

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

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Abstract

Background

Across Europe there is limited attention paid in media, policy and empirical research to the situation of young carers (YCs) and their needs for support, while similarly to adult carers, they provide care to ill family members. The Delphi study, which provides the focus for this article, had the overall aim of exploring existing successful strategies to support AYCs (Adolescent Young Carers) aged 15-17 years. Compared to YCs, even less is known about 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.

Methods

A two-round Delphi study was conducted with 66 experts on YCs from 10 European countries. Topics included: (1) visibility and awareness raising of AYCs at local, regional, and national levels, (2) current interventions to support AYCs, and (3) future strategies to support AYCs.

Results

Experts reported that there is 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 AYCs differs, with most countries mainly offering support on a local level. Diverse views were expressed regarding future strategies to support AYCs. Experts highlighted the importance of specific legislation to formalize the rights of YCs, and the issue of whether young people should be safeguarded from caregiving or if this is part of regular family life. They also emphasised the relevance of available integrated support services for AYCs, including schools, family, health and social care.

Conclusion(s) with key message

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

Statement

Identification alone is not sufficient, rather recognition of YCs by society is needed combined with the necessary resources to ensure integrated AYC friendly support services.

1. 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: children and young people under 18 who provide or intend to provide care, assistance or support to another family member. They carry out significant or substantial caring tasks, often on a regular basis, 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 wellbeing of their family member [5].

Growing up with an ill family member is particularly recognized as a risk factor for mental health and well-being [4, 5]. Also, being an AYC increases health inequalities during the life-course [6, 7, 8, 9]. It is known that AYCs 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 [10, 7, 11, 12].

The number of recognised AYCs is relatively low yet varies per country and region [13]. It is important that AYCs are identified and recognized in order to positively impact on 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 their 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.

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 AYCs and to identify their future support needs and preferences with a focus on promoting their mental health and wellbeing. The Delphi study described in this article forms part of a larger EU Horizon funded research and innovation project [17] 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 wellbeing 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 AYCs by focusing on successful strategies to support AYCs.

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 AYCs on a local, regional, and national level; ii) current interventions to support AYCs and iii) on future strategies to support AYCs.

2. Methods

To address the above core aims, a two-round Delphi study among experts on YCs was conducted. The Delphi method is an acknowledged 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].

In this Delphi study, interviews were performed and after the first-round of interviews information from the expert panel evaluations was structured. In the second round, the feedback on this overview of findings of round 1 of the panel was monitored. At the start of round 1, the interviewer defined AYCs as: "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." Central in round 1 were the experiences with - and knowledge on - YCs. Interviews also focused on existing strategies and programmes (if available) to improve AYCs' mental health and well-being for YCs known by the expert panel. Specific attention was paid to the opinions of the expert panel on barriers and drivers of these existing strategies and programmes. Round 2 was performed to gather an insight into optimizing programmes and developing future scenarios to best support AYCs. Experts were interviewed for approximately 1 hour per round. The questions were semi-structured to be able to compare the results across experts, regions and nationalities, and also to ensure flexibility for individual input.

2.2.1 Participants

In total, 66 participants, i.e. 'experts' participated in the two-round Delphi study (see Table 1 for an overview per country. For the selection of experts, researchers from the EU ME-WE project identified a group of experts on AYCs or related fields in their respective countries which was balanced and comprised a mixed group from the fields of academia, policy, and health and/or social care and education sectors. 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, organization of events/programmes for YCs and/or young adults, development and support of care or social policies, practice: in health, social care or education fields). The eligibility of the experts was cross checked by the national investigator teams. 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.

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

	<i>Round 1</i>		<i>Round 2</i>	
	<i>n</i>	<i>Female n</i>	<i>n</i>	<i>Female n</i>
Italy	10	8	10	8
The Netherlands	10	8	9	7
Slovenia	9	2	9	2
Sweden	10	9	10	9
Switzerland	10	4	10	4
United Kingdom	13	9	13	9
Austria	1	0	1	0
Belgium	1	1	1	1
Ireland	1	1	1	1
Germany	1	0	1	0
Total N	66	42	65	41

2.2.2 Material and data analysis

Experts received an invitation for the individual interview by email, including a questionnaire in English or - if preferred - in the relevant national language (translations made by national investigators) to gather some basic characteristics such as demographics, occupation and experience with the topic of AYCs, and an informed consent form in which consent was asked for their participation and audio recordings of the interviews.

