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Intergenerational Justice Review

Issue topic:
Young Carers (I)

Table of Contents

Issue topic:
Young Carers (Part I)

Articles

Book Reviews

The peer-reviewed journal *Intergenerational Justice Review* (IGJR) aims to improve our understanding of intergenerational justice and sustainable development through pure and applied research. The IGJR (ISSN 2190-6335) is an open-access journal that is published on a professional level with an extensive international readership. The editorial board comprises over 50 international experts from ten countries, representing eight disciplines. Published contributions do not reflect the opinions of the Foundation for the Rights of Future Generations (FRFG) or the Intergenerational Foundation (IF). Citations from articles are permitted upon accurate quotation and submission of one sample of the incorporated citation to FRFG or IF. All other rights are reserved.

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Editorial

Intergenerational justice is not only about climate protection and balanced budgets – but that the members of the next generation have at least the same chances to fulfil their needs as the members of the present generation. Preferably, they would have *better* chances to fulfil their needs than we do.

In most of recorded human history, care has been a family task. Only recently, it became a matter of public policy, predominately in the Global North. But even there, it is still to a large extent a family task, usually performed by adults.

But in a few cases, children and young people are involved on a regular basis in informal care settings. 'Young carers' are young people who provide care, assistance, or support to another family member. The person receiving care is often a parent but can be a sibling, grandparent or any other relative who is disabled, has some chronic illness, mental health problem, or other condition. The young carers carry out substantial caring tasks, including physical, emotional, and medical support for the person with the illness or disability. Young carers thereby take on a level of responsibility that would usually be associated with an adult. Studies from different countries show a prevalence rate of 6–8 percent within the age group of 18–25 years, although a number of unreported cases must be assumed.

The possible effects experienced by young carers are as varied as the tasks they undertake. Some young carers report negative physical, emotional, social, and educational effects. Being a young carer can lead to higher drop-out rates from education, difficulties to find a partner, and lower employability than their peers without an ill or disabled family member. However, positive aspects related to caring responsibilities are also mentioned by young carers themselves and experts who are familiar with the field. It is unclear whether or not young (underage) carers should be safeguarded from caregiving. What is clear is that the effects that young carers experience often shape their whole lives in different ways. How young carers experience and perceive their situation seems to be influenced, among other things, by whether children, adolescents, and young adults have a real choice in deciding whether and to what extent to provide support to family members.

Until now, underage carers – in particular – have received little or no recognition for their caring work in the form of relief or other forms of compensation.

IGJR 1-2023 and IGJR 2-2023 are special issues with a focus on the specific situation of young carers. This is done through republished articles. The first article, written by a consortium of 21 authors as one outcome of an EU Horizon 2020 funded research project, reports the findings of a Delphi study on young carers with 66 experts from ten European countries. It highlights that the level and type of support available for young carers differs, with most countries mainly offering support on a local level. The question of new legislation was contested. Some experts were in favour of new laws to formalise the rights of young carers. Some experts raised that young carers might not self-identify as being in need, because they may find caring normal and they may not be aware of the concept of young carers. Furthermore, according to a number of experts, young carers rather do not want to draw attention to themselves.

The second article, originating from the same EU project, displays the results of the first cross-national study of young carers aged 15–17 years in six European countries. This study sheds light on the difficulties to identify young carers and to assess their number. It provides, for the first time, a cross-national profile of adolescents who provide unpaid care to their ill or disabled family members. Using an online survey, 2099 young people were identified in Italy, the Netherlands, Slovenia, Sweden, Switzerland and the UK. The article focuses on the impact of unpaid care on their mental health, well-being, physical health, and education. Their preferences for informal and formal support were also examined. These groundbreaking findings help promote a 'rights' approach to adolescent young carers, which can serve as a critical driver for supportive policy creation on both a country-specific and pan-European level.

There will always be young people growing up in families faced with illness or disabilities. One takeaway from many studies seems to be that whenever starting from a whole family approach, it can open up opportunities for identifying the roles and needs of all family members. This can certainly improve the situation of young carers, but possibly also the situation of the (mostly) older adults for whom they provide care.

Finally, this issue concludes with the book review section. As the topic of young carers is so far an under-researched field, the reviewed books engage with intergenerational issues more generally. First, Michael Haiden reviews Brian Christian's monograph *The Alignment Problem: How Can Artificial Intelligence Learn Human Values?* (2020), exploring the ethics of AI and methods of machine learning. Continuing this theme, Philipp Köbe reviews John Lennox's *2084: Artificial Intelligence and the Future of Humanity* (2020), which presents a sobering outlook on the potential consequences of an AI-dominated world from a Christian perspective.

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The awareness, visibility and support for young carers across Europe: a Delphi study*

by Henk Herman Nap, Renske Hoefman, Nynke de Jong, Lieke Lovink, Ludo Glimmerveen, Feylyn Lewis, Sara Santini, Barbara D'Amen, Marco Socci, Licia Boccaletti, Giulia Casu, Alessandra Manattini, Rosita Brolin, Karina Sirk, Valentina Hlebec, Tatjana Rakar, Tjasa Hudobivnik, Agnes Leu, Fabian Berger, Lennart Magnusson, Elizabeth Hanson

Abstract: *Across Europe, young carers (YCs) and their need for support receive limited attention in the media, policy and empirical research, even though, similar to adult carers, they also provide care to ill family members. The Delphi study, a qualitative research methodology, which provides the focus for this article, had the overall aim of exploring existing successful strategies to support YCs. Compared to YCs, even less is known about adolescent young carers (AYCs), a group that is in a critical life transition phase. The study forms part of an EU Horizon 2020 funded research project on AYCs aged 15–17 years old.*

The two-round Delphi study was conducted with 66 experts on YCs from 10 European countries. Topics included: (i) visibility and awareness-raising of YCs at local, regional, and national levels, (ii) current interventions to support YCs, and (iii) future strategies to support YCs.

Experts reported a lack of visibility and awareness about YCs in general, and AYCs in particular. Although awareness is slowly increasing in most countries, with the UK ranked highest, experts acknowledged that it remains challenging to identify YCs in many countries. Furthermore, the level and type of support available for YCs differs, with most countries mainly offering support on a local level. Diverse views were expressed regarding future strategies to support YCs. Experts highlighted the importance of specific legislation to formalise the rights of YCs, and the issue of whether young people should be safeguarded from caregiving or if this should be considered part of regular family life. They also emphasised the relevance of available integrated support services for YCs, including schools, family, health and social care.

In most European countries, there is a lack of awareness and visibility on YCs. Identification of YCs is a crucial first step and there is need for a common definition of YCs, together with greater opportunities for young adults to identify themselves as YCs.

Keywords: *Informal care; family care; Delphi study; adolescent young carers; young carers; support services; European research; cross-national research*

Background

In families where one of the family members has a physical or mental health problem, children or adolescents are often involved in caregiving roles [1, 2]. These young people are defined in the literature as young carers (YCs), that is: "young people under the age of 18 who provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial tasks and assume a level of responsibility that would usually be associated with an adult" [3]. These tasks are, among others, administrative and/or household tasks, personal or nursing care and/or providing company to an ill family member [4]. Besides these caring tasks, YCs often worry about their ill family member. It is not only the practical, visible tasks YCs are engaged with, but also the 'worries in their head and in their hearts' over the health and well-being of their family member [5].

Growing up with an ill family member is particularly recognised as a risk factor for mental health and well-being [4, 5]. Also, being a YC increases health inequalities during the life course [6-9]. It is known that YCs often experience the consequences of social exclusion, with higher absenteeism and drop-out rates from education and lower employability than their peers without an ill family member [7, 10-12].

The number of recognised YCs is relatively low yet varies per country and region [13]. It is important that YCs are identified and recognised in order to positively impact their well-being and mental health [5]. A promising way to facilitate this could be the use of technology, such as online support groups or gamified apps that could support YCs and strengthen their resilience in the transition to adulthood [14, 15]. A recent Swiss study focused on the needs of YCs for support and relief [16], however, overall there remains a dearth of knowledge about YCs' needs and preferences for support and the ways in which (if any) they are currently being supported.

Growing up with an ill family member is particularly recognised as a risk factor for mental health and well-being. Also, being a YC increases health inequalities during the life course.

Thus, in order to address this knowledge gap, the overall goal of the current study was to gain insights into the awareness and visibility of the situation of young carers (YCs), with a specific interest in adolescent young carers (AYCs) aged 15–17 years old due to their critical life transitional phase to adulthood. The purpose was to identify their future support needs and preferences with a focus on promoting their mental health and well-being. The Delphi study described in this article forms part of a larger EU Horizon-funded research and innovation project, [17] ("Psychosocial Support for Promoting *Me*ntal Health and *We*ll-being among Adolescent Young Carers in Europe"; ME-WE project), dedicated to strengthening the resilience of AYCs in transition to adulthood (15–17 years old) in order to impact positively on their mental health and well-being and to mitigate the negative influence of psychosocial and environmental factors in their lives [17]. The Delphi study formed part of the first phase of the project, which aimed to systematise knowledge on YCs by focusing on successful support strategies.

The aim of this article is to present and discuss the main and overall Delphi study results focusing on i) the visibility and awareness-raising of YCs on a local, regional, and national level; ii) current interventions to support YCs, and iii) on future strategies to support YCs.

Methods

To address the above core aims, a two-round Delphi study among YC experts was conducted. The Delphi method is an acknowledged qualitative research method to gather different opinions of experts, cultures and countries, and search for consensus on a topic, especially in a new field of study such as AYCs, with the possibility of diverging views [18]. A Delphi study ensures anonymous responses, which are aggregated and shared with participants after each round. Experts are allowed to adjust their answers in upcoming rounds and reflect on the results from the other participants. In this study, the goal was not to reach full consensus, but to search for consensus on certain topics and identify differences between countries in two interview rounds.

Central in round 1, were the experiences with – and knowledge on – YCs. Interviews also focused on existing strategies and programmes (if available) to improve (A)YCs' mental health and well-being known by the expert panel. Specific attention was paid to the opinions of the panel on barriers and drivers of these existing strategies and programmes. Round 2 was performed to discuss the results from round 1 and to gather an insight into optimising programmes and developing future scenarios to best support AYCs.

Recruitment

In total, 66 participants, i.e. 'experts' participated in the two-round Delphi study (see Table 1 for an overview per country). Participants were intentionally selected based upon the EU ME-WE project partners' knowledge and professional network on YCs or related fields. All the experts had been working in the field of YCs or related fields, if not available in the country (such as youth policy), with an identifiable track record (e.g., peer-reviewed publications, organisation of events/programmes for YCs and/or young adults, development and support of care or social policies, practice: in health, social care or education). The eligibility of the experts was cross-checked by the national investigator teams. One expert from the Netherlands was not able to participate in the second round. A couple of candidates who were approached, recommended other experts (with name) more knowledgeable about the topic than themselves. These experts agreed to participate. They received an invitation for the individual interview by email, including a questionnaire in English or, if preferred, in their desired language to gather some basic characteristics, such as demographics, occupation and experience with the topic of (A)YCs, and an informed consent form agreeing to their participation and audio recordings of the interviews. The informed consent form also included a letter with information on the aim of the study and the interviews, and the applied method of the Delphi study. Furthermore, the experts received information on the project leader of the Delphi Study and the national investigators in the ME-WE-project.

Ethics

Before the start of the Delphi study, all experts received information on the aim of the project and the Delphi study and were asked to sign an informed consent form. The procedure included the assurance of full anonymity and the possibility to withdraw from the study at any stage without explanation and without consequences. All experts gave consent for participation and use of the findings for publication prior to both round 1 and 2 of this Delphi study.

Interview process

The Delphi study ran over a period of 6 months in 2018. The individual interviews in both rounds were conducted via telephone,

Table 1: Descriptives of the experts per country that participated in both Delphi rounds

	Round 1 & Round 2		**Main Occupational Field**				
	n	**Female n**	**Academia**	**Education**	**Policy**	**Health Care**	**Social Care**
Italy	10	8	2	2		3	3
The Netherlands [a]	10	8	2	2	1	1	4
Slovenia [b]	9	2	1	3	1	1	2
Sweden	10	9	3		2	3	2
Switzerland [c]	10	4	1	1		5	1
United Kingdom	13	9	5	1	1	2	4
Austria	1	0	1				
Belgium	1	1			1		
Ireland	1	1			1		
Germany	1	0		1			
Total *N*	**66**	**42**	**15**	**10**	**7**	**15**	**16**

a 1 expert could not participate in Round 2

b of 1 expert the occupational field data was missing

c of 2 experts the occupational field data was missing voice Microsoft Skype or face-to-face (only in Slovenia), using an interview script translated to the national language, which was cross-checked by the national investigators (see Additional files 1 and 2 for English versions of the interview scripts). Participants were interviewed by a qualified national investigator from the ME-WE project team (MA, MSc or PhD) with multiple years of experience in performing qualitative research (see Additional file 3 for the interviewers' personal characteristics). The interviews were recorded by means of a voice recorder or a mobile application. At the start of the interview, the interviewers introduced themselves and the ME-WE-project and reminded the experts that detailed information could be found in the information letter of the informed consent form. At the start of round 1, the interviewer defined AYCs as follows: "Adolescent young carers are children who provide care for another person (normally for other family members). They often assume significant responsibility for care on a regular basis. This responsibility is something normally associated with adults. The person needing care is usually a parent. However, it may also be a sibling, a grandparent or another relative with a physical, mental or cognitive health issue."

A semi-structured questionnaire was used in round 1 to be able to compare the results across experts, regions and nationalities, and also to ensure flexibility for individual input. The questions were pilot-tested among Dutch experts on the topic of (A)YCs. The following three main topics were selected for the open-ended questions in the first Delphi round: 1. visibility and awareness-raising of YCs on a local, regional, and national level; 2. current strategies, interventions and/or programmes to identify or support YCs (pros & cons); 3. future needs to support the well-being and health situation of YCs (see Additional file 1). These topics were selected from an academic literature review, and a grey literature search including social media. In keeping with the main target group of the ME-WE project, respondents were informed that the main focus of the study was on adolescent young carers aged 15 – 17 years old. Given that it was anticipated that it could prove difficult for the participants to focus solely on the age range 15 – 17 years, interviewees were instructed to also consider YCs attending secondary school / high school. Furthermore, if knowledge was limited, interviewees were offered the possibility to share examples on interventions for YCs aged 8 – 12 years. The national investigator strived to provide at least 10 min discussion time per topic. The main topics and answers were summarised at the end of the interview, followed by an informal debriefing with the participants. In this informal debriefing, the participants were asked if they had additional questions, thanked for their participation, and given information about the second round of the Delphi study. The first Delphi round took approximately 1 h per participant and varied slightly per country.

The second Delphi round took place approximately 2 months after the first round. The procedure for the second Delphi round was similar to the first and started with a summary of the previous interview, both on a national and European level. The second interview then focused on the overall summary of the most successful strategies identified to support YCs across Europe and the future needs by various end-users and stakeholders to support the well-being and health situation of YCs, and, where feasible, specifically for AYCs. The participants could reflect on these findings from the first round and adjust their own views and options. Again, the interview lasted for approximately 1 h and the participants were asked if they were willing to participate in future studies on (A)YCs.

Data analysis

All individual interviews were transcribed in a text editor such as Microsoft Word and relevant quotes translated to English. All national investigators analysed the content and discussed the preliminary results, first with the national investigators and later, with the investigators from the other countries. The discussion was summarised by the national investigators from the Netherlands who led the Delphi study. After this, three data coders coded the data and the code tree with an initial set of broad concepts, and a legend was shared in English with the national investigators by the lead author with sufficient flexibility to share their regional and national themes. This was followed by a thematic analysis [19-21] on a national level, and the interviews were further labelled and coded by means of the qualitative data analysis software, MAXQDA of VERBI GmbH. After analysis on the national level, themes with relevant quotes were aggregated and analysed to gather insights into generic overall themes, and also on culture- or region-specific themes. An overall summary was written by the lead partner about the most successful strategies identified to support YCs, and in particular AYCs across Europe, as well as the future needs by various end-users and stakeholders to support the well-being and health situation of YCs. The summary was sent to all participants, and they were asked to read it prior to the second Delphi round (see Additional file 2). After the second Delphi round, a narrative analysis was performed on the results per country by the national investigators followed by an overall narrative analysis by the lead authors from the Netherlands.

Results

The findings are presented first in the form of a summative table for the Delphi study round 1 interviews, followed thereafter by a narrative synthesis of the main Delphi round 1 study findings with illustrative quotes. The Delphi study round 2 findings then follow in the form of a narrative synthesis.

First Delphi Round

Table 2 below provides a comprehensive overview of the Delphi round 1 findings per country and at European level.

