

A STUDY OF YOUNG CARERS IN MALTA

SOS MALTA
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Thanks are owed to everyone who has given their time to assist with the research. Their support has enabled the researcher to produce the first report on the needs of young carers in Malta.

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1. INTRODUCTION

For many years, the focus of service provision to help families with young carers has been to support the member of the family who needs the care. It has been assumed that this support would indirectly help the other members of the family, including the main carer, but has failed to consider that young carers may require specific services designed to meet their own needs (Thomas et al, 2003). However, recently there has been a growing interest in studying and addressing the needs of young carers in several countries. The United Kingdom is one of the countries that has made great strides in this direction, promoting research in the area as well as the design and implementation of specific services to address these carer's needs.

Such children and young adults are often forced by circumstances to mature relatively early and, therefore, they miss out on important aspects of their childhood such as educational and recreational opportunities. Additionally, the overload of responsibilities and emotional involvement that their caring role requires will have an impact in several areas of their future life.

The general lack of awareness within families, schools, and professional and health services of the impact of the caring role in childhood and young adult life makes it difficult to identify and support these children and young adults (Aldridge & Becker, 1999). Furthermore, young carers are frequently unwilling to disclose their situation, as they often fear that they will be taken away from the family, that they will feel ridicule or be bullied, or betray their family and they will, instead, try to survive feeling lonely and isolated in many cases, and often facing very stressful situations (Shah & Hatton, 1999; Crabtree & Warner, 1999). The young carers' reluctance to disclose their situation further contributes to the 'invisibility' of this population and reduces efforts towards specific service provision.

Movements to support Young Carers started over 15 years ago, at different levels in different countries. The UK has been the country where most change has been achieved in this line. The Princess Royal Trust for Carers and Crossroads Care were the first organisations to fight for the rights of the Young Carers in the UK. Several changes have taken place in the past decade favouring young carers in that country. Changes in legislation and service provision have been some of the most important achievements. For instance, The Carers (Recognition & Services) Act 1995 and the Carers and Disabled Children Act (2000) both require that all informal carers (including young carers) who provide regular care are assessed and supported in their locality. Additionally Young Carers Projects have been established throughout the country, with the intention to raise awareness and provide support to this population.

Other countries such as Australia, New Zealand, the US and Canada also have launched efforts to identify these young carers, assess their needs and to provide specific services to support them.

1.1 Definition of the terms 'young carer' and 'adult young carer'

Young carers are children or young people under the age of 21 who provide regular care to a member of their family suffering from a physical, medical, mental or intellectual disability, addiction problems, or any other care requirement. These caring activities go beyond the normal responsibilities that would be expected from a child or a young person in their age group. Some of the caring activities that young carers often take on include excessive housework such as cleaning and cooking, shopping, nursing, personal care, and emotional support (Barnardos, 2014). However, the duties that young carers perform

do not conform to a homogeneous group and can be very diverse, depending on the individual needs of the person who is being cared for.

Additionally the term ‘adult young carer’ in this research will refer to the participants over the age of 21 who were young carers during their childhood and/or adolescence.

There has been some controversy in regards to establishing age ranges for young carers. Some have considered young carers to be children and young people under the age of 25, while others thought that young carers were only children under the age of 18. In this study, 21 was the age established to differentiate between young carers and adult carers. As mentioned above, the term ‘adult young carer’ was used to refer to those adults who were caring for a relative during their childhood.

1.2 The impact of the caring role – research findings from the UK

Although caring has been shown to have a positive impact on the life of the young person, such as building resilience and empathy (Halpenny and Giglian, 2004), research has consistently shown that it also has negative aspects that, if not considered and addressed adequately, can affect young carers dearly (Bibby and Becker, 2000). For instance, The Carers Trust in the UK estimates (2014) that there are currently 700,000 young carers in the UK according to a survey carried out by the BBC in 2010. From these young carers there are 13,000 who provide care for over 50 hours a week.

Furthermore, Hounsell has recently (2013, cited in Fives et. all, 2010) carried out an in-depth study in the UK on government commissioned data and found important conclusions regarding young carers. Some of the relevant findings are summarised below:

- Around 1 in 20 young carers in the UK misses school because of their caring responsibilities.
- Young carers are 1.5 times more likely than their peers to present a disability or special educational needs.
- Young carers have significantly lower educational attainment than their peers.
- Young carers are more likely than the national average not to be in education, employment or training (NEET) between the ages of 16 and 19.

Impact on academic attainment

With regards to the impact of the caring role on academic functioning, there is strong evidence from the research that young carers are likely to see their academic performance affected. Barnardo’s (2006) reported that 43% of the young carers’ school work was ‘adversely affected’ by their caring responsibilities. However, Frank et al. (1999) suggested a greater impact, pointing out that over 70% of the young carers in the UK reported that their caring role had negatively impacted their school performance.

Also, Yeandle & Buckner (2007) indicated that young carers face restricted opportunities to reach their educational potential and are less likely to engage in further education, due to the difficulties that they experience because of their caring role. In the same vein Frank et al. (1999) pointed out that young carers are also less prone to engage in training or employment, making them often become NEET.

More specifically, Frank (1995) stated that at school young carers often experience regular lateness, have difficulties in completing school work on time, present disruptive behaviour, have difficulties interacting with peers, experience bullying, and are likely to leave education without formal qualifications.

Impact on emotional/psychological functioning

Frank (1995) found that young carers often experience feelings of anger, anxiety, frustration, stress, resentment and guilt. Additionally, several authors agree in pointing out that low self-esteem and depression are also often experienced by young carers (Dearden & Becker, 1998; Frank et al., 1999; Dearden & Becker, 2000; Armstrong, 2002). Furthermore, other studies found that a high number of young carers had also reported other mental health problems such as eating disorders and self-harm

(Aldridge, 2003; Dearden & Becker, 2004). On top of that, Dunn (1993) pointed out that adults who had a mentally ill parent during their childhood recalled having experienced high levels of abuse and neglect as a child.

Impact on social life

According to Frank (1995), young carers are at higher risk of becoming isolated and often find no support for relieving the pressure that they experience at home and for enjoying a normative childhood. Young carers often report of feeling a lack of time and opportunity for socializing (Shah & Hatton, 1999; Roche & Tucker, 2003; Cree, 2003). A substantial number of young carers have also reported being victims of bullying (Roche & Tucker, 2003; Cree, 2003).

1.3 The situation in Malta

In Malta, there is currently no national legislation nor any particular services that specifically protect the rights and welfare of young carers. Several organizations in the country do offer indirect support to young carers through service provision for the relatives in need of care and their families. Some examples are the Association for Solidarity with Persons with Special Needs, Agenzija Appogg, Agenzija Sapport, Agenzija Sedqa, Caritas, Saint Jeanne Antide Foundation, and Hospice Malta. All these organisations will, in many cases, offer some form of support to young carers. However, there is no organisation, at present, that specifically focuses on supporting and addressing the young carer's needs.

Some efforts have been made in the country to raise awareness about young carers. Two articles were published in *The Times of Malta* during 2014: 'Lost childhood: concern for Malta's hidden carers', and 'Young carers stay silent to keep families together' (Chetcuti, 2014), that specifically addressed this issue and highlighted the need for launching support services for such carers.

On the other hand, there are three dissertations at the University of Malta (Zammit, 2013; Chircop, 2001; Cassar & Spiteri, 1999), that have focused on young carers and provided a very valuable review of relevant literature from other countries. Additionally, these dissertations provide a good input to the understanding of the impact of the caring role on the personal life of young carers in Malta; for instance, Zammit (2013) interviewed four adult young carers and carried out an in-depth analysis of their experiences.

However, and despite the efforts to raise awareness about such carers in Malta, the reality is that Maltese young carers in most continue to be 'hidden' from the support services and they have to find their own ways of coping with the stresses of the caring role, without any external help.

1.4 Purpose of this study

The purpose of this study is to raise awareness about young carers in Malta, to gain an initial understanding of the circumstances and lives of these children and young people in Malta and the best way to assist them. In order to achieve this, four objectives were established:

1. To examine the mechanisms to identify young carers in Malta.
2. To explore the characteristics of young carers in Malta.
3. To assess the impact of caring in the lives of Maltese young carers.
4. To identify the best ways to assist young carers in Malta.

2. METHODOLOGY

2.1 Collection of data and ethical considerations

Ethical considerations for this research were established by following the guidelines in Ethical Research Involving Children (ERIC, 2014) and the World Health Organisation (WHO, 2014). After assessing the key areas for ethical concern (harm and benefits; informed consent; privacy and confidentiality; payment and compensation) it was decided that data for the research was to be obtained mainly through questionnaires that were to be completed on an anonymous basis by children and young people under the age of 21 thereby maintaining the privacy and confidentiality of young the carers' personal details. Additionally, young carers were offered to engage in an interview if they wished, but no contact between the researcher and the young carer was to be made until consent had been obtained from the young carer, and his or her parents/tutors, through the referral form (Appendix 1). Invitations to young carers to participate in interviews were expected to have a low rate of response due to additional issues arising from the specific policies and procedures for child protection and confidentiality in each of the organisations that helped to identify and approach young carers. Adult young carers (adults over the age of 21 who were young carers during their childhood/teenage years) were also invited to participate in interviews.