The individual interviews in both rounds were conducted via telephone, voice Microsoft Skype or face-to-face (only in Slovenia), using an interview script and recorded by means of a voice recorder or a mobile application. All individual interviews were transcribed in a text editor and relevant quotes translated to English. All national investigators discussed the preliminary results first with the national investigators and later with the investigators from the other countries. The discussion was summarized by the national investigators from The Netherlands who led the Delphi study. After this, a 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 [19,20,21] 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, then themes with relevant quotes were aggregated and analysed to gather insights into generic overall themes, but also on cultural or regional specific themes. An overall summary was written by the lead partner

about the most successful strategies identified to support Young Carers (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 AYCs. The summary was sent to all participants, and they were asked to read it prior to the second Delphi round. 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.

2.2.3 Questions

A semi-structured questionnaire was used for the individual interviews with the experts with an introduction on AYCs. The following 3 main topics were selected for the open-ended questions in the first Delphi round: 1. visibility and awareness raising of AYCs on a local, regional, and national level; 2. current strategies, interventions and/or programmes to identify or support AYCs (pros & cons); 3. future needs to support the well-being and health situation of AYCs. Whenever there was a lack of personal and/or public awareness on AYCs, then experts were asked to consider the experience of young adults without caring roles generally, in the themes for discussion.

2.2.4 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 including the assurance of full anonymity and the possibility to withdraw from the study at any stage without any repercussions. All experts gave consent for participation and use of the findings for publication prior to both round 1 and 2 of this Delphi study.

2.2.5 Procedure

The Delphi study ran over a period of 6 months in 2018 and identified experts received an invitation sheet with a demographic questionnaire to complete as described in the material section. Information was given about the Delphi procedure in two telephone, Microsoft Skype or face-to-face interview rounds and participants could identify preferred dates for the first and second round of the Delphi study and received a confirmation about the actual dates within one week. Participants received a reminder for the interview five days before the date/time. In case of a telephone or Microsoft Skype interview, the participant was rung up on the planned date and time and were given a short introduction about the interview and the topic of AYCs; this was followed by discussing the three main topics as described above. The national investigator strived to provide at least ten minutes discussion time per topic. The main topics and answers were summarized 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 and information was given about the second round of the Delphi study. The first Delphi round took approximately one hour 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, starting with a reminder for the interview and 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 AYCs across Europe and the future needs by various end-users and stakeholders to support the well-being and health situation of AYCs. The participants could reflect on these findings from the first round and adjust their own views and options to reach consensus. Again, the interview lasted for approximately one hour and the participants were asked if they were willing to participate in future studies on AYCs.

3. Results

The findings are presented firstly 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 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.

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	<ul style="list-style-type: none"> - Different abilities/accessibility of formal care for YCs in different regions - On a national level an increase of awareness by television programs 	<ul style="list-style-type: none"> - 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) 	<ul style="list-style-type: none"> - 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.
	Visibility and awareness raising	Strategies, interventions and programs to support AYCs	Future needs to support well-being / health situation
Sweden	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 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. 	<ul style="list-style-type: none"> - 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

- 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
- 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.

	Visibility and awareness raising	Strategies, interventions and programs to support AYCs	Future needs to support well-being / health situation
Switzerland	<ul style="list-style-type: none"> - 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) <ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 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., organizing 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 	<ul style="list-style-type: none"> - 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

- 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')
- Professionals need to be more aware of AYCs and understand issues in order to support AYCs better
- NGO's need more funding
- Whole society is responsible and need for a cultural change

	Visibility and awareness raising	Strategies, interventions and programs to support AYCs	Future needs to support well-being / health situation
Italy	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - A couple of known interventions (support action in a school and by ANS in area of Carpi (in Northern Italy)) 	<ul style="list-style-type: none"> - Need for information and training for all health and social professionals and policy makers - Long-term multi-actor programs (ICT app) - Promote self-awareness - 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

	Visibility and awareness raising	Strategies, interventions and programs to support AYCs	Future needs to support well-being / health situation
The Netherlands	<ul style="list-style-type: none">- Low visibility and AYCs do not always recognize themselves as AYCs.- Differences in visibility between regions, municipalities are responsible for support adult caregivers and well-being of youth (struggle)- Formal policies exist on informal care, but not young carers- Schools could play an important role for increasing visibility- Welfare organizations and youth healthcare try to increase visibility	<ul style="list-style-type: none">- 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	<ul style="list-style-type: none">- AYCs should be seen as a specific group of informal carers- Focus on AYCs own strength and do not 'problematicize' 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 co-creation with AYCs.
- Need for integral approach (welfare, healthcare, educational and local governments that work together)