Visibility and awareness-raising

In the first round, experts reported on the low visibility of YCs across Europe, including a lack of systematic studies on the subject of (A)YCs. The term YCs is not recognisable in all the countries according to the experts, which can make identification challenging. Especially on a national level, experts reported that the visibility and awareness on YCs is low. Hence, when visibility and awareness is raised, this primarily takes place on a local level. Experts did report that despite a lack of visibility, awareness has slowly been increasing in recent years supported by attention in the media, such as in television shows or in newspapers. Experts argued that the majority of health and care systems across Europe still work in silos with a lack of integration. Some experts added that this also contributes to difficulties in identifying and reaching YCs because they can fall in between different care or support systems/legislations.

> The person needing care is usually a parent. However, it may also be a sibling, a grandparent or another relative with a physical, mental or cognitive health issue.

Table 2: Summary of the Delphi results from the first round per country

	Visibility and awareness raising	**Strategies, interventions and programs to support AYCs**	**Future needs to support well-being / health situation**
United Kingdom	· Different abilities/accessibility of formal care for YCs in different regions · On a national level an increase of awareness by television programs	· Current policy is 'The Care Act' and 'The Children and Families Act' (2014) working together to give AYCs legal right to a carers assessment on appearance of need · Well known are hundreds of young carer projects across the country (however, severe cuts in funding) · Young Carer Health Champions programme of the NHS · Child and Adolescent Mental Health Service teams (CAMHS)	· Need for general public to know about AYCs · Austerity policies have a negative impact on their situation · New legal rights for young carers in Care Act and Children and Families Act have little actual benefit.
Sweden	· Lack of visibility, to very low regarding AYCs · Children as next of kin is the term commonly used. · Childhood should be free from having a caring role · AYCs not directly mentioned in Swedish legislation	· Swedish Health Care Act 2010, children have a right to receive information about their parents' illness. This means that health care professionals have a legal obligation to provide children of parent/s with mental illness, serious physical illness or disability or have unexpectedly died, with information, advice and support · People with disabilities or severe illnesses have certain rights for help and support from the community, which means that AYCs' responsibilities for care can be reduced. · Parental support · Beardslees family intervention – when a parent suffers from mental health problems or addiction. · Group activities for families who have a member suffering from cancer, and for families in grief · Supportive groups for children/ adolescents whose parent/s have a disability, mental ill-health or addiction. · Relaxation in e.g. summer camps	· Identify fragile families at an early stage and provide support they need · Make AYCs visible · Reduce stigma · Legislation needed · Digital group meetings · Have someone to listen to their story · Education about AYCs · Funding and digital solutions to provide help and support · Increase children's knowledge of their parents' illness · Provide opportunities for children to talk about their situation, to meet and get support · Opportunity to relax together · Society should be responsible for all care and AYCs should be relieved from caring tasks.
Switzerland	· Difference in coping between Swiss migrant children was mentioned. Where Swiss children hide problems because they consider them as private, migrant children find their caring role more normal · Interventions successful at schools (local level) · On a national level no visibility · Difficult to reach group (do not communicate situation to their GPs) · Research on the topic has raised awareness with some organisations	· Few local programs to support AYCs (German part offers more than the French and Italian part) · Some programs support AYCs but focus only on children of parents with mental health problems · Focus on relieving relatives (e.g., organising summer camp) · Role of child protection service and < 18 legislative framework · Different programs have been carried out in schools to increase awareness · Few schools offering counselling to students who identify themselves as an AYC	· Schools should support AYCs to a greater extent · Increase awareness · Children under 18 should not take on board too many responsibilities · More flexibility needed in schools · Individual as well as collective intervention are needed to address different needs of AYCs and their families · The topic should be taught in the school curriculum · Professionals need to be more aware of AYCs and understand issues in order to support AYCs better

	Visibility and awareness raising	**Strategies, interventions and programs to support AYCs**	**Future needs to support well-being / health situation**
		· In one Higher Education Nursing School, the topic of 'caregivers' and family is taught which includes young carers. Differences between Swiss children and migrants in respect to coping (migrants caring role 'normal')	· NGO's need more funding · Whole society is responsible and need for a cultural change
Italy	· Lack of visibility and awareness on AYCs at all levels · A couple of examples of visibility/awareness raising (schools & hospital) · Visibility dependent on experience of teachers or medical professionals	· A couple of known interventions (support action in a school and by ANS in area of Carpi (in Northern Italy)	· Need for information and training for all health and social professionals and policy makers · Long-term multiactor programs (ICT app) · Promote selfawareness · Ministry of Education, Welfare and Health are responsible, as schools and regional school offices · Funding (public with private and non-profit) · Many other actions that could be applied/transferred to AYCs · Need for a law on informal carers · Local authority as main actor · Role for schools and teachers in supporting AYCs (awareness raising) · Long term programs and whole-family approach
The Netherlands	· Low visibility and AYCs do not always recognise themselves as AYCs. · Differences in visibility between regions, municipalities are responsible for support adult caregivers and wellbeing of youth (struggle) · Formal policies exist on informal care, but not young carers · Schools could play an important role for increasing visibility · Welfare organisations and youth healthcare try to increase visibility	· Plays at schools and programs to support leisure activities, resilience training, support groups, etc. · Awareness programs at high schools · Guest lessons · Online platform (e.g., Sharepoint) for AYCs · Children's Ombudsman · Activities for young carers (meet other carers) at local support centers	· AYCs should be seen as a specific group of informal carers · Focus on AYCs own strength and do not 'problematise' the group · Integral approach is needed. · Strive for regulation and need for having discussion on level of responsibility suited for youngsters. · Reduce stigma. · Acknowledgement of the group. · Create funding (e.g., via municipalities) for support for young carers. · Recognition of AYCs that they are AYCs · Need for specific policy and support for AYCs and putting the topic on the agenda · Need to focus on parents of children who are responsible for their care. · Need for cocreation with AYCs. · Need for integral approach (welfare, healthcare, educational and local governments that work together)
Slovenia	· AYCs are an overlooked subject in Slovenia and also not regulated under any law · The importance to develop a definition, emphasising that id does not relate to short-term, but long-term care		· Develop an integral approach, coordinated by different ministries, with cooperation of schools and other public institutions and NGOs, connected to children and their wellbeing.

	Visibility and awareness raising	Strategies, interventions and programs to support AYCs	Future needs to support well-being / health situation
	· Organisations that are in contact with young people should be responsible for detecting the problem (primarily school, physicians and organisations engaged in the field of social home care) · There is no awareness about AYC in the educational field.		· The need to build on what we have · There is no need to develop a new system, what is needed is a cooperation between existing systems and infrastructure, good prevention programmes in the community · Raising awareness and getting in contact with AYC in the social media · Need to develop awareness and destigmatisation programmes · Need to develop working relationships with the family in which the AYC is living · Empower AYCs with needed information about caring and also where he/she can turn to for support · It is important that the AYC is voluntarily caring for relatives and that he/she is not under constraint · Need for early recognition (important role for schools)
International/ Europe	· Overall, visibility is low (e.g., also in Germany). · Large differences in visibility and level of awareness between countries. · Higher numbers than one would expect. · Focus on all children, not only 15–17 years old Schools play a role · Conference on AYCs raises awareness · Awareness raising at European Commission by – among others Saul Becker	· Media echo of TV shows (Germany) · Brochures at schools and doctors · Events to share experiences · Website in Austria (Superhands) · Holiday activities · Carers' card in UK · Peer groups	· Raise awareness · Early prevention (ACE 'Adverse Childhood Experiences' screening) · Improve skills · Look and learn from support systems for children in similar situations (parent in prison) · Ensure that children are aware of and can access their rights · Should be less inequality within and between countries · Need for support for themselves, awareness of peers · More funding and staff at schools. · There is shared responsibility (family, parents, local authorities, occupations therapists, etc.) · More visibility of AYCs in society, for example carers week · Reduce Stigma · Practical and emotional support in schools · Need for recognition · Focus on a local level · Children have rights

"We don't want it [young adults in the role of a carer] to occur in Sweden, I would say. So, we actually don't see, and there isn't so much support for them [YCs], which means that they often live in a very vulnerable situation" (Participant 7 (P7), Round 1 (R1), Sweden). *"I think that in Switzerland there is not much visibility [on YCs] at this moment. I think that it is a topic that no one talks about. I think the people that know about this topic talk about it. But all others they don`t know that this is a topic in Switzerland because it's invisible."* (P4, R1, Switzerland).

Strategies, interventions and programmes to support YCs
Experts from most countries reported that there are existing support programmes, projects and activities relevant for YCs. It is worth noting that there were differences reported within countries and between regions. The available programmes do not always target AYCs in particular, as shared by experts from Italy and Switzerland. The programmes differ in their approach by targeting individuals or groups, their duration and frequency, and demonstrated effectiveness. Experts shared a variety of strategies, interventions and programmes, such as support groups for children and adolescents with a parent or sibling with a disability or illness. Through these support groups, YCs are provided with information and realise they are not alone. Respite care is also important to support YCs according to the experts, with activities where they can relax and detach from their home situation for a while and get in contact with fellow YCs for peer-support. In addition, there are multiple initiatives in schools to raise awareness on the subject of AYCs in school plays, guest lessons or workshops. Additionally, experts explained that to follow a whole family approach, support groups for families have been set up in various countries. Finally, training programmes exist for professionals on how to identify and support AYCs.

"We carry out psycho-educational interventions for parents and also for children if they want. We are in the preventive sphere in our case and therefore [they] have their own space of speech, they can express as well as they can listen to their parents. Our function is to improve communication within this family. And then this improves family relationships." (P8, R1, Italy)

Within the interventions and programmes, experts reported a focus on a number of coping strategies of YCs, such as providing them with tools to try to gain control over the situation. In addition, several experts raised the fact that YCs may often feel responsible to do what is needed and might not self-identify as a YC because they may find caring normal and may not be aware of the concept of YC. Furthermore, according to a number of experts, YCs rather do not want to draw attention to themselves, because they do not perceive themselves to be the one in need.

Future support to meet the needs of YCs with a focus on supporting their well-being / health situation
Experts expressed the future needs for YCs with respect to their well-being and health situation. They argued that adults and professionals need to be better trained in identifying YCs, so they can identify who and where they are, and can offer support. Experts shared that there is a need to accept the existence of YCs and reduce the stigma of caregiving. Experts shared that we should notice children who are YCs and listen to them. Further, they argued that whenever support is developed – in digital or non-digital form – it should always be developed in co-creation with YCs to fit their needs and preferences.

Experts reported that there is an increasing need to adopt a perspective or approach in which the whole system, as well as the family, is involved, with collaboration between stakeholders from social care, healthcare, government, and education.

Some experts expressed the need for specific legislation for YCs. At the same time, they addressed the question if, and to what extent young people should be responsible for providing care tasks. Furthermore, experts stated that there should be less inequality within countries concerning access to support services. For YCs themselves, it is important that they can get in touch with fellow YCs, face to face and/or digital, according to the experts. Furthermore, schools should be more flexible towards YCs in respect to school times and deadlines. Experts reported that there is an increasing need to adopt a perspective or approach in which the whole system, as well as the family, is involved, with collaboration between stakeholders from social care, healthcare, government, and education. Experts reported that such an integrated approach is necessary so knowledge can be shared and disseminated.

"Public and private associations must have a family-based approach to the problem, not an individual approach. You can start from one but then you have to consider all family." (P10, R1, Italy)

Second Delphi round
The synthesised findings and results from the discussions of round 2 are presented in narrative form below, according to the main identified themes from the qualitative data analysis supported by illustrative quotes.

Visibility
In round 2, experts confirmed the results of round 1 on low, but increasing, visibility of YCs. To support the visibility of YCs across Europe, most experts agreed and expressed the need for a European NGO with structural funding independent of national budgets and for fewer inequalities within and between countries. They also mentioned a lack of recognition and knowledge among adults working with youngsters for instance, social care and schools.
According to some experts, increased visibility of YCs might also have a negative effect. Visibility means recognising YCs as a problem, which could contrast with the idea of a family where it is viewed as natural for family members to support one another, and caring roles are viewed as being private and hidden. Furthermore, experts acknowledged that sometimes YCs themselves might not want attention.
To increase visibility, Italian experts shared that some actions currently targeting other groups, such as children (not necessarily seen as carers) of parents with mental illnesses or youngsters at risk of dropping out of school early, could be positively applied to YCs. One example of this could be an app to share information about health and social services.

"About the AYCs' visibility, I agree that it is quite lacking, because everything is always due to the individual action, to good sense of the individual or to the upbringing that the individual has had or to personal experience […] This in regard to visibility." (P3, R2, Italy)

Visibility means recognising YCs as a problem, which could contrast with the idea of a family where it is viewed as natural for family members to support one another, and caring roles are viewed as being private and hidden.

Awareness-raising
As found in round 1 of the Delphi study, awareness is steadily increasing, according to the experts. Experts reached consensus on the differences in the level of awareness on the topic of YCs in organisations such as schools, welfare organisations and social services, with there being greater awareness in the UK, followed by Sweden, and the least awareness in Slovenia and Italy. More-

over, concerning the role of schools, it was questioned by some experts what the extent of responsibility is for schools concerning the phenomenon of YCs.

Within countries, experts noted that channels that could be used for dissemination of knowledge – and especially individual YC stories – are reports, brochures, films, social media, and mass media. Some Swedish experts reported that the YCs they know are happy to get attention, which contrasts with the results from some other countries. Some experts pointed out that campaigns only create some awareness for a short period of time, and sustainability of interventions and awareness-raising is highly needed. They argued that long-term awareness is not necessarily guaranteed in most countries, even in countries scoring relatively high on awareness of YCs, such as the UK. Dutch experts confirmed an increasing national awareness of YCs with a considerable shift compared to the first round of interviews – for example, due to a research report on young carers by the Netherlands Ombudsman for children that was officially reported in a letter to the Dutch parliament. On an international level, knowledge could be disseminated at international conferences. The information should include a definition of the term (A)YC, their life situations, YCs' rights, their families' rights and available support. An introduction of a national/international day for YCs was also proposed.

"[…] films can help to make the children's and youth's perspective clearer, because it affects you. That's why we usually watch films in our meetings for children's advocates. There are films on the Swedish Family Care Competence Centre's website, where children and youngsters tell their stories, making it life-like and clear" (P6, R2, Sweden).

Identification
Experts from diverse European countries acknowledged that on a national level, they struggle with 'formally' identifying YCs. Screening, assessment and early identification are needed. Whenever YCs are identified – and if they are acknowledged – then formal support should be put into place, according to experts. They see the responsibility for developing programmes and strategies as primarily belonging to the state, to support and develop laws and regulations concerning YCs, and to provide them with information and additional help to relieve YCs of their caring tasks. Experts stated that without proper services in place, the identification could feel meaningless at best, and harmful at worst.

According to Swedish experts and one expert from Ireland, identification implies acknowledgement that YCs exist and it contrasts with a strong – mainly Western – value that young adults should not take up roles reserved for parents (parentification), i.e. (un) paid work. Moreover, experts noted that we should be aware that children may be afraid that whenever they are identified, that they may be taken away from their home by social services.

With respect to responsibilities for identifying YCs, the primary responsibility is – according to some experts – on the school system, while in addition, many experts agreed that it should be routine for healthcare professionals to always ask about children and whether they have any needs when a parent is ill. Several experts agreed that social conditions of a child should be screened when enrolling to school, i.e. that schools should act as a gatekeeper.

Experts stated that without proper services in place, the identification could feel meaningless at best, and harmful at worst.

Furthermore, experts suggested integrated actions in which educational, social and health services should be jointly involved. However, in contrast to the advantages of involving schools in identification and support, some of the experts expressed concerns with placing too high expectations on schools due to limitations in availability, funding, time, and formal responsibilities.

"Across all sectors, early identification and intervention for all children in need is required. Yes, so experts identified other key stakeholders and it's got CAMHS (Child and Adolescent Mental Health Service teams) who can play a more significant role if they are trained to deliver sessions for children and their families. Additionally, educators within the school system are important stakeholders." (P6, R2, UK)

Definition
Experts emphasised in the round 2 interviews that there is a need for a shared definition and terminology of YCs and AYCs across Europe, which is crucial for identifying them. However, it was acknowledged that YCs experience their caring role differently and labels can have different meanings. Swedish experts reported that to go ahead and develop functional and effective support interventions, the distinction between the terms 'children as next of kin' and 'AYC' must be defined, clarified and disseminated. Experts from Slovenia stressed that it is important to be careful not to invent the problem by forming too broad a definition of YCs. Experts stressed that we should be cautious that the term YC takes on a negative connotation and becomes a label, in particular, in research where academics try to give insights for helping policymakers to solve citizens' problems.