Three versions of informed consent forms and one assent form were designed following the World Health Organisation guidelines for research (WHO, 2014 – Appendix 2):

1. an informed consent form for questionnaires;
2. an informed consent form for interviewing parents/guardians of young carers;
3. an informed consent form for interviewing adult young carers;
4. an assent form for interviewing young carers.

In the case of young carers who only participated in the research by completing the anonymous questionnaire the signature on the informed consent form was not required by the researcher as no disclosure of personal details was involved. However, some of the organisations that distributed the questionnaires decided to use the consent forms for the young carers in their organisation. In any case, there was no contact between the researcher and the young carers who only completed the questionnaires. Ethical issues were managed by each organisation independently.

If a young carer wished to engage in an interview, consent from his or her parent/guardian and from the young carer himself was required before there would be any contact between the researcher and the young carer or his/her family. Once consent was provided, through the referral form, the researcher would arrange a meeting with the parent/guardian in order to explain the project to them and to obtain the signed informed consent forms. If after this meeting the parent/guardian agreed that his/her child would be interviewed, another meeting would be arranged with the young carer to explain the project and sign the assent form.

For adult young carers, the process was similar: first consent was provided through the referral form and then the researcher would contact the participant in order to arrange a meeting and discuss the informed consent form. If the adult young carer agreed, then the researcher proceeded with the interview.

The participants were also given the option to contact the researcher directly, instead of completing the referral form. In such cases the procedure would be the same as that described above, with the difference that initial contact would be made by the participant and not by the researcher.

2.2. Sampling and recruitment of young carers

Sampling

The researcher used a convenience sample, which is defined by Bryman (2008 p. 183) as the ‘one that is simply available to the researcher by virtue of its accessibility’. The researcher created a list of contacts of organisations that could potentially interact with young carers and requested their assistance to distribute the questionnaires and refer potential participants.

Procedure

A methodological triangulation (Mitchell, 1986) was used for data collection in this study: different methods were used in order to collect data from the participants; more concretely interviews and questionnaires were used in this research. Research has shown that triangulation is useful in increasing understanding of the phenomenon under investigation (Fielding & Fielding, 1986).

Identification of young carers and distribution of questionnaires

The strategy to identify young carers and distribute questionnaires began with the compilation of a comprehensive list of organisations and agencies that could potentially have contact with young carers and be in position to distribute the questionnaires. These organisations and agencies included schools (public, church and independent), government agencies (Ministry of Education and Employment, Foundation for social welfare services – Agenzija Appogg; Agenzija Sapport; Agenzija Sedqa), NGOs and other non-profit organisations.

Initial contact was by e-mail, which included an introductory letter containing a definition of the term young carers, an explanation of the aims and purposes of the study, and guidelines for distributing the questionnaires and referring participants. Soft copies of the referral form, the questionnaires (Appendix 3) and a document with information for children and their families (Appendix 4) were also attached.

Follow up letters were sent to all the agencies and organisations, including a hard copies of the documents e-mailed together with a poster for awareness raising to be displayed on their premises (Appendix 5).

From this first contact, it emerged that many organisations referred to have no knowledge of young carers and, although they were supportive of the purpose of the research they were unable to assist neither in the identification of participants and distribution of the questionnaires. However, other organisations indicated their willingness to assist with the research.

The organisations and agencies that expressed an interest to participate in the study were contacted and meetings were arranged in order to provide them with a more comprehensive view of the aims and purposes and clear guidelines how to support this research.

Follow-up calls were made to the agencies that indicated they had no knowledge of young carers, in order to ensure that they had understood the definition of young carers and the aims and purposes of the research. Some of them agreed to schedule meetings for further clarification.

Additional meetings were arranged with existing contacts from relevant organisations in order to ask them to assist the research by managing the process in their own organisations.

Issues encountered with the identification and participation of young carers in the research

1. Lack of awareness and understanding of young carers needs: The term ‘young carer’ was new to most of the individuals/organisations that were approached through the research, including professionals from different areas, families of young carers, and the young carers themselves. Additionally, a general lack of understanding of their needs led some young carers and families to refuse to participate in the research even after the aims and objectives of the research were explained.
2. Ethical issues: Most organisations had their own policies and procedures to ensure protection and confidentiality of their service users and therefore the process of arranging interviews with children would have been overly complicated and time-consuming and impossible to complete within the set time frames. It was also found that families and the young carers themselves were extremely concerned about confidentiality.

Referrals for interviews

Some of the participants who agreed to participate in the interviews were referred to the researcher by staff from the agencies mentioned above. In other cases, the participants contacted the researcher directly. Once referral was made or the initial contact took place, a meeting was scheduled to proceed with the Informed Consent Forms and the interviews.

Collection of questionnaires

Completed questionnaires were returned to the researcher by post or by e-mail; in some cases, the researcher collected the completed questionnaires personally from the agency or organisation.

Final sample

A total of 25 young carers and 6 adult young carers participated in the research. Young carers only completed the questionnaires while adult young carers were interviewed individually.

Table 1

	Questionnaires	Interviews
Number of participants	25	6
Age range	12 - 20	22 - 43

2.3. Materials used**Questionnaires**

Measurement tools from the Manual for Measures of Caring Activities and Outcomes for Children and Young People (Joseph, Becker, Becker, Regeal, 2009) were used in this study to collect data from young carers in Malta under the age of 21. It was decided to use these tools because they had been tried and tested in other countries and had proved to be useful in screening and assessing young carers’ needs.

1. PANOC – YC20 - Positive and Negative Outcomes of Caring (Joseph, Becker, Becker, Regeal, 2009): This is a 20 item self-report measure that provides an index of the subjective cognitive and emotional impact of caring and it provides two scores indicating the positive and negative impact of caring in young people.
2. MACA-YC42 - Multidimensional Assessment of Caring Activities-Young Carers (Joseph, Becker, Becker, Regeal, 2009): This is a 42 item self-report measure that provides an overall index of caring activities; the higher the score the greater the level of caring activity. Additionally, six subscales were used in order to assess the caring pattern: domestic activity (items 1,4,8), household management (items 16, 17, 18), financial and practical management (items 20, 21, 22), personal care (items 28, 29, 30), emotional care (items 35, 36, 37), and sibling care (items 38, 39, 40).

3. YC-QST-20 Questionnaire and screening tool (Young carers Research Group – Loughborough University): This is a questionnaire designed to identify young carers and assess their level of understanding of their relative's illness or disability, the nature and extent of children's caring responsibilities and their needs as carers. In this research the YC-QST-20 was used to gain information on the following variables: age; gender; relationship with the person being cared for; illness/condition being care for; support available fro the ill person; provision of information for young carers; communication between the young person and the relative in need of care; support from the family; length of time spent caring; hours per week of caring; perceived reduction of time for oneself; desired support.

Interviews

Interviews were designed (Appendix 6) to gain additional understanding of the impact of caring in the young carers' academic attainment, leisure and recreational opportunities, social life and psychological impact. It was considered by the researcher that the information collected through the questionnaires was lacking in these particular areas. Additionally, other information such as type of caring activities and positive and negative outcomes of caring were also assessed through the interviews in order to gain a better understanding of the specific caring roles of the adult young carers who participated in the interviews.

The questions made were mostly open-ended in order to allow the participant to evoke different responses. The interviews were not audio-taped as there was a concern that, taking into consideration that personal data of sensitive nature was likely to arise during the interview, audio-taping could lead the participants to feel less comfortable and therefore condition their answers. Notes were taken during the interview and processed immediately afterwards in order to ensure that the information recorded was as accurate as possible. Interviews lasted between 30 and 60 minutes and all the appropriate ethical measures were taken, as explained in section 2.1.

2.4. Analysis of data

Analysis of data was also performed through a triangulation of methods, which means that more than one method was used to analyse the sets of data (Kimchi, Polivka, & Stevenson, 1991). Data obtained through the questionnaires was analysed both qualitatively and quantitatively. The qualitative analysis of the questionnaires focused on understanding the types of responses that the participants gave to the questions. Statistical analysis using SPSS software was also performed in order to find out whether there were any particular variables significantly influencing the emotional positive and negative outcomes of caring, as experienced by the young carers. Qualitative analysis was performed to gain understanding of the data obtained through the interviews.

2.5. Limitations of the study

One of the limitations of this research is that the sample of young carers was not fully representative of the different backgrounds and circumstances of young carers. Given the process followed to recruit the participants in this study, involving the engagement of different agencies and organisations, as well as consent from the parents or guardians, children coming from more vulnerable backgrounds were considered to be unlikely to participate in the research, as it is often considered that such families are less likely to be willing to share information about their situation or permit external involvement in their affairs. For instance, there were no young carers in this research, who looked after a relative suffering from substance misuse.

The total sample of participants was also relatively small, which could raise some concern when generalising the results, especially in the case of statistical analysis. However, and as other researchers have also found in their studies (Franck, 1995), it was expected to have a small sample of participants, given the lack of awareness about young carers in the community.

3. RESULTS

3.1. Questionnaires – Analysis of responses

Gender and age of participants

The majority of the participants were females (n = 17) and only 8 were male (Table 2.). All the males that participated in the research were under the age of 15 while the females were spread within the age range of 12 and 20. The average age of the participants was 15 years, the youngest participant being 12 years old and the oldest 20.

