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Where are we in the Recognition of Young Adult Carers in France?

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Abstract

Young adult carers (YACs) are people aged 18-25 years who provide care to a relative who is ill or has a disability. France begins to come to the YAC issue. YAC students were mentioned for the first time in a national policy document in 2018. By interviewing 110 students, this review showed that more than 80% of them did not know what a YAC was. If students are not aware of this status, they cannot self-identify as carers and seek support. During policy development, it is therefore important to support YACs by raising awareness.

What is a Young Adult Carer?

Individuals who provide regular, nonprofessional assistance with activities of daily living or support to a relative who has an illness, disability, or loss of autonomy due to age, are called *carers* (Blanc, 2010). Carers are often adults, but can also be children, adolescents, or young adults, in which case they are referred to as *young carers*. The term *young adult carers* (YACs) is used to define the 18-25 years age group (Levine et al., 2005). YACs are therefore young people “who provide or intend to provide care, assistance or support to another family member on an unpaid basis. The person receiving care is often a parent but can be a sibling, grandparent, partner, own child or other relative who is disabled, has some chronic illness, mental health problem or other condition (including substance misuse) connected with a need for care, support or supervision” (Becker & Becker, 2008a, p. 6).

Only few studies investigated YAC prevalence. Among the youth, prevalence is reported to be 18.10% in the United States (Grenard et al., 2020), 6% in Australia (Australian Bureau of Statistics, 2016), and 9.80% in New Zealand (McDonald et al., 2009). There are no prevalence studies among youth in Europe while Becker and Becker (2008a) estimated that 5.30% of 16-24 years old are carers in the United Kingdom. Regarding specifically the student population, only one study investigated it in Norway and put it at 5.50% (Haugland et

al., 2020). Among French students, an initial estimate put it at 19% (Dorard et al., 2021). YACs are acknowledged to be an understudied population (Levine et al., 2005) who need to be specifically targeted (Day, 2015).

Taking on a caregiving role in young adulthood has been associated with poorer physical and mental health, as well as reduced education, employment, and future life opportunities (Becker & Sempik, 2019; Kettell, 2018). Kent (2020) recently argued that it is time to recognize and support YACs, highlighting the need to examine current policies, cultural narratives, and norms surrounding family caregiving.

Awareness and Policies Worldwide: The French Situation

In a cross-national study and in line with Leu and Becker's (2017) classification, Leu et al. (2022) ranked countries according to their awareness and policy responses to young carers. They identified seven levels of awareness: (1) incorporated/sustainable (i.e., extensive awareness with sustained and sustainable policies, legal rights, and services); (2) advanced (i.e., widespread awareness with specific legal rights, but policy responses still fragmented and not sustained); (3) intermediate (i.e., some awareness with some dedicated services, mostly local but a few nationwide, with partial legal rights); (4) preliminary (i.e., little awareness with few, if any, dedicated services at national or local levels, and no legal rights); (5) emerging (i.e., growing awareness but with no specific services); (6) awakening (i.e., embryonic awareness with the idea of *vulnerable children*); and (7) no response (i.e., nonawareness). These different levels of awareness reflect a wide range of policies and legislation, from protection and support with a clear definition of young carers to a total lack of recognition (Leu et al., 2021). Nevertheless, no country has yet reached the incorporated/sustainable level. The top levels implies that young carers are precisely defined in legislation and benefit from clear legal rights such as financial grants or right to respite. It also implies that they benefit from specific service frameworks within all academic institution

and local health services through national programs and practice models (Leu et al., 2022).

Above all, the top levels of awareness could not be reached until responses and law built are not based on reliable research evidence and clear legal rights (Joseph et al., 2020).

Young carers, and more precisely YACs, more often than not go unrecognized and fall into a gap between adult and children's services (Becker & Becker, 2008b; Leu et al., 2021). In the United Kingdom, classified as an *advanced country*, specific legislation to protect and support young carers are well developed. Nevertheless, there is no national services policy which results in unequal offers across the country (Leu et al., 2022) and only few services are specifically designed for YAC as carers aged 18-25 (Becker & Becker, 2008a). Regarding *intermediate countries* such as Australia, or *emerging countries* like the United States, there is no support service infrastructure (Day, 2015; Hamilton & Adamson, 2013; Kent, 2020).

