EXAMINING THE EVIDENCE – PSYCHOSOCIAL AND SUPPORT NEEDS OF THE MAIN CAREGIVERS FOR ADOLESCENTS AND YOUNG ADULTS UNDERGOING TREATMENT FOR CANCER

by

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A thesis submitted to the University of Birmingham for the degree of

CLINICAL HEALTH RESEARCH (MRES) FOR NURSING AND MIDWIFERY

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September 2022

ABSTRACT

Background

Adolescents and young adults with cancer (AYAC) are identified as a population with unique needs requiring age-appropriate, specialist care. The concept of age-appropriate care recognises individuality and takes into consideration the wider context of young people’s psychosocial and developmental circumstances. Family relationships and social networks are known to be critically important, impacting on the young person’s experience and wellbeing throughout the cancer trajectory. Caregivers play a prominent and critical role both practically and psychologically, however this can create significant emotional, psychological, physical, and practical burdens. Given the developmental life stage of AYAC a cancer diagnosis impacts on evolving independence and developing identity. This can present additional challenges and conflict for caregivers of this age group. Together they and the AYAC must renegotiate relationships and carefully navigate the unfolding situation, against a backdrop of changing autonomy. Health care professionals have a supportive and educational role to play for AYAC and caregivers.

Objectives

To examine the evidence relating to the psychosocial and support needs of the main caregivers for AYAC.

Structure and methods

This thesis is presented in three parts: a scoping review (Part 1), a secondary data analysis of the only multicentre, specific AYAC carer unmet needs questionnaire undertaken in England (Part 2,) and a reflective report on the period and process of

MRes study (Part 3). The National Institute for Health and Care Excellence (2014)[1] quality standards for AYAC psychological and social needs assessment were used as a framework to define caregiver needs. A reflexive approach to thematic analysis was taken to synthesise the data. A thematic matrix was developed to identify themes and report the findings (Part 1). For the secondary data analysis, descriptive statistics and correlations were used (Part 2). Finally, the Peshkin Approach[2] provided a reflective model. Through the identification of my '*Subjective I's'*, understanding and approaches to learning were examined, broadened and deepened.

Findings

The scoping review (Part 1) identified six themes relating to the psychosocial and social needs of the main caregivers of AYA undergoing treatment for cancer; carer type, practical and information needs, place of care, emotional impact, assessment of caregiver needs, and shared experience. Considerable heterogeneity of needs experienced was demonstrated. Examination of the themes found caregiver needs relating specifically to this cohort of cancer patients. These included the impact of developmental life stage on parents and partners, conflicts relating to information provision, the effect of place of care on caregivers, the need to consider a dyadic approach to care, and lack of assessment tools to capture the specific needs of AYAC caregivers.

In Part 2, the secondary data analysis found that over half the respondents (n=516) had been given information about their needs as a caregiver, with the majority

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[1] NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE (2014) Cancer services for children and young people (QS55). National Institute for Health and Care Excellence. London
[2] PESHKIN, A. (1988). In Search of Subjectivity - One's Own. Educational Researcher, 17, 17-22.

finding this very or fairly helpful. Of those that had not received the information, 80% would have liked it. Responses showed caregivers reported high levels of negative emotional and psychological wellbeing, with 91% experiencing self-diagnosed symptoms of feeling depressed or anxious, always or often since the young person's diagnosis (41%). Creation of a 'total distress' construct demonstrated significant results for parents, females, those unemployed or earning a below average wage and younger caregivers

The examination of my *'Subjective I's'* in Part 3 provided powerful personal realisations and enhanced learning experienced through the period of my Masters study. Recognition of the impact of COVID-19 across my *Expert, Novice, Caregiving, Imposter, Empathetic and Encouraging I's* brought self-awareness and acceptance with a new found confidence in my research. This has generated future aspirations for study to benefit young people with cancer and their loved ones.

Conclusions

Diagnosis of cancer in a young person negatively impacts the emotional and psychological wellbeing of their main caregivers. The developmental life stage of AYAC presents unique challenges for their caregivers and the health care professionals providing support through treatment. The psychosocial and support needs of caregivers are broad and multidimensional. Who and where the caregivers are appears to impact needs. Some characteristics may present a higher propensity to distress, partners are often overlooked, information needs can generate conflict and place of care may influence the support experienced. When specific information relating to caregiver needs is provided it is generally well received and can have a positive impact.

Findings offer health care professionals increased awareness around AYAC caregiver needs, highlighting individual characteristics that may require more attention. Tailoring service provision to meet needs will necessitate the incorporation of a wide range of offers as one size will not fit all and preferences will vary. Bespoke assessment of caregiver needs is a significant area for future development, especially those of partners. Findings will inform future research into more directed areas of caregiver information design and provision, signposting and support. Caregivers need help to fulfil their role, thus become better equipped to contribute to AYAC experiences positively.

ACKNOWLEDGEMENTS

This Clinical Health Research MRes was funded by the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care West Midlands (NIHR CLAHRC WM), now recommissioned as NIHR Applied Research Collaboration West Midlands.