Table 2

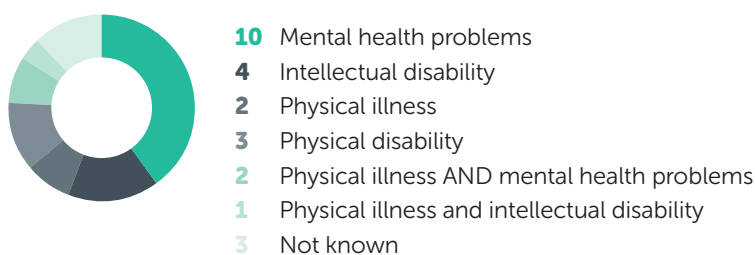
Age \ Gender	Male	Female	Total
12-15	8	10	18
16-20	0	7	7
Total	8	17	25

Analysis of responses to the questionnaire YC-QST -20

Illness/condition

Most participants (n=10) cared for a relative with mental health problems. These relatives had a condition that was affecting their psychological functioning and it included illnesses such as schizophrenia, bipolar disorder, depression, etc. On the other hand, there were some participants (n=4) who looked after a relative who had an intellectual disability (i.e. autism, down syndrome). Some other young carers (n=2) had relatives with a physical illness, which involved chronic physical conditions and illnesses such as cancer. There were also some participants (n=3) who had a relative with a physical disability, namely mobility impairment. Some of the participants cared for a relative/s with more than one condition; therefore, there were some young people (n=2) who cared for relatives with both a physical illness and mental health problems, and one participant who cared for a relative with a physical illness as well as an intellectual disability. Finally, there were some participants (n=3) who reported not knowing what kind of illness/condition the relative that they were looking after was suffering from.

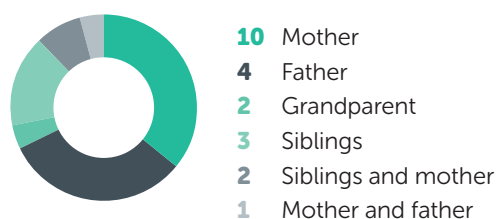
Chart 1: Illness/condition



Relationship between the young carer and the relative in need of care

The majority of the participants in this study cared for one of their parents, eight who looked after their father and nine their mother. Next in line, having a sibling with an illness/condition was the most common situation for the young carers (n=4) who participated in this research. There was only one participant who looked after one of her/his grandparents, and there were three young carers who had more than one relative in need of care: Two young people looked after their mother and a sibling at the same time and one participant had both parents with an illness/condition that required constant care.

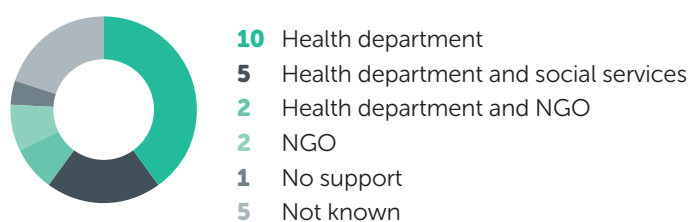
Chart 2: Relationship with the young carer



Support available for the young carers' relative

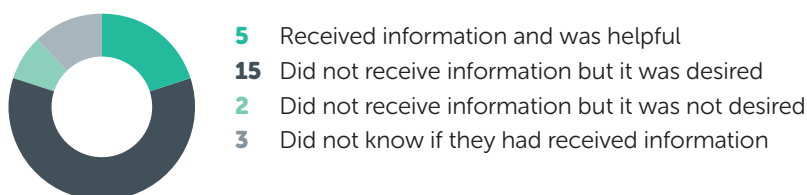
The participants were asked, through the questionnaire, to mention any support they knew their relative was receiving. The majority of the young carers reported that their relative was receiving help from the health department (n=15). There were also some participants (n=5) who said their relative received help from the social services department over and above of the support provided by the health department. Other participants (n=4) mentioned NGOs and other organisations as source of support and help for their relative, some of them (n=2) were also receiving services from the health department at the same time. On the other hand, there were several participants (n=5) who reported not knowing exactly what kind of support their relative was receiving, if any. There were two young carers who said that their relative was not receiving any support at all.

Chart 3: Support available for the young carer's relative

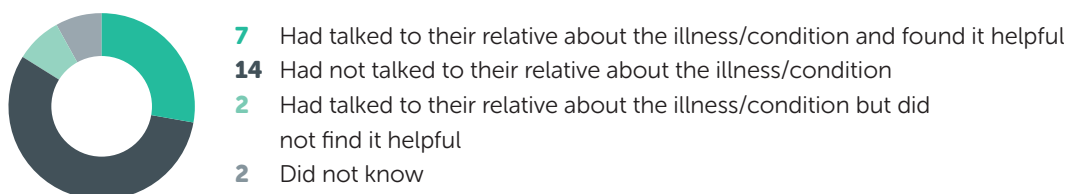


Provision of information

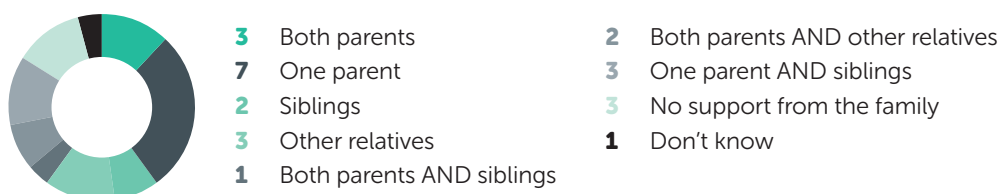
The participants were asked if anyone from the health services, social services or any other organisation had talked to them about their relative's illness and how had it affected them and their family. The majority of the young carers (n=15) said they had not received any professional information about their relative's illness, but wished they had. On the other hand, some participants (n=5) reported that they had received information from a professional regarding their relative's illness/condition, and they all considered that the information provided had been helpful for them and their families. Two participants said that had not received any information but also they said they did not want to receive any; one of them added that she thought receiving this information would not help her anyway. Some participants (n=3) did not know whether they had received any information from a professional regarding their relative's illness.

Chart 4: Provision of information**Communication between the young carer and the relative being cared for**

The young carers were asked whether they had talked to their relative about their illness and whether they had found it helpful. Most of the participants (n=14) reported not having talked to their relative about the illness/condition. Some of them specified the reason why: for example, the relative does not like to talk about it, the relative would not accept having an illness/condition, the relative was too young to talk about it (in the case of young carers who looked after a sibling). Seven young carers said that they had talked with their relative and thought it was helpful. On the other hand, two other young carers reported that they had talked to their relative about the illness/condition but they had not found it helpful. Finally, there were two participants who said they did not know whether they had talked to their relative about the illness/condition.

Chart 5: Communication between young carer and relative being cared for**Support from the family**

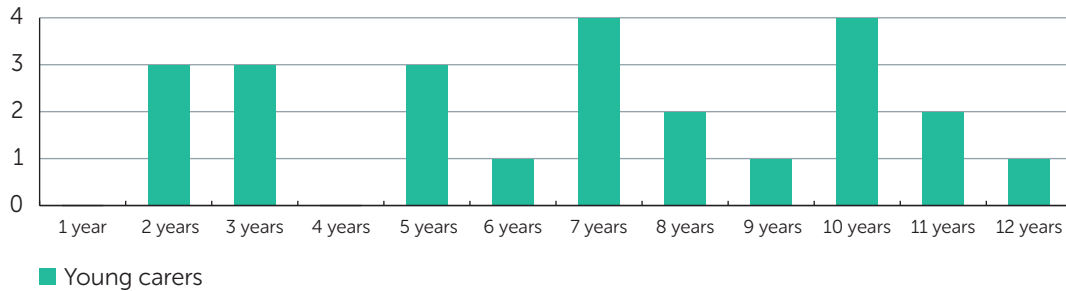
Another question the participants were asked through the questionnaire was whether they were receiving help from anyone else in the house to look after the relative who needed care. Most of the participants (n=7) were receiving help with the caring duties from one of their parents; other sources of support at home were siblings and other relatives. Some participants said they were receiving support from more than one family member; for example, some of them received support from one parent but also from their siblings or other relatives. Some young carers (n=3) said that they were receiving support from both of their parents. On the other hand, some of the participants (n=3) were not receiving any kind of support from anyone else at home, and one of the participants reported not knowing whether he/she was receiving support at home.

Chart 6: Support from the family

Length of time caring

The young carers were asked how long had they been helping/caring for their relative. The average time that the participants had spent caring was 6.7 years. The participants (n=3) who had spent less time caring had been young carers for only two years, and the young person who had been caring for the longest period of time reported to have been caring for twelve years. There was one participant who did not answer this question.