France is an *emerging country* with growing public and specialist awareness of young carers, as is also the case of countries such as Ireland, the United States, and Finland (Leu et al., 2022). Since 2016, an NGO called the National Association for Young Carers (Jeune AiDants Ensemble; JADE) has been working to increase awareness and offer respite for young carers. Initially active at a local level, JADE is currently extending its presence across the country. In parallel, other NGOs have been developing specific responses to young carers' needs, such as the creation of support groups or hotlines (Thual, 2021). Currently, no public services specifically target YACs. The COVID-19 pandemic drew attention to young adult students' needs, and several support solutions were put in place (e.g., Charbonnier et al., 2021), but YAC students remained invisible. Within the scientific community, specialist awareness has increased, with new research projects focusing on young carers and the YAC issue. These projects span several disciplines. For example, in psychology, the University Paris Cité is the lead partner in funded projects focusing on the education, health and wellbeing of young carers and YACs, as well as the awareness of health professionals. In law,

funded projects hosted by the University of Aix-Marseille are examining carers' legal rights, with a focus on YAC students. Research so far has led to the development of training programs for carers, aimed specifically at young carers and YACs in several French universities. At the legislative level, the Carers' Act passed in 2008 concerned all carers without distinction. More recently, a carers action plan ("Agir pour les aidants") launched in October 2019 identified young carers as a distinct social group for the first time in a national policy document. Two of the measures concern young carers: the first is designed to enhance the awareness of education professionals, and the second one gives YAC students greater flexibility in their pace of study. This strategy assumes that education professionals and young adult students are actually aware of YAC issues, for how can young adult students benefit from it if they do not know what a YAC is? This raises the question of how aware French students are of YAC issues.

Investigating French Students' Awareness of YAC Issues

Compared to other European countries, the pursuit of studies in higher education is a strong societal expectation in France (van de Velde, 2008; Minni & Galtier, 2015). Under this "diploma tyranny" (van de Velde, 2008), in 2016, only 8.8% of 18-24 years had no diploma and was not in education or training program (Institut national de la jeunesse et de l'éducation populaire, 2019). This is partly explained by the difficulty of finding a job without a higher education degree (Minni & Galtier, 2015). The pursuit of studies is facilitated by particularly low university fees and national grants. In this specific context, it is then expected that YACs could be students.

As part of the CAMPUS-CARE project¹ on the effect of caregiving on the health and wellbeing of a sample of young adult students, we conducted interviews with 110 French students ($M_{age} = 21.25$ years, $SD = 2.00$; 75% female). Of these, 86% were enrolled on a BA

¹ The CAMPUS-CARE project is led by researchers from the University Paris Cité, is funded by Klesia and had been approved by a French ethical research committee (CERES, N° 2019-62; and CNIL, N° 20200828_Campus-care). For more information, see: <https://jaid.recherche.parisdescartes.fr/campus-care/>

course, and 14% on an MA course (58.41% studying literature, art and human sciences; 19.80% studying law and economics; 4.95% studying science and technology; 3.96% in medicine school; information missing for 9 participants). These programs are representative of the French university context and are mostly composed of females (Abdouni et al., 2016). All participants were recruited at university, and all gave their informed consent to participate in an interview. The latter consisted of a maximum of four algorithm-based questions. The first question was “Do you know what a YAC is?” If participants answered “yes”, they were then asked to provide a definition. If they answered “no”, they were asked a second question: “Do you know what a carer is?” If they answered “yes”, they were then asked to give a definition, as in the first question. Interviews were independently realized by four female researchers, were recorded and then transcribed for analysis. The responses were not cross-checked, but they were first analyzed by one person who proposed a coding which was discussed with two senior researchers for validation and final analysis

Results demonstrate that only 17.27% of the 110 participants were able to give a correct definition of a YAC, by giving all the following elements: providing assistance, supporting an ill/disabled family member or friend; helping in a weekly or regular basis; and being unpaid to do that; $\chi^2(N = 110, df = 1) = 41.13; p < .001$. In other words, 82.73% of participants were not able to provide a precise definition. These participants could be divided into different subcategories, according to their degree of knowledge: (1) those who truly did not know (75.52%); (2) those who had a partial understanding but whose definitions lacked precision (4.39%); and (3) those who thought that they knew but who gave incorrect definitions (20%). Among the participants in the first subcategory, 94.23% did not know how to define the term *carer*. Among those in the third subcategory, results revealed a variety of definitions, such as being a volunteer for a charity, mentoring university students, or being

altruists. Overall, results demonstrated that the overwhelming majority of our sample did not know about YACs.

A Relevant Illustration: French Students are not Aware of YACs

Despite the French Government's action plan, our results were a relevant illustration that more than 80% of the students interviewed did not know what a YAC was. This lack of awareness and recognition of the carer status is partly related to the fact that, until recently, young people were not thought to play a role in informal caregiving (Leu et al., 2018). Moreover, young adults who take on a caregiving role may regard it as a family duty or a normal responsibility (Struckmeyer, 2013), such that if the recipient of their care is a family member, they will define themselves solely according to their family relationship (e.g., child, grandchild, sibling; Lewis, 2017). Even though they were given a definition of a carer at the beginning of interview, participants did not identify themselves as YACs (Struckmeyer, 2013). Identifying and assessing YACs is therefore a major challenge (Kettell, 2018; Kent, 2020).