BRIGHTIGHT Caregiver data was collected as part of an NIHR Programme Grant for Applied Research (Grant Reference Number RP-PG-1209-10013).

This thesis presents independent research, the views expressed are those of the author and not necessarily those of the NIHR or the Department of Health and Social Care.

Immense thanks to my Supervisors, Dr Susan Neilson (SN) and Professor Annie Topping (AT). Thank you for all the encouragement since I started my journey on the CAIP, the understanding shown when I was not in a position to prioritise my academic studies, and for all the patience when I struggled to articulate what I was actually trying to say. I am forever grateful for your expertise and guidance.

Huge thanks go to Dr Rachel Taylor and the research team for the BRIGHTLIGHT Cohort Study who granted me permission to review the data generated by the BRIGHTLIGHT Carer Questionnaire. Special thanks to Dr Anika Petrella, your patience and support through the data analysis was unwavering. You made coding and SPSS almost fun, that’s a skill indeed.

Dr Maria Cable, friend, and source of academic inspiration for over a decade, thank you.

To the caregivers who submitted their experiences to the study, thank you for sharing. I hope that I have done your responses justice and that this research makes a change to others in the future.

Finally, to my long-suffering family, be careful what you wish for – you get me back now…

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PART ONE

Identifying the psychosocial and social needs of the main caregivers of adolescents and young adults undergoing active treatment for cancer: a scoping review

Introduction

Adolescents and young adults with cancer (AYAC) have been identified as a population with unique needs requiring age-appropriate, specialist care (Cable and Kelly, 2019; Smith et al., 2016). As a group they are defined by age rather than malignancy. The recognised United Kingdom (UK) age-range used to categorise AYAC is 13-24 years (National Institute for Health and Care Excellence, 2005), and the definition used in this review. AYA often present with rare and diverse tumour types, with diagnoses in this age group accounting for 1% of all cancer cases in the UK (Cancer Research UK, 2022). Outcomes for AYAC remain poorer than for children and older adults, often attributed to underrepresentation in clinical trials (Fern and Taylor, 2018; Close et al., 2019).

Social networks are the structure or web of social relationships around an individual. The type, frequency, and strength of the relationships in that structure are key components of how an individual experiences social participation and integration (Berkman et al., 2000). Social networks can be dynamic and changeable, and in the course of an illness journey require careful navigation, negotiation and renegotiation. Given their developmental life stage, AYAC present with unique social networks which can include families, friends, partners and communities, many of whom may participate in and share the cancer journey. It is inevitable that a member or members of an AYAC social network will become caregiver.

The role of caregiving in this age group predominantly falls to parents, with mothers historically identified as taking the main caregiving role (Grinyer, 2002). Assumptions can be made that mothers will automatically take up the mantel of main caregiver. This can be problematic within the nature of families which are becoming overall increasingly complex due to new relationships, changing partners and blended domestic arrangements. Nonetheless, family relationships are known to be critically important, impacting on the young person's experience and wellbeing throughout the cancer trajectory (Corey et al., 2008; Grinyer, 2009; Breuer et al., 2017).

Conceptualised by Lea et al. (2018b), age-appropriate cancer care recognises individuality and considers the wider context of AYAC's unique psychosocial and developmental circumstances. Within the concept, care is delivered in an age-appropriate environment, by health care professionals (HCPs) with clinical expertise and knowledge, a solid understanding and passion for young people, and effective communication skills (Lea et al., 2021). A key feature of this care delivery relates to the increasing autonomy and evolving independence of young people. Key adult milestones such as ability to consent to medical treatment and the shift in legal responsibilities from parent to young person can generate complexities. HCPs must navigate this in partnership with the caregiver and AYAC at a time of intense anxiety and distress for all involved (Davies et al., 2018).

The specialism of AYAC care has developed over the past 20-30 years in the UK and internationally. The main focus of research has been on AYAC patient care, service delivery and clinical trials (Cable and Kelly, 2019), with little attention given to the specific needs of caregivers fulfilling a vital role supporting AYAC through treatment. Guided by Arksey and O'Malley (2005) framework, caregiver needs are considered in this systematic scoping review (ScR). ScR's are increasingly a commonly used method for synthesising research evidence and may be particularly valuable when a topic has not yet been extensively explored or is of a complex or heterogeneous nature (Levac et al., 2010; Peters et al., 2015).

The aim of this ScR was to examine the evidence relating to the psychosocial and social needs of the main caregivers of AYAC undergoing treatment. The objectives were to:

a) Identify the characteristics of main caregivers of AYAC,
b) Explore the psychosocial and social needs described,
c) Describe how these needs were identified or measured,
d) Identify potential implications for practice or further research.

Methods

Stage 1: Identifying the research question

The review addresses the following question: What are the psychosocial and social needs of the main caregivers of AYA undergoing active treatment for cancer? This was reached through reflection on clinical practice and discussion with supervisors. An area of AYA service delivery which was felt to impact the care experiences of patients and families, to generate challenges for HCPs was identified. Initial inclusion and exclusion criteria were created which articulated the target population, (namely caregivers), and kept the parameters of need broad (Arksey and O'Malley, 2005). The inclusion and exclusion criteria were then adapted and refined in accordance with initial searches (Table 1).