"The young carers that I've spoken to don't seem to have a consistent view on what that terminology should be, so I don't know that there will ever be a terminology that meets the needs of everyone, and everyone is satisfied with." (P2, R2, UK)

"As I understand it, in Slovenia, the definition of who is and is not a young carer will, in my opinion, affect the recognition and future definitions of this problem. Therefore, it seems logical to create this definition as broad as possible […] to acknowledge a number of situations in which young carers can find themselves in." (P8, R2, Slovenia)

Support for young carers
Whole family approach
It was found that most experts agreed that for interventions to be successful, it is relevant to have the family involved in the intervention and work from a family perspective. In the second round, experts explained that whenever starting from a family perspective, it could open up opportunities for identifying YCs, and the roles and needs of all family members. In addition, experts argued that starting from a whole family approach makes it possible to provide concrete, practical and emotional support to all family members, thus relieving YCs. It also makes it easier to arrange follow-ups.

Experts reported that there is a need for better services for the care recipients, as well as for relief and respite for YCs. In addition to a family-oriented perspective, it is important to look beyond the family and include the broader social network, such as friends and neighbours.

"I mean if I look at the health field that's really where we need the focus away from the individual to the family […] force the idea that health problems always affect the whole family and not just the individual and it's the medical field's responsibility to look at the whole family." (P3, R2, Switzerland)

"A whole family approach is […] a very good approach. And this is a tricky one but obviously we know that the earlier you receive this kind of support, then the better. Later on, there are some things about how you might pick up these families quite early. And that's really, really important. You can't really optimise that if it comes in too late." (P3, R2, UK)

Experts reported that there is a need for better services for the care recipients, as well as for relief and respite for YCs.

Interventions and personalisation
During the second round, some promising examples of personalisation of interventions were reported by experts. In the UK, the voluntary sector has historically provided the most support for YCs compared to the governmental sector, which lags behind in providing support. Experts reported on flexible interventions that are tailored to different YCs' needs that could differ for social, financial and individual conditions. From the Swedish results, to be able to explain what they need and want, experts explained that YCs first need help to reflect on their situation, their perceptions, experiences, thoughts and feelings. Some experts pointed out that support and interventions should be provided at schools. As noted earlier, they also acknowledged it was important to create flexibility for students, for example with support of a carers' card to ensure flexibility in homework and exams. A relevant issue was raised by several experts – that programmes and support should run through all levels of education – from primary school to university, i.e. transition support or transitional services. This support is important due to the gap in existing transitional services.
With respect to tailored support for young carers in the welfare sector, experts underlined that YCs need access to tools and support to find useful coping strategies and help build their own resilience, such as summer camps. Experts shared and acknowledged that it is important to be aware and observant of the risks with support groups, for example, that participants in the group influence each other negatively. Furthermore, they reported that YCs also sought more holistic support, i.e., guidance on career choices, nutrition, and life management skills. Experts agreed on some limitations of interventions used in the welfare sector. These revolved around four issues: (1) interventions not matching the needs of (A)YCs, (2) good interventions that remain underused because people are not familiar with them, (3) a lack of research to substantiate the effectiveness of interventions in the welfare domain, and (4) lack of capacity or finances to arrange formal support programmes. Experts stressed that it is important not to simply focus on and create new programmes and interventions specifically for AYCs, as support for AYCs could be included in already existing interventions and programmes designed for groups such as, informal carers or children in general. As reported by UK experts, these existing programmes could be accepted as support by AYCs, since they do not specifically focus on their role as a carer and it is important that these programmes are less dependent on funding.

"I think in some respect, it's gotten worse more recently as a result of cuts to local authorities [in the UK] in terms of the budgets. Some areas may have had support groups for young carers in the past but have now discontinued funding for those." (P2, R2, UK)

Online support, interest in apps and co-creation
Multiple experts expressed their preferences for providing online support by means of websites or mobile applications. Overall, they agreed that modern and concrete approaches are needed to raise awareness and support YCs, such as YouTube films, social media and apps. According to the experts, there is a need for an individual approach which is based on self-organisation and is easy to access by means such as an information platform or app. UK experts also pointed to digital online-based peer support to be most effective with YCs.
Experts from a variety of countries pointed out that whenever an app for YCs is built, the organisations behind the initiative also have a responsibility to exercise control through moderation and dedicated professional support, as well as structural financing for continuation of the app. Furthermore, online information about support for YCs should be directly available and not hidden via complex menus with lots of other information on care-related topics. According to UK experts, several national online support spaces in the UK have been closed because of lack of funding. With respect to online support programmes and apps, many experts agreed that the programmes should be designed in co-creation with and for YCs.

"If we think of 'parental support', if you look at how it […] the municipalities' websites […] It's about fifteen clicks before you get some information about this. And I think that 'young carers' may be twenty-five or thirty clicks away, before you can get some information about it" (P4, R2, Sweden).

"I absolutely agree that the programmes should be designed in cooperation with them (AYCs), so we would be able to really originate from their needs." (P7, R2, Slovenia)

Overall, they agreed that modern and concrete approaches are needed to raise awareness and support YCs, such as YouTube films, social media and apps. According to the experts, there is a need for an individual approach which is based on self-organisation and is easy to access by means such as an information platform or app.

Laws and regulation
A considerable number of experts reached consensus and expressed the need for laws and regulations to formalise the rights of YCs and AYCs on a national or European level. The idea of a specific law is considered positive according to some experts, to give visibility and promote the integration of interventions but, at the same time, they emphasised that it should rather not be a rigid law and that it should not become reduced to purely financial support. Furthermore, by some experts, it was questioned what the effect could be of laws and regulation on the level of responsibility placed by society on YCs.

Some experts are impressed by the laws in Sweden (Health Care Act) and the Children and Families Act of 2014 in England and Wales. However, it is relevant to note that – according to the UK experts – the current legislation has little real benefit for YCs.

Overall, according to some experts, we should rather highlight the group of YCs and support them where necessary, instead of requiring some specific legislation without being able to enforce the law and provide follow-up due to a lack of funding. Like the UK experts, a Swedish expert pointed that although laws are reformulated, there is a risk that this will have little impact on the individual. Experts from Slovenia also emphasised that there is no need for creating new laws/legislation, as is also reported by experts from the Netherlands. Some of the Slovenian experts stressed the need to create a small body or pressure group to address the problem of YCs. Existing laws on e.g., long-term care or youth care should be sufficient to protect and support YCs where necessary. YCs and AYCs in Switzerland could be protected by the legislative framework for young persons under the age of 18 years, and according to Swiss experts, changing the legislative framework in Switzerland is extremely difficult due to the political structure. Therefore, in Switzerland it would be better to create a new national policy first.

"Yes, you can make regulation for that. But we all know, rules only give some direction […]. It's the people in society who themselves make this real […]. And look, in the Netherlands we have plenty of good regulation. But still, we see that when people interact with one another, that people get hurt or disappointed […]. Well, regulation is insufficient. A rule is only a kind of guideline and takes the sharp edges of injustices." (P3, R2, the Netherlands)

Training, education & the role of schools

According to the experts, there is a need to increase the training and education of care and welfare professionals and to create a common knowledge base including: how to approach children, young people and parents; how to identify YCs; how to talk to YCs; how to continue once a professional has identified a YC; and available support efforts, also at schools. In addition, schools should be more involved in identifying and supporting YCs with trained personnel. As already discussed, at the same time, experts also considered the scarce time that is available among teachers. There could be training days or networks formed that meet regularly. Such education for professionals should be included in the professionals' basic education programs. Experts suggested that training should instead be organised for all sectors (health, education, and social).

"What are the strategies on which a school must work? First of all, create a teacher staff meeting in which professionals are involved, who are trained on all the problems of AYCs, a teacher staff meeting that shares educational management, the teaching guidelines, and then work a lot on the class group… I think that many strategies from the point of view of the school with regard to AYCs must work on the class group, which must be self-supporting, must become a team […] and support each other according to everyone's needs, so for me, in school you have to work now, above all, on the class group." (P6, R2, Italy)

Schools should be more involved in identifying and supporting YCs with trained personnel.

Discussion

The study is the first cross-national Delphi study on YCs, including AYCs, providing relevant insights into the visibility, awareness, interventions and future support strategies of YCs across Europe. A heterogeneous, inter-professional and geographically spread sample of 66 experts from 10 different EU countries were involved. The experts shared their views and knowledge on YCs in two interview rounds and reached consensus on the visibility and awareness-raising of YCs on a local, regional, and national level. In addition, several strategies, interventions and programmes were identified and agreed on by the experts to support YCs. Finally, experts shared their knowledge and reached consensus on future needs to support the well-being and health situation of YCs.

With respect to visibility, YCs are an invisible and neglected group in many countries and regions. Similarly to Leu and Becker [13], the Delphi study shows that there is a general lack of awareness and support for (A)YCs across nations, with varying degrees of visibility and supporting resources available depending on the country. However, despite differences among regions, visibility and awareness are increasing in most countries and there are many initiatives to support YCs on a local level, however these are less visible. Leu and Becker [13] provided a classification of countries on six levels related to awareness and policy response to young carers. According to the authors – among others – the UK is advanced at level 2, Sweden and others at level 3 (intermediate), and at level 5 are emerging countries such as Italy, the Netherlands and Switzerland. Although the present Delphi study was not intended to provide a classification, the classification level has likely shifted for some countries compared to 2017. As discussed, support for YCs in the UK is decreasing due to reduced budgets and funding, while Switzerland and the Netherlands seem to have increased media attention and have more support programmes in place on a local/regional level. It can be argued that this study provides current evidence that could feed into an updated classification in the near future to show changes in country awareness and policy responses to young carers. Leu et al. [22] also showed that, for example, in Switzerland the visibility and awareness differ between the social, healthcare and education fields, and that professionals from the health care and education sectors are more familiar with the term 'young carers', but feel less responsible in comparison to professionals from the social sector. The impact of awareness campaigns using television, and social networking and the media can be quite large, such as in Germany or in the Netherlands.

Concerning identification, experts expressed the need for a common definition, which is currently lacking and opportunities for young adults to identify themselves as YCs. A common definition could also facilitate gathering more insights into actual numbers of AYCs in Europe and better targeting support whenever identified. However, since YCs have difficulties in identifying themselves as YCs and vary in their experiences and care they provide, a general overall definition and concept might be challenging to construct. Nevertheless, localised or nationalised definitions can potentially support (self)identification of YCs and AYCs. The present Delphi study shows that tools to identify YCs in schools, welfare and health care are needed. Moreover, a European or international NGO for YCs could facilitate the dissemination of current knowledge on identification and support for the education, welfare and health care sectors. A European or international NGO for YCs is also, potentially, more likely to increase long-term awareness, because they are less dependent on short-term (subsidy) financial resources (in contrast to many local organisations within countries) for their YC awareness-raising activities. With respect to identification, other countries can learn from the UK, where there is already a carers' assessment in place. Whenever YCs are identified and made visible, then society must recognise them and also acknowledge their situation as a challenge, reduce the need for young caring and provide formal support.

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Providing formal support to YCs can be difficult since informal care is characterised as being provided on a voluntary basis and usually without financial compensation [23]. According to some experts, YCs should actually not be carers in the first place. However, it should be noted that YCs do exist and may be in need of support. It is likely that there will always be young people growing up in families faced with illness or disabilities, and we should provide the support they need, for example, respite care, information, social contacts, and support at school. Related to this issue is the need for specific laws, regulation, and policy on young carers. A considerable number of experts expressed that having these in place could formalise the rights of YCs on a national and/or European level. According to Jopseph, Sempik, Leu & Becker [24], rights do not necessarily need to be legal rights, yet, if they are not legal rights, how strong are these rights and are they enforceable? It can be questioned if specific laws are needed for YCs and in the present Delphi study, some experts expressed that the rights for YCs are already covered in existing (non YC specific) legislations or could be included in existing legislations for social support or informal care.

Regarding interventions for YCs, rich insights were gained in the UK successes and the hundreds of (school) programmes and interventions to support YCs. However, as noted before, these initiatives are mostly based on temporary funding, so follow-up is usually lacking. With a bearish UK economy [25], the COVID-19 pandemic and the Brexit in 2020, more cuts in care are expected that could reduce the support for YCs even further. YC support should rather be an integral part of health and social care, and welfare to strengthen the sustainability of support programmes and interventions. Experts addressed the need for integrated care and support for YCs, in which schools, welfare organisations and social services work closely together. Integrated care can help to potentially improve the quality of care, engage in better performance management, inter-professional teamwork, and make clear the different roles and tasks, including commitment [26]. Professionals need to be educated about YCs – their situation and what professionals can do to support them. Creating flexibility for children/students at school is essential, e.g., by means of a carers' ID. The UK can be used as a model on how to implement a carers' ID, yet it is unclear if such an ID will be accepted and successful in other national contexts.

The Delphi results further illustrate that overall, to support YCs, many (mostly local) interventions are running in the various EU countries. Access to interventions and programmes vary between countries, states, municipalities, and even between schools. A time, distance, culture and language independent support platform for YCs, such as an app or online platform, could overcome inequalities between regions and countries to ensure that they can receive a basic level of support [14,15]. In fact, the development and/or provision of an online platform or app to support YCs is preferred by many of the experts who participated in the Delphi study, who also recommend that such an app be connected to available local services. An online platform can serve as an information channel with an agenda to activities in various localities. Online welfare interventions could focus on the provision of information by, for example, flyers, children's helplines or a national information campaign. Overall, as emphasised by the experts, co-creation is key for the success of any intervention or app, and all stakeholders and end-users should be part of the co-design process [27].

> It is likely that there will always be young people growing up in families faced with illness or disabilities, and we should provide the support they need, for example, respite care, information, social contacts, and support at school.

From the Delphi study, recommendations can be provided based on the main findings at EU, national, and/or regional/local level for different stakeholders, i.e. scholars, policy makers, health and social practitioners, teachers and parents. Parents are the first educators of adolescents and youngsters and who also have a role in supporting young carers from a family perspective. At the research level, it would be recommended to set up parameters to identify YCs that are agreed on across the scientific community, albeit country sensitive. These should be calibrated according to the national and cultural specificities, and the services provided. Moreover, as discussed, there needs to be consensus on a common definition of ‘young carer ’and ‘adolescent young carer’. This may enhance the quality of the research and the comparability of international results. It may also strengthen the evidence of the efficacy of interventions and policies to design evidence-based, psychosocial interventions and services. Research on YCs is a precondition, not only to developing a comprehensive support for them, but also to identify the main gaps in the social and healthcare systems that should be addressed as a priority in order to relieve the burden on these young carers. Researchers on YCs of disabled parents also addressed a reduction in the need for young caring and this has been a long-standing call from the disability community [28-30]. The results from the present study can be used to define future research. To be effective in promoting YCs' healthy functioning, support interventions should be evidence-based. Randomised controlled trials are currently lacking and should be encouraged in future research.

The study shows that next to scholars, full alliance is required between researchers, and health and social professionals (nurses, general practitioners, psychologists, social workers), and between the latter and the YCs. This could be accomplished by means of open listening and open dialogue with professionals and can lead to co-designed, tailored services. This cooperation may be reached by means of appropriate research methods that help the co-building of meanings and interventions, e.g. the blended learning networks (BLNs) employed within the EU ME-WE project [17]. A BLN is a group of people (i) who share a common interest, (ii) contribute with expert and/or experiential knowledge, (iii) have commitment and enthusiasm to work together to achieve (a) common goal(s) and (iv) includes key stakeholder groups. The members of a BLN together create a learning network, engage in a learning project and their meetings take place ‘face to face' and/or electronically [31].

Concerning the education, welfare and healthcare sectors, training for teachers, health professionals and social workers is needed at local level to enhance the capability of recognising YCs, help orient YCs to the most appropriate service, and to avoid paternalism and involuntary processes of stigmatisation. It is also valuable if the education, welfare and healthcare sectors strengthen their cooperation and hence, offer more integrated care to YCs and their families. Here, it is also important to apply a family perspective and focus on the whole system, and not merely the YC or the care recipient.

To address the general lack of awareness facing YCs across Europe, as also found by Leu & Becker [13], following on from the Delphi study findings, media campaigns are recommended as a way of increasing general societal awareness that young people can be carers. At a national level, guidelines for the identification and management of YCs should be delivered and spread as much as possible within diverse sectors. Moreover, since awareness is steadily increasing, there seems momentum to set up European policy and further support NGOs such as the Eurocarers Young Carers Working Group that address the topic of YCs and AYCs and ensure continuity, without being dependent on funding as demonstrated in the UK where support programmes are steadily disappearing due to decreasing funding opportunities.