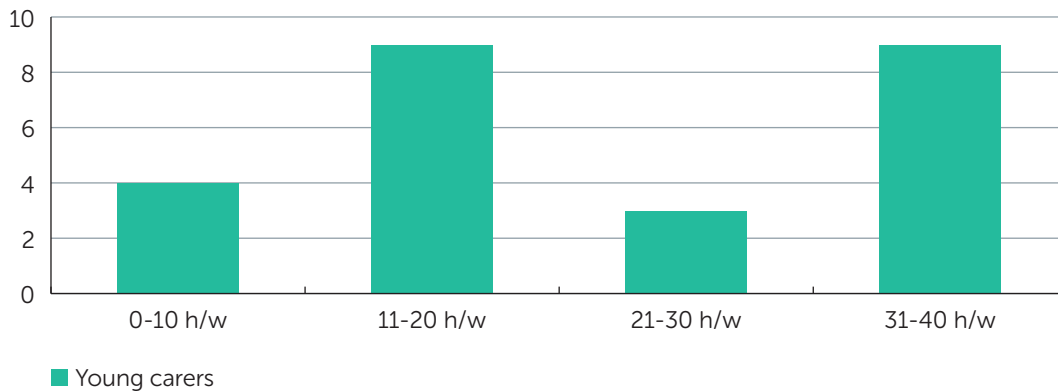
Chart 7: Length of time caring



Hours per week caring

Regarding the hours per week that the young people spent caring, the participant who reported the least hours per week said he/she looked after his/her relative for only two hours per week. On the other hand, the participant who reported spending most hours caring said he/she cared for forty per week. On average, the participants cared for their relative for twenty-three hours a week.

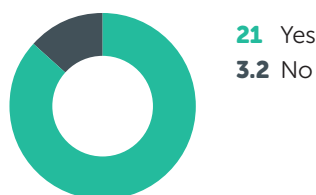
Chart 8: Hours per week caring



Perceived reduction of time for oneself

The young carers were asked whether they felt that caring for their relative had affected the amount of time they had for themselves, for example, going to school, doing homework, spending time with their friends, for hobbies etc. Only four participants said they did not feel that their caring role had impacted on the amount of time that they had for themselves. On the other hand, the large majority (n=21) felt that being a young carer had reduced the amount of time that they had for themselves.

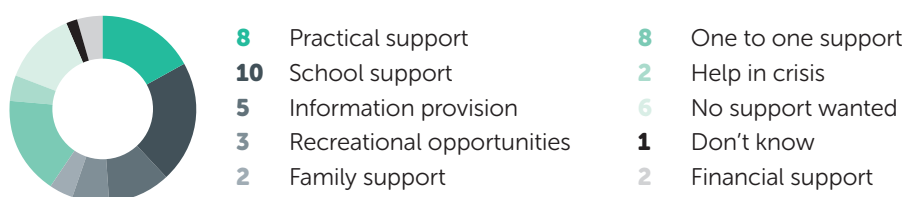
Chart 9: Reduction of time for oneself



Desired support

Finally, the participants were asked what kind of support they would like to receive in order to make their life easier as young carers. The responses were very diverse; the researcher organised them in 10 groups to make analysis easier. The three kinds of desired support most commonly mentioned by the young people were: (1) practical support - support with the tasks of caring directly, for example, someone to help the young carer with domestic activities, someone to look after the relative in need of care when the young carer needs to do other things, etc.; (2) school support - support from the teachers, flexibility for young carers at school, support with homework, etc.; and (3) one-to-one support - individual counselling/therapy/mentoring for the young carer; (4) provision of information- someone to talk to the young carer about the illness/condition that his/her relative suffered, explaining its causes, symptoms and ways of coping; (5) leisure and recreational opportunities - opportunities to perform activities they like, hobbies, etc.; (6) family support - external support directed to help to improve family interactions and functioning; (7) help in crises; and (8) financial support. On the other hand, there were six participants who stated that they did not want any support, and one who was unsure as to what kind of support he/she would like to receive.

Chart 10



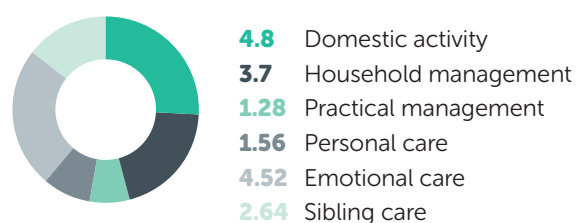
Analysis of questionnaire MACA YC42

The Multidimensional Assessment of Caring Activities – Young Carers (MACA-YC42) provides an overall summary index of caring activity. The lowest score a participant could obtain was 0 and the highest 84. Higher scores indicate greater levels of caring activity. The average score was 33, which indicates medium to low levels of caring activity by the participants. The lowest score was 13 and the highest 69.

Additionally, six subscales of three items each were used in order to identify patterns of caring activities. These subscales were: (1) domestic activities - activities such as cleaning, cooking, washing dishes, etc.; (2) household management - activities to keep running the household, such as shopping, household repairs, etc.; (3) financial and practical support - practical adult responsibilities such as paying bills, managing accounts, etc.; (4) personal care - activities such as helping the person dress/undress, wash and use the bathroom, health care, etc.; (5) emotional care - company and emotional support; (6) sibling care - looking after siblings.

The highest score for each subscale was 6 and the lowest 0. The average scores for each subscale are compared in Chart 11. Help with domestic activities was the type of help most commonly provided by the young carers who participated in this study (4.8 average). Next were emotional care (4.52 average) and household management (3.7). Sibling care had an average of only 2.64 and the type of help least commonly provided by young carers was personal care (1.56 average) and practical management (1.28 average).

Chart 11



Analysis of questionnaire PANOC – YC20

The Positive and Negative Outcomes of Caring (PANOC – YC20) (BECKER....) questionnaire was used to assess the subjective cognitive and emotional impact of caring on the participants of this study. The questionnaire provided two scores, one to indicate how much caring is experienced negatively and another showing how much caring is experienced positively. The lowest score that each participant could obtain in both cases (positive and negative outcomes) was 0 and the highest was 20. For the positive score, a result of 0 would indicate that no positive outcomes were reported and, therefore, there is a potential for concern. Scores between 1 and 12 would indicate just a few positive outcomes and, therefore, also a potential for concern. Scores of 13 and over denoted relatively high positive outcomes of caring and, therefore, no concern. On the other hand, for the negative scores, a result of 0 would indicate no negative outcomes reported. A score between 1 and 8 would suggest relatively few negative outcomes of caring and indication no need for concern. Finally, a score between 9 and 20 indicates relatively high negative outcomes, resulting in a potential for concern.

The average positive outcomes score from among the participants was 10.9. This would indicate therefore, that there were relatively few positive outcomes from among the participants indicating a reason for concern. The lowest positive outcomes score was 4 and the highest 19. The negative outcomes score average was 12.8, with the lowest score 0 and the highest 19. Therefore, the average negative outcomes score indicates relatively high negative outcomes and a potential for concern.

Table 3

Scores	Average	Lowest	Highest
Positive Outcomes	10.9	4	19
Negative Outcomes	12.8	0	19

3.2 Questionnaires – Statistical Analysis

SPSS software was used to perform the statistical analysis in this study. Through the statistical analysis it was intended to find out whether there was any variable that had a significant influence on the positive or negative outcomes of caring.

The tests Shaphiro-Wilk and Kolmo were performed to assess the normality assumption of the variables 'Positive outcomes of caring' (PANOCp) and 'Negative outcomes of caring' (PANOCn) score distribution. Results are shown in table 1. Both tests showed that PANOCp had a normal distribution ($P > 0.05$). Conversely, PANOCn did not have a not normal distribution, as both tests' P value was less than 0.05.

Table 4 Tests of Normality

	Kolmogorov-Smirnov			Shapiro-Wilk		
	Statistic	df	P-value	Statistic	df	P-value
Positive outcomes of caring	.123	25	.200	.951	25	.266
Negative outcomes of caring	.206	25	.008	.873	25	.005

After the normality assumption had been analysed, it was decided that one-way ANOVA would be carried out to analyse the relationship between categorical variables and PANOCp, and Pearson would be used to analyse the correlation between PANOCp and numerical variables. On the other hand, in order to assess the influence of parametrical variables on PANOCn, the Kruskal Wallis test was performed, while the Spearman correlation the test was used in the case of numeric variables.

The above-mentioned tests were run in order to determine the relationship between the variables PANOCp and PANOCn, and the variables: age, gender, relationship between the young carer and the relative in need of care, type of illness/condition, support for relative in need of care, provision of information, communication between the young carer and the relative being cared for, support from the family, length of time caring; hours per week caring, perceived reduction of time for oneself, desired support, total output on caring activity, domestic activity, household management activity, financial and practical help, personal care, emotional care and sibling care. Only those tests that showed a significant relationship are presented in these section.

Negative outcomes of caring and provision of information

A Kruskal-Wallis test showed that there was a statistically significant difference in negative outcomes scores between young carers who received and those that did not receive information about their relative's illness: $X^2(3) = 14.004$, $p = .003$ with mean PANOCn scores of 16.33 for 'No, but desired', 10.60 for 'Yes and helpful', 7 for 'No and not desired' and 3 for 'don't know'. This indicates that those young carers who had not received any information regarding their relative's illness/condition had experienced significantly more negative outcomes of caring.