-

	Visibility and awareness raising	Strategies, interventions and programs to support AYCs	Future needs to support well-being / health situation
Slovenia	<ul style="list-style-type: none">- AYCs are an overlooked subject in Slovenia and also not regulated under any law- The importance to develop a definition, emphasizing that it does not relate to short-term, but long-term care- Organizations that are in contact with young people should be responsible for detecting the problem (primarily school, physicians and organizations engaged in the field of social home care)- There is no awareness about AYC in the educational field.	<ul style="list-style-type: none">- Develop an integral approach, coordinated by different ministries, with cooperation of schools and other public institutions and NGOs, connected to children and their wellbeing.- 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 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)

	Visibility and awareness raising	Strategies, interventions and programs to support AYCs	Future needs to support well-being / health situation
International/ Europe	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 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

Visibility and awareness raising

In the first round, experts reported on the low visibility of AYCs across Europe, including a lack of systematic studies on the subject of AYCs. The term YCs is not recognizable 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 AYCs is low. Hence, when visibility and awareness is raised then 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. According to some of the experts, this also contributes to difficulties in identifying and reaching AYCs because they can fall in between different care or support systems/legislations.

"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).

"Firstly, I would like to emphasize, that this [YCs] is a relatively overlooked subject, especially in Slovenia" (P1, R1, Slovenia).

"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 programs to support AYCs

Experts from most countries reported that there are existing support programs, projects and activities relevant for AYCs. It is relevant to note that there were differences reported within countries and between regions. Overall, whether formal support is available for AYCs or not can depend on the regional availability of care for this group. The available programs do not always target AYCs in particular as shared by experts from Italy and Switzerland. The programs differ in their approach by targeting individuals or groups, their duration and frequency, and demonstrated effectiveness of the program. Experts shared a variety of strategies, interventions and programs, such as support groups for children and adolescents with a parent or sibling with a disability or illness. By these support groups, AYCs are provided with information and realize they are not alone. Respite care is also important to support AYCs according to the experts, with activities in which AYCs can relax and detach from their home situation for a while and to get in contact with fellow AYCs 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. Further, experts explained that to follow a whole family approach, support groups for families have been set up in various countries and some programs provide a combination of the above-mentioned programs. Finally, training programs 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 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)

"For example, we used to deliver a project when I was working in South London, a programme that's called Kidstime. That's where young carers who are impacted by the mental health condition of a parent the whole family will come to an evening where they will do some group work together to help them to understand about a theme [...]" (P10, R1, UK)

"Different group activities for children and young people with parents with substance abuse or mental illness [exist]" (P2, R1, Sweden).

Within the interventions and programs, experts reported a focus on a number of coping strategies of young carers, such as providing AYCs tools to try to gain control over the situation. In addition, several experts raised that AYCs may often feel responsible to do what is needed and might not self-identify as an AYC, because they may find caring normal and they may not be aware of the concept of YC.

Furthermore, according to a number of experts, AYCs 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 AYCs with a focus on supporting their well-being / health situation

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

Some experts expressed the need for specific legislation for the group of AYCs and addressed the discussion about how far the responsibility for care tasks reaches for youngsters and stated that there should rather be less inequality within countries for access to support services. For AYCs themselves it is relevant that they can get in touch with fellow AYCs, face to face and/or digital, according to the experts. Furthermore, schools should rather be more flexible to the group of AYCs 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 and family is involved with collaboration between stakeholders from social care, healthcare, government, and education. Experts reported that such an integral approach is needed in which knowledge is shared and disseminated.

"A home care professional or community nurse of course sees a lot. When a young carer is present in a family [...] what you would like is that all those professionals are aware of the role of young carers and feel free to ask about it and make referrals to support." (P1, R1, The Netherlands)

"Education is a big issue for them [young carers]. So, I think the education support on one-to-one basis would be very good. I think recognition from the school in terms of flexibility, in terms of the time." (P2, R1, UK)

"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 synthesized findings and results from the consensus 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 AYCs. To support the visibility of AYCs across Europe, most experts agreed and expressed the need for a European NGO with structural funding independent of national budgets and there should be less inequalities within and between countries. Experts mentioned a lack of recognition and knowledge among those actors working with AYCs in - among others - social care or schools. In Switzerland it was noted that low visibility is also related to Swiss families not speaking about these issues because they fear interference from the social services. In Swiss families, children tend not to talk about their caring roles as it is viewed as being private and hidden. According to some experts, an increased visibility of AYCs might also have a negative effect. Visibility means recognising AYCs as a problem, which could contrast with the idea of a family where it is viewed as natural for family members to help and support one another. Most experts agreed that we should consider the needs of AYCs and that AYCs themselves might not want attention whenever we target this group by creating visibility. Based on the synthesized findings, experts agreed that various activities are organized for AYCs across Europe. To increase visibility, Italian experts shared that it is positive that actions - currently targeting other groups - could be applied and/or transferred to AYCs. Such as an ICT app to share information about health and social services, peer-support, workshops in schools, support to children of parents with mental illnesses, programs to prevent earlier educational system dropouts, alternative school programs, and more generally the application of a whole family approach.