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No study comes without limitations, and the main limitations of this study are related to the recruitment of the experts, the means of conducting the interviews, and the involvement of several different interviewers and research staff in the various countries, resulting in a variation in the qualitative analysis of the country-specific data. The experts were known by the ME-WE project consortium, which consists of researchers, educators and representatives from civil society – or recruited via included experts – thereby resulting in a selection bias. To address this potential bias of using convenience sampling, future studies on this topic could make a call for participation of a national or European level of expert panels which would better reflect the EU situation. Nevertheless, since the (research) field of AYCs is relatively small and even non-existent in some countries, we did manage to include 66 experts from 10 different European countries who overall reached consensus on the visibility, awareness, and needs of (A) YCs. The Delphi study focused mainly on scholars, policy makers and health service providers, and it would be supportive for the development of future support programmes to have an additional specific focus on educators and school staff. In addition, future research could extend the Delphi study with European policymakers on the topic of YCs to gain more insights into differences in policy between countries, to extract best practices and to build European policies to support AYCs.

The interviews varied in the way they were held, from telephone, voice conferencing to face-to-face interviews. It is possible that the various interview methods had an influence on the flow of the interviews and results. Telephone interviews limit visual cues resulting in a loss of contextual and nonverbal data and to compromise rapport, probing, and interpretation of responses [32]. However, telephone interviews may allow respondents to feel comfortable and relatively anonymous, which is particularly relevant in Delphi studies with possibly conflicting views and opinions among experts. In addition, evidence is lacking that telephone interviews produce lower quality data [32]. Finally, multiple national investigators from the ME-WE project consortium in the six partner countries performed the interviews and first data analysis on the transcripts of the experts from the countries. The variability between the countries might have resulted in a bias between the quality of the interviews and following data analysis. Yet, all national investigators received training and specific instructions on how to perform the interviews and data analysis, including a webinar and preliminary code trees for analysis. In addition, since the interviews had to be performed in the native language of the interviewees (e.g., Dutch, Slovenian, and Italian), a relatively large group of national investigators were required for the Delphi study.

Conclusions

In this cross-national two-round Delphi study, insight was provided into the visibility, awareness, interventions and future needs of young carers (YCs), and more specifically adolescent young carers (AYCs) aged 15 – 17 years, across Europe. Sixty-six experts on YCs from Sweden, Switzerland, United Kingdom, Italy, Slovenia, the Netherlands, Austria, Belgium, Ireland, and Germany reached consensus on a number of topics. Namely, that there is a lack of visibility and awareness about YCs and hence the difficulty to identifying them. Identification of YCs is crucial for providing support and a common definition of YCs and AYCs is required, together with possibilities for young people to identify themselves as carers. In this regard, practical tools are needed to aid recognition of YCs and their needs and preferences. However, identification alone is insufficient, as recognition of YCs by society as a whole is required, together with the necessary resources to secure integrated support services for and with YCs. These must address the various needs of YCs and include family, schools and the welfare and healthcare sectors. Furthermore, the level and the type of support available for YCs differs between countries, with many countries mainly offering support on a local rather than national level. Divergent views were found concerning specific legislation and needs for future support. To conclude, although there are country differences in the levels of awareness, visibility, services, and needs for support for YCs, many commonalities were observed between countries regarding challenges to accurately address the often overlooked situation of YCs in Europe.

Abbreviations

ACE: adverse childhood experiences
AYC: Adolescent Young Carer
EU: Europe
ID: Identification
MA: Master of Arts
ME-WE project: Project on Psychosocial Support for Promoting Mental Health and Well-being among Adolescent Young Carers in Europe
MSc: Master of Science
NGO: Non-Governmental Organisation
PhD: Doctor of Philosophy
YC: Young Carer
UK: United Kingdom

Endnotes

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The first cross-national study of adolescent young carers aged 15 – 17 in six European countries*

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Abstract: *For the first time, this article will provide a cross-national profile of adolescents who provide unpaid care to their ill or disabled family members in six European countries with varied levels of awareness, policy and service provision regarding adolescent young carers. Utilising an online survey, 2,099 adolescent young carers were identified in Italy, the Netherlands, Slovenia, Sweden, Switzerland and the UK. This article focuses on the impact of unpaid care on their mental health, well-being, physical health and education. Their preferences for informal and formal support were also examined. These groundbreaking findings help promote a 'rights' approach to adolescent young carers, which can serve as a critical driver for supportive policy creation on both a country-specific and pan-European level.*

Keywords: *Adolescent young carers; mental health; well-being; Europe*

Introduction

Children and young people with caring responsibilities in families, often referred to as 'young carers', have been historically marginalised in research, scholarship and policy developments in many European states and generally across the globe. Over the last decade, however, there has been some recognition of this group of children among a small number of researchers, non-governmental organisations (NGOs), policymakers and professionals in some European and other countries. While the UK has 30 years of research on young carers and a 'patchwork quilt' of legislation (Aldridge 2018), other countries are beginning to move forward, albeit very slowly (Leu/Becker 2017).

The commonly accepted definition establishes that young carers are: "children and young persons under 18 who provide or intend to provide care, assistance, or support to another family member. They carry out, often on a regular basis, significant, or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult" (Becker 2000: 378). The term 'adolescent young carer' (AYC) will be used here to refer to young people with caring responsibilities between the ages of 15 and 17 years old – the transitionary phase between 'childhood' and 'adulthood' (Gilmore/Meersand 2014). Becker and Becker (2008) also coined the phrase 'young adult carers' to identify carers aged between 18 and 24 years old, as well as their specific experiences, needs and rights as young adults and as carers (see also Rose/Cohen 2010; Sempik/Becker 2013a; 2013b). AYCs are therefore a subgroup within the young carer population, sandwiched between 'young carers' and 'young adult carers'. They are recognised as having their own particular experiences and needs, as they transition to being considered, labelled and treated as adults, with their corresponding move to adult legal status and adult health and social care services and interventions.

Children and young people with caring responsibilities in families, often referred to as 'young carers', have been historically marginalised in research, scholarship and policy developments in many European states and generally across the globe.

In this article, for the first time, we systematise knowledge on AYCs by identifying their profiles, caring characteristics, needs and preferences across six European countries: Italy, the Netherlands, Slovenia, Sweden, Switzerland and the UK. The European Union (EU) Horizon 2020-funded 2018-21 research project *Psychosocial support for promoting mental health and well-being among adolescent young carers in Europe* (ME-WE for short) sought to further understanding of the mental health and well-being of European adolescents with caring roles as they navigate both this phase in their lives and their changing relationship with 'adulthood', while maintaining their contribution of unpaid care. This research also recognises that the experience and needs of AYCs may be associated with the specific setting in which they reside due to societal and cultural factors, law, policy, and national/local population demographic characteristics. This is explored later in the article.

These six countries were brought together in the ME-WE research project because they each represented a specific phase or 'level' on the cross-national and comparative classification of awareness and policy responses to young carers devised by Becker (2007) and developed by Becker and Leu (2019), Leu and Becker (2017) and Leu et al. (2019). Each country also has a research organisation/unit that was interested in commencing or developing research in this field. Leu and Becker's (2017) classification illustrates the levels of awareness and response to young caring within and between those (few) countries that had a discernible and verifiable engagement with young carers in 2017 and 2021. The classification takes account of, for example, whether a country has specific legal rights for young carers, whether there is an established body of rigorous and reliable research, and whether there are codes of guidance for professional practice (Leu/Becker 2017).

At the time of Leu and Becker's (2017) classification scale and the start of the ME-WE research project (in 2018), the UK was classified as 'advanced' and was the only country to receive an advanced classification. The UK is generally considered the 'global leader' in young carer research, awareness and policy responses due to its development of dedicated legislation to give young carers legal rights and access to formal supportive services, as well as the hundreds of dedicated support services for young carers, called 'young carers projects', across the UK. All these advances have been based on a foundation of research (Leu/Becker 2017).

Figure 1: Classification of in-country awareness and policy responses to 'young carers' (Leu and Becker 2017)

Levels 1–7	Characteristics	Country Example
1 Incorporated / Sustainable	· Extensive awareness at all levels of government and society of the experiences and needs of young carers · Sustained and sustainable policies and interventions aimed at meeting young carers' needs and promoting their health, well-being and development · Responses and law built on a foundation of reliable research evidence and clear legal rights	None
2 Advanced	· Widespread awareness and recognition of young carers amongst public, policy makers and professionals · Extensive and reliable research base, and growing · Specific legal rights (national) · Extensive codes and guidance for welfare professionals and national and local strategies · Multiple dedicated services and interventions nationwide	United Kingdom
3 Intermediate	· Some awareness and recognition of young carers among public, policy makers and professionals · Medium-sized research base, and growing · Partial rights in some regions · Small but developing body of professional guidance · Some dedicated services and interventions, mostly local but a few nationwide	Australia, Norway, Sweden
4 Preliminary	· Little public or specialist awareness and recognition of young carers · Limited research base, but growing · No specific legal rights but other laws may be applicable or relevant · Few, if any, dedicated services or interventions at national or local levels	Austria, Germany, New Zealand
5 Emerging	· Growing public or specialist awareness and recognition of young carers Small but growing research base · No specific legal rights but other laws may be applicable or relevant No specific services or interventions for young carers, but other services might be applicable	Belgium, Ireland, Italy, Sub-Saharan Africa, Switzerland, The Netherlands, United States
6 Awakening	· Embryonic awareness of young carers as a distinct social group within the 'vulnerable children' population	Greece, Finland, United Arab Emirates, France
7 No response	· No apparent awareness or policy response to young carers as a distinct social group	All other countries

Sweden was classified as 'intermediate' (Level 3) in view of its medium-sized research base, specific legislation within the Swedish Health Care Act and localised formal supportive services. Italy, Switzerland and the Netherlands were classified as 'emerging' (Level 5) countries, highlighting that there is a lack of services for young carers, as well as a lack of an established body of scholarly research and legal rights. In Switzerland, to date, there have been a small number of research studies focused on young carers (Leu et al. 2022). The first national research programme on young carers was launched there in 2014 (Leu/Becker 2017). There has also been very little scholarly research in Italy, despite recent figures in 2015 indicating that there are at least 391,000 carers aged 15–24 years old in Italy (Italian Institute of Statistics 2015). In the Netherlands, estimates on the probable number of adolescents who have a family member with a chronic illness or disability range between 11 and 37 per cent, but the actual prevalence of these young people with caring roles has hitherto been unknown (De Roos et al. 2017, 2020). In 2020, a national study of schoolchildren (12-16 years old) growing up with a long-term ill family member was conducted (De Roos et al. 2020). An estimated one in five schoolchildren aged 12-16 grow up with an ill family member in the Netherlands. Between 6 and 8 per cent of the 12- to 16-year-olds provide care tasks for these ill family members, and 3 per cent provide intensive care tasks (four or more hours per week). Furthermore, research involving Dutch AYCs only commenced in 2018 (Van Loon et al. 2017; Boumans/Dorant 2018). The Netherlands was thus classified as 'emerging' (Level 5). Finally, Slovenia was classified as 'awakening' (Level 6) due to its lack of research (there is only one study published) and only the most rudimentary awareness (Hlebec 2019; Leu et al. 2022). For some time now, it has been recognised that there is a need for large-scale survey research to identify the size and scope of the problems faced by young people who care (Joseph et al. 2020). The cross-national profile of AYCs presented here for the first time was collected through an online survey in these six countries, utilising quantitative and qualitative methods, and it is the quantitative and statistical results of that survey that are the focus of this article. The qualitative, open-ended question on informal and formal support preferences was designed with the aim of giving AYCs the opportunity to disclose their desires for support, including original ideas for formal support that may not have already been identified by the research team in the online survey's multiple-choice format. This present article has three objectives: (1) to describe the demographic information of participants in each of the six countries; (2) to assess the extent of caring and its outcomes for AYCs in each of the countries; and (3) to compare results across each of the countries.

While the definition of young carers (see earlier) can be understood and applied conceptually and in policymaking by all six countries, the terms used to denote (and label) young carers can and do vary between these and other countries. In Sweden, the term 'children as next of kin' is more commonly used in discourse, policy and law to reflect those children who are affected by parental illness, disability, substance abuse or death (Hjern et al. 2017). In Italy, the Netherlands, Sweden and Slovenia, there lacks a commonly accepted term and, instead, 'young carer' is simply translated into their respective national languages (Nap et al. 2020). In Switzerland, the term 'young carer' is used, usually with a brief definition in German and Italian; in the French region, the term is translated into French: *'jeune aidant'*. Our study agreed on the term 'adolescent young carers' to draw attention to the specific physical, psychosocial and emotional circumstances of young carers in this transition phase, and to highlight the implications for social policy, services and intervention (Dearden/Becker 1998; Lewis 2018; Becker/Sempik 2018; Rolling et al. 2020).

Previous research has acknowledged that AYCs are at risk of a variety of negative impacts to their mental health and well-being (Carers Trust 2016; Becker/Sempik 2018). A total of 50 per cent of AYCs sampled in research with the Carers Trust (2016) in the UK experienced stress related to their caring activities, and 40 per cent experienced mental health problems. AYCs are typically at risk of a host of other health inequalities, such as physical health problems because of caring (for example, back strain), exhaustion, lack of sleep and disrupted sleep, and emotional difficulties, such as anxiety and depression (Aldridge/Becker 1993; 2003; Cree 2003). Furthermore, AYCs often experience severe impacts to their educational and work experiences, with many young carers facing chronic problems of lateness, absenteeism and inability to maintain paid employment due to caring responsibilities (Aldridge/Becker 1993; Hamilton/Adamson 2013; Becker/Sempik 2018). Migrant AYCs are at particular risk of ill health and social disadvantages, as their increasing family responsibilities for ill or disabled family members coexist within their experience of trauma, displacement and instability (Children's Society 2013).

> While the definition of young carers can be understood and applied conceptually and in policymaking by all six countries, the terms used to denote (and label) young carers can and do vary between these and other countries.

Confounding the issues facing AYCs, they are considered to be a vulnerable group of young people 'hidden' from the view of educators, health and social care professionals, and policymakers (Nap et al. 2020). The terms 'hidden' or 'hard to reach' have been used by academics to describe the position of young carers who are not in contact with formal support services. Conversely, their caring role is 'unknown' to others in their daily life, especially those who might be gatekeepers to support services, such as teachers and health and social care providers (Aldridge et al. 2016). However, caring can be fulfilling and has positive aspects, such as love and strengthened attachment bonds between the AYC and the care recipient (Santini et al. 2020).

Methods

The study featured an online survey in six countries, made available in two data collection periods: April 2018–December 2018 (all six countries) and January 2019–July 2019 (Switzerland, Sweden, the Netherlands and the UK only). The survey included: a demographic section; two specific psychometric instruments that have been designed for use with young carers – the Multidimensional Assessment of Caring Activities (MACA) and the Positive and Negative Outcomes of Caring (PANOC) (Joseph et al. 2009); a section on education, employment, health and support; and an open-ended qualitative question on support preferences. In Italy and Slovenia, the survey included an additional open-ended qualitative question on the difficulties experienced when caring for an older family member. In Italy and Slovenia, the ageing population and lack of long-term formal care provision provided a rationale for asking a more specific question on care for older family members. In addition, the survey included the KIDSCREEN-10 Measure of Health-Related Quality of Life, an instrument used in the context of childhood well-being (Ravens-Sieberer 2006; Ravens-Sieberer et al. 2010). The demographic section featured questions on age, gender (including gender identity), place of residence, nationality/citizenship, family composition and caring role (for example, who they care for and the condition of the person cared for).

AYCs were identified by their answers to a series of questions in the demographic section. The questions were designed in recognition that the survey would be taken in some countries with a low awareness of young caring and therefore that direct questions on young caring (such as 'Are you a young carer?') might not fully capture AYCs who had never been identified (or self-identified) as a young carer. Thus, the following series of questions were designed with the aim of capturing responses from AYCs who might not have previously considered or thought of themselves to be an AYC:

Q1. Do you have someone in your family with a health-related condition?
Q2. What type of health-related condition does these persons have?
Q3. Who are these persons (for example, parent[s], sibling[s], grandparent[s] and so on)?
Q4. Do you live with the family members who have a health-related condition?
Q5. Do you look after, help or support any of these family members with a healthrelated condition?

Affirmative answers to Q5, 'look after, help or support', were used to classify a respondent as a carer of a family member. Respondents were then asked the same series of questions regarding friends or other close individuals in their life. Affirmative answers to the 'look after, help or support' question in the 'close friends' section were used to classify a respondent as a carer of a close friend. This research study was concerned with the mental health and well-being of 15- to 17-year-old carers; thus, once a respondent was classified as a carer, their age was used to determine whether they were an AYC. Only respondents aged 15–17 years old who provided affirmative answers to the 'look after, help or support' questions – either for a family member or close friend, or both – were classified as AYCs for the purpose of this study.