Table 5 Mean PANAC N score clustered by provision of information

	N	Mean	Std. Deviation	95% Confidence Interval for Mean	
				Lower Bound	Upper Bound
Yes and helpful	5	10.60	5.413	3.88	17.32
No, but desired	15	16.33	2.498	14.95	17.72
No and not desired	2	7.00	4.243	-31.12	45.12
Don't know	3	3.00	2.646	-3.57	9.57

$X^2(3) = 14.004$, $p = .003$

Negative outcomes of caring and perceived reduction of time

A Kruskal-Wallis test showed that there was a statistically significant difference in negative outcomes scores between young carers who perceived that their time was reduced due to their caring role and the young carers who did not: $X^2(1) = 8.002$, $p = .005$ with mean PANOCn scores of 14.52 for 'yes', 10.60 for 'Yes' and 4 for 'No'. This means that those young carers who said that their time was reduced because of their caring role, had experienced significantly more negative outcomes of caring.

Table 6 Mean PANAC N score clustered by perceived reduction of time

	N	Mean	Std. Deviation	95% Confidence Interval for Mean	
				Lower Bound	Upper Bound
Yes	21	14.52	4.501	12.47	16.57
No	4	4.00	2.944	-.68	8.68

$X^2(1) = 8.002$, $p = .005$

Negative outcomes of caring and hours per week caring

A Spearman's correlation was performed in order to determine the relationship between PANOCn and hours per week caring. There was a strong positive correlation between these two variables, which was statistically significant ($r_s = .876$, $p = 0.000$). This indicates that the young carers who spent more hours per week caring were experiencing significantly more negative outcomes from their caring role.

Table 7 Spearman Correlation between PANOCn and hours per week caring

		Negative outcomes of caring		Hour per week caring	
Spearman's rho	Negative outcomes of caring	Correlation Coefficient	1.000	.876**	
		Sig. (2-tailed)	.	.000	
		N	25	25	
Spearman's rho	Hour per week caring	Correlation Coefficient	.876**	1.000	
		Sig. (2-tailed)	.000	.	
		N	25	25	

($r_s = .876$, $p = 0.000$).

Negative outcomes of carting and total output of caring activity

A Spearman's correlation was run to determine the relationship between PANOCn and total output of caring activity. There was a strong positive correlation between these two variables, which was statistically significant ($r_s = .744$, $p = 0.000$). This suggests that the young carers who provided higher levels of caring were experiencing significantly more negative outcomes from their caring role.

Table 8 Spearman correlation between PANOCn and total output of caring activity

			Negative outcomes of caring	Total output of caring activity
Spearman's rho	Negative outcomes of caring	Correlation		
		Coefficient	1.000	.744**
		Sig. (2-tailed)	.	.000
		N	25	25
Spearman's rho	Total output of caring activity	Correlation		
		Coefficient	.744**	1.000
		Sig. (2-tailed)	.000	.
		N	25	25

($r_s = .744$, $p = 0.000$).

Negative outcomes of caring and emotional care

A Spearman's correlation was performed to determine the relationship between PANOCn and emotional care. There was a strong positive correlation between these two variables, which was statistically significant ($r_s = .585$, $p = 0.002$). This indicates that the young carers who provided higher levels of emotional care were experiencing significantly more negative outcomes from their caring role.

Table 9 Spearman correlation between PANOCn and emotional care

			Negative outcomes of caring	Emotional care
Spearman's rho	Negative outcomes of caring	Correlation		
		Coefficient	1.000	.585**
		Sig. (2-tailed)	.	.002
		N	25	25
Spearman's rho	Emotional care	Correlation		
		Coefficient	.585**	1.000
		Sig. (2-tailed)	.002	.
		N	25	25

($r_s = .585$, $p = 0.002$).

3.3. Interviews

In order to analyse the data obtained through the interviews, the researcher focused mainly on the commonalities found in the young carers' experiences, as analysing in-depth each of the individual cases would have exceeded the purpose of this study.

Sample of participants

All the participants were over the age of 21 and had been young carers during their childhood and/or adolescence and were still informal carers at the time of the study. Therefore, the experiences that they reported were retrospective.

Some of the interviewees were extremely worried about confidentiality and had to be reassured several times that all their information would be kept totally confidential and that when the report is published it will not be possible for anyone to link experiences described in this study with the relative individuals. Information on the participants has therefore been kept as confidential as possible and the researcher analysed the experiences of the adult young carers in general without giving specific profiles of the interviewees.

Age and gender

Referrals for the interviews came exclusively from NGOs. A total of six adult young carers participated in the interviews; participants' age ranged between 22 and 43. There were four participants between the age of 22 and 29 and two participants between the age of 30 and 43. It was not possible to arrange interviews with young carers under the age of 21 due to the issues mentioned in section 2.2. All the adult young carers interviewed were females; no males were referred for interviews.

Table 10

Age \ Gender	Male	Female	Total
22-29		4	4
30-43		2	2
TOTAL	0	6	6

Type of carer

The criteria employed by Frank (1995) in his classification of young carers was used in this research, in order to clarify the different roles adopted by young carers. A sole carer refers to young carers who take sole responsibility for the care of the family member in need. Sole young carers do not receive any support within the home from any able adult. On the other hand, supportive young carers are children who support an able adult to care for another family member. From the adult young carers that participated in the interviews there was only one who was a sole carer; the five remaining interviewees were supportive carers.

Table 11

Type of carer	Number of adult young carers
Sole carer	1
Supportive carer	5

Household structure

Among the six interviewees, there was only one who, as a young carer, lived in a single parent family and had no siblings. The remaining five lived with both their parents when they were young carers. Three of them had siblings; the other two were the only child in their nuclear family.

Table 12

Household structure	1 Parent	2 Parents	TOTAL
Siblings	0	3	3
No siblings	1	2	3
TOTAL	1	5	6

Relationship to the person being cared for and type of condition

Among the six participants, there was one that looked after both of her parents suffering from mental health problems. Two of the interviewees cared exclusively for their mother, also suffering from mental health problems. One of the participants cared for her mother who was suffering from a physical illness. One of the participants looked after only her father, who suffered from mental health-related problems as well as a physical illness. Finally there was also one participant that cared for her brother who had an intellectual disability. Therefore, there were three participants who cared exclusively for their mother, one caring for both parents, one caring for her father, and one caring for her brother. Three adult young carers cared for relatives suffering from mental health problems, one who was a young carer of a relative suffering from mental health problems as well as a physical illness combined, one young carer who looked after her relative suffering from a physical illness, and one who cared for a relative with an intellectual disability.

Table 13

PERSON CARED FOR	Mother and father	Mother only	Father only	Brother only	Total
CONDITON					
Mental health and physical illness			1		1
Mental health only	1	2			3
Physical illness only		1			1
Intellectual disability				1	1
Total	1	3	1	1	6

Support provided

The six participants said that they provided mostly support with keeping the house running and with domestic activities such as cleaning, cooking and shopping. Emotional care was mostly provided by those young carers who looked after their mother by talking and listening to them, or by providing companionship. On the other hand, personal care and physical help (moving, lifting, etc.) were only reported by those carers who looked after a member of the family who had a physical illness. Three of the adult young carers reported to have also been in charge of the medicines and making sure their relative took them. All the interviewees noted that supervising their relative was also one of their main duties. Only two young carers provided practical help such as helping with the bills and paperwork; both these young carers said that one or both of their parents was/were unable to read and write properly.

Impact of the caring role on the young carer's academic attainment

All the interviewees reported to have perceived a general negative impact of the caring role in their academic performance. Four out of six interviewees mentioned the fact that education was not a priority in their home and that no one had told them how important it was. One of the participants specifically noted that 'I was never encouraged to do better at school and I abandoned education as soon as I could'. Another interviewee recalled not having the appropriate conditions to concentrate at home: 'even if I wanted to study, it wasn't possible in the middle of that chaos'. Also, five out of six participants mentioned the fact that they never had any kind of support at home with their studies and could never ask for help with homework or assignments. One of the interviewees mentioned that 'going to school was something that had to be done but for no apparent reason'.

All the interviewees recalled having to miss school very often. Four out of six mentioned that they missed school particularly when their relative had a crisis. Three interviewees noted that, many times they had to miss school so that their relative would not be left alone. Additionally, two of the participants commented that they often missed school but no adult at home cared about it.

Five of the six participants recalled finding it difficult to keep up with school work. All of them referred 'lack of motivation' as the main factor, but also lack of support with homework. Additionally, three of the interviewees mentioned that they were all busy with helping to take care of their relative and 'helping around the home' so school work was always left to be done late at night, by when they felt exhausted. Three out of six interviewees reported that being a carer also affected their punctuality at school.

Only two of the participants told their teachers about the situation at home, but they recalled that the teachers were not particularly helpful. The remaining four interviewees said that they had not talked to anyone at the school about their situation at home. Three of the interviewees recalled being afraid of ridicule (especially those carers who cared for a relative with mental health issues) as the main reason for not talking to teachers about their situation. One of the participants mentioned that 'I would not have expected any kind of help even if I said what was going on at home'.

Impact of the caring role on leisure and recreational opportunities

The six participants agreed on the fact that they had less leisure time and recreational opportunities than their peers. Four of them stated that they had never been on a family day out like other children; the other two said that family outings were very rare. The participants also recalled less opportunities for leisure time or recreational activities on their own, such as going out to play with their friends. One of the interviewees stated that 'I never got to do things I liked just for fun'. Two of the participants recalled members of their extended family taking them out occasionally.