"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 formation that the individual has had or to personal experience [...] This in regard to visibility." (P3, R2, Italy)

"I would expect that the UK is further along in terms of visibility and awareness but it's still nowhere as perfect and so it's maybe just further along on that scale in terms of the types of things that are being identified [in other countries]" (P2, R2, UK)

"Well, I totally agree with the visibility and awareness raising with all the points mentioned [...] one of the hardest points is to identify young carers which says the term young carers is not recognisable in all countries and so I think this is crucial to identify young carers." (P5, R2, Germany)

Awareness Raising

As found in Round 1, awareness is steadily increasing, according to the experts. Experts reached consensus about differences in the level of awareness on the topic of YCs in organizations such as schools, welfare organizations and social services, with there being greater awareness in the UK, followed by Sweden and the least awareness in Slovenia and Italy. Moreover, 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 are reports, brochures, films, social media, and mass media such as TV, radio and the press. Television programs and social network campaigns in particular, were considered by the experts as good ways for

improving awareness. By sharing individual stories in posts or films, awareness can be raised according to experts. However, experts questioned whether a campaign would be useful or would have any effect regarding visibility and awareness raising. Some experts stressed 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. Some Swedish experts reported that the YCs they know like to get attention, which contrasts with the results from some other countries. Dutch experts confirmed an increasing national awareness on AYCs with a considerable shift compared to the first round of interviews. On an international level, knowledge could be disseminated at international conferences. The information should include a definition of the term AYC, AYCs' life situations, what are AYCs' rights, their families' rights and available support. An introduction of a national/international day for AYCs was also proposed.

"[...] awareness is not just an issue with teachers and adolescent young carers, but it is also an issue about healthcare providers of the parent. I think there is also a complete lack of awareness." (P3, R2, Switzerland)

"[...] 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 agents[1]. There are films on the Swedish Family Care Competence Centre's website, where children and youngsters tell their stories, making it lifelike and clear" (P6, R2, Sweden).

"I think that we have caught up in the extent to which young carers are visible [...] the fact that the Children's Ombudsman has done research into it [YCs] and that there is a letter to parliament reflecting that. Apparently, the time is right for thinking about these issues more seriously. And we've moved beyond the phase in which every municipality is muddling through a bit by itself." (P6, R2, The Netherlands)

Identification

Experts from diverse European countries acknowledged that on a national level they struggle with 'formally' identifying AYCs. Whenever AYCs are identified, and if they are acknowledged, then formal support is needed to be put into place, according to experts. According to Swedish experts and the expert from Ireland, identification implies acknowledgement that AYCs 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 acknowledge that children may be afraid that whenever they are identified, that they will be taken away from their home by social services. Finally, experts also stressed that immediate referral to a YCs service may not be what all YCs need, particularly at the first instance of a parental ill- health diagnosis.

With respect to responsibilities for identifying AYCs, the primary responsibility is - according to some experts - on the school system while in addition, many experts agreed that it should be a routine that health care professionals always ask about children and whether they have any needs when a parent is

ill. Screening, assessment and early identification is needed, and several experts agreed that adverse childhood experiences (ACE) screening could be used as a tool to identify AYCs. Social conditions of a child should be screened when enrolling to kindergarten/school and ACE could be supported herein.

Experts suggested integrated actions in which educational, social and health services should be involved. Italian experts highlighted that in Italy, one of the main weaknesses of the Italian educational system in managing AYCs is the lack of awareness and knowledge among school professionals, in particular schoolteachers, and the absence of a multidisciplinary team in the school embedding psychologists. However, in contrast to the advantages of involving schools in identification and support, some of the experts did express concerns with too high expectations concerning schools due to limitations in availability, funding, time, and formal responsibilities. Nevertheless, experts agreed that schools may act as a gatekeeper and detect AYCs via screening.

In the UK, it was acknowledged that it is quite unique that a carers' assessment already exists. However, experts argued that it is crucial to have a follow-up, which was also perceived as being a problem in the UK to provide actual help as they acknowledged that funding is lacking. Further they admitted that there is no value in assessment without having a follow-up as well as funding, time and people to carry out follow-ups. Experts viewed that the responsibility for developing programmes and strategies is primarily on the State, to support and develop laws and regulations, considering AYCs, and to provide them with information and additional help to relieve AYCs. Current cutbacks in services across Europe, Brexit, and the increasing welfare, care, and health costs were viewed by many experts as the main barriers for effective follow-up and interventions. Experts stated that without proper services in place, the identification can feel meaningless at best, and harmful at worse.