Table 1 Inclusion and exclusion criteria

	Inclusion criteria	**Exclusion criteria**
Types of participants	AYAC aged 13-24 years at diagnosis (in line with NICE (2005) age definitions*). Main caregivers were defined as parents, spouse, partner. Papers were included if they described key care pathway points of; diagnosis, treatment, and end of treatment comparable with NICE (2014)	Care of AYAs with non-cancer illnesses. AYAs as caregiver, not patient. Other family members such as siblings or grandparents. Healthcare professionals views.
Types of interventions / phenomena of interest	Quantitative, Qualitative and Mixed Method studies were included to enable a variety of approaches to measurement and description of needs.	Grey literature. Reports. Unpublished theses.
Context	Studies conducted in either Europe, United States of America, Canada or Australia only, as these countries have identified services for AYAC. The psychological and social needs of the main caregivers had to be discussed and clearly identifiable within the results and the discussion. Papers were included if the focus fell within the NICE (2014) care pathway key points of; diagnosis, during treatment, or end of treatment.	Papers focusing on survivorship, long term follow up (generally defined as 5 years post treatment end) or end of life were excluded.
Time limits	2005-2020 given the recent emergence of the specialism.	Studies older than 15 years.
Language	Only studies published in English.	Non-English publications.
*Where age was not clear, for example if broader age definition was considered by the study, papers were included if the mean, median or average age fell in this range, or the result of the 13-24 year olds was extractable and made up more than 50% of the sample.		

Stage 2: Identifying relevant studies

In keeping with the framework, a broad search on CINAHL was conducted. Findings such as target age-range of AYAC, time period on care pathway and research considering young people as caregivers to parents with cancer guided the final search strategies. Three health and social care, subject-specific journal databases were explored: CINAHL, PsycINFO and MEDLINE. These databases were chosen as likely to include the research published by the different disciplines that form the multidisciplinary teams and researchers working in AYAC. Key words were identified from papers identified during initial search. Truncation, spelling variations and Boolean operators were used to aid searching. Subject heading were used in Medline, MESH headings in CINAHL database searched. All three groups of terms were combined with AND. Peer review was the only consideration of quality of papers (Table 2).

Table 2 Key words / search terms and limiters

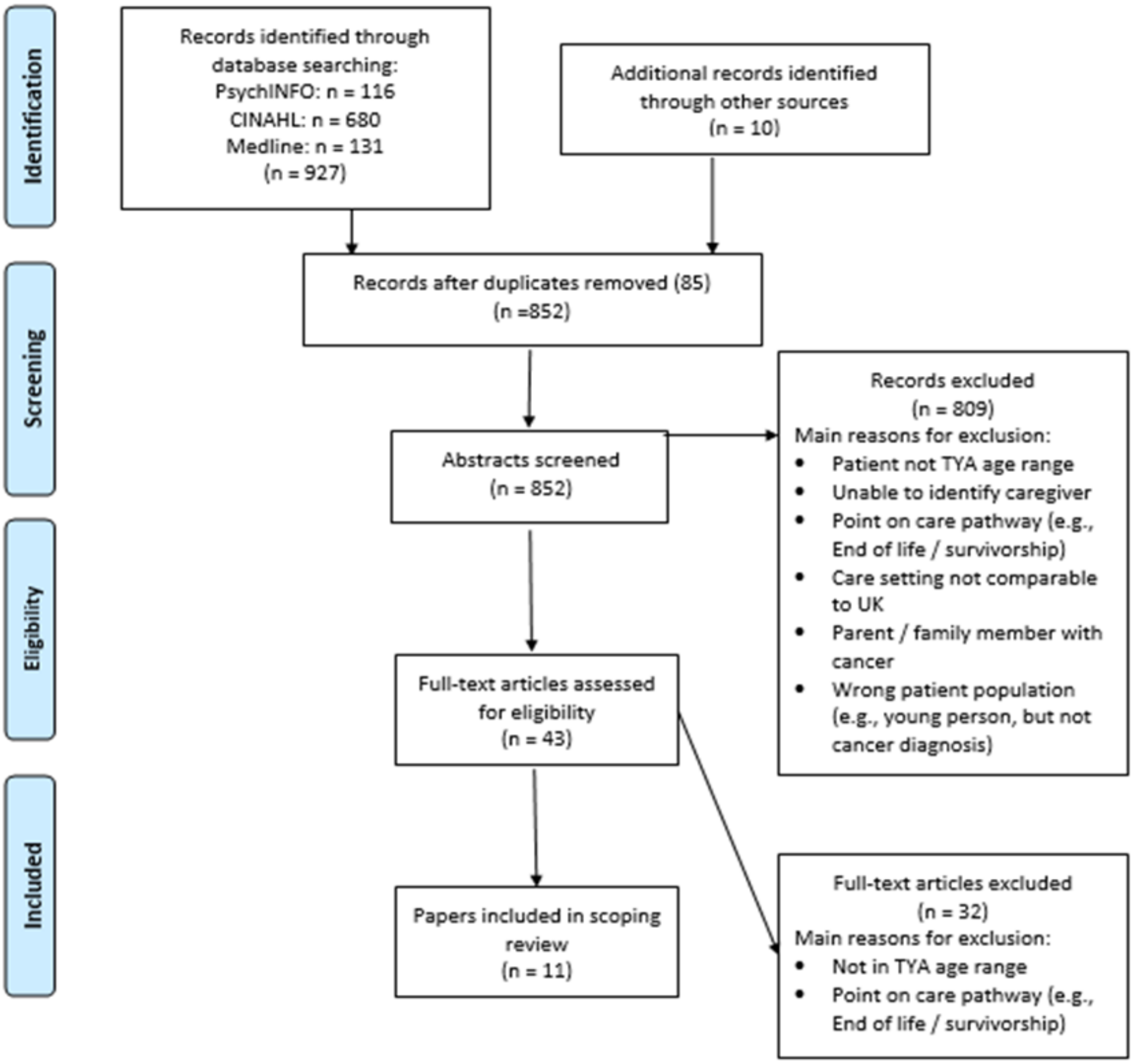
Teenage* OR Adolescen* OR Young Adult* (Adolescent, Adult, Young Adult) AND	
Cancer OR Neoplasm* OR Oncology (Neoplasms, Oncology Nursing, Psycho-Oncology) Family, Caregiv* OR Parent* (Family Nursing, Family Relations, Professional-Family Relations, Caregivers, Parent-Child Relations) AND	
Psychosocial Support OR Information Needs. (Psychosocial Support Systems, Information Services)	
Limiters	
Published since 2005	English language
Full text availability	Peer reviewed articles only