Impact of the caring role on social life

Only one interviewee did not perceive a big impact of her caring role on her social life. She recalled not being able to go out with her friends as much as she wanted to, but she had a solid group of friends and enjoyed their support. On the other hand, another interviewee mentioned that she had a group of friends but did not feel fully integrated in the group; she always felt 'different' and knew that something was not 'normal' but she could not understand why she was feeling like that and she had no one to talk to about it. The remaining four young carers experienced severe difficulties in their social life: 'I



didn't have a social life', said one of them. They could not establish a group of friends and did not feel confident interacting with their peers. One of them stated that 'I could not go out, I was too worried about her' (referring to her mother). Two of them recalled having been bullied, and they reported that this had a serious impact on them, in the short as well as the long term. Two of the participants reported feeling that the negative impact of their caring role on their social life had been extended to their adult life and that even nowadays they struggle to make friends and they lack interpersonal skills.

Four of the interviewees recalled that their peers knew about their relative's problem although only one of them found their friends supportive and talked to them about her feelings as a carer. There was general agreement among the interviewees that they did not like talking outside their family about what was going on at home. One of the interviewees said that 'if I couldn't understand I was a young carer, other children wouldn't either'.

It seems worth noting that the four interviewees that recalled a more negative impact on their social life were those who looked after a relative with mental-health related problems. In fact, one of the participants highlighted that 'mental health problems are even nowadays very stigmatised; no one understands that is not the person's fault'.

Impact of the caring role on emotional and psychological development

All the adult young carers agreed that their caring role had impacted them emotionally and psychologically. The researcher found that adult young carers used very similar words to describe this impact, the most commonly employed were frustration, anger, stress and loneliness. One of the interviewees said 'I grew up being worried and sad all the time, feeling lonely and not being able to talk to anyone about it'.

Four of the interviewees mentioned 'having to grow up fast' as one of the outcomes of being a young carer and they agreed that they had to mature much faster than their peers. One of the interviewees said 'I didn't have a childhood; they (her parents) were my children'.

Three of the participants also commented on the fact that they would constantly worry about their relative when they were not with them: 'I was thinking of her all the time, even when I wanted to concentrate in other things I still was worried about her'. The level of distress caused by this 'constant worrying' was particularly significant in those young carers whose relative/s had severe mental health-related problems: 'I would be at school, worrying about coming back home and finding her dead'.

Having ambivalent feelings towards the relative in need of care was also a common theme among the interviewees. They reported how they loved their relative/s and felt the need to provide as much help as possible but on the other hand they also felt angry at them sometimes, and wished they could have a 'normal family'.

Feeling emotionally lost and uncontained was reported by one of the interviewees. On the other hand, growing up with low self-esteem was mentioned by four of them. Three participants reported having low self-esteem even in their adult life and that, they believe it is related to the fact of having had a 'difficult childhood'.

All of the interviewees recalled they had a difficult transition to their adult life. Four of them were involved in substance abuse during their adolescence, three of them suffered from mental health-related issues: 'I was diagnosed with depression at the age of 19; I couldn't cope with it all'. They all dropped out of school at some point, although three of them returned to education at a later stage and undertook university degree studies.

The best and worst part of being a young carer

When the researcher asked what was the best part of being a young carer, two of the participants stated that there were 'no positives about being a young carer'. On the other hand the other four participants pointed out the following positive outcomes: being more responsible than their peers, empathy, and interest in the caring professions.

To the question 'what was the worst part of being a young carer?' isolation and 'lost childhood' were the common themes mentioned by the interviewees. One of the participants said that the worst part of being a young carer was 'having no one to talk to and having to go through so much on your own'. Another participant mentioned 'not being able to have a happy childhood like other children'.

Other commonalities in the young carers' experiences

During the interview, participants could shift the conversation towards areas that were particularly significant for them. The researcher found three themes repeated by the young carers when talking about their experiences.

The three young carers who looked after their mother reported feeling that their father tended to avoid the situation by spending long hours at work, therefore, care of the mother into the young carer's lap, for most of the time.

Young carers also reported a general tendency by their families to avoid talking about the illness/condition of the relative in need of care, and to undertake a passive role, avoiding any opportunity to seek external help or try to make things easier for the family.

The three young carers who had siblings reported finding their biggest source of support from them; in fact, these young carers reported a higher degree of coping with the struggles of the caring role than others who were the only child in their nuclear families. It seems, therefore, that having siblings was a protective factor for the interviewees in this study.

Support received and support desired

Support received

The interviewees reported not having received any kind of support at the time particularly designed to cover their needs as carers. The participants agreed that the relatives who were being cared for also received support from other sources, including the health department, social workers and NGOs. However, five out of the six interviewees felt that the support received was not enough even for the relative in need of care.

Support desired

The interviewees pointed out what kind of services they would have liked in order to feel supported in their caring role. A summary is provided below.

- One to one emotional support/mentoring for the young carer: The six interviewees pointed out they all wished they had someone to talk to about how they felt and to receive guidance in different areas of their lives (e.g. education).
- Provision of information: Five of the six interviewees said that to have someone explain to them the illness/condition of their relative, its causes and associated symptoms, would have been very helpful at the time.
- Support at school: Four of them reported that help from the teachers, encouragement, and guidance at school would have helped them to achieve more, academically.
- Family therapy: Two of the adult young carers mentioned professional support for improving family interaction.
- Young carers meetings: Two of the interviewees pointed out they wish they had had the opportunity to meet other children in similar circumstances in order to discuss their feelings and experiences.

4. KEY FINDINGS AND RECOMMENDATIONS

There is a general lack of awareness among many professionals and practitioners working with children about young carers and their needs. This further contributes towards complicating the process of identifying young carers in Malta. Training to educate these professionals and general practitioners about young carers and what their needs are could potentially contribute towards improving the situation of these children in Malta.

Many organisations were concerned about breaking their own policies and procedures regarding confidentiality and child protection if they were to agree to participate in the research. The young carers and their families also proved to be very concerned regarding the confidentiality of their personal details. This further complicated the task of receiving referrals for interviews. Therefore, one can say that for future research, efforts to address these issues in advance could facilitate the process of identifying and contacting young carers in Malta.

Through the questionnaires, the young carers indicated that their relatives were receiving help mostly from the health department. However, the large majority of the participants said that no one from the health or social care services, or any other organisation, had talked to them directly about their relative's illness. Furthermore, young carers also declared not having talked to their relatives about their illness. This indicates that service provision in this area is needed in order to help young carers understand the illness/condition of their relative and to provide them with suitable coping strategies.

Regarding the support received from their family, the young carers often reported one of their parents as the main source of support, but there were also some participants who stated that they had not received any kind of support at home. One can understand the overload of responsibilities that these sole carers may face by having to support a member of the family without any kind of help from the family. Further research is needed in this area in order to clarify whether supportive and sole young carers in Malta have the same or different needs.

The majority of participants, including the adult young carers, reported having perceived a reduction of available time for themselves which turned into lower opportunities for leisure and recreational activities. This is another issue that needs to be taken into consideration when designing services that should include opportunities in this area for young carers.

Furthermore, results from the questionnaire PANOC indicated that young carers in Malta are experiencing low positive but high negative outcomes of caring; this further raises the concerns about the impact of the caring role on young Maltese carers, and the urgent need to start supporting them.

Additionally, the statistical analysis indicated a significant relationship between the negative outcomes of caring and the variables: (1) provision of information, (2) perceived reduction of time, (3) hours per week caring, (4) total output of caring activity, and (5) the provision of emotional care. This reveals that the negative outcomes of caring were greater among those young carers who had not received information about their relative illness, those who reported having perceived a reduction of time for themselves because of having to care for their relative, those who spent longer time per week caring, those who reported higher degrees of caring activity, and those who offered greater levels of emotional care to their relative. This provides good insight for understanding the struggles of young carers when designing specific services to help them.

The information obtained from the interviews also serves to gain a better understanding of the impact of the caring role in academic attainment, leisure and recreational opportunities and social, emotional and psychological development. In fact, the adult young carers who participated in this study reported significant impairment.

Interviewees commonly mentioned lack of motivation and encouragement from the family, difficulty in keeping up with schoolwork, difficulty to attend school regularly, and a lack of support at school, as the main barriers to their educational performance.

Furthermore, the adult young carers reported feeling isolated as children/young people. The majority of them faced difficulties to interact and integrate with peers and they believed that such difficulties would remain with them throughout their adult lives. The interviewees who reported a higher impact of the caring role in their social life were those who cared for a relative with mental health-related problems.

The participants commonly used words such as frustration, anger, stress and loneliness when describing the impact of caring on their emotional and psychological development as young carers. The themes frequently raised by the young carers as handicaps of their social and psychological development were “lost childhood”, ambivalent feelings towards the relative in need of care, low self-esteem, and struggle in the transition to adult life.

Finally, it was found that both young carers and adult young carers wanted the same kind of support, including practical help, support at school and one-to-one support. This matches the findings from other countries such as the UK (Frank, 1995) and provides the basis for designing services for young carers in Malta.



5. CONCLUSION

In conclusion, the overall results of this study give a limited picture of the situation of young carers in Malta, as the number of participants was low and not representative of the different backgrounds of young carers. However, the findings suggest that there are young carers in the country who have specific needs that are impacting their lives to a higher degree. As this research was intended to serve as an initial study, it should be emphasized that not all issues could be explored in-depth, and further research is needed.