*"We use 'Föra barnen på tal'**[2]** with all parents who receive support from the disability care centre. We perform conversations about their children once every six months, when we write their individual support plan. We do this because the children grow so fast and you need to ask for different things due to the children's ages. And we sometimes talk to each individual child [...] there the parent also has an opportunity [...] or you together with the parent, have the opportunity to see if the child's responsibilities are acceptable in relation to the child's age" (P5, R2, Sweden).*

"This [carers assessment] is something we recommend in general for carers. So, it's nothing really specific for children as carers but this needs to be a programme in general for carers and whether by this it will be possible to identify more or to better identify children as carers, I'm not even sure, but at least it could be. I think it's the only instrument that might bring us a bit further. And this is also an area for further research [...] of such programmes." (P1, R2, Austria).

"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 of YCs and AYCs. Experts agreed that there needs to be a shared and common definition of AYCs across the world, which is crucial for identifying them. However, it was acknowledged that AYCs experience their caring role differently, so a common terminology might not necessarily reflect the definitions of YCs and AYCs themselves and labels can have different meanings. However, most experts agreed that there is a need for a general language or terminology across Europe. 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 also emphasized the importance of developing a definition of AYCs and stressed that it is important to be cautious not to invent the problem by forming too broad a definition of AYCs. Experts stressed that we should be cautious that the term AYC has a negative connotation and becomes a label, in particular in research where academics try to give insights for helping operators 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)

"About our Swedish approach being [...] more 'children as next of kin' [...] That we have this approach in Sweden, also says something about our view of 'children as next of kin' [...] children as victims, children as exposed, children as vulnerable. [...] Children as 'young carers' is more about children who actually do something, who is an actor. We have to gather these two, I think. It's not one or the other, it's both together" (P2, R2, Sweden).

"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 a family perspective is indeed needed to support AYCs. Most of them agreed that it is needed to work with family and to empower them, so that we could avoid that AYCs become burdened with care work. Whenever starting from a family perspective, it can open up opportunities for identifying AYCs and the roles and needs of all family members. In addition, starting from a whole family approach can provide concrete, practical and emotional support to all family members, thus relieving AYCs and arrange follow-ups, according to the experts.

Experts reported that there is a need for better services for the care recipients as well as for relief and respite for the carers. For interventions to be successful, it is also relevant to have the family involved in

the intervention. According to an expert, the weakness of support interventions is that they typically only reach AYCs and not the whole family. 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, according to experts.

"In my opinion there is the need for an approach that involves the family too, so a global approach." (P6, R2, Italy)

"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 optimize that if it comes in too late." (P3, R2, UK)

Interventions and personalization

According to the experts, interventions for AYCs exist on a local level, and then mainly in the UK, Sweden, and The Netherlands. In the UK, the voluntary sector has historically provided the most support for AYCs compared to the governmental sector which lags behind in providing support. Experts reported on flexible interventions that are tailored to different AYCs' needs, that could differ for social, financial and individual conditions. From the Swedish results, to be able to explain what they need and want, AYCs first need help to reflect on their situation, their perceptions, experiences, thoughts and feelings. Some experts pointed out to provide support and interventions at schools. As noted earlier, creating flexibility for students is important according to experts, for example with support of a carers' card to ensure flexibility in homework and exams. Furthermore, experts value long-term commitment of schools to the topic of caregiving. 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 transitional services. In the Netherlands and in other countries several interventions within schools are running, such as an online communication and information space for YCs (e.g., via Microsoft SharePoint), expertise lab, elective course, student symposia, drama, guest lectures and awareness programs such as the UK 'Who Cares' programme. Despite some successes, experts acknowledged that the interventions are - without creating new specific professions or roles - too dependent on the workload and possibilities of teachers, whenever it is not their main responsibility to support AYCs.

With respect to welfare, some experts discussed that interventions should focus on the provision of information by e.g., information flyers, children's helplines or a national information campaign. AYCs also need to receive information about their rights. Furthermore, AYCs need access to tools and support to find useful coping strategies which is a relevant requirement for intervention and support programmes,

according to the experts. Experts argued that group support for AYCs such as peer groups are needed to provide children with the insight that they are not alone which can also empower them. Hereby supporting those children to move on but also to build on their experiences as building their own resilience. Resilience can potentially be increased by getting away from home and participating in summer camps and other activities together with children/young people in similar situations. AYCs can also be supported by being given the opportunity to be involved in completely ordinary activities with children/young people who do not have similar experiences. 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. Also, experts mentioned mentoring and individual support, fun activities and respite care. Furthermore, experts reported that AYCs 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 AYCs, (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 some AYCs may state that they do not need or want support, for example because they do not want to be medicalized. Moreover, it is important not to simply focus on and create new programs and interventions specifically for AYCs, as support for AYCs could be inclined in already existing interventions and programs designed for e.g. 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.