Stage 3: Study selection

Selection and review of articles took one month to complete and was conducted in March 2020. Each database search was uploaded into RAYYAN, a web and mobile application designed to expedite initial screening of titles and abstracts. RAYYAN enabled the screening process to occur transparently using the blinding option. Progress of individual reviewers could be followed through a dashboard. Documenting individual rationale for exclusion facilitated sharing and tracking of decisions (Ouzzani et al., 2016).

An initial yield of 927 references were retrieved. The titles and abstracts were screened separately by NP and AT. 825 references (with 85 duplicates noted), were considered for further assessment of the full paper, resulting in 43 papers being read independently in full-text for eligibility by NP and SN. The National Institute for Health and Care Excellence (2014) quality standards for AYAC psychological and social needs assessment was used as a framework to define needs. This clarity was required to support decision making through this iterative stage as we became more familiar with the literature (Levac et al., 2010). Eleven papers were selected for review (Figure 1).

Figure 1 PRISMA Flow diagram (Moher et al., 2009)



Stage 4: Charting the data

A data charting form was devised to capture general information about the papers and specific details about study design, eligibility and overall findings (Table 3). Published between 2009 and 2020, papers originated from Australia (5), UK (4), Canada (1) and Denmark (1). Three of the Australian papers reported separate elements of a four-stage study (Sawyer et al., 2016).

Table 3 Summary of Papers

Author / Year / Country / Journal	**Title**	**Study Design**	**Aim / Purpose**	**AYA (Patient) eligibility**	**Findings/Conclusion**
Davies et al. (2018) Wales, UK *Journal of Advanced Nursing*	The experience of partners supporting Adolescents and Young Adults with cancer	Exploratory qualitative case study design. Purposeful sampling using maximum variation. Thematic Analysis	Share interview data derived from a larger study (investigating choice & control in decision-making in AYA cancer) to report of the experiences of young peoples' partners. Sharing information to stimulate debate relating to partner experience	Eligible if 16 to 24 years, undergoing curative treatment, minimum of 2 months post diagnosis	Partner experiences are not well understood
Goodall et al. (2011) Australia *Health Policy*	Preferences for support services among Adolescents and Young Adults with cancer or a blood disorder: A discrete choice experiment	Discrete choice experiment (DCE). Based on the economic theory of value (Lancaster, 1966) 'Choice sets' of six attributes (4 with 2 levels, 2 with 4 levels) describing support services. Participants randomly assigned to one of 16 choice set versions & asked to answer 16 choice decisions	Use DCE to determine which types of support are most valued by AYA and their families	Eligible if 16 to 32 years, diagnosed with cancer or blood disorder at least 3 months prior	AYAC patient & families need support systems that encompass financial aid, return to work/study and emotional support. High levels of heterogeneity in results therefore 'one size' of service will not meet all needs
Hart et al. (2020) Scotland, UK *BMC Health Services Research*	The challenges of making informed decisions about treatment and trial participation following a cancer diagnosis: a qualitative study involving Adolescents and Young Adults with cancer and their caregivers	Critical realism. Qualitative description. Inductive, semi structured interview design	Explore interviewees experiences of, & views about, making decisions about treatment and/or trial participation following a cancer diagnosis, in order to understand, and help facilitate, informed treatment - related decision-making in this age group	Eligible if 16 to 24 years (stage not elicited)	Decision making about front line treatment is challenging context for AYAC, Caregivers and HCPs. Information provision for AYAC & Caregivers may require different approaches due to age/recall of information ability
Martins et al. (2019) England, UK *Cancer Nursing*	The BRIGHTLIGHT National Survey of the Impact of Specialist Teenage and Young Adult Cancer Care on Caregivers' Information and Support Needs	Survey containing 15 multi-item questions covering 4 domains	Evaluate whether caregivers of TYAC have fewer unmet information and support needs if they received some or all of their care in a Principal Treatment Centre. 5 hypothesis presented	13 to 24 years at time of diagnosis, within 4 months of starting treatment	Caregivers of AYAC in non specialist settings have most unmet information and support needs
McCarthy et al. (2016) Australia *Journal of Adolescent & YoungAdult Oncology*	Psychological Distress and Posttraumatic Stress Symptoms in Adolescents and Young Adults with Cancer and Their Parents	Survey including validated measures of psychological distress with additional measures and study specific questionnaires	Investigate the prevalence and predictors of psychological distress in AYAC and their parent caregivers	15 to 25 years at diagnosis, within 6-24 months of diagnosis	Nearly half of caregivers reported distress and posttraumatic stress symptoms. Early identification of distress, appropriate developmental perspectives to understand AYAC distress and the need for family based psychological assessment and intervention