The low level of awareness about young carers is a matter of concern and, therefore, efforts towards raising awareness at all levels among professionals and organisations working with children, young carers, families and schools, is an urgent priority.

Nevertheless, it would be unfair to the young carers if a project to raise awareness were to begin without also providing services to them. Therefore, as well as raising awareness and conducting further research, there is a need to design and develop specific services for young carers in Malta, including assessment and intervention.

A young carers strategy, considering all of the above, is urgently needed if the country is to implement support for young carers.

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7. APPENDICES

Appendix 1 – Referral form

Referral Form – Research Young Carers

REFERRER'S DETAILS			
NAME			
AGENCY			
ADDRESS			
PHONE NUMBER		E-MAIL	
PARENT/ GUARDIAN DETAILS			
NAME			
AGENCY			
ADDRESS			
PHONE NUMBER		E-MAIL	
YOUNG CARER'S DETAILS			
CHILD OR YOUNG PERSON'S NAME	DATE OF BIRTH	GENDER	Male Female
ADDRESS			
PHONE NUMBER			
SCHOOL/ COLLEGE			

I agree to give my contact details to SOS Malta in order to receive further information about the research on young carers:

Print Name of Parent/Guardian: _____

Signature of Parent/Guardian: _____ Date: _____

I agree to give my contact details to SOS Malta in order to receive further information about the research on young carers:

Print Name of Child/Young Person: _____

Signature of Child/Young Person: _____ Date: _____

Appendix 2 – Example consent forms

(1) Informed Consent Form for Interview – Adult Young Carer

Information and Purpose: The interview for which you are being asked to participate in, is a part of a research study that is focused on examining the impact of the caring role in Maltese young carers and what are the specific needs of these children. The purpose of this study is to gain a better understanding of young carers in Malta in order to identify ways of supporting them.

Your Participation: Your participation in this study will consist of an interview lasting approximately one hour. You will be asked a series of questions about your experience as a young carer. You are not required to answer the questions. You may pass on any question that makes you feel uncomfortable. At any time you may notify the researcher that you would like to stop the interview and your participation in the study. There is no penalty for discontinuing participation.

Benefits and Risks: The benefit of your participation is to contribute information about how young carers feel and what difficulties they encounter. This may assist professionals to find ways of supporting young carers in Malta. There is a slight risk that you may share some personal or confidential information by chance or that you may feel uncomfortable talking about some of the topics. However, as mentioned in the previous paragraph, you may refuse to answer any question or not take part in a portion of the interview if you feel the question(s) are too personal or if talking about them makes you uncomfortable.

Confidentiality: The information about personal details that we collect from this research project will be kept confidential. Any information about you will have a false name on it. Only the researchers will know what your name is and we will lock that information up. There are however some exceptions in which this confidentiality could be broken, but it would be only in the case that me or any member of the SOS Malta team would find or think that you or any other person is in danger; in this situation we would need to talk to someone to make sure you or the person in danger is helped to be safe.

Sharing of Research Findings: At the end of the study, we will be sharing what we have learnt with the participants and with the community. We will do this by meeting first with the participants and then with the larger community. A written report will also be given to the participants which they can share with their families if they wish. We will also publish the results so that other interested people may learn from our research. In all cases the information published will not contain any of your personal details, which will remain confidential as explained above in this document.

Researcher Contact Details: Maria Machi Rosello

Telephone: +356 21244123

Email: maria.machi@sosmalta.org

Address: 10 Triq il-Ward, Santa Venera, SVR 1640

By signing below I acknowledge that I have read and understand the above information. I am aware that I can discontinue my participation in the study at any time.

Signature _____ Date _____

(2) Informed Assent Form for Young Carer's Interview

Maria Machi Rosello

SOS Malta

Project: Young Carers – SOS Malta

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you agree that your child may participate)

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet**Introduction**

My name is Maria Machi and my job is to research what are the experiences of young carers in Malta and to find ways to help them.

A young carer is someone under the age of 18 who helps look after a relative who has a disability, illness, mental health condition, a drug or alcohol problem or any other condition that requires constant care. The majority of young carers look after one of their parents or care for a brother or sister. They do jobs in and around the home, such as cooking, cleaning, or helping someone to get dressed and move around. Young carers may need to help a relative deal with their feelings by talking to them, listening and trying to understand their problems. The difference between young carers and other young people who help in the home is that young carers are often responsible for someone else in their family in a way that most other young people aren't. Some young carers give a lot of physical help to a brother or sister who is disabled or ill. A young carer might also care for a grandparent or someone else from their extended family.

I am going to give you information and invite you to be part of a research study. You can choose whether or not you want to participate. We have discussed this research with your parent(s)/guardian and they know that we are also asking you for your agreement. If you are going to participate in the research, your parent(s)/guardian also have to agree. But if you do not wish to take part in the research, you do not have to, even if your parents have agreed.

You may discuss anything in this form with your parents or friends or anyone else you feel comfortable talking to. You can decide whether to participate or not after you have talked it over. You do not have to decide immediately.

There may be some words you don't understand or things that you want me to explain more about because you are interested or concerned.

Purpose: Why are you doing this research?

We want to understand better how young carers in Malta, feel, what are their experiences and what kind of help they would like to receive so that we can find new ways of offering support to these children and young people.

Choice of participants: Why are you asking me?

We are interviewing children who are young carers and live in Malta.

Participation is voluntary: Do I have to do this?

You don't have to be in this research if you don't want to be. Its up to you. If you decide not to be in the research, its okay. Even if you say "yes" now, you can change your mind later and its still okay.

What is going to happen to me?

If you decide to participate in this study, you will meet with the researcher who will ask you some questions about how does it feel being a young carer and how you would like to receive help.

Risks: Is this bad or dangerous for me?

Participating in this study is not dangerous, it may happen that you feel a bit uncomfortable when talking about certain things like illnesses. You do not have to answer questions that makes you feel uncomfortable and you can ask the researcher to move to the next question.

Benefits: Is there anything good that happens to me?

Nothing good will happen to you immediately after the interview, but we hope that it helps us to find ways to help you and other young carers in Malta.

Confidentiality: Is everybody going to know about this?

We will not tell other people that you are in this research. Once the research is finished we will publish the conclusions to let other people know how Young Carers feel and how they can be helped. Any information about you will have a fake name on it instead of your name. Only the researchers will know what your name is and we will lock that information up.

Sharing the Findings: Will you tell me the results?

When we are finished the research, I will sit down with you and your parent and I will tell you about what we learnt. I will also give you a paper with the results written down. Afterwards, we will be telling more people, scientists and others, about the research and what we found. We will do this by writing and sharing reports and by going to meetings with people who are interested in the work we do.

Right to Refuse or Withdraw: Can I choose not to be in the research?**Can I change my mind?**

You do not have to be in this research. No one will be mad or disappointed with you if you say no. It's your choice. You can think about it and tell us later if you want. You can say "yes" now and change your mind later and it will still be okay.

Who to Contact: Who can I talk to or ask questions to?

You can ask me questions, I have written the contact details where you can reach me:

Maria Machi Rosello
Telephone: +356 2124 4123
Email: maria.machi@sosmalta.org
Address: 10 Triq il-Ward
Town: Santa Venera
Post code: SVR 1640

If you choose to be part of this research I will also give you a copy of this paper to keep for yourself. You can ask your parents to look after it if you want.

PART 2: Certificate of Assent

I understand the research is about understanding how Young Carers in Malta feel and finding ways to help them. I have read this information (or had the information read to me) I have had my questions answered and know that I can ask questions later if I have them.

I agree to take part in the research.

OR

I do not wish to take part in the research and I have not signed the assent below. _____

(initialled by child/minor)

Only if child assents:

Print name of child _____

Signature of child: _____

Date: _____

day/month/year

Appendix 3 – Questionnaires

The caring jobs I do

MACA-YC42

Below are some jobs that young carers do to help. Think about the help you have provided over the last month. Please read each one and put a tick in the box to show how often you have done each of the jobs in the last month. **Thank you.**

	Never	Some of the time	A lot of the time
1. Tidy / dust your own bedroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Hoover your own bedroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Hoover other rooms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Tidy / dust other rooms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Lay the table	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Make snacks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Make main meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Wash up dishes or put dishes in a dishwasher	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Wash your own clothes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Wash clothes for other people you live with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Iron your own clothes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Iron clothes for other people you live with	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Mow the grass	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Weeds or back edges the garden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Do repairs to the home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Decorate rooms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Take responsibility for shopping for food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Help with lifting or carrying heavy things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Help with paperwork e.g. writing letters for someone, filling in forms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Help with financial matters such as dealing with bills, banking money, collecting benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Work part time to bring money in	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