In the light of the present findings, the second measure in the French carers action plan, which is YAC students' flexibility in their pace of study, may well go unnoticed. If students are not aware of the issues surrounding YACs, they cannot identify themselves as carers and subsequently ask for support. The measure concerning students should therefore be coupled with a public awareness campaign. For example, there could be a themed day in the academic community that would be open to students and education professionals, with interventions from carers' and students' associations, researchers, and healthcare or social professionals with expert knowledge of the issue. In September 2021, the University of Aix-Marseille staged such an event. It was organized by the faculty of law, and focused on YAC rights. More interventions of this kind should be held: they should be extended to cover all YAC needs, and driven by the French Government so that they reach all French students.

Awareness Amongst Professionals

Due to the hidden nature of the caring role (Leu et al., 2020), providing support to an illness/disabled relative could be seen as a familial obligation or a normal responsibility (Lewis, 2017; Struckmeyer, 2013). Most YACs do not regard themselves as carers until a health or social care professional defines them as such (Becker & Becker, 2008a; Lewis, 2017). Therefore, if professionals are not aware of YAC issues, most YACs will remain hidden. This constitutes a societal issue (Smyth et al., 2011), and to overcome this issue, education, health and social care professionals must be capable of identifying YACs at an early stage. In a recent study in Switzerland, a country considered to be at the *preliminary* level, with little awareness and recognition (Leu et al., 2022), fewer than 50% of professionals were found to be familiar with the term (Leu et al., 2020). In France, recent research revealed that more than 80% of education professionals were unfamiliar with the young carers issue, even though almost all of them stated that they had already met one, after being given a broad definition (Justin et al., 2021). This finding for education professionals from primary, secondary and high school highlights all the work that still needs to be done. Raising awareness among education professionals is a first step that should be extended to professionals in higher education, to ensure that YAC students can also be identified. Furthermore, as recommended by Leu et al. (2021), health and social care professionals working with the relative who has an illness or disability should also be involved, as they are more likely to ask about the family situation and the possible presence of young carers. Raising awareness by providing information through different support mechanisms (websites, brochures, newsletters, and checklists) could be useful (Leu et al., 2020), but the question is whether this is enough.

Implications for Policy and Practice

In France, like in other *emerging countries*, much remains to be done at the public policy level. Our present finding showed that more than 80% of young adult students interviewed are not aware of YACs issue. This result could be compared to the one of Justin et al. (2021) who came to the same conclusion among French education professionals. The current French Government's measures for young carers are a first step that should be acknowledged, but they will not be sufficient if they are not coupled with awareness-raising campaigns.

The first measure about education professionals' awareness should concern all professionals who come into contact with young carers. Taking the example of more advanced countries, specific training, like in Switzerland and the United Kingdom, or information campaigns using media, like in Sweden (i.e., *intermediate country*), could be imagined raising professionals' awareness and young carers' recognition. To improve identification, the carers' alert thermometer for young carers, which could be used by all professionals and allows identifying young carers and screen the support needed, should be democratized (Kettell et al., 2021). Nevertheless, professionals' involvement implies a heightened understanding of the issues as well as a need to know how effectively support and help young carers (Leu et al., 2021). To go further, in the Netherlands (i.e., *preliminary country*), an NGO has developed some guidelines for professionals through a toolkit on how to support children of parents with mental health problems (Leu et al., 2022). NGOs should be considered as a key building block of policy development toward professionals.

Concerning the second measure on YAC students, we assume that much more could be done. Regarding literature, Kettell (2018) suggested several ways to improve YAC students support at university. For example, a "carers' passport", like a card or a booklet, that would signify to all university staff that a student is also a carer. It could also be to clearly identify one member of the university staff as a resource to discuss YACs' needs and

difficulties or to establish YACs student associations or societies to develop a sense of belonging and peer support. Furthermore, in time of the COVID-19 pandemic, YAC students appear more vulnerable than non-carers (Landi et al., 2022) which suggests that COVID-19 support solutions should have a specific attention on YACs. The implementation of devoted support services at universities is underpinned by awareness campaigns for students and university professionals. Above all, in a more general perspective, it could be imagined, like in the United Kingdom, an annual young carers festival where young carers and government policy makers exchange to improve young carers' support at the national level (Leu & Becker, 2017).

Conclusion

Emerging countries (e.g., France) with regard to the issues of young carers should follow the example set by more *advanced* countries, by giving carers specific legal rights, dedicated services and interventions, and providing guidance for professionals (Leu et al., 2022). Researchers should work with NGOs and the media on how to raise awareness and develop new policies. The transfer of research findings to society through policy is the precursor of change (Leu & Becker, 2017). New policies should factor in the need to raise awareness among professionals as well as the general population, in order to support YACs. Awareness is strength.

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