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Factors Influencing Aspects of Quality of Life (QoL) in Young Carers: A Translational Review of Literature Giving Specific Consideration to Young Cancer Caregivers and Education

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Abstract

Research Background: Cancer caregivers and other carers are a niche community, particularly within education. Research has identified that quality of life may be negatively affected in carers, including mental health problems, as well as educational and employment issues, all of which are the focus of this review. **Methods:** Literature was identified for inclusion in the review by utilising relevant search engines, Boolean searches, and filters. **Results:** Findings indicate that there is a prevalence of mental health issues in carers to include cancer caregivers and that educational attainment is reduced when compared to non-caring peers. Carers also experience employment difficulties which may be attributed, in part, to reduced educational attainment. **Conclusion:** Initiatives suggested to address this and change the trajectory of carers to include cancer caregivers are those at an educational level, such as adapting pedagogical approaches, providing funding options for carers and opportunities to disclose they are a carer at initial application. Charities could be more involved with educational institutions to offer advice and guidance on the support needs of carers and the government could introduce policy specifically aimed at carers within education to provide consistency in the support and opportunities available to carers across the United Kingdom.

Keywords

Carer, Cancer Caregiver, Quality of Life, Education, Education and Support

1. Introduction

Cancer is now considered a chronic illness (Hofmarcher et al., 2020; Kim et al., 2021). This is in part due to advances in personalised treatments as well as improvements in prevention and early diagnosis, all of which have led to a decline in mortality rates (Hofmarcher et al., 2020; Gambardella et al., 2020). Consequently, more people are now surviving cancer (van Leeuwen et al., 2018), however, they may experience a combination of late and long-term effects that can have a negative impact on their quality of life (QoL) (Erdmann et al., 2021; Brownlee et al., 2018).

Whilst undergoing cancer treatment, as well as living with the late and long-term effects of cancer, a patient or survivor may require additional help and support (Merluzzi et al., 2016) which literature and statistics indicate (Applebaum & Breitbart, 2013; Miller et al., 2016), often falls to relatives due to an overwhelmed National Health Service (NHS) within the United Kingdom (UK) (Alderwick, 2022). As such, relatives adopt the role of caregiver in addition to, or absence of, the healthcare system and these can be both young and mature caregivers.

Considering the impact of this, key resources summarise imperative statistics in relation to cancer caregivers, as a whole (Miller et al., 2016). They identified that in 2016, there were approximately 1.4 million people who were over 15 years of age and looking after a friend or relative with cancer. This was predicted to rise to around 4 million by 2030 (Miller et al., 2016). Cancer caregivers provide support with financial, practical, and emotional matters, indicating that this may be an intensive undertaking, particularly for young caregivers (Sun et al., 2019). In addition to this, the average amount of support provided by a caregiver has been documented to be between 8.3 hours a day and 17.5 hours a week (Applebaum & Breitbart, 2013), which to some, would be considered a full or part-time job (Applebaum & Breitbart, 2013; NHS England, 2022). Considering young carers in particular, the time spent caring could impact upon their mental health, education and social activities (Wong, 2017). For the purpose of this review, when referring to young carers and young cancer caregivers, this may be applicable to carers aged between 5 - 25 years old, as defined by the Carers Trust (2022).

In their role as a cancer caregiver, carers have been reported to experience a range of psychological complaints, such as anxiety, depression, mood disturbances and feelings of hopelessness (Weitzner et al., 1999; Shahi et al., 2014). Between 30% - 50% of carers identified they experienced anxiety and 12% - 59% depression (Applebaum & Breitbart, 2013). Furthermore, in some instances, the level of psychological morbidity exceeded that of the patient themselves (Applebaum & Breitbart, 2013; Cliff & MacDonagh, 2000).

The factors that contribute to psychological morbidity in cancer caregivers (Miller et al., 2016), have been referred to as “caregiver burden”, which summarises the negative connotations associated with being a cancer caregiver (Sun et al., 2019; Nijober et al., 1998).

Considering the caregiver burden, it is known that cancer caregivers often face significant disruption to their own QoL, which can include disruption to employment, social activities, relationships, health status and finances, to name but a few (Weitzner et al., 1999; Akpan-Idiok & Anarado, 2014). However, one area that has received little attention is to young cancer caregivers who are within education or aspiring to progress onto further and higher education.