“A network meeting for family counsellors and family coordinators in municipalities [is a supportive intervention]. As a result of the network meeting, several of the municipalities that did not do this before, have raised the issue in their municipality and, at least one municipality has signalled that we have now gotten the ok to work with this group of children” (P1, R2, Sweden)

“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)

“Yes, I think that the local government should provide some guidelines. And that this target group [...] is recognized and that policy is made, but also resources are made available. Because that is of course often not yet the case. And that they’re willing to work together with one another and share knowledge, because otherwise they will remain [...] separate activities that run in parallel to each other. And that’s a waste of money.” (P10, R2, The Netherlands)

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 AYCs, 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 of e.g., an information platform or app. UK experts also pointed to digital online based peer support to be most effective with AYCs.

Experts from a variety of countries pointed out that whenever an app for AYCs is built, then the organizations behind the initiative also have a responsibility for control by means of moderation and support of dedicated professionals and structural financing for continuation. Furthermore, the information should rather be directly available and not hidden within a complex website with lots of other information. 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 AYCs.

"I think they [ICT apps] are still in development at the moment, at least one that I'm aware of in the UK that's targeted at carers more generally. And that obviously will have benefits to the young carers as well. So, I think that's an effective and perhaps innovative way of trying to get information to people and particularly young people." (P2, R2, UK)

"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)

Laws and regulation

A considerable number of experts reached consensus and expressed the need for laws and regulations to formalize 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 does 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 young carers.

Some experts are impressed by the Acts 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 AYCs 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 a very small actual significance for the individual. Experts from Slovenia also emphasized that there is no need for creating a new system/legislation, or a new law as also reported by experts from The Netherlands, while 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.

"What I found really striking, in the UK, the legislation does talk about the rights of the person with care needs and the young carer. And since it's sort of in that caring relationship, it's striking how that's missing in the strategies and interventions kind of part of the relationship. [...]. I think that was quite remarkable, really." (P3, R2, UK)

"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)

"I mean a legislative framework is extremely difficult to change in Switzerland and I'm not sure if that's the realistic way to approach this [...] there are very big topics that we lack a legislative framework and that's very difficult in the current climate to change that so I'm not sure that that should be the main focus and if so it would be on a Canton level which again means you would have to address 26 different Cantons and work on legislative frameworks there so that's very difficult." (P3, R2, Switzerland)

Training, Education & the Role of Schools

According to the experts, there is a need for increasing the efforts in training and educating care and welfare professionals about AYCs and how to support them. In addition, schools should be more involved in identifying and supporting AYCs with trained personnel. As already discussed, at the same time experts considered the scarce available time among teachers. Experts explained that professionals need to be educated about AYCs, about their situation and what professionals can do to support them. There could be training days, or form networks that meet regularly and work with various themes. Such education for professionals should be included in the professionals' basic education programs. Experts admitted that training should rather be organized for all sectors (health, educational, and social). Experts argued that there is a need for a common knowledge base including: how to approach children, young people and parents; how to identify AYCs; how to talk to AYCs; how to continue once a professional has identified an AYC; and available support efforts, also at schools.

"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)

[...] School and college does seem to be very important for young people, young carers. And to support that, then schools do need multiple counsellors or more funding, more dedicated staff." (P3, R2, UK)

[...] a school should be able to be flexible, [...] when a child misses her or his mother for three weeks and therefore can't do her/his homework or take exams." (P9, R2, The Netherlands)

4. Discussion

The study is the first cross-national Delphi study on AYCs providing relevant insights into the visibility, awareness, interventions and future support strategies of AYCs 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 AYCs in two interview rounds and reached consensus on the visibility and awareness raising of AYCs on a local, regional, and national level. In addition, several strategies, interventions and programmes were identified and agreed on by the experts to support AYCs. Finally, experts shared their knowledge and reached consensus on future needs to support the well-being and health situation of AYCs.