McCarthy et al. (2018) Australia *Supportive Care in Cancer*	Information needs of adolescent and young adult cancer patients and their parent-carers	Survey instrument included validated questionnaires and additional study-specific questions	Explore health-related information needs of AYAC and their parent-carers and to examine demographic and clinical variables associated with unmet information needs, including patient activation	15 to 25 years at diagnosis, within 6-24 months of diagnosis	Importance of information needs for AYAC and their parents is needed to promote family-centred care and help with associated emotional distress
Moules et al, (2018) Canada *Journal of Family Nursing*	"Family Is Who They Say They Are": Examining the Effects of Cancer on the Romantic Partners of Adolescent and Young Adults	Hermeneutic Phenomenology. Data capture through interviews, with transcripts interpreted individually then through research teams in-depth, rigorous, reflexive conversations and consultation with experts in the field	Examine the effects of cancer on romantic partners (i.e., boyfriends, girlfriends, social/romantic/intimate partners of AYA experiencing or who have experienced cancer	Partner (current or past) of 14 to 24 year old patient in remission or still on treatment or when diagnosed. Any partner of AYA now RIP. AYA 14-24 years old who could speak to the experience of their partners	Romantic Partners relationships with AYAC and their families are affected by treatment in many varying ways, often with negative impact, effect, and repercussion. Partners experience conflict and their needs are not considered or recognised
Olsen & Harder (2009) Denmark *Cancer Nursing*	Keeping Their World Together - Meanings and Actions Created Through Network-Focused Nursing in Teenage and Young Adult Cancer Care	Classic/Constructivist Grounded Theory. Data generated through interviews, observations and informal conversations	To generate a substantive theory that would conceptualise what happens when oncology nurses engage in supporting TYA with cancer and their significant others to maintain, establish, and strengthen social relationships and a social network during the treatment period	On active treatment or up to 1 year off	Nursing programme can enhance support for caregivers though encouraging and facilitating connection with their family and wider social networks
Sawyer et al. (2017) Australia *Support Care in Cancer*	Unmet need for healthcare services in adolescent and young adults with cancer and their parent carers	Self-administered questionnaire of validated psychosocial measures and study-specific items	Describe the healthcare support service needs of AYAC and parent carers to explore the association of unmet need and emotional distress	15 to 25 years at diagnosis, within 6 to 24 months of diagnosis	High levels of AYA and parental unmet needs for clinical/healthcare services leads to greater emotional distress for both
Stevens et al. (2018) England, UK *Journal of Adolescent and Young Adult Oncology*	Understanding and Utilising the Unmet Needs of Teenagers and Young Adults with Cancer to Determine Priorities for Service Development: The Macmillan On Target Programme	Questionnaires, focus groups and interviews undertaken, then Requirement Management Methodology used to specify components for potential services interventions, which were then scored and prioritized	A systematic attempt to identify and address unmet needs among patients in a large, regional AYAC service, including perspectives obtained from patients themselves, their families / supporters and professionals	16 to 24 years at diagnosis or recurrence, known to be alive, on or off treatment	High impact of AYA cancer on lives of networkers such as physical wellbeing, impact on spare time / leisure activities, financial circumstances & other relationships. Networkers want help to fulfil their role, delivered face to face by hospital staff
Wakefield et al. (2012) Australia *Pediatric Blood Cancer*	Family Information Needs at Childhood Cancer Treatment Completion	Semi Structured telephone interviews, data then coded with inductive approach. Quantitative data collected through list of seven information sources then scored using Likert Scale 1-10	Investigate the experiences of young cancer survivors, their parents and their siblings in receiving information in the first year after treatment. Also to determine unmet information needs and preferences for information delivery in the post-treatment period	Patients aged over 12 years at time of study, parents eligible if they were mother, father, primary caregiver of child who had undergone treatment for cancer, completed treatment, less than 5 years post-diagnosis	Information needs of family members are unmet such as fertility and post treatment challenges. Provision of correct & timely information in a highly stressful period is a clinical challenge

