer mental health outcomes in a pandemic, no matter how well-designed a psychosocial intervention may be.**

THE EXPERIENCE OF STAKEHOLDERS

Stakeholders were enthusiastically positive and affirming of the ME-WE programme. They reported that the AYCs found the programme exceptionally beneficial, especially as a means to combat their sense of isolation during the COVID-10 pandemic government-sanctioned "lockdowns". The intervention proved advantageous to their own sense of learning with their work with young carers external to the ME-WE project. Stakeholders indicated that **they would use the ME-WE model in the future with other young carers.**

The ME-WE programme was found to augment the already robust competency skills of the UK professionals, who were all already well-versed in young carer issues.

The respondents expressed that **the ME-WE programme added "tools to their toolbox"** and enhanced their way of working. The ME-WE programme was found to give the respondents a new vocabulary to talk about AYCs' experience of their caring role.

Respondents mentioned few challenges:

- In regards to challenges in the recruitment process, the facilitators reported that the **COVID-19 pandemic** and government-imposed closure

Conclusions

of schools and restriction on in-person group gatherings **severely limited their ability to recruit AYCs**.

- Several of the facilitators noted that the **rigorous scientific requirements** (e.g., the AYC assignments into control and experimental groups or the age parameters) **made it difficult to recruit and keep AYCs engaged in the programme**.
- Nearly all of the facilitators highlighted the **challenges encountered because of technical issues**. Poor wifi and the difficulties in adapting the materials to an online format were cited as reasons for the negative experience of implementation. Online groups were not as desirable to the AYCs as meeting face to face. Some AYCs experienced fatigue from the sheer amount of online activities that increased throughout the pandemic (e.g., online school classes) and the ME-WE groups only added to their sense of fatigue.

Stakeholders put forward the following suggestions for the future:

- **It was recommended that the ME-WE programme is delivered to a wider age range of young carers, in recognition that young caring often begins in early childhood.**
- Future RCT research with this population should consider the **potential likelihood of the participants to already be enrolled in therapy due to the distressing nature of their caring role.**
- Another crucial recommendation was to **avoid conducting further randomized control trials during the global pandemic**—a time when young carers (and their project workers) are experiencing a great deal of stress and anxiety. (NB. The project consortium and external International Advisory and Ethics Board members deemed the benefits to outweigh the risks in terms of continuing the clinical trial, as in many countries the usual supports and services were discontinued due to the pandemic).

The ME-WE programme holds many firsts: it stands as the first randomised control trial (RCT) with adolescent young carers, its unique inclusion of six European nations with a varied level of approaches and awareness to young carers is ground-breaking on a pan-European level, and it is the first time that the DNA-V model has had dedicated use with a young carers population.

The fact that the RCT study was conducted during a pandemic—and moreover, the encouraging, positive feedback from the AYCs and facilitators, indicates the intervention programme such as **the ME-WE programme was necessary and indeed timely.**

Its online mode of delivery also provided a unique opportunity to "pilot" an **original intervention that can now be used both face to face and online**, furthering the inclusion of AYCs living in areas with little to no formal support services.

Recommendations for policy and practice

1. RECOGNIZE THAT TECHNOLOGIES ARE NOT A LUXURY BUT A GATEWAY TO ACCESS AND PROVIDE SUPPORT

The online delivery of the ME-WE programme exposed existing inequities present in the lives of vulnerable children like AYCs: more young carers than expected did not have access to computers, webcams and a reliable internet connection. The UK Government must view such technologies as critical in the lives of young carers. Far from being a luxury, sound technology facilities serve as a gateway to access support and prevent social exclusion. **Policy budgets for the education sector should include stipends for technology in the home for vulnerable families.**

The online mode of delivery also highlighted that practitioners themselves may not have technologies such as computers or high- speed internet at home. The pandemic brought the dire need of preparedness in the social care sector for all eventualities—such as remote working—to our attention. The Government can play a necessary and important role in ensuring that formal support services are better financed and resourced with modern technology for its staff.

2. ENSURE FUNDING FOR YOUNG CARERS SUPPORT PROGRAMMES

Facilitators of the ME-WE Model repeatedly asserted that they would adapt the UK ME-WE programme for future use with either (or both) young carers and adolescents generally. Yet, there were **concerns about the feasibility of replicating the programme without external funding**, noting the relative high cost of the training materials.

3. ENABLE ALL YOUNG CARERS – INCLUDED THOSE WHO ARE HIDDEN- TO RECEIVE THE SUPPORT THEY NEED

Some young carers (e.g., those in rural areas or in other regions with few or inexistent formal support services; or those not enrolled in school or education) are even more considerably hidden than their other young carer peers. It is crucial to offer them access to a proven, validated, supportive programme.

As the UK version of the ME-WE programme was delivered completely online, the intervention acted as an unexpected pilot study of an online mode of delivery in England. Its success establishes that the online ME-WE programme has substantial usefulness for the extensive country landscape of the UK.

The online version of the ME-WE programme offers a critical avenue of formal support for all young carers. **Young carers who usually are hidden can also take advantage of the online version of the programme**, furthering the programme's inclusiveness.

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