When evaluating literature relating to this topic, information must be taken mostly from studies investigating carers as a whole, as opposed to those caring specifically for a relative with cancer, due to limited research being undertaken in this area. The aim of this review is to evaluate the existing literature about the impact of caring on a carer's QoL, whilst considering this in the context of a cancer caregiver. In addition, based on current findings, suggestions are put forward in how best carers, to include cancer caregivers, can be supported throughout the different stages of education as well as identifying areas for further research.

2. Methodology

Literature searches were conducted between February 2022 and July 2022 using the following search engines; Google Scholar, EBSCO, PubMed, Medline and Science Direct. References obtained from relevant studies were also used for inclusion in this review.

A Boolean approach to literature searching was undertaken and filters were applied to further narrow results. These included refining the year to those articles published within the last 5 years, full text only and written in English language.

3. Discussion

3.1. Mental Health Issues Are Prevalent within the Carer Community

Mental health issues vary vastly and include diagnosed conditions such as depression, anxiety and phobias, an example being agoraphobia (Manwell et al., 2015). Many of these are often experienced by young carers as well as young carers of cancer patients, who may be involved in practical, emotional and medical support, often for significant periods of time (Justin et al., 2021).

In light of this, there is an evident lack of formal and informal support for young carers, with 64% of those identified receiving no assistance outside of the home (Janes et al., 2021) and there are numerous variables which play a role in stemming these issues. One example of this is social isolation, which has been identified as a foundation for the development of mental health issues (Payne, 2012; Murayama et al., 2021). When surveyed about time spent caring, 26% of young carers responded with four or more hours a day, which suggests there may be a lack of time for personal enjoyment and socialisation, which could develop into isolation (Poon et al., 2017). In support of this statement, Wang et al. (2017), looked at the implications of social isolation on mental health and found common relationships between depression, anxiety, and agoraphobia type symptoms and those who were socially isolated. Social isolation was defined as spending the majority of their time amongst their own company. It is worth noting that this study focused solely on individual impacts and did not consider the effects because of formed or broken relationships during the caring period. In addition, House et al. (1998) highlighted a distinguished difference regarding social and support relationships and their possible negative relation with the mentioned symptoms. Wang et al. (2017) emphasised how these relationships may also be factors in affecting mental health and stated how they therefore did not fully explore the negative aspects, of which include criticism and overinvolvement, of relationships and their impact on mental wellbeing in terms of adding additional stressors that may be contributing factors to underlying or new mental health illnesses.

It should be considered that these negative mental implications are not evident in all young carers and cancer caregivers (Lacey et al., 2021). In fact, some studies (Gough & Gulliford, 2020; Tehrani, 2007) have highlighted the often common, sense of achievement, which is felt upon carrying out their role. Gough & Gulliford (2020) investigated what is known as "benefit-finding" which, by definition, is "the process of deriving positive growth from adversity", and found that it is often the case that young carers are particularly resilient and will use this benefit-finding technique to form a sense of satisfaction and achievement stemming from their duties. The positive attributes that may be felt by young carers have been highlighted within further studies. For example, Wong (2017) found that positive impacts were experienced by care givers for cancer patients including more friendships and a better personal understanding. Although, on the contrary, Dittman (2004) states that benefit-finding can eventually have negative effects, including further damaging mental health (Dittman, 2004; Bower et al., 2009). A psychological explanation for this is that the brain soon becomes accustomed to striving and finding positives from traumas, of which, if it becomes repetitive, can cause greater distress over a period time, due to the carer simply having no time to emotionally grieve and manage the trauma or stress (Avry et al., 2020). Preventing such pressures is important and whilst it is vital to remain positive, it is equally important for carers to share emotions and not supress negative feelings (Avry et al., 2020). For young cancer caregivers, it is important that they have suitable access to talking therapies, which may support this by preventing any severe mental health issues early on and provide them with someone to listen (Avry et al., 2020; Dharampal & Ani, 2020). Furthermore, Gough & Gulliford (2020) identified examples of self-efficacy amongst young carers, an area supported by Berardini et al. (2022) who argues that self-efficacy enhances human accomplishment and thus positive outcomes, by allowing people to view challenging situations as experiences to overcome and master, therefore moving on quickly from setbacks and not allowing them to dwell and cause continual mental strain.

In summary, although there are differences in the literature, one conclusion that can be drawn is a need for balance between the caring role and personal time, as identified through Wong (2017) and Gough & Guillford (2020) as well as a need for support, as suggested by Avry et al. (2020). This way, the young carer can adopt positive aspects of the caring role and limit any negative impacts.