Stage 5: Collating, summarising and reporting the results

A ScR provides a methodological framework to illustrate a research field of interest and identify gaps in the evidence base, not to present a detailed analysis or quality appraisal of the literature (Arksey and O'Malley 2005). Therefore, in order to synthesis the data and present the findings, a thematic matrix was developed using Braun and Clarke (2006), a reflexive approach to Thematic Analysis. Basic coding was used to systematically label topics and aspects of interest. These were then integrated into key themes to address the research question (Spencer et al., 2014). Six themes provide an overall framework to report the findings (Table 4).

Table 4 Thematic matrix

Author / Year	**Themes**					
	Carer type	**Practical and information needs**	**Place of care**	**Emotional impact**	**Assessment**	**Shared experience**
Davies et al. (2018)	x	x		x	X	
Goodall et al. (2012)	x	x		x		
Hart et al. (2020)	x	x	x	x		
Martins et al (2018)	x	x	x		x	
McCarthy et al. (2016)	x	x		x	x	x
McCarthy et al. (2018)	x	x	x	x		x
Moule et al. (2018)	x	x	x	x	x	
Olsen & Harder (2009)	x	x	x	x		x
Sawyer et al. (2017)	x	x	x	x		x
Stevens et al. (2018)	x	x		x	x	
Wakefield et al. (2012)	x	x				

Results

Carer Type

Caregiver characteristics are summarised in Table 5. The papers report 890 participants in total. Sample sizes ranged from 3 to 476, with women and mothers being the most represented characteristics. Participants numbers were often small (qualitative designs) therefore limited demographic information was reported to avoid potential identification of individuals. Eight studies focused primarily on parents in their discussion, (Goodall et al., 2012; Hart et al., 2020; Martins et al., 2019; McCarthy et al., 2016; McCarthy et al., 2018; Olsen and Harder, 2009; Sawyer et al., 2017; Wakefield et al., 2012). Three studies recruited participants nominated by the AYAC as their main caregiver; parents were nominated with the highest frequency (Goodall et al., 2012; Martins et al., 2019; Stevens et al., 2018). Partners were identified in eight of the studies in smaller numbers and only two studies (Davies et al., 2019; Moules et al., 2018) focused solely on partners as caregivers. Ethnicity of caregivers was only specified in four of the studies, with a majority identifying as White (≥80%)

Table 5 Summary of caregiver participant characteristics

Study	**Sample Size**	**Caregiver definition / identified**	**Place of Care (where specified)**	**Caregiver Characteristics (where specified)**					
				Age	**Relationship**	**Gender**	**Ethnicity**	**Education or Occupation Status**	**Other**
Davies et al. (2018)	n = 3	Partners	Single geographical site (service type not specified)	19 & 20 years	Partners (Relationship length 1 to 2.5 years)	1 Male 2 Female			
Goodall et al. (2012)	n = 74	Nominated carers	Adult & children's hospitals (3 different hospitals)	20 to 60+ years (59.5% 40 to 49 years)	86% Parents 7% Partners	85.1% Female	82.4% European descent	52% completed high school, 23% graduate degrees	Marital status (86.5% married, 9.5% separated / divorced)
Hart et al. (2020)	n = 15	Caregiver (parent / partner)	3 children's and 5 adult centres across Scotland (adult hospital with AYA unit 78%, children's hospital with AYA unit 17%, adult hospital without AYA unit 6%)		11 Mothers (73%) 3 Fathers (20%) 1 Partner (7%)		14 (93%) White British	8 (53%) Professional 6 (40%) Semi-professional / skilled	
Martins et al. (2018)	n = 476	Main caregiver (since diagnosis)	97 hospital trusts across England (children's, AYA specific and adult)	15 to 65+ years 242 (51%) 45-54 yrs. 95 (20.1%) 35-44 yrs. 66 (14.2%) 55-64 yrs.	401 (84.5%) Parents 54 (11.4%) Partners 18 (3.8%) Others	381 (80.2%) Female	425 (80.2%) White	312 (65.7%) Employed 7 (1.5%) Education 15 (3.2%) Unemployed 15 (3.2%) sick/disabled 126 (26.5%) other	369 (78%) Married or cohabiting 104 (22%) Divorced/single/widowed
McCarthy et al. (2016) Sawyer et al. (2017) McCarthy et al. (2018)	n = 204 (126 dyads)	Nominated parent most involved in care	17 hospitals providing AYA care (12 adult, 5 children's)		89% Mothers 9% Fathers 2% Other	90% Female	Country of birth (Australia 69%, other 31%)	78% completed secondary school / higher education 72% Employed	Area of residence 60% metropolitan district Relationship status (77% married / partner, 11.5% separated / divorced, 11.5% single)
Moule et al. (2018)	n = 3	Romantic partners		Early 20's	1 Wife 2 Partners	2 Female 1 Male			
Olsen & Harder (2009)	n = 19	Significant others	Single AYA care setting		11 Mothers 6 Fathers 2 Partners				
Stevens et al. (2018)	n = 28	'Networkers' those whom the patients perceived as most	Specialist AYA Regional Service at principal treatment centre, with network of 6 designated hospitals	25% respondents aged 18-25 years	50% Family members (of which 32% Parents) 25% Friends 14% Partners	82% Females			