The MACA is an 18-item self-report questionnaire that asks young people about the frequency of their caring activities (Joseph et al. 2012). Each item is rated on a three-point scale: 'never' = 0; 'some of the time' = 1; and 'a lot of time' = 2. As such, scores on the total MACA have a possible range of 0 to 36, with 0 indicating that no care activities take place and 36 indicating the highest amount of caring. Scores of 10–13 indicate a moderate amount of care activity, scores of 14–17 indicate a high amount and a score of 18 and above demonstrates a very high amount of caring (Joseph et al. 2012). The MACA can also be scored to produce six three-item subscale scores for domestic tasks, household management, personal care, emotional care, sibling care and financial/practice care. Each subscale score has a possible range of 0 to 6, with higher scores indicating greater activity on that domain of caring.

The PANOC is a 20-item self-report measure that can be used to obtain an index of the positive and negative outcomes of care provision (Joseph et al. 2012). This measure recognises that young caring can feature both positive and negative effects in a young person's life. The PANOC is typically used to determine whether the receipt of formal support has resulted in a reduction of the negative effects of caring and an increase in the positive effects of caring. Each item is rated on a three-point scale: 'never' = 0; 'some of the time' = 1; and 'a lot of the time' = 2. The PANOC contains two ten-item subscales for positive responses and negative responses, with a potential range of 0 to 20 on both subscales. Higher scores indicate a greater positive and negative score, respectively. Scores less than 12 on the PANOC positive scale and/or greater than 8 on the PANOC negative scale indicate potential concern (Joseph et al. 2012).

Both the MACA and the PANOC are validated psychometric instruments that are now being used in 15 countries. The New Zealand government's 2019 National Carers Action Plan, for example, calls for the MACA to be used to identify young carers in that country (New Zealand Carers Alliance 2019). The MACA has also been used in the UK by the British Broadcasting Corporation (BBC) in two national surveys (in 2010 and 2018) to identify the proportion of young carers in schools and the population of young carers in the UK (BBC News 2010; Joseph et al. 2019).

The recruitment strategy of all partner countries involved the targeting of schools, in which AYCs would be in classrooms with children who are not AYCs. The survey was designed in such a manner that children who are not AYCs could also take the full length of the survey. The answer choices for the MACA and PANOC were revised to allow non-young carers to select 'not applicable'. This approach ensured that non-young carers and young carers would take the same reasonably expected time to complete the survey (and therefore that AYCs would not be exposed in the classroom for taking longer). An outcome of this approach means that we have a large database on AYCs in the six countries and a larger database on other young people who do not have a caring role. Thus, we are able to make meaningful (and statistically reliable) comparisons between the two groups (see the 'Results' section later).

The KIDSCREEN-10 questionnaire is a widely used and respected ten-item measure used by children and young people to report on the health-related quality of life standard. The instrument was designed to provide an overview of the subjective quality of health of a young person and has been validated in over 13 European countries. The KIDSCREEN-10 instrument has been used in another school survey involving young carers (Schlarmann et al. 2008; Kuhne et al. 2012; Ravens-Sieberer et al. 2010). The KIDSCREEN-10 is a shortened version of a larger, 27-item questionnaire. A total sum score (range 10–50) is indicated, and higher scores indicate greater well-being. The next section of the survey included questions on education (for example, institution attended, educational achievements, employment and vocational training status), impacts from caring on education, paid employment and mental and physical health, and support received (for example, formal services provided by government and voluntary agencies [if any], and informal support by friends or school staff). The online survey was first designed in English by the UK research leaders and hosted on the 1ka online platform (a survey development tool similar to SurveyMonkey). The English version of the online survey was then translated by each country partner into the languages necessitated by their specific country context: Italian, Dutch, Slovene, Swedish, Swiss German, Arabic and Dari. The online survey was designed to be taken on a personal computer, laptop, tablet or mobile phone. Paper-and-pencil versions of the survey were utilised in a very few instances in all six European countries; however, the unavailability of electronic devices within the sampled schools in Italy required a greater use of paper-and-pencil questionnaires. The answers to the paper-and-pencil surveys were then entered electronically by country partner teams during the data-collection period and checked for data-entry accuracy.

To reduce the risk of sampling bias as much as possible, all partners agreed to adopt a multistage facility sample: (1) using regional differentiation within the countries, ensuring participants from urbanised, somewhat less urbanised and rural areas; and (2) using various recruitment channels for AYCs through schools, care organisations, interest groups of care recipients and municipalities. Due to challenges in recruitment, this strategy was not always adhered to in low-AYC-awareness countries, that is, for example, rural areas were particularly difficult to reach, and in Slovenia and Italy, recruitment occurred only in schools. Information about the survey was disseminated through formal support services for carers and health service users. Social media and traditional media were also used to promote the survey. The project had a target sample size of 200 AYCs per country to enable meaningful statistical analysis.

In Italy, recruitment only took place in high schools of two Italian regions: Marche and Emilia-Romagna. The gatekeeper was the head or a teacher who was contacted by the research team for an introductory meeting. At the meeting, the research team provided the participant information sheet and consent form to be distributed to the students and their parents/guardians. On the day of data collection, the researchers had paper-and-pencil versions of the survey, as well as the online version.

In the Netherlands, the recruitment strategy included social care and support centres for carers, schools, and a social media campaign that especially targeted sibling carers. A total of 95 AYCs were recruited through schools (48 per cent) and the other 104 AYCs were recruited through care organisations, support centres or patient organisations (using direct invitations or social media channels). In the Netherlands, schools are registered in a database, and using this information, schools were approached to participate in the study by the researchers, explaining the objective and method of the study using telephone calls or site visits. Schools that agreed to participate were offered promotional material to be distributed in school or in class. All pupils in a class were invited to fill in the online survey, or, alternatively, pupils received an invitation to fill in the survey using their online school communication channels.

In Slovenia, the recruitment strategy targeted vocational schools that train health and educational professions; all AYCs were recruited from schools. In Slovenia, parents express consent for their children to participate in survey research at the discretion of school administrations. This consent is collected every year prior to the start of classes. Discussion as to whether or not a particular school considers it appropriate to allow survey research is held with the representative of the school administration, usually the school directors.

In Switzerland, recruitment primarily took place through vocational training schools and high schools in the German-speaking part of Switzerland. For the first data-collection period, three schools with three departments (Health and Social Science, Industrial Science, and Commercial Science) took part. In order to reach the target sample size of AYCs, a second data-collection period (January–July 2019) took place, reaching more vocational and high schools and four training hospitals. In total, over the two recruitment periods, 11 schools and two hospitals were engaged in the study. Schools were contacted via email and phone calls. In some schools, the research team delivered a presentation to give greater detail about the project. Informational materials were also provided to teachers and parents. The teachers were invited to forward the online survey link to their students and, where possible, to conduct the survey during one lesson (lasting 40 minutes).

In Sweden, 647 AYCs were recruited via schools. A survey was sent to the schools and a total of 3,015 young people aged 15–17 years old answered the questionnaire, both carers and non-carers. A total of 19 AYCs were recruited via other channels (NGOs, brochures, general practitioners, pharmacies or municipalities' websites). The Swedish research team contacted the education administration in 11 municipalities in the south of Sweden to get their approval to carry out the study in schools. After approval, the research team informed the schools' principals, both orally and in writing, about the research project and the survey. The principals forwarded the oral and written information to the teachers in each class and instructed them to set aside lesson time (40 minutes) for the students to complete the questionnaire online on the schools' electronic devices or on paper. Two classes in one school pilot-tested the questionnaire on paper. In classes where the questionnaire was completed on paper, one member of the research team was present in the classroom, collected the completed paper questionnaires and added the answers online.

In the UK, recruitment of participants took place mainly through formal support organisations for young carers across England and Wales. The research team emailed the online survey weblink to formal support organisations for young carers and made phone calls to organisations across the country. Calls for participants were posted on Twitter, Facebook and Instagram by the lead UK researcher. Phone calls were made to over 50 secondary schools across the UK, requesting to send paper versions of the survey or to email the online survey weblink; however, uptake from schools was extremely low. Heads of schools expressed that their students were over-surveyed and that they would therefore not allow any further survey research to take place in their schools. The majority of the research participants accessed the online survey via a weblink sent through social media or distributed through the online newsletters of formal organisations for young carers. The lead UK researcher also attended festivals for young carers in England and Scotland and distributed the paper version of the survey. A research assistant entered the answers on the paper surveys into the online survey. Only a small number of participants were recruited from schools: the UK research team attended a sixth-form college in Brighton and Hove, England, and distributed the online survey on tablets to four classes of fewer than ten students; the paper version was also mailed to a secondary school in Northern Ireland.

Ethics

Institutional ethical approval or detailed ethics opinions (Switzerland) were secured by all country partners in their respective countries in April 2018. The practice of ongoing informed consent held utmost priority in the study. The process of informed consent was utilised to ensure that AYCs were involved in the study on a voluntary basis, without coercing their participation, either directly or indirectly, in any way. In keeping with the Oviedo Convention on Human Rights and Biomedicine, all participants involved in the research were fully informed about the study appropriately to their age. The participant information sheet and consent form were written in clear, easy-to-understand language and described all relevant aspects of the research protocol in full. Informed consent also necessitated that the information sheet and consent form included the foreseen benefits and possible risks of participation, while drawing attention to their ability to withdraw participation at any time without consequence. Country partners translated the English version of the participant information sheet and consent form into their relevant national languages. In addition to the language translation, country partners added their country-specific referral mechanisms to external education, care and support professionals in case of need. Where necessary and applicable due to national legislation, informed consent was also secured by the participants' parents/legal guardians. Each country partner followed the General Data Protection Regulations (GDPR) in addition to their respective national laws and EU laws governing data protection. No data were collected that would identify a specific participant, thus keeping the identity of all participants anonymous.

Data analysis

Data were analysed using IBM SPSS Statistics (version 25.0). In order to address the first research objective of describing the demographic information of participants across the six countries, descriptive data, including frequency, mean and standard deviation, were reported. To address the remaining two objectives, which looked at the extent of caring and its effects, both within each country and across them, descriptive data were again presented, along with inferential tests, including independent-samples *t*-tests, paired-samples *t*-tests and Pearson's correlation coefficient.

Results

General demographics

The figures presented in this section are from the final data set in the ME-WE research project; figures in earlier project publications and reports may have slight differences due to data-collection waves and subsequent data cleaning. A total of 9,437 participants across six countries responded to the online survey. Of these, 7,146 were aged 15–17 years old. A total of 2,746 participants (all ages) were identified as carers. Using the survey's filtering questions, the total number of identified AYCs aged 15–17 was 2,099. In terms of individual countries, Sweden had the largest sample of AYCs (with 702), followed by the UK (402), Slovenia (342), Switzerland (240), Italy (214) and finally the Netherlands (199).

The majority of the AYCs identified as female (1,476). A further 558 AYCs identified as male, 15 identified as transgender and 25 identified as 'other'. Table 1 shows the gender breakdown for AYCs in each country.

Of the 2,099 AYCs in all partner countries, 1,444 indicated that they care for a 'family member', with 77 per cent stating that they live with this person. A total of 1,121 AYCs care for a 'close friend', with 7 per cent living with that person. Some AYCs provide care to family members and close friends.

Of those caring for a 'family member', two fifths (42 per cent) of AYCs reported that they provide care for their mother. Fewer AYCs provide care for their father (25 per cent), followed by their brother (19 per cent), grandmother (17 per cent), sister (16 per cent) and grandfather (11 per cent). All remaining categories, such as aunt or uncle, were selected by less than 10 per cent.

The research was also concerned to observe any country-specific patterns and themes. In regards to the identity of the cared-for family member, there is a preponderance of care provided for grandparents in the Italian sample (59.3 per cent). However, a significant amount of care provided to grandparents is also indicated in the Swiss (34.2 per cent) and Slovenian (37.8 per cent) samples. In contrast to grandparent care, the Italian sample indicated much lower levels of parental care (12.9 per cent for mother; 10.7 per cent for father) than other countries. For example, 54.3 per cent and 23.4 per cent of the UK sample indicated that they care for their mother and father, respectively. In terms of sibling care, Sweden (20.6 per cent for sister; 18.8 per cent for brother), the UK (22.3 per cent for sister; 25.2 per cent for brother) and the Netherlands (15.3 per cent for sister; 29.3 per cent for brother) showed much higher rates in comparison to the other countries in the sample, such as the Italian carers, who had the lowest figures (5.0 per cent for sister; 9.3 per cent for brother).

In terms of the health-related conditions that these family members required care for, more AYCs indicated that they provide care for family members with physical disabilities (46 per cent) and mental illness (40 per cent) than cognitive impairments (26 per cent) or substance addiction (10 per cent). It should be noted that totals exceed 100 per cent because many family members who receive care have a number of conditions ('co-morbidity').

Examining the six countries for potential cross-cultural differences, we observe some between-sample patterns. Swedish AYCs caring for family members selected physical disabilities less frequently (28.7 per cent) than the other countries (ranging from 49.8 per cent among the Slovenia AYCs to 57.0 per cent among the Dutch AYCs).

A total of 9,437 participants across six countries responded to the online survey. Of these, 7,146 were aged 15-17 years old. A total of 2,746 participants (all ages) were identified as carers. Using the survey's filtering questions, the total number of identified AYCs aged 15-17 was 2,099.

There is a divide in terms of the number of participants selecting mental illness, with higher rates observed in the UK (56.5 per cent), Switzerland (48.1 per cent) and Sweden (45.7 per cent) than in Italy (17.7 per cent), the Netherlands (30.4 per cent) and Slovenia (21.9 per cent). Cognitive impairment was fairly consistently selected across the six countries, however, with participants in the Netherlands selecting it most frequently (34.2 per cent) and participants in Slovenia the least likely to select it (17.4 per cent). Finally, addiction was also fairly consistently selected, though noticeably less so in the Netherlands (4.4 per cent) than in the other countries (ranging from 7.7 per cent in Slovenia to 15.0 per cent in Sweden).

In addition to the care provided to family members, the survey also investigated the AYCs' caring responsibilities for their 'close friends'. Of the 2,099 AYCs, 1,121 indicated that they have a close friend for whom they provide care. The majority of these AYCs reported that they provide care for their friend (80 per cent), with fewer AYCs providing care for their partner (10 per cent), colleague (7 per cent), neighbour (4 per cent) and ex-partner (7 per cent). Only 7 per cent of the AYCs stated that they live with the friend they care for.

Looking at the health-related conditions that these friends have, mental illness (69 per cent) was the most frequently reported condition requiring care. A smaller number of AYCs provide care for their friends with physical disabilities (20 per cent), cognitive impairment (18 per cent) and addiction (20 per cent).

There are, however, some interesting differences between the countries. For example, while the majority of the samples reported a high frequency of mental illness, such as the UK (82.2 per cent), Sweden (77.5 per cent) and the Netherlands (70.3 per cent), the Italian sample is markedly lower (30.1 per cent). In

Table 1: Gender identified among AYCs across each country

	Female	**Male**	**Transgender**	**Other**
Italy	141 (67.1%)	67 (31.9%)	1 (0.5%)	1 (0.5%)
Netherlands	141 (72.3%)	48 (24.6%)	3 (1.5%)	3 (1.5%)
Slovenia	298 (88.7%)	34 (10.1%)	1 (0.3%)	3 (0.9%)
Sweden	447 (64.3%)	238 (34.2%)	2 (0.3%)	8 (1.2%)
Switzerland	193 (80.8%)	45 (18.8%)	0 (0%)	1 (0.4%)
UK	256 (64.2%)	126 (31.6%)	8 (2%)	9 (2.3%)
Total	1,476 (71.2%)	558 (26.9%)	15 (0.7%)	25 (1.2%)

Note: Valid percentages are reported, which do not take account of missing data (that is those who selected 'prefer not to say' in response to gender).

contrast, the Italian participants, compared to those in the other countries, more frequently reported that the friend they care for has cognitive impairments (25.2 per cent) or substance abuse issues (32.0 per cent).

Looking at the number of participants who care for multiple people, across all six countries, 332 AYCs indicated that they care for more than one family member (28.4 per cent). Swiss AYCs most frequently reported this (40.0 per cent), closely followed by the Dutch (31 per cent) and UK (29.4 per cent) AYCs, while the Swedish AYCs reported the lowest levels of multiple caring roles within their family (22.7 per cent). Additionally, 466 AYCs indicated that they care for at least one family member and one close friend (22.2 per cent). In this instance, the UK sample shows the most frequent rates (28.4 per cent), followed by the Swedish (23.9 per cent) and Slovenian (21.6 per cent) samples, with the Italian AYCs reporting the lowest frequency (14.0 per cent).