3.2. Caring Negatively Impacts Education and Employment Opportunities

It is evident that, under normal circumstances, an average of 25 hours a week are spent on education, however, this can significantly fall for someone who's role is a young carer, including those who are young cancer caregivers (Aldridge, 2016). Often, time spent caring for an individual is taken from that education time, with studies, such as that by Wong (2017) suggesting that 1 in 20 young carers miss school because of their responsibilities and other figures suggesting that 22% of young carers aged between 5 - 15 years old missed school or had educational difficulties (Dearden & Becker, 2004). This is carried on throughout the teenage years, with young carers being far more likely to not be in education, employment, or training between the ages of 16 and 19 (Aylward et al., 2018). In light of this, it could be argued that lower educational level has a direct impact on career prospects and employment later in life (Sadler et al., 2014), as well as impacting negatively on socioeconomic status (Reynolds & Ross, 1998).

Hamilton & Redmond (2020), found that young carers with intense responsibility, are often up to a year behind in achievement rates and also less likely to fully complete secondary school education, thus consequently, less likely to move onto further and higher education (Henderson et al., 2019), a finding supported by Aylward et al. (2018). It is worth noting however, that studies regarding this issue are based on young carers as a whole and does not consider them based on their individual caring role, for example, a carer for a relative with cancer or carer for a relative with dementia (Gowen et al., 2021), as they may be affected differently. There is a need for further research into the specific impacts faced by young carers for cancer patients in particular and any specific bearings this may have on their education (Shin et al., 2018). Caring roles vary between all individual cases, however, for young cancer caregivers, they may experience stressors such as, weekly hospital visits (Heynsbergh et al., 2018), regular visits from medical professionals to the household, performing medical tasks such as administering injections, medications and changing dressings (Helping Hands, 2021), not forgetting less personal tasks such as shopping and prescription collection (Macmillan Cancer Support, 2019). There are multiple reasons as to why a young carers education is affected, including, mental and physical health impacts such as fatigue and depression (as discussed previously), as well as being occupied with caring duties (Saragosa et al., 2022).

Considering this, there is research highlighting a correlation between poor attendance within education and lower achievement in examinations, which could impact carers who want to continue their educational journey onto further and higher forms of teaching (Randy, 2003; Credé et al., 2010). This, therefore, sits hand in hand with the lowered attendance rates which can be seen from those in a position of care (Moore et al., 2022). Robison et al. (2020) analysed young carers and their individual outlooks on educational opportunities. It was found that young carers were, in fact, less likely to believe or hold the motivation to progress onto further and higher education. This finding is supported in other research, including that of Darling et al. (2019) where it was highlighted that a large proportion of young carers are facing negatively impacted QoL due to missing out on vital school and training work. In addition, Robison et al. (2020) highlighted a lower QoL in young carers, which was not necessarily due to the fact there was an ill relative within the household, but more so due to the pressures of the responsibilities that come hand in hand with being a young carer, therefore preventing possible progression within education. Wepf & Leu (2022) noted that it is often likely a caring role adds extra burden in the form of perceived stress, therefore supporting the notion that young cares are in fact negatively impacted by the additional stress of care. This idea can be reinforced by the bounded agency concept which investigates that often adolescents and youths within a position of care feel constrained by their responsibilities (Shanahan & Hood, 2000; Deakin et al., 2021). However, contrasting to this statement and from the perspective of higher education, Hamilton (2013) looked at this concept and found young carers may not necessarily be bound by personal motivation to attend university, but instead bound by limitations such as university choice, course options, and time allocated for study. Kettell (2018) supports this statement, highlighting that young carers are amongst the most under-represented and disadvantaged groups targeted within the National Strategy for Access and Student Success in Higher Education within the UK, and that the ability to move away and choose idealist study options becomes much harder. This is specifically relevant to cancer patients and survivors, who may often require life-long care with little respite for the young carer, making it difficult for them to access higher education, particularly if this involves moving out of the local area.

There is also research to suggest an association between time allocated to study and its impact upon educational attainment. Marshall (2017) found that student grade averages were strongly correlated with time spent on studying, as well as being strongly influenced by a student's self-belief and motivation. This statement is supported in other literature, including Adams & Blair (2019) who further cements the findings that time management is associated with greater academic performance, thus meaning young cancer caregivers' academic achievement may be negatively affected by this, due to the inability to spend the warranted time necessary on study. In turn, this may then affect employment opportunities (Robison et al., 2020). It should be considered, however, that whilst Robison et al. (2020) provides relevant findings, the sample size covered was small, which may be due to the fact carers and cancer caregivers are a niche population. Reaching a niche audience may require specific sample collection methods for future research, including contacting national public services such as the NHS as well as more specifically, young carer foundations and charities, such as The Children's Society, Barnardo's, the Carers Support Centre and Macmillan Cancer Support (The Children's Society, 2022; Barnardo's, 2022; Carers Support Centre, 2022; Macmillan Cancer Support, 2022). These organisations could be instrumental to progressing within this field.