		important to them		25% aged less than 50 years	11% Others (including flat mate, spiritual advisor, school head and work manager)				
Wakefield et al. (2012)	N = 68	Mother, Father or primary caregiver	Single children’s hospital	Mean age at interview; Mothers 42.5 years, (range 29 to 64) Fathers 45.9 years (range 28 to 61)	44 Mothers 24 Fathers			Highest level of education, 21 Mothers & 13 Fathers Degree Employment status, full/part time, 20 Mothers & 29 Fathers	

Although small in numbers, unique needs relating to partners as main caregivers were identified. Partners of AYAC described the impact of accepting the responsibilities associated with caregiving, but also the role navigation required to manage the potential conflict and tension that the often relatively newly formed romantic relationships generated with parents. As individuals jostled for position, negotiating and redefining who mattered most, disputes could arise creating family and relationship boundaries to shift and change (Moules et al., 2018). Davies et al. (2019) describe the disagreements and conflicts of interest that could occur with parents when the partner acted as a confidante for thoughts, feelings and emotions and was an ally in decision making.

Practical and information needs

The practical needs of caregivers were included broadly in all the papers. Returning to education or employment (Goodall et al., 2012; Sawyer et al., 2017), financial advice (McCarthy et al., 2016; Stevens et al., 2018), location and travel to the hospital, general life stressors (McCarthy et al., 2016), and disruption to everyday life (Olsen and Harder, 2009; Davies et al., 2019) were identified. A consistent thread was the need for information. This ranged from general advice and information to fulfil the role of caregiver (Stevens et al., 2018), to specific medical and treatment information (McCarthy et al., 2018; Hart et al., 2020), fertility related issues and coping after treatment ends (Wakefield et al., 2012). Martins et al. (2019) found information provision varied with both caregiver and AYAC characteristics. More information was provided to female caregivers, parents, caregivers aged 35 to 54 years of age, when the AYAC was aged 13 to 18, or being treated for haematological malignancy.

Importantly, the unmet need for information was not universally experienced. McCarthy et al. (2016) noted that 20% of participants reported no unmet needs, comparable with Martins et al. (2019) who report that more than 30% of caregivers were satisfied with information provided. Information preferences were explored by Wakefield et al. (2012), with the top three preferences of caregivers being information booklets, online support and question prompt sheets.

A key feature of Olsen and Harder (2009) model of '*network focused*' nursing, the nurse led network meeting presented a novel way to share information. Offered after the first month of treatment, the AYAC and family were given the opportunity to invite their wider social contacts to meet HCPs, to learn about and discuss the individual's disease, treatment plan, side effects and the overall impact on life and relationships. Participant's perceptions of engaging in the network meeting created concepts such as '*finding their way*' and '*telling it straight*' which led to diminished uncertainty in caregivers.

A unique feature of the information needs of caregivers is the potential distress and conflict generated. McCarthy et al. (2018) identified high levels of information need for parents, with significantly greater unmet needs around medical information concerning their child. Hart et al. (2020) explored the challenges of informed decision-making at diagnosis. AYAC needed to receive information to make treatment decisions but felt extremely unwell, caught up in a whirlwind of activity, consequently struggling to process information. Caregivers sought to protect them and compensate for the limited engagement, however this led to conflicting priorities around information need. AYAC expressed the desire to maintain a positive, recovery focused outlook, with parents describing a more realistic need for information about prognosis. This led to delicate balance of parents either shielding AYAC or satisfying their own needs, both with the potential to generate distress.

Place of care

Place of care, (PoC) was elicited in the recruitment strategy in all but one study (Table 5). The majority of care was provided in a mixture of children's, AYAC or adult service settings, with a single study recruiting solely from a children's setting (Wakefield et al., 2012), and one exclusively from AYAC care settings (Olsen and Harder, 2009). Hart et al. (2020) identify the impact of arriving at a specialist cancer centre at diagnosis on caregivers, and the associated escalation of activity. To enable analysis of the cohort by PoC in the Martins et al. (2019) study a 'Teenage and Young Adult Cancer Specialism Scale' (TYA CSS) was developed (Taylor et al., 2019). This defined age-appropriate care experience as none, some, or all care in a principal treatment centre (PTC). Findings indicated that caregivers of AYAC who received all or some care in a TYA PTC had more satisfaction with support received and the services specifically provided for carers.