In consideration of family structure, most of the AYCs in this sample reported that they live in two-parent households, including step-parents (80.2 per cent). A total of 19.8 per cent indicated that they were from one-parent households, selecting only their mother (16 per cent) or only their father (3 per cent). Two thirds (67 per cent) of AYCs stated that they live with at least one sibling, while only 10 per cent stated that they live with at least one grandparent.

Adolescent young caring also exists in migrant families. A total of 174 (8.3 per cent) AYCs disclosed that they were born in a different country than their current residence. This was most prevalent among the Italian AYCs (12.2 per cent), closely followed by the Swiss (11.3 per cent) and the Swedish AYCs (10.5 per cent). It was less frequently shown among the UK (7.4 per cent), Dutch (4.0 per cent) and Slovenian (3.2 per cent) AYCs. Additionally, 527 (25.2 per cent) AYCs disclosed that at least one of their parents was born in a foreign country. This was indicated by 44.6 per cent of the Swiss AYC sample. The other countries showed fairly similar lower levels, ranging from 15.6 per cent among the Dutch AYCs to 21.4 per cent in the Swedish sample.

The MACA

The MACA questionnaire indicates the number of caring activities an individual carries out in the home, with higher scores indicating that they perform more caring activities. In order to investigate whether those participants who identified as AYCs via the survey's filtering questions did complete more caring activities than the 15- to 17-year-old participants who did not identify as AYCs, a series of independent-samples *t*-tests were conducted.

When examining the data overall, the scores on the MACA demonstrate that when compared to their non-caring peers (M = 8.81; SD = 4.57), AYCs perform a greater number of caring activities in the home (M = 12.57; SD = 5.64) (*t* [3210.93] = 26.73; *p* < .001; *d* = 0.73). As can be seen in Table 2, this finding is consistent across each of the six countries.

In addition to investigating differences in MACA scores between carers and non-carers, we also investigated gender differences between AYCs. Overall, it is shown that female AYCs (M = 13.07; SD = 5.70) scored significantly higher on the MACA than male AYCs (M = 11.24; SD = 5.16) (*t* [1051.11] = 6.80; *p* < .001; *d* = 0.34). For the Dutch AYCs, female participants scored significantly higher (M = 12.86; SD = 5.22) than male participants (M = 10.15; SD = 4.16) (*t* [101.42] = 3.65; *p* < .001; *d* = 0.57). Likewise, the female AYCs in the UK sample scored significantly higher (M = 15.64; SD = 6.14) than the male AYCs (M = 11.98; SD = 3.99) (*t* [341.20] = 6.91; *p* < .001; *d* = 0.71). In each country, female AYCs, on average, scored higher than male AYCs. However, this difference is only significant in the Netherlands and the UK.

The PANOC

The PANOC questionnaire is split into two scales: the PANOC positive, which assesses the level of positive adaptation associated with the participant's caring responsibilities; and the PANOC negative, which assesses the negative effects. Scores below 12 on the positive scale and/or scores above 8 on the negative scale may indicate that the AYC is suffering from emotional distress. Table 3 shows the proportion of AYCs whose scores indicate potential concern for each country.

Inspection of Table 3 reveals some between-country differences. The UK and Sweden both had a high proportion of AYCs scoring below 12 on the positive scale (44 per cent and 46 per cent, respectively), as well as a high proportion of those scoring above 8 on the negative scale (40 per cent and 34 per cent, respectively). Italian AYCs had the lowest proportions on average, with only 23 per cent scoring below 12 on the positive scale and 12 per cent scoring above 8 on the negative scale. There was a relatively high proportion of Dutch AYCs scoring below 12 on the positive scale (44 per cent); however, the proportion scoring above 8 on the negative scale was relatively low (13 per cent).

Table 2: Independent-samples t-tests on mean MACA score (SD) for both AYCs and 15–17 year old non-carers, separately for each country.

	AYCs	**Non-AYCs**	***t***	***df***	***p***	***d***
Italy	11.42 (5.38)	8.33 (4.51)	7.54*	307.83	< .001	0.62
Netherlands	12.24 (5.37)	7.48 (3.58)	11.35*	280.98	< .001	1.04
Slovenia	14.22 (5.81)	10.81 (4.62)	9.35*	555.99	< .001	0.65
Sweden	10.92 (4.97)	8.50 (4.12)	11.46*	964.42	< .001	0.53
Switzerland	13.15 (5.84)	9.66 (5.96)	7.65	846	< .001	0.59
UK	14.44 (5.72)	7.95 (4.12)	17.41*	692.39	< .001	1.30
Total	12.57 (5.64)	8.81 (4.57)	26.73*	3210.93	< .001	0.73

Note: * Equal variances not assumed.

Table 3: Number of AYCs scoring below 12 on the PANOC positive scale and number scoring above 8 on the PANOC negative scale, separately for each country.

	PANOC positive score below 12		PANOC negative score above 8	
	N	**%**	**N**	**%**
Italy	42	23.0%	20	11.8%
Netherlands	64	43.8%	19	12.7%
Slovenia	57	23.3%	31	12.7%
Sweden	230	45.5%	166	34.2%
Switzerland	52	29.5%	37	22.4%
UK	157	44.4%	143	39.6%
Total	602	37.4%	416	26.4%

Table 4: Independent-samples t-tests on mean KIDSCREEN-10 score (SD) for both AYCs and 15–17 year old non-carers, separately for each country.

	AYCs	Non-AYCs	*t*	*df*	*p*	*d*
Italy	33.46 (6.45)	34.63 (5.68)	2.36*	319.63	.02	0.19
Netherlands	36.08 (7.06)	38.50 (6.07)	3.94*	310.66	< .001	0.37
Slovenia	30.58 (7.14)	33.09 (6.96)	5.16	926	< .001	0.36
Sweden	34.40 (7.17)	38.27 (6.09)	12.78*	1003.47	< .001	0.58
Switzerland	33.29 (7.12)	36.29 (6.33)	5.52*	369.87	< .001	0.45
UK	30.74 (7.57)	35.78 (6.94)	8.94	673	< .001	0.69
Total	33.04 (7.38)	36.72 (6.53)	19.28*	3346.25	< .001	0.53

Note: * Equal variances not assumed.

Additionally, the study examined whether there was a gender difference in both PANOC positive and negative scores. In order to investigate this, a series of independent-samples *t*-tests were conducted. With all countries combined, the results show that there is no significant difference in PANOC positive scores between male AYCs (M = 12.48; SD = 4.66) and female AYCs (M = 12.98; SD = 4.45) (*t* [1559] = 1.92; *p* = .06, *d* = 0.11). However, there is a significant difference in PANOC negative scores, with male AYCs (M = 4.44; SD = 4.55) scoring significantly lower than female AYCs (M = 5.64; SD = 5.10) (*t* [793.71] = 4.40; *p* < .001; *d* = 0.25). This suggests that while male and female AYCs have similar positive experiences of caring, female AYCs report more negative effects than their male counterparts.

When looking at individual countries, the same is true in each for the PANOC positive scores, with no significant difference between male and female AYCs in any of the six countries. The PANOC negative did produce some gender differences. In the Swedish sample, the female AYCs (M = 6.66; SD = 4.94) scored significantly higher on the PANOC negative than the male AYCs (M = 5.45; SD = 4.47) (*t* [473] = 2.61; *p* = .01; *d* = 0.26). The same was true in the UK, with females (M = 8.56; SD = 5.61) scoring significantly higher than the males (M = 4.34; SD = 4.97) (*t* [235.73] = 7.03; *p* < .001; *d* = 0.80 [equal variances not assumed]). However, in the remaining countries, no such significant difference arises.

Finally, in order to examine whether there is a relationship between the level of caring activities and negative effects of caring, a Pearson's correlation coefficient was conducted to test for the association between scores on AYCs' MACA and PANOC negative score. The results indicate that there is a significant positive correlation between the two variables (*r* [1545] = .29; *p* ≤ .001; *R*2 = .08). This suggests that the more caring responsibilities an AYC has, the more negative effects of caring they perceive. However, while the relationship between these variables is significant, it is nevertheless a weak correlation, explaining only 8 per cent of the variance shared by both variables. This suggests that there are other, as yet unknown, factors impacting the level of negative effects associated with caring.

> While male and female AYCs have similar positive experiences of caring, female AYCs report more negative effects than their male counterparts.

KIDSCREEN-10

The reported scores on the KIDSCREEN-10 help to indicate a comprehensive state of well-being in young people. A total score of 50 indicates extremely high well-being. In order to examine whether there is a difference in well-being between 15- to 17-year-old carers and non-carers, a series of independent-samples *t*-tests were conducted (see Table 4). The analyses reveal that

Table 5: Independent-sample t-tests on mean KIDSCREEN-10 score (SD) for female and male AYCs, separately for each country.

	Female	**Male**	***t***	***df***	***p***	***d***
Italy	32.65 (6.58)	35.53 (5.69)	3.05	203	.003	0.47
Netherlands	35.39 (6.81)	39.31 (6.35)	3.29	169	< .001	0.60
Slovenia	30.24 (7.09)	33.57 (6.12)	2.47	305	.01	0.50
Sweden	33.33 (7.10)	36.65 (6.74)	5.87	664	< .001	0.48
Switzerland	33.05 (7.09)	34.33 (7.19)	1.06	220	.29	0.18
UK	29.26 (6.76)	34.73 (7.43)	6.86	350	< .001	0.77
Total	32.11 (7.21)	35.95 (6.87)	10.55	1921	< .001	0.55

Table 6: Number (valid %) of AYCs who indicated they had experienced issues and difficulties due to their caring responsibilities

	Negative Effect on School Performance	**Experience of Bullying**	**Physical Health Problems**	**Mental Health Problems**	**Considered Hurting Self**	**Considered Hurting Others**	**Harmed Care Recipient**
Italy	19 (9.0%)	17 (8.1%)	52 (29.1%)	34 (19.0%)	18 (8.5%)	14 (6.6%)	8 (57.1%)
Netherlands	22 (12.3%)	24 (13.3%)	23 (18.9%)	15 (12.3%)	20 (11.2%)	6 (3.4%)	2 (33.3%)
Slovenia	32 (10.1%)	14 (4.4%)	62 (23.7%)	38 (14.5%)	23 (7.3%)	15 (4.8%)	11 (78.6%)
Switzerland	36 (16.1%)	36 (16.1%)	68 (36.0%)	64 (33.9%)	41 (18.3%)	11 (4.9%)	3 (27.3%)
Sweden	90 (13.1%)	68 (10.0%)	73 (12.2%)	157 (26.2%)	77 (11.3%)	31 (4.6%)	8 (26.7%)
UK	139 (37.3%)	136 (36.2%)	81 (29.6%)	157 (57.3%)	105 (27.9%)	43 (11.5%)	20 (48.8%)
Total	338 (17.0%)	295 (14.8%)	359 (22.1%)	465 (28.6%)	284 (14.3%)	120 (6.1%)	52 (44.8%)

Note: The valid percentage is presented, ignoring missing values. For the 'harmed care recipient' column, the percentage reflects the valid percentage of the participants who indicated they had considered hurting others'

with all countries included, the AYCs score significantly lower on the KIDSCREEN-10 (M = 33.04; SD = 7.38) than the 15- to 17-year-old participants who were not identified as AYCs (M = 36.72; SD = 6.53) (t [3346.25] = 19.27; $p < .001$; $d = 0.53$). This indicates that the AYCs, on average, consider themselves to have a lower state of well-being than non-AYCs.

Inspection of Table 4 reveals that this finding is consistent across all six countries, with AYCs reporting significant lower KIDSCREEN-10 scores than non-AYCs in each country. Looking at scores between the countries, the data show that the Slovenian AYCs report the lowest state of well-being, closely followed by the AYCs in the UK. The AYCs in the Netherlands report the highest average levels of well-being, followed by the Swedish AYCs. The Italian and Swiss AYCs fall in the middle, with similar average KIDSCREEN-10 scores.

In order to investigate whether there is any gender difference in well-being among the AYCs, another series of independent-samples t-tests were conducted (see Table 5). The findings reveal that there is a significant gender difference in the KIDSCREEN-10 scores overall, with female AYCs scoring significantly lower (M = 32.11; SD = 7.21) than male AYCs (M = 35.95; SD = 6.87) (t [1921] = 10.55; $p < .001$; $d = 0.55$). Looking at the findings from individual countries, this pattern appears to be consistent, with female AYCs rating their own well-being significantly lower than their male counterparts in all six partner countries.

Closer inspection of Table 5 shows that the female AYCs based in the UK have the lowest KIDSCREEN-10 score, followed by those in Slovenia. The female AYCs in the Netherlands recorded the highest average score, followed by the Swedish and Swiss AYCs. Taken together, the results from the KIDSCREEN-10 survey indicate that the UK and Slovenia both have a potential issue with AYCs experiencing poor well-being in their sample of AYCs, with female AYCs appearing to experience this more strongly.

Difficulties in school, health and risk of 'harm'

In order to examine the potential issues and difficulties that arise due to caring, the survey asked a number of questions (see Table 6). First, the participants were asked whether they believed their school performance had been negatively affected because of providing care to someone. Overall, 17 per cent of AYCs indicated that their school performance has been negatively affected. AYCs from the UK are most likely to report this, with 37 per cent stating this to be the case. Second, they were asked whether they had been bullied, teased or made fun of at school because of their caring. Overall, 15 per cent reported that this is the case, with bullying again being substantially more prevalent in the UK sample (36 per cent) than the samples of other countries.

Table 7: Independent-groups t-tests on average MACA score (SD) between AYCs who answered 'yes' and 'no' to questions regarding care-related issues and difficulties

	Answered 'yes'	**Answered 'no'**	***t***	***df***	***p***	***d***
Negative effect on school performance	15.81 (6.05)	12.33 (5.36)	9.61*	462.13	< .001	0.61
Experience of bullying	16.27 (6.23)	12.30 (5.23)	10.04*	367.92	< .001	0.69
Physical health problems	15.08 (6.03)	11.92 (5.42)	8.84*	520.12	< .001	0.55
Mental health problems	14.28 (5.91)	11.96 (5.49)	7.21*	779.63	<.001	0.41
Considered hurting self	14.73 (6.27)	12.62 (5.39)	5.24*	361.02	< .001	0.36

Note: * Equal variances not assumed.

Table 8: Formal and Informal Support Received in Connection to Caring Role

	Familial adult working and in receipt of wage	**Family receipt of government assistance**	**AYC receipt of support**	**Family receipt of support**	**School awareness of caring**	**Employer awareness of caring**	**Friend awareness of caring**
Italy	205 (97.6%)	50 (23.8%)	46 (22.1%)	58 (27.6%)	23 (10.8%)	10 (4.8%)	93 (44.1%)
Netherlands	169 (94.9%)	79 (45.9%)	39 (22.4%)	62 (35.8%)	52 (30.8%)	22 (13.1%)	107 (62.2%)
Slovenia	301 (97.1%)	67 (22%)	42 (13.8%)	91 (30.1%)	43 (14.2%)	13 (4.3%)	134 (44.5%)
Sweden	661 (96.1%)	186 (27.2%)	279 (41.8%)	77 (11.4%)	213 (31.8%)	31 (4.7%)	342 (51.3%)
Switzerland	210 (94.6%)	52 (24.0%)	37 (16.8%)	41 (18.8%)	20 (9.1%)	29 (13.5%)	140 (63.6%)
UK	267 (72.8%)	236 (64.5%)	168 (45.8%)	165 (46.2%)	215 (58.6%)	36 (10.1%)	247 (67.1%)
Total	1813 (91.8%)	670 (34.4%)	611 (31.5%)	494 (25.5%)	566 (29.2%)	141 (7.4%)	1,063 (54.8%)

Note: The valid percentage is presented, ignoring missing values.

The AYCs were also asked whether, in their opinion, their own physical health had been affected because of caring. Overall, 22 per cent of AYCs indicated that their physical health had been impacted. On this occasion, Switzerland exhibits the highest rate (36 per cent) (see Table 6). Next, they were asked if their caring is related to them experiencing any mental health problems. This is more common, with 29 per cent of AYCs overall reporting it to be the case. Again, the UK-based AYCs are the most frequent to report mental health problems associated with caring (57 per cent), followed by Sweden (34 per cent).