Considering employment, Joseph (2013), found that 49.6% of young carers were unemployed after leaving school and this may suggest a correlation between lack of employment and exam results achieved, as the largest proportion of respondents highlighted that their highest grade during GCSE examinations was between D and G. Further studies highlight this gap between young carers and their peer's achievement, with The Children's Society (2022), stating that overall, young carers GCSE results were around one grade lower than their peers. This is further supported by the University of Oxford (2015), who found that 54% of surveyed carers said they felt they would have achieved higher, had they not had a responsibility of care whilst studying. Whilst this lower-than-average attainment may be accredited to the substantial responsibilities held by young carers (Wong, 2017), this may highlight a need for further, more established, frameworks to be placed in schools to recognise the specific needs of those in a position of care (Moloney et al., 2020), with the aim to close the attainment gap, which may improve employment rates within young carers.

Often young carers will find themselves working for larger companies with high employee turnovers, and salaries around national minimum wage (Bagot, 2022). In addition, young carers will find themselves restricted by distance and flexibility of the role, with many arguing that they must remain within a reasonable distance of the person requiring care, thus limiting employment options (Skovdal et al., 2009). The same could apply for further and higher education, as not all carers will have access to a local university (Moloney et al., 2020) and travel restriction not only affects long term work and education prospects, it could also negatively impact upon personal development and career progression (Crawford et al., 2016).

Overall, the literature suggests there is a need for early intervention to prevent lowered educational attainment rates for young carers and to mitigate factors also known to contribute to lower achievement such as poor attendance, increased dropout rates and mental health issues, which have been identified in carers (Wilson et al., 2011). Whilst not always linear, there is a link between those with lower academic achievement throughout education and difficulty finding employment beyond school.

3.3. Educational Support Initiatives Promote Inclusivity and Achievement

Whilst there are some support initiatives available for young carers and cancer caregivers, levels of personalisation and the accessibility of these remain somewhat undeveloped (Moore, 2005; Kavanaugh & Stamatopoulus, 2021). Information is readily available through local constituency websites, and council websites often list relevant contact details for the support systems available within each area (NHS England, 2021). However, access to these initiatives is available only through personal research and therefore acted upon only through an individual's motivation (Wepf et al., 2021). Consequently, to promote awareness of these initiatives as well as offer additional support, there is a need for education establishments to offer a broad range of support to ensure those in a position of care are not disadvantaged compared to their peers. As previously discussed, young carers and cancer caregivers may be disadvantaged for a number of reasons, including, mental health difficulties, lowered educational attendance rates and the lack of external support as well as access to leisure activities outside of the home environment (Chouhury & Williams, 2020), all of which impact upon QoL.

To promote inclusivity and achievement, initially, education establishments could work closely with charities which offer support for young carers, including young cancer caregivers (Chouhury & Williams, 2020) and although there is limited research available on the effectiveness of this, it could still be an option to be explored as well as further researched (Powell & Taylor, 2018). Charities such as Macmillan Cancer Support and Young Lives vs Cancer, both offer readily available information regarding young carers but only at the retrieval of those who choose to search for the information (Macmillan Cancer Support, 2022; Young Lives vs Cancer, 2022). It would be advantageous for schools, colleges and universities to work with these charities, who can offer knowledge regarding the best solutions to the educational problems and barriers faced by cancer caregivers. Charities could engage in careers and outreach activities, attend open events as well as work with support teams on a regular basis, for example (Carers Trust, 2015).

In addition, across all stages of education, the development of a carers policy with the inclusion of elements specific to cancer caregivers, as previously discussed, could be a mechanism to ensure consistent support across each institution as well as promote inclusivity and equal opportunities for carers (Carers Trust, 2015), similarly as there is for special educational needs (Estelle, 2001) and widening participation (Connell-Smith & Hubble, 2018). The policy could then be used to inform staff training or workshops on the best support initiatives and pedagogical adjustments for cancer caregivers and carers generally, something which is not commonplace within the UK and for which no policy exists.