In respect to visibility, AYCs 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 AYCs across nations, with varying degrees of visibility and supportive resources available dependent upon the country. However, despite differences among different regions, visibility and awareness are increasing in most countries and there are many initiatives to support AYCs 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 emerging countries such as Italy, The Netherlands and Switzerland. Although the present Delphi study was not intended to provide a classification, the classification is likely shifted for some countries compared to 2017. As discussed, support for YCs in the UK is decreasing due to decreasing 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 differs between the social, healthcare and education fields and that professionals from the health care and education sector are more familiar with the term young carers, but feel less responsible in

comparison to professionals from the social sector. Successful awareness campaigns using television and social networking and the media echo of these activities 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 AYCs have difficulties in identifying themselves as AYCs and vary in their experiences and care they provide, a general overall definition and concept might be challenging to construct. Nevertheless, localized or nationalized definitions can potentially support (self)identification of YCs and AYCs. The present Delphi study shows that tools to identify young carers in schools, welfare or health care, are needed. Moreover, a European or worldwide NGO for AYCs could support in dissemination of current knowledge on identification and support for educational, welfare and health care sectors. An NGO for AYCs can also - potentially - ensure the continuation of these activities independent of funding. In respect to identification, other countries can learn from the UK, where there already is a carers' assessment in place. Whenever AYCs are identified and made visible, then society must recognise AYCs and also acknowledge their situation as a challenge that needs formal support.

Providing formal support to YCs can be difficult since informal care is emphasized by the fact that care is provided on a voluntary basis and usually without financial compensation [23]. According to some experts AYCs should actually not be carers in the first place. However, it should be noted that AYCs are there 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, such as - among others - respite care, information, social contacts, 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 formalize the rights of AYCs 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 AYCs and in the present Delphi study, some experts expressed that the rights for AYCs are already covered in existing (non AYC specific) legislations or could be included in existing legislations for social support or informal care.

In respect to interventions for AYCs, rich insights were gained in the UK successes and the hundreds of (school) programmes and interventions to support AYCs. However, as noted before, these initiatives are mostly based on temporary funding, so that currently when the UK economy is becoming bearish [25] and the Brexit in 2020 might even cause more cuts in care and support, actual help and follow-up is lacking. This implies that AYCs' support should be an integral part of health and social care or welfare. Experts addressed the need for integrated care and support for AYCs, in which schools, welfare organizations and social services work closely together. Integrated care can help to potentially improve the quality of care, engage in better performance management, interprofessional teamwork, and make clear the different roles and tasks including commitment [26]. Professionals need to be educated about AYCs, about 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 an exemplar on how to implement a carers' ID, yet, it is unclear if such an ID will be accepted and successful in other national contexts of use.

Overall, experts acknowledged and reached consensus that support programs need to be sensitive to the individual situation of carers, offered in different sectors such as educational, welfare and health care sectors and aim to (i) raise awareness and identify AYCs early on, (ii) improve skills and provide emotional support to move on and strengthen resilience- also at as early a stage as possible in the care process (prevention, peer support and gatekeeping), (iii) provide respite from caring, (iv) ensure that children are aware of and can access their rights, (v) provide support for the person that is being cared for and follow the whole family approach, (vi), reduce stigma about mental illnesses and increasing the reputation of care, and (vii) respect the (variety in) needs of young carers by being developed in co-design with young carers.

Furthermore, the Delphi results further show that overall, to support AYCs, 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 AYCs - such as an app or online platform - could overcome inequalities between regions and countries to ensure that all AYCs can receive a basic level of support [14,15]. In fact, the development and/or provision of an online platform or app for supporting AYCs is preferred by many of the experts who participated in the Delphi study and such an app should 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 e.g., information 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].

From the Delphi study, recommendations can be provided on the basis of 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 (who are the first educators of adolescents and youngsters). At the research level it would be recommendable to fix parameters to identifying AYCs agreed across the scientific community albeit country sensitive, i.e. calibrated on the cross-national cultural specificities and services provided. Moreover, as discussed, a common definition of "adolescent carer" and "young carer" needs to be agreed. This may better the quality of the research and the comparability of international results and may strengthen the evidence of the efficacy of interventions and policies to design evidence-

based psycho-social interventions and services. Research on AYC is a precondition not only to develop a comprehensive support to AYCs, but also to identify the main gaps in the social and healthcare systems that should be addressed as a priority in order to release the burden from AYCs. The results from the present study can be used to define future research. To be effective in promoting AYCs' healthy functioning, support interventions should be evidence-based and randomized controlled trials are lacking and 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 AYCs, by means of an open listening of AYCs' needs and an open dialogue with professionals can lead to co-design 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 (BLN) employed within the EU ME-WE project [17]. A BLN is 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 [28]. Concerning the educational, welfare and health care sectors, training for teachers and health professionals and social workers would be needed at local level for enhancing the capability of recognizing AYCs, help orient AYCs to the most appropriate service avoiding paternalism and involuntary processes of stigmatization. Also, it is valuable if the educational, welfare and health care sectors strengthen their cooperation and hence, more integrated care could be offered 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 young carer or the care recipient.