...Continued on next page



The caring jobs I do ...continued

	Never	Some of the time	A lot of the time
22. Interpret for someone you live with because English is not their first language	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Signing for someone you live with because they are hearing impaired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Give medicines to someone you live with e.g. making sure s/he takes their pills, giving injections, changing dressings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Prepare special food or diet because of medical needs of the person you care for	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Take someone you live with to the doctors or hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Help someone you live with to walk, get up the stairs, get into and out bed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. Help someone you live with to dress or undress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. Help someone you live with to hair or wash	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30. Help someone you live with to have a bath or shower	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31. Help someone you live with to shave	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. Help someone you live with to cut their nails	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. Help someone you live with to use the toilet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34. Help someone you live with to eat and drink	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35. Keep someone you live with company e.g. sitting with them, reading to them, talking to them, playing cards with them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36. Keep an eye on someone you live with to make sure they are alright	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
37. Take someone you live with out esp. for a walk or to see friends or relatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
38. Raising brothers or sisters in school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
39. Look after brothers or sisters whilst another adult is there by	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
40. Look after brothers or sisters on your own	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
41. Talking with officials (eg doctor or benefits officer) about the person you care for	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42. Miss out on sleeping have to get up in the night or stay up late in order to look after someone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

MACA-YC-2

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Multidimensional Assessment of Caring Activities (MACA-YC2)

We care
What YCU think



How caring affects me

PANOC-YC20

Below are some things young carers like you have said about what it feels like to look after someone. Please read each statement and tick the box to show how often this is true for you. There are no right or wrong answers. We are just interested in what life is like for you because of caring. **Thank you.**

	Never	Some of the time	A lot of the time
1 Because of caring I feel I am doing something good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 Because of caring I feel that I am helping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 Because of caring I feel closer to my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4 Because of caring I feel good about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5 Because of caring I have to do things that make me upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 Because of caring I feel stressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7 Because of caring I feel that I am learning useful things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8 Because of caring my parents are proud of the kind of person I am	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9 Because of caring I feel like running away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10 Because of caring I feel very lonely	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11 Because of caring I feel like I can't cope	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12 Because of caring I can't stop thinking about what I have to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13 Because of caring I feel so sad I can hardly stand it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14 Because of caring I don't think I matter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15 Because of caring I like who I am	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16 Because of caring life doesn't seem worth living	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17 Because of caring I have trouble staying awake	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18 Because of caring I feel I am better able to cope with problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19 I feel good about helping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20 Because of caring I feel I am useful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PANOC-YC20
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 Developed for The Princess Royal Trust for Carers by Young Carers International Research and Evaluation,
 School of Sociology and Social Policy, University of Nottingham, University Park, Nottingham NG7 2RD.





YC-QST-20

Young Carers: Questionnaire and Screening Tool (Identifying and Recognising Young Carers)

1. Do you live with a relative (parent, grandparent, brother, sister or other family member) who is ill or disabled?

- Yes
- No
- Don't Know

2. What is their relationship to you (mother, father, brother, sister, grandparent, other)?

3. How long has your relative been ill or disabled? _____

4. Do you know what type of illness or disability they have?

- Yes
- No
- Don't Know

4a. If yes, what is this? _____

5. Has your relative's illness or disability been diagnosed by a Doctor or other health professional?

- Yes
- No
- Don't Know

6. Does your relative receive help from health, social care services or any other organisation for their illness or disability?

- Yes
- No
- Don't Know

6a. If so, what kind of help do they receive?



7. Has anyone from health, social care services or any other organisation talked to you about your relative's illness or disability and how it affects you and your family?

- Yes
 No
 Don't Know

7a. If not, would you like this?

7b. If yes, has this helped you at all?

- Yes
 No
 Don't Know

8. Have you talked to your relative about their illness or disability?

- Yes
 No
 Don't Know

8a. If not, why not? _____

8b. If yes, has this helped you at all?

- Yes
 No
 Don't Know

9. Do you provide any practical help in the house because of your relative's illness/disability (such as cooking, cleaning, helping with household chores)?

- Yes
 No
 Don't Know

9a. If yes, what type of help do you provide? _____



10. Do you provide any nursing-type help for your relative (such as helping to wash or dress them, give medication, helping them to move)?

- Yes
- No
- Don't Know

10a. If yes, what type of help do you provide? _____

11. Do you provide any emotional help to your relative (such as sitting with them, trying to make them laugh, cheer them up, talking to them about their problems)?

- Yes
- No
- Don't Know

11a. If yes, what type of help do you provide? _____

12. Does anyone else in your house provide help for your relative who is ill or disabled?

- Yes
- No
- Don't Know

12a. If yes, who does this? _____

12b. If not, why not? _____

13. How long have you been helping/caring for your relative?

14. Approximately, how many hours a week do you spend helping to look after your relative at home? _____



15. Has caring for your relative affected the amount of time you have for yourself (for example, going to school, doing homework, spending time with friends, hobbies)?

Yes

No

Don't Know

16. Would you like someone to help you understand more about your relative's illness or disability?

Yes

No

Don't Know

17. Is there any other kind of help or support you would like?

Yes

No

Don't Know

18. Please tell us what kind of support or help you would like _____

About Yourself:

19. What is your age? _____

20. Are you: Male Female

Appendix 4 – Information for children and their families

YOUNG CARERS IN MALTA – Information for children and families

What is a young carer?

- A young carer is someone under the age of 18 who helps look after a family member who has a disability, illness, mental health condition, a drug or alcohol problem or any other condition that requires constant care.
- The majority of young carers look after one of their parents or care for a brother or sister.
- A young carer might also care for a grandparent or someone else from their extended family.
- Young carers do jobs in and around the home, such as cooking, cleaning, or helping someone to get dressed and move around.
- Young carers may need to help a relative deal with their feelings by talking to them, listening and trying to understand their problems.
- The difference between young carers and other young people who help in the home is that young carers are often responsible for someone else in their family in a way that most other young people aren't.
- Some young carers give a lot of physical help to a brother or sister who is disabled or ill.

How do young carers feel?

Being a young carer can be difficult sometimes as these children or young people take on many responsibilities that other children don't. Sometimes young carers find it difficult to keep up with the school work as they have to spend a lot of time helping around the house. They may also find that they don't have time to go out with their friends as much as they would like to. Some young carers feel sad, frustrated, worried... In some cases young carers don't know that they are young carers and they miss out on the opportunity of asking for help. In other cases young carers don't talk about their experiences because they fear feeling embarrassed or ridiculous.

How will you help young carers?

We know very little about young carers in Malta and how they feel, and for that reason it is difficult to find ways to help them. Our project wants to get to know young carers in Malta and understand how they feel and how they would like to be helped.

What can I do?

If you think you may be a young carer and you would like to help us to understand better young carers in Malta you can complete the young carers questionnaires to let us know how do you feel.

If I complete the questionnaires, will you tell anyone?

If you decide to complete the questionnaires we will not ask you for any personal information such as your name, your participation will be anonymous. However you can tell other people if you want to.

CONTACT DETAILS

Maria Machi Rosello

Telephone: +356 21244123

Email: maria.machi@sosmalta.org

Address: 10 Triq il-Ward

Town: Santa Venera

Post code: SVR 1640

Appendix 5 – Poster

Do you look after a member of your family who has a physical disability, mental health condition, long term illness or substance misuse?

Do you struggle to find time to socialize with your friends because of your caring responsibilities?

Do you find it difficult to keep up with your school work?

You may be a Young Carer, and you are not alone!

YOUNG CARERS (YCs) are children or young people under the age of 18 who provide regular care to a member of their family as a result of a physical, medical, mental or intellectual disability, addiction problems, or any other care requirement.

WE ARE HERE TO HELP YOU!

Contact SOS Malta
Young Carers
10, Triq il-Ward, Santa Venera
TEL: 21 24-4-123 • Email: maria.macki@sosmalta.org
Ask for Maria Macki

We will inform you on all our services, and all the information you provide will be kept **CONFIDENTIAL**

Appendix 6 – Interview

PERSONAL DETAILS OF YOUNG CARER	
Name	
Date of birth	
Address	
E-mail	
Telephone	
DETAILS OF PERSON BEING CARED FOR	
Relationship to YC	
Reason for needing care	
Age	

INTERVIEW YOUNG CARERS – ADULT**GENERAL INFORMATION**

1. Who is/was it that you look(ed) after?
2. What were their problems/illness/disability?
3. What kind of support/care did you provide?
4. Can you tell me a bit about your experience as a young carer? How would you say it had impacted on you?

ACADEMIC AREA

1. Do you think being a young carer impacted your academic attainment?
2. Did you have to miss school sometimes because of your caring role?
3. Did you find it difficult to keep up with school work?
4. Were you late sometimes to school because of your caring responsibilities?
5. Did your teachers or other adults at school know about your situation? If yes, where they helpful?

SOCIAL AND RECREATIONAL

1. Do you feel you missed out on some leisure/recreational opportunities during your childhood?
2. Did you have enough time to go out with your friends?
3. Do you think being a young carer had an impact in your social life?
4. Did your friends know about you being a young carer? If yes, did you feel supported by them?

EMOTIONAL

1. Did you often worry about the person that you were looking after when you were not with him or her?
2. How do you think being a young carer impacted on you emotionally?

GENERAL IMPACT

1. What was the best part of being a young carer?
2. What was the worst part of being a young carer?
3. Do you think being a young carer benefited you in some aspects in a long term?
4. Do you think being a young carer has had a negative impact on you in a long term?

SUPPORT

1. Did you as a young carer, or the person that you looked after, receive any help or services from anyone? If yes, what was it?
2. Was it the help that you needed at that time?
3. If you could have chosen, what kind of help would you have liked?