The survey additionally investigated the risk of 'harm' linked to caring responsibilities. Initially, the AYCs were asked if they had thought about hurting themselves due to caring. Overall, 14 per cent confirmed that they had. The UK-based AYCs are again the most frequent to report this finding (28 per cent). Second, they were asked if they had considered hurting others due to caring. This is less commonly reported, with 6 per cent of AYCs overall indicating that they had. Again, it is the UK-based AYCs who most frequently reported this (12 per cent). Finally, the participants who had indicated that they had considered hurting others were asked whether the person they considered hurting was the person they care for or someone else. Overall, 45 per cent of the AYCs who said that they had considered hurting others indicated that this person is the family member or friend that they care for.

In order to determine whether the level of caring responsibility is associated with increased health and other problems among the AYCs, a series of independent-groups *t*-tests were performed between the MACA scores of those who answered a selection of the questions reported earlier (see Table 7). The results show that there is a significant difference between those who had answered 'yes' and 'no' to questions about caring-related difficulties. In each case, those who answered 'yes' had a significantly higher average MACA score. This indicates that higher levels of caring responsibility are indeed associated with a greater incidence of caring-related difficulties and issues, including experiences of bullying, poorer self-perceived mental health and difficulties in school.

Support received

The survey also assessed the AYCs' access to formal and informal support structures. Table 8 shows the number of AYCs across each country who indicated that they receive these forms of support. Looking at each, most AYCs have an adult family member who is employed and receives wages. Overall, 92 per cent indicated this to be the case. The outlier in this question is the UK, where 73 per cent of AYCs reported that they have an employed family member. Moreover, the UK-based AYCs are the most frequent to report that they have a family member who receives government assistance, for example, social security benefits (65 per cent).

UK-based AYCs are also the most frequent to state that both they themselves (46 per cent) and their family (46 per cent) receive support in connection to their caring responsibilities. Both are considerably higher than the overall average frequencies of 32 per cent and 26 per cent, respectively. This pattern continues with the remaining questions. Overall, 29 per cent of the AYCs across all countries reported that their school is aware of their caring responsibilities, while 55 per cent indicated that they have a close friend who is aware. Although, again, the UK-based AYCs demonstrated the highest frequencies for these methods of support, with 59 per cent indicating that their school is aware and 67 per cent reporting they have friends who are aware, this finding can be explained by the recruitment strategy of outreach to young carers projects. Therefore, relatively many of the AYCs that filled in the survey have received support – or their family did – given that they were identified as AYCs by social services.

Strengths and limitations of the study

For the first time, this research provides findings of a large sample of AYCs in six European countries. However, there are limitations to the study. Country partners made concerted efforts to create harmonious sampling through dedicated discussions and the drafting of an agreed-upon, multistage, facility-based sampling strategy, highlighting, first, the regional differences within the partner countries (urban, semi-urban or rural) and, second, the various recruitment channels of AYCs, such as schools, municipalities and carer organisations. Previous research with young carers in European countries has utilised schools as a way to gain access to spaces inhabited by large numbers of young people (Metzing-Blau/Schnepp 2008; Leu et al. 2018). However, the realities of conducting research with vulnerable young people who are hidden from the view of wider society means that difficulties in recruiting AYCs are to be expected. In the UK, difficulties in gaining access to schools required a focus on the recruitment of AYCs through young carers projects. Historically, research with young carers and AYCs in the UK has typically utilised young carers projects (Earley et al. 2007; Aldridge et al. 2016). Thus, while the sample in the UK includes only two high schools, the origin of the sample (for example, young carers projects) reflects other established research with AYCs in the UK. It is important to stress that relatively many ‘identified’ AYCs are included, who may also have higher care responsibilities or care needs than those (unidentified) AYCs recruited through surveys in schools in other countries. Furthermore, recruitment efforts in all six European countries focused primarily on schools that would grant access to classrooms to host the online survey. In Switzerland and the Netherlands, vocational schools were targeted; however, the process of data cleaning and analysis revealed that the classrooms sampled included students older than the target age range of this study, who then had to be excluded through data cleaning. Due to the variance between the six countries’ sampling strategies and the lack of a known representative sample in all six countries, this research study is limited in its scope to make extrapolations to the wider (AYC) population; hence, the reader should keep this in mind when country differences are highlighted in this study.

Despite limitations, this research study, the first of its kind, contributes substantial new knowledge about AYCs, especially those in EU countries, where there was (mostly) little research in this field. The statistical profile of 2,099 AYCs presented here provides a clear picture of the characteristics of these carers and the impact of caring on their (self-perceived) health, well-being and school life. Moreover, it is the first time that the PANOC and other instruments have been used for a sample of this scale, involving AYCs across Europe. Thus, this study presents the first opportunity to use validated tools to assess the positive and negative outcomes of young caring on a substantial sample. The study’s originality and significance rests on this being the first-ever cross-national survey of adolescent young caring, with analysis within and across six European countries.

Discussion

This is the first-ever study at the European level providing demographic information on AYCs, investigating their self-reported health and well-being, and focusing on their needs and support received. A generalised profile of adolescent young caring in Europe emerges from the data presented here, suggesting that an AYC is most typically a girl who provides care for her mother who has a physical disability. However, this is a gross oversimplification of the complete data set and between-country differences, and the findings presented here show a complex and varied cross-national profile of the characteristics of AYCs within and between the six nations. In each of these countries, AYCs are found to carry out high or very high amounts of caring activities in the home, though there are cross-national differences in the types of roles performed by AYCs. It is also clear that AYCs perform greater amounts of caring-related activities in the home than non-caring peers in all six European countries, as would be expected. The AYCs sampled in Slovenia and the UK do more caring on the whole than AYCs in the other European countries, which could be due to the recruitment strategies inviting more AYCs in caring situations with (probable) higher care needs. The total MACA scores indicate that girls perform a greater amount of care activities than boys; however, the differences are only statistically significant in the Netherlands and the UK.

In consideration of overall well-being, this research finds that AYCs in the six countries experience both positive and negative outcomes related to caring. It is of note that there are between-country differences, as some AYCs report positive effects from caring, for example, only 23 per cent of Italian AYCs scored below 12 on the positive scale of the PANOC. This finding serves as a signal that the act of caregiving during adolescence is not a wholly negative or detrimental experience for all AYCs, but can also be a role from which young people learn and grow personally. However, and perhaps more predictably, the more caring an AYC performs, the more negative effects they feel, though this is a weak correlation. In relation to the KIDSCREEN-10, the AYCs in this research were found to more likely self-report a lower state of well-being in comparison to their non-caring peers. AYCs in the UK and Slovenia were shown to have the worst self-reported well-being. AYCs in the UK and Slovenia were also found to have a greater number of caring tasks than AYCs in the other countries, and recent research also supports such a relationship (Kallander et al. 2020; Santini et al. 2020). Further research should continue to examine the relationship between higher amounts of caring and poor well-being in AYCs. Furthermore, girls are demonstrated to have poorer self-reported well-being than boys, and considering that girls generally perform more caring tasks than boys, these findings suggest that the amount of caregiving that an adolescent engages in can have negative ramifications for their own health and well-being. This may be especially true for adolescent girls.

In consideration of overall well-being, this research finds that AYCs in the six countries experience both positive and negative outcomes related to caring. It is of note that there are between-country differences, as some AYCs report positive effects from caring.

Generally, the UK AYCs report more significant negative mental health impacts in comparison to the other European countries in this study. Perhaps surprisingly, while the AYCs sampled in the UK report the greatest number of formal support services received in connection to their caring role, they also have the highest negative mental health and negative school impacts, as well as the second-highest poor physical health scores, reported across all nations. Cross-country differences in mental health and well-being may be influenced by the sampling strategy in the UK in particular, as there was a focus on recruiting AYCs from young carers projects, and the AYCs found within those projects have likely been providing care activities at a higher intensity and caring for longer periods of time. Indeed, these higher levels of caring may be a precondition ('eligibility criteria') for being able to access young carers projects in the UK. Moreover, a recruitment strategy utilising patient organisations (in addition to schools) in Slovenia may also help explain why the AYCs in Slovenia self-reported poorer well-being. We should also consider the state of the mental health and well-being of adolescents in the UK generally, including those children who do not encounter a caring role. Previous research has suggested that UK adolescents have the highest prevalence of mental health problems across Europe (Polanczyk et al. 2015; Kovess-Masfety et al. 2016). It may be that UK adolescents already experience poorer mental health compared to their European counterparts and UK AYCs further reflect this cross-national difference.

An additional finding includes the relatively high percentage of AYCs across the six European nations who have reported thoughts of self-harm or harm towards others due to their caring role. This finding indicates that many AYCs are at significant risk of mental distress and likely points to a lack of dedicated, appropriate psychosocial and other support designed to reduce feelings of harm to self or others. These are the first-ever data concerning the thoughts of AYCs of hurting themselves and others, especially the care recipient, due to caring activity. This study therefore contributes to shedding light on the severe mental health condition of some AYCs and a need for timely and adequate support to reduce the risk of violence and harm to people with care needs or others, as well as self-harm to AYCs themselves.

This research also provides new understanding about the family demographics of European AYCs. An unexpected result concerns the identity of the cared-for family members across the six countries. In Italy, there is a higher number of adolescents caring for older family members (that is, grandmothers and grandfathers). It may be that Italian AYCs are being pushed or nudged into caring roles through the lack of a formal, long-term eldercare system, a cultural reliance on intergenerational familial care, and ageing demographic trends of a large number of older people (Tosi/Oncini 2018; Martani et al. 2020; Santini et al. 2020). Nevertheless, these findings signal that the care of an ageing European population is sometimes the responsibility of children and young people aged 15-17, rather than a role that might be assumed to fall to much older family carers.

The research also finds that AYCs providing care for siblings are a strong feature of young caring in Sweden, the Netherlands and the UK. While the significance of AYCs caring for siblings in the UK sample is not readily explained, the differences observed in the Swedish and Dutch samples likely reflect their community-care practices, in which ill or disabled family members are often cared for in the home, thus increasing the numbers of siblings needing to take on caring roles in their families. In the Netherlands, the recruitment strategy can partly account for the significance of caring provided by sibling AYCs: utilising social media platforms for sibling carers meant that many more sibling carers received an invitation to participate in the study. In addition, due to the recruitment strategy, more sibling carers may have been included in the Swedish sample. The care that siblings provide is underdeveloped in young carers research and requires more attention.

Regarding formal and informal support, the AYCs generally reported relatively low amounts of formal dedicated support in connection with their caring role. The exceptions include Sweden and the UK. In Sweden, the welfare state model of formal support may help to explain why there is a greater receipt of formal support services within this specific country context. In the UK, the sampling strategy relied predominately on dedicated young carers services and is thus reflected in the comparatively high numbers of AYCs receiving formal support in this research. Overall, AYCs indicate that they have informal support through a close friend who is aware of their caring role and offers some support. This is an important finding in considering the resilience of some AYCs and their ability to resource peer support without the intervention of formal dedicated services through governmental, charitable or other health and social care agencies.

> Many AYCs are at significant risk of mental distress and likely points to a lack of dedicated, appropriate psychosocial and other support designed to reduce feelings of harm to self or others. These are the first-ever data concerning the thoughts of AYCs of hurting themselves and others, especially the care recipient, due to caring activity.

This research shows that adolescent young caring is present in all six European countries, irrespective of their economic circumstances or welfare model (Nordic, Continental, Anglo-Saxon or Mediterranean) (Bambra/Eikemo 2009; Hay/Wincott 2012; Casu et al. 2021). Italy, the Netherlands, the UK, Slovenia, Switzerland and Sweden are European countries that traditionally uphold the values of social protections for all citizens, with varying approaches to welfare programmes and delivery. Yet, as this research shows, AYCs remain at risk of a range of negative outcomes (poor self-reported physical health, mental health and well-being, educational disadvantage, bullying, self-harm, and potential danger to others), albeit with important variations between countries. In the UK particularly, dedicated formal support services provided or funded by the state or charitable organisations (or a combination of both) have been regarded internationally as 'best practice' to addressing the needs, experiences, circumstances and negative outcomes experienced by young carers. Hundreds of young carers projects exist across the UK, and previous research has found that such projects deliver positive experiences, and outcomes, for young carers (Becker/Becker 2008). However, receipt of a formal support service should not be relied on (by the state or families) as the sole intervention in the lives of AYCs, as our research findings indicate that AYCs can identify sources of informal and formal support yet still experience detrimental effects in school, employment and on their own mental and physical well-being, including risk of harm to self or others. Thus, young carers projects are only a 'partial solution' to the needs of AYCs, and more systemic interventions within schools, families and communities, and from health and social care, will need to be developed and delivered in all six countries (and beyond) to reduce the amount of caring performed by adolescents and the negative outcomes that some AYCs experience, as well as to help maximise the positive impacts of caring. Progress will also require a shift in thinking and discourse about the 'rights' of adolescents who are carers, in keeping with current European policy emphasising the rights of the child in general (European Commission 2021a) and vulnerable children in particular (European Commission 2021b).

The push for policy and legislation to give explicit rights and protections to young carers has emerged in recent years as a possible panacea to the adverse childhood experiences facing AYCs. This approach is especially argued for by young carers advocates and researchers in the six EU countries sampled in this research, and this view is also promulgated by the premier cross-national European network for informal, unpaid carers, Eurocarers. Indeed, the pursuit of a 'rights' discourse and policy approach by countries in Leu and Becker's (2017) classification has been one of the key factors that has led to progress within those countries.

Continued engagement of advocates on young carers issues has proven fruitful, as named policy in England giving young carers a legal right to a carer's assessment and to have their needs met was established in 2014 (under the Children and Families Act 2014 and the Care Act 2014). However, the Children's Commissioner for England (2016) estimated that approximately four out of five young carers may not be receiving any support from their local authority. In Italy, Sweden, Switzerland, Slovenia and the Netherlands, no specific policy or legislation on young carers exists. Swedish laws to protect children from parental harm or neglect in situations of parental illness, substance abuse or disability may be applicable to AYCs but do not recognise young caring as a concept or terminology (Häls ooch sjukvårdslag 2017: 30). Similarly, Dutch law recognises that children have a right to education (Leerpflichtwet [Compulsory Education Act] 1969) and that they should be protected from child labour (Jeugwet [Child and Youth Act] 2015), but there is an absence of any legislation that refers to young carers specifically. In Italy, family carers are recognised not by national law, but by regional laws. Similar to the Netherlands, there are laws to protect children, but those laws do not specifically mention young carers. In Switzerland, the Swiss Federal Council has endeavoured to collect information about children who care for family members in a three-year project that ended in 2020 (Leu et al. 2022). Slovenia, deemed an 'awakening' country (Leu/Becker 2017; Leu et al. 2022) is in a notably worse position on dedicated policy for young carers, as Slovenia has only recently instituted specific policy targeting youth generally.

As the basis of the development of policy and practice across countries, a 'rights' approach or paradigm to furthering the recognition and identification of young carers offers young carers hope and opportunity that their experiences and needs will be more greatly recognised and supported. Noticeably, in the discussion on the need to have a right-based approach, experts also point to whether AYCs should be responsible for caring tasks (Nap et al. 2020). However, as the UK shows, even with legal rights, many young carers are still left behind and have no access to (or are excluded from) formal health and social care support, whether provided by state, market or the charitable sector. Thus, many young carers are hidden and unsupported, relying on their own informal family and friendship networks to provide them with some support or respite. The research presented here casts a light, for the first time, on the experiences and needs of a large sample of AYCs in six European countries, and offers a platform on which future policy can be developed.

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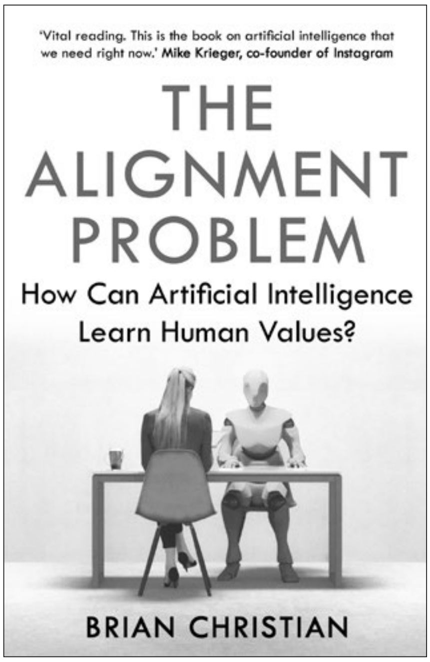
Brian Christian: The Alignment Problem: How Can Artificial Intelligence Learn Human Values?