In Olsen and Harder (2009), network-focused nursing was only available in a specialist, cancer youth unit for 15 to 22-year-olds. Here AYAC and caregivers benefitted from the flexible, youth focused environment. McCarthy et al. (2018) related their finding of high unmet information needs to the fact that the majority of AYAC received care in adult centres and therefore the care delivery was patient focused, with greater potential for carers to be excluded. In contrast, Moules et al. (2018) noted that in a children's, family-focused care setting HCPs may not recognise that AYAC's are sexually active, feel uncomfortable talking about sexual relationships, may make a judgement or not afford enough respect to romantic partners.

Emotional Impact

Linked closely to unmet practical and information needs, the emotional impact of AYAC was identified in nine of the papers. The vast majority (90%), of networkers in Stevens et al. (2018) study wanted emotional support. Hart et al. (2020) describe the rush of emotions experienced at diagnosis alongside the need to protect and support loved ones. Caregivers expressed changing life plans and putting their own wellbeing to one side to be present alongside the AYAC (Davies et al., 2019; Stevens et al., 2018). Olsen and Harder (2009) identified the significant burden and pressure of communicating and sharing the AYAC experience with wider networks. In the quantitative papers this was assessed and quantified using a variety of measures (Table 6), of posttraumatic stress (PTSS) and psychological distress (McCarthy et al., 2016; Sawyer et al., 2017; McCarthy et al., 2018), with up to half of caregivers scoring highly in relation to clinical cut-offs for intervention.

Table 6 Summary of tools / measures used

Paper	**Tool / measures used**			
	No.		**Validated**	**Description**
Goodall et al. (2012)	1	Discrete Choice Experiment (DCE)	Not validated in this setting	Lancaster (1966) economic theory of value. Individuals derive utility from underlying attributes of a ‘good’. Preferences across goods are revealed through consumption choices. Respondents choose preferred bundles of alternatives from hypothetical choice sets.
Martins et al. (2018)	2	BRIGHTLIGHT carer questionnaire (BCQ)	Not validated	Developed specifically for the study based on questionnaires developed for carers of adults with cancer.
McCarthy et al. (2016)	3	Posttraumatic Stress Disorder Checklist (PCL-S)	Validated	17 item self-report measure Bothered by symptoms over the past month on a five-point scale.
	4	Kessler Psychological Distress Scale (K10)	Validated	10 item self-report measure Global distress (anxiety and depression) symptoms over the past 4 weeks
	5	Multidimensional Scale of Perceived Social Support (MSPSS)	Validated	12 item instrument 3 subscales designed to measure perceptions about support and family friends and significant others
	6	Medical Outcomes Social Support Survey (MOS)	Validated	Measures perceived social support across four domains. Subscale used for parents – Emotional or Informational Support – 8 items
	7	Life Impact Scale	Validated	19 Item self-report measure Modified to assess cancer impacts relevant to AYA resulting in 18 item AYA life Impact checklist 13 item parent version developed to measure specific impacts of cancer on the parents
	8	Life stress	NA	Single item questions to identify pre-existing or current stressors
McCarthy et al. (2018)	9	Adolescent and Young Adult Health Outcomes and Patient Experiences (AYA HOPE)	Validated Slightly adapted for the Australian context	21 item questionnaire adapted from the 13 item AYA HOPE study and 2 items from the AYA HOPE follow up study to assess information needs (outcome measure). Four additional items added to include need for information & financial support for themselves, talking to child about cancer, talking to siblings and opportunities to meet other parents of AYA with cancer (peers).
	(3)	Posttraumatic Stress Disorder Checklist (PCL-S)		
	(4)	Kessler Psychological Distress Scale (K10)		
Sawyer et al. (2017)	(9)	Adolescent and Young Adult Health Outcomes and Patient Experiences (AYA HOPE)	Validated Slightly adapted for the Australian context	10 item measure, modified for parents (5 questions related to parents’ perceptions of son/daughter’s needs, 5 related to their own needs)
	10	Cancer Needs Questionnaire for Parents and Carers of Young People with Cancer (CNQ-PC)	Not Validated	9 items selected that related to practical and support needs. Response options modified into 2 components (rating importance of item and then rate difficulty encountered with item)
	(3)	Posttraumatic Stress Disorder Checklist (PCL-S)		
Stevens et al. (2018)	11	Requirements Management	Not validated in this setting	Systematic approach to collection, documentation, organisation, and evaluation of inputs from different sources. Inputs (participants feedback) are translated into ‘findings’, which are in turn analysed and transformed into a ‘requirement for change’. Used in systems engineering and software development, through identification of tasks, determines the conditions required to meet a new/altered ‘product’ (in this study a service intervention) taking into consideration potentially conflicting ‘requirements’ (views) of various stakeholders.

Assessment of Caregiver needs

A total of 11 tools or measures for psychosocial or social experiences or needs were used across the quantitative and mixed methods studies, with three being used two or more times (Table 6). Not all were validated at the time of the study and several studies adapted the original measures to better fit the target participants or healthcare setting. Two studies used tools whose theory base was outside healthcare setting, economics (Goodall et al., 2012), and system engineering (Stevens et al., 2018). Early identification (McCarthy et al., 2016), assessment of information needs (McCarthy et al., 2018), support determination (Davies et al., 2019), and networker support (Stevens et al., 2018) were all proposed as important in understanding the needs