To address attendance issues, this could be achieved by adapting pedagogical strategies, such as through the inclusion of hybrid teaching (Carers Trust, 2015). Here, the option of online lessons could be available to those who may struggle to physically attend education, for a full timetabled day, due to the demands of caring (Lalima & Dangwal, 2017). The use of this form of teaching has been proven to be successful over the past two years, where it was deemed necessary due to the ongoing Covid-19 pandemic (Lapitan Jr. et al., 2021) as well as for supporting students with a chronic illness (Klunder et al., 2022). Mukhtar et al. (2020) concluded that online learning can be positive in that it provides comfort and accessibility to those participating. Supporting this idea is Lee et al. (2022)

who states there is a need for a "more holistic, realistic and sensitive" approach to studying, of which, this can aid in yielding generally happier students and greater result averages, which could be applied to the needs of young carers.

In relation to further and higher education institutions specifically, offering carer specific bursaries may provide financial support to carers and remove potential barriers to continuing within education (Carers Trust, 2015). Currently, within the UK, carers are not entitled to carers allowance if they are a full-time student (Gov, 2022) and furthermore, they are not entitled to Disabled Students Allowance (DSA) for their role as a carer (Gov, 2020). This may leave some carers unable to attend college and university due to financial constraints. In addition, the creation of carers student societies may promote inclusivity and allow student support networks to be formed (Carers Trust, 2015).

These institutions could also ensure that students can disclose that they are a carer from initial application (Carers Trust, 2015), and this would serve two purposes. Firstly, a caregiver disclosure could be linked to student support teams, who could then follow this up with the student to ensure that support is put in place for the start of their academic programme, which would promote inclusivity. Secondly, this would provide reassurance to the carer that their caring role has been acknowledged and that they would receive support in relation to this throughout their studies (Carers Trust, 2015), which may promote the retention of carers within further and higher education.

Higher education institutions within the UK could also make full use of the governments widening participation agenda to support young carers and cancer caregivers. This could be achieved by adapting recruitment policies to consider mature carers who may not meet the standard entry requirements, but who have other relevant life and work experience. There could also be engagement with charities and support groups, nationally and internationally, such as those mentioned above as well as adopting different pedagogical strategies. In combination, these efforts to promote widening participation may encourage applications from the caring community (Carers Trust, 2015). The inclusion of higher education within further education establishments should be promoted locally and may make attending university more accessible for carers, as this could prevent the need to travel or move out of the area to attend university.

To encompass all of these initiatives, over each sector of education, the government could provide an agenda aimed at young carers and cancer caregivers which include those raised in this review, or adaptations could be made to existing policies such as the widening participation agenda. This may have a widespread impact on the support initiatives for young cancer caregivers in education whilst promoting inclusivity and consistency between institutions.

Overall, it is evident that there is a need for consistent support initiatives for young cancer caregivers and carers in general throughout all levels of education and that government backing to implement these within the UK would be a crucial driver of change within this field (Carers Trust, 2015).

4. Conclusion

In summary, young carers, including cancer caregivers, are a minority group, who have been identified to be negatively affected in relation to their QoL due to their caring role. Examples discussed herein include a higher incidence of mental health conditions, lower educational attainment and reduced employment opportunities. In relation to education, this is often associated with absence from school and a perceived negative outlook on their education by carers, as well as lower levels of progression from school onto further and higher education. In addition, caregivers are often disadvantaged in relation to employment opportunities due to factors such as lower educational attainment rates and travel requirements.

To address this, initiatives which could be implemented in educational institutions include working with charities, to ensure that carers are best supported throughout their education, including a carers policy to promote consistency, and adopting hybrid teaching to allow studying remotely, which may prevent students from missing content and falling behind. In addition, there could be financial support offered by further and higher education institutions for young carers and cancer caregivers as well as the creation of student carer societies to allow student carers to meet others with caring responsibilities, which, in turn, could create a support network. Higher education institutions could consider widening participation in relation to carers, to promote enrolment at university and in addition, there could be the inclusion of higher education programmes within further education institutions to make university more accessible for carers. Finally, if the government and educational institutions implemented these initiatives, this would contribute towards closing the gap between student carers and their peers in QoL outcomes, such as those discussed within this review.

Conflicts of Interest

The authors have no relevant financial or non-financial interests or disputes to disclose.

Authors' Contributions

Jessica Iyamu contributed to the study conception and design. Jessica Iyamu and Ellie Brown wrote the first draft. Jessica Iyamu approved the final manuscript.

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