Reviewed by Michael Haiden



In *The Alignment Problem,* author Brian Christian talks about humans, animals, and – centrally – artificial intelligence. As book's title suggests, his focus is the 'alignment problem', more precisely the task of ensuring that artificial agents behave the way we want them to. The author at one point quotes MIT researcher Norbert Wiener, who in 1960 stated the problem as follows: "If we use, to achieve our purposes, a mechanical agency with whose operation we cannot efficiently interfere once we have started it […], then we had better be quite sure that the purpose put into the machine is the purpose which we really desire and not merely a colorful imitation of it." (295). As Christian makes clear, this is easier said than done.

The first part of the book (*Prophecy*) fulfils two purposes: it shows us the problems we might encounter when we deploy artificial intelligence, and it explains why these problems matter. The author confronts us with the amazing abilities of artificial intelligence, learning faster than any biological agent, recognising patterns better than the most intelligent human – sometimes even seeing things we miss altogether.

One is easily convinced that we are standing in front of a powerful tool. However, the positive outlook is dimmed by the problems Christian outlines. The crucial challenge in this part is the possibility of algorithms making 'wrong' decisions – meaning that the machine acts not as we want it to. There are various reasons for this. For example, a lack of training data leads a Google AI to classify images of black people as Gorillas, because it does not have enough pictures of black people in its database (25–26). Another instance is that when AI is used to decide whether criminals deserve parole, it treats black people much harsher than white people (60). This is not because black people actually are more likely to offend again – rather, the algorithm makes a decision based on the data we provide, in which black people are more likely to be caught offending, due to the over-policing of black neighbourhoods (76).

It is not that the algorithm is knowingly biased, as Christian stresses. It simply makes decisions based on our (biased) data. Thus, the complexity of these technical issues mirrors the complexity of the societal problems that underlie them. And for such complex problems, there are no easy solutions. For instance, if one wants to avoid biased outcomes based on race, it is not enough to remove race as an attribute from the data, because the impressive pattern-recognition of AI allows it to still see relationships between race and the attributes that correlate with it – something called 'redundant encodings'. In a society where black people are arrested more often than white people, the number of arrests can be tied to race. Put simply, those who are arrested more often will be judged more negatively by the algorithm – and those people will happen to be black. Removing race can make matters even worse, since it makes us blind to the racial bias behind the number of arrests (64).

The beginning of the book thus sets the stage, outlining how our social problems could be perpetuated and even worsened by AI. By using it, we are not only modelling the world, but changing it – potentially leading to dangerous feedback loops. An algorithm to rank job applicants that is biased in favour of men – because its data was collected in a professional world that is biased – will prefer men in the hiring process, which then further enlarges the gender gap, as the algorithm influences the training data for future iterations (49). As Christian puts it: "Our human, social, and civic dilemmas are becoming technical. And our technical dilemmas are becoming human, social, and civic. Our successes and failures alike in getting these systems to do 'what we want,' it turns out, offer us an unflinching, revelatory mirror." (13).

It is only natural that the second part of the book (*Agency*) tries to understand how agents – biological and artificial – actually learn. While the first part outlines the problems, the second provides the necessary knowledge to understand how we may solve them. The chapters in this part are populated by algorithms trying to drive cars or play complicated video games, which serve as examples to discuss different ways to teach them the behaviour we want them to exhibit.

Christian offers a comprehensible guide in these chapters, which discusses different strategies to teach agents. Can we give them rewards for acting in the desired way, chapter four asks? This question seems straightforward, but it faces problems. More precisely, how do you keep agents motivated through long, complicated tasks, where the reward only waits at the end? Very often, agents give up before reaching their goal – it comes as no surprise, for instance, that PhD students suffer from depression and procrastination, since they have little intermediate rewards but only the promise of their doctorate at the end (179).

To solve this, chapter 5 suggests "shaping", or structuring the environment in a way that encourages the desired behaviour (151). Instead of rewarding a job well done, we reward limited actions that approximate the desired behaviour (154-155). Simply put, if you want to teach a pigeon how to bowl, do not reward it only for moving the ball. A good start may instead be rewarding it for looking at the bowling ball, at which point you can gradually work your way forward (153).

This avoids depression and procrastination, but is hardly safe from complications. For instance, Christian notes, if we reward the approximation of a desired action, we may encounter 'reward hacking', where agents repeat the rewarded act over and over. The cognitive scientist Tom Higgins recounts in the book how he would praise his daughter for cleaning the floor, until the child emptied the collected dirt on the floor, only to clean it up again (165–166). Thus, we should instead reward a state of affairs – the fact that the floor is clean, rather than the act of cleaning. We reward progress towards the goal and subtract rewards for moving away from it – in this case, dirtying the floor again (169–170).

Chapter 6 tackles another issue: How do we make agents explore things on their own? How do we make our agent interested in cleaning the floor in the first place? Especially with rather complicated tasks, this becomes a key issue.

These excursions into the world of learning form the backdrop for the book's main focus: How can we teach AI the values we want it to have? Part three (*Normativity*) ties the insights of the previous part into the wider theme of the book. It begins with another chapter (chap. 7) on learning, this time by imitation. It quickly becomes apparent why this chapter is located in part three: through imitation, we are now asking the machine to draw its own inferences.

Learning by imitation means that humans tell the machine to "watch me and do as I do." This avoids many of the problems above, such as reward-hacking, but carries its own issues, such as how many data points a machine needs to imitate us in all potential circumstances. For instance, an algorithm that learns how to drive by imitating a human driving in the middle of their lane may make terrible errors once it is not in the middle of the lane (229).

Chapter 8 delves deeper into algorithms drawing their own conclusions. We learn of inverse reinforcement learning, where algorithms observe our actions and infer our goals from that (255). A promising way is to let humans and machines work together, towards a reward that only the human knows in the beginning. Dubbed 'cooperative inverse reinforcement learning', this offers an engaging way to address the alignment problem – not guiding the machine to the right behaviour, but letting it infer it for itself (268-272). A good side effect: humans tend to trust the machine-colleagues more when they work together first (272).

It is in chapter 9 that Christian opens up more frightening issues, starting by recounting the story of the Soviet soldier Stanislav Petrov. In 1983, serving in a Moscow bunker, Petrov received a warning of five incoming American nuclear missiles. The system instructed him to launch a counter-strike. But instead of reporting to his superiors, Petrov started thinking: would the United States not send more than five missiles if they attacked? Luckily, his doubts were legitimate. The warning system had erred and no strike was happening. Thanks to his doubts, humanity potentially avoided nuclear war.

The element which had no doubt in this entire scenario was the system – reporting that the reliability of its assessment was "highest" (277–278). The issue of *Uncertainty* (the title of the chapter) pervades through the alignment problem. Since algorithms do not express epistemic humility, how far should we actually trust them if they are sure about their own assessments? This affects many issues, albeit usually in less dramatic ways than with Petrov. For instance, Christian recounts how an image classifier will tag every image you give it, even if it is random static. Instead of opening up about its inability, or saying that it is unsure, the algorithm will give you a classification with more than 99% confidence (279).

In a different sense, uncertainty affects human agents as well. Specifically, we know that we have no perfect knowledge of the values we want to teach AI – and this is a problem. As the philosopher William MacAskill noted in his famous book *What We Owe the Future (2022)*, it is dangerous to think that we already know the correct moral values. What we see as normal may be completely abhorrent in the future. This entails, of course, a certain danger. Not only do we have to ensure that AI follows our values, but we must first define what these values should even be (306–307).

MacAskill identifies with the long-termist movement, a collective of people who think about ensuring a decent life for humans living in the very far future. MacAskill argues that one of the biggest existential risks to these people – and maybe the most likely one – is being under the spell of the wrong moral values (309). And it is possible that AI could solidify the wrong values, making it more difficult to improve on them. As Christian himself puts it: "We must take caution that we do not find ourselves in a world where our systems do not allow what they cannot imagine – where they, in effect, *enforce* the limits of their own understanding" (327, emphasis in original).

The scale of the alignment problem grows as one reads this book, as its implications and the obstacles to solving it become clearer with every page. Christian tries and mostly succeeds in giving an overview of the problem, while giving the reader enough knowledge on the underlying issues to understand it. There is little for which one could fault the book, except that an additional chapter on the human obstacles to the alignment problem might have been worthwhile. It would have been interesting to explore the human side of the alignment problem more deeply. We read much about incentives for humans and machines to learn, but little about *incentives for humans to teach.* Will autocratic states have a different view on alignment than democracies? Do all firms understand it the same way? Are there incentives for researchers to neglect alignment for the sake of quick deployment?

The book could have used a discussion on how to make humans follow the optimal course for AI alignment. Without this, the book seems to be missing an essential part of AI alignment – which is clearly noticeable in a work that gives such a comprehensive overview otherwise. This is a regrettable state, since one cannot help but ask these questions after having finished reading the book. The first step of the alignment problem is aligning our own ideas about alignment. If the reader is interested in exploring this, they will sadly have to reach for another book after having finished *The Alignment Problem.*

Brian Christian (2020): The Alignment Problem: How Can Artificial Intelligence Learn Human Values. London: Atlantic Books: 476 pages. ISBN: 9781786494313. Price 9,99 € (paperback).

John Lennox:
2084: Artificial Intelligence and the Future of Humanity

Reviewed by Philipp Koebe

In a world dominated by atheistic scientists and believers in technology, John Lennox presents a differentiated view of artificial intelligence and superintelligence with regard to universal divine characteristics in his work *2084: Artificial Intelligence and the Future of Humanity* . This critique of an atheistic worldview uses biblical analogies and evidence to introduce numerous new arguments into the discussion and broaden the perspective on AI.

John Lennox is a British mathematician, philosopher and Christian apologist, as well as an emeritus fellow of mathematics and the philosophy of science at the University of Oxford. He has published numerous books in which he explores the dialogue between science and faith and argues for the compatibility of science with a Christian worldview. His life and work reflect a unique combination of scientific excellence and deep-rooted faith. In contrast to other works on the subject of AI or superintelligence, Lennox focuses on religious-spiritual arguments, while other protagonists highlight Enlightenment rationalism or longtermism. This is certainly the main added value of this book in a discussion on this topic that has been going on for years.

The initial sections of the manuscript commence by delineating the potential and also the challenges intrinsic to artificial intelligence (AI) and superintelligence. Chapter 1 functions as a preamble to the discourse, introducing for the first time the historical oeuvre of George Orwell, which concurrently serves as an allegory for the book's title (11-13). In this context, explicit allusions are made to the conceivable hazards that a manifestation of AI might pose, concurrently outlining the author's overarching argumentative framework. Lennox underscores Orwell's *1984* (published in 1949) as a seminal work, positing mass surveillance and media information control as pivotal elements of the debate, contending that these are "ideas that nowadays increasingly come up in connection with developments in artificial intelligence (AI)" (13). Lennox further engages in a comparative analysis of dystopian fiction with Aldous Huxley's *Brave New World* and cites Neil Postman's insights from *Amusing Ourselves in Death* (12). Additionally, Lennox draws upon Dan Brown's novel *Origin* to depict a dystopian future, reinforcing his thematic exploration (13).

Chapters 2 and 3 pivot towards inquiries regarding the origin and trajectory of humanity. In pursuit of this, the author delves into a multitude of recent philosophical works so as to scrutinise the essence of AI. Key focal points include the works of Yuval Noah Harari, specifically *Sapiens* (2011) and *Homo Deus* (2015), with recurrent references to perspectives articulated by John Gray and Ray Kurtzweil throughout the monography. Lennox adeptly weaves an analytical narrative, incorporating arguments that substantiate his theses while concurrently addressing those he approaches with a more critical lens.

Chapters 4 and 5 of the monograph delineate diverse facets of weak artificial intelligence and elucidate its transformative impact on human lives. Emphasis is placed on authoritative studies in AI research, particularly those scrutinising the evolving landscape of employment (56-61). The text delves into the functionalities of digital assistants, AI applications in the medical domain, autonomous vehicle technology, and automated marketing (56-61). Lennox adeptly engages the reader through a highly informative and accessible introduction, effectively immersing them in the subject matter. The fifth chapter assumes a critical stance, scrutinising the precarious dimensions inherent in AI utilisation. Lennox scrutinizes extant models, such as the social credit system (which uses AI-facial recognition to assign citizens a social credit score based upon their behaviour and assumed trustworthiness), and issues encompassing data collection, manipulation, and surveillance via social networks and emerging technologies (68-71).The central focus of Chapter 6 is on transhumanism, with an exhaustive exploration of Harari's perspectives. Lennox critically examines Harari's assertions regarding the aspirational realisation of goals such as "a serious bid for human immortality" (86) or the pursuit of "ensuring global happiness" (87) through AI. Chapter 7 revisits the perils associated with AI governance, probing historical antecedents derived from authoritarian events. Chapters 8 to 10 pivot around an examination of human perspectives, particularly the diverse interpretations of morality and ethical values within religious contexts. Lennox posits that moral rationalism becomes "not liveable" in the context of AI integration, drawing parallels with the biblical narrative of the 'Fall of Man'. The concluding chapters (chapters 11-13) intricately interweave analogies to biblical passages, extensively quoting and contextualising them within the thematic discourse. These references, particularly enlightening for individuals without a Christian background, introduce novel arguments into the overarching discussion.

The overarching theme is Lennox's keen interest in the progressive trajectory of artificial intelligence, coupled with a nuanced critique of those who posit technological conquest as a substitute for divine existence. Lennox critically examines transhumanism, contending that the aspiration to supersede divine authority through AI is unfounded. He delineates clear distinctions between human capacities and the inherent limitations of AI. Lennox underscores the necessity for a higher authority in the development of AI models, akin to the example of China's social credit system. However, he cautions against the utopian notion of omniscient control by a select few, citing historical precedents such as National Socialism and Soviet communism as cautionary tales. Lennox rejects the misguided notion of creating an all-knowing authority to govern the world through a super-intelligent computer, advocating instead for reliance on an existing divinely guided system, as referenced in numerous biblical passages which critique attempts to attain divine abilities.

The book's title *2084* draws a parallel to Orwell's novel *1984*, depicting a dystopian society wherein technological means are employed for the comprehensive monitoring, control, and sanctioning of the entire population. Throughout the book, Lennox asserts that many possibilities portrayed in dystopian novels of the last century are currently technologically feasible in certain domains. However, the absence of a nationwide social credit system in China prompts him to acknowledge that the technical feasibility and societal acceptance of such a system, particularly within the context of the populous People's Republic with 1.3 billion people, remain unverified. Lennox addresses this example at various points. It underpins his thesis that an AI cannot be given the function of a sovereign power or even simulate one. Despite technological advancements and the concomitant wield of power by authoritarian regimes, instances of initial resistance to stringent measures surfaced in China during the coronavirus pandemic. Globally, widespread real-time surveillance and restrictions to freedoms encountered robust criticism and opposition, especially in Western liberal democracies. The implementation of such a system appears improbable in the foreseeable future within these democratic frameworks.

Lennox advocates for a tempered assessment of transhumanism, contending that access to transhuman technologies will not be universally distributed. He posits Silicon Valley as the focal point for these considerations, where tech billionaires and technology-oriented atheists aspire to transcend mortality. However, Lennox suggests that this pursuit might be confined to a certain sphere of influence, potentially failing to attain universal acceptance. He points out that transhumanism will be the goal or dream of a fraction of the population and that an injustice paradigm could therefore emerge. Despite notable progress towards achieving the United Nations' Sustainable Development Goals, Lennox emphasises that a substantial portion of the global population aspire to a better quality of life, free from hunger, exploitation, or subsistence, rather than pursuing immortality. The dichotomy between the pursuit of technological advancements on the one hand and the persistent, fundamental human needs on the other underscores Lennox's nuanced exploration of the societal implications of emerging technologies.

Lennox presents a somber outlook on the potential consequences of realising assumptions surrounding a world dominated by artificial intelligence. Despite extensive reference to documents, historical experiences, and risk assessments from the past century, the overly optimistic expectations of future technologies have proven to be inflated, while excessively pessimistic predictions about humanity have proven untenable. Consequently, the work *2084* can be characterised as a contribution to enhancing literacy in the future. It provides subsequent generations with inspiration, a foundational platform for discussion, and a means to critique prevailing opinions, thereby facilitating the anticipation of desirable futures and aiding decision-making processes. Lennox's arguments offer pathways of action that can play a pivotal role in strategic foresight within political, institutional, or corporate contexts.

In the realm of education, it is advocated that young individuals engage with the inherent conflicts surrounding superintelligence and the associated technologies and data processing. Furthermore, the work has the potential to contribute significantly to religious education across all denominations by fostering a harmonious relationship between technological progress and spiritual attitudes. The integration of Lennox's insights into educational curricula holds promise for cultivating a nuanced understanding of the ethical and societal implications of emerging technologies, thereby promoting a more informed and responsible engagement with the challenges posed by AI.

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