To address the general lack of awareness facing AYCs across Europe, as also found by Leu & Becker [13], following on from the Delphi study findings that media campaigns are recommended to increase awareness that young people can be carers of society in general. At national level, guidelines for the identification and management of AYCs 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 supporting NGO's 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.

No study comes without limitations, and the main limitations of the study are related to the recruitment of the experts, the means for conducting the interviews, and the involvement of multiple different interviewers and research staff in the diverse countries and thereby a variation in the qualitative data 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. 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 AYCs. 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 AYCs 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 via Microsoft Skype to face-to-face interviews. It is possible that the various ways of holding the interviews 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 [29]. 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 [29]. 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 mother language of the interviewees (e.g., Dutch, Slovenian, and Italian), a relatively large group of national investigators who spoke the native language of the interviewees were required for the Delphi study.

5. Conclusions

In this cross-national two-round Delphi study insight was provided into the visibility, awareness, interventions and future needs of adolescent young carers (AYCs) across Europe. 66 experts on AYCs 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 AYCs and the difficulty to identify AYCs. Identification of AYCs is crucial for supporting them and requires a common definition of AYCs and possibilities for young adults to identify themselves as YCs. However, identification alone is insufficient, as recognition of YCs by society is needed, and resources are needed to arrange integrated support services for AYCs. Furthermore, the level and the type of support available for AYCs differed between countries, with many countries mainly offering support on a local level and not on a national level. Different views were found concerning specific legislation and needs for future support. Experts recommended to take actions to increase awareness of AYCs in society at large and especially in sectors such as education, welfare and health care. Practical tools are also needed to identify AYCs and assess their needs. The need for offering integrated support services - that address the variability in needs of AYCs - to AYCs including their schools, family and the welfare and health care was stressed. Concluding, although there are country differences in the level of awareness,

visibility, services and needs for support for AYCs, many overlaps between countries were observed in challenges to accurately address the often-overlooked situation of young carers in Europe.

Abbreviations

ACE: adverse childhood experiences

AYC: Adolescent Young Carer

EU: Europe

ID: identification

MA: Master of Arts

MSc: Master of Science

PhD: Doctor of Philosophy

YC: Young Carer

UK: United Kingdom

Declarations

Ethics approval and consent to participate

Ethics approval was not deemed necessary in any of the six countries according to national regulations NL: the ‘Medical Research Involving Human Subjects Act’ (WMO, 1998/2020); IT: “Balduzzi Law”, n. 189/2012, art. 12, c.10 and the Ministerial Decree n. 96 /2013; SE: ‘Swedish Act concerning the Ethical Review of Research Involving Humans’ (SFS:2003:460, 3-5§§); CH: The Human Research Act (HRA), Federal Act on Research involving Human Beings of 30 September 2011 (Status as of 1. January 2020, SR 810.30); UK: The UK Policy Framework for Health and Social Care Research (2017); SI: ‘Slovenian legislation about conducting research’ (2014, p6).

Participants were recruited as professional, policy and research experts and were asked to contribute with their views and experiences. The project researchers considered that there was an extremely low risk that the Delphi interviews compromised the physical or psychological integrity of the participants in any way. No sensitive personal data were collected. All participants were recruited on a voluntary basis in accordance with international regulations and declarations and guidance documents, i.e. Declaration of Helsinki (1964, 2013); Council of Europe Convention on Human Rights and Dignity of Human Being with regard to the application of Biology and Medicine, Oviedo, (1997; Universal Declaration of Bioethics and Human Rights adopted by UNESCO’s General Conference on 19 October 2005.

Written informed consent was obtained from all participants across the six countries by the project's national research teams. The Delphi interviews were conducted after receiving the signed informed consent forms from the participants.

Consent for Publication

Not applicable.

Availability of data and material

In accordance with the ME-WE project's data management plan, the datasets used and/or analysed during the study are available at the end of the project from the corresponding author.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

HHN, RH, NdJ, LL contributed to the study design, conducted the NL and International/European data collection and analysis and the cross-national data analysis and synthesis work. FL conducted the UK data collection, analysis and interpretation. SS, MS, BD'A, LB, GC, AM conducted the IT data collection, analysis and interpretation. RB conducted the SE data collection, analysis and interpretation. KS, VH, TR, TH conducted the SI data collection, analysis and interpretation. AL, FB conducted the CH data collection, analysis and interpretation. LG and LM contributed to analysis. HHN was responsible for writing the first and all consecutive drafts and the submitted paper. EH contributed to the study design and writing, reviewing and refining of the manuscript, acquired the funding and led the ME-WE project consortium. All authors provided critical commentary in the draft revisions. Further, they all approved the submitted version of the manuscript and agreed to be personally accountable for the accuracy or integrity of any part of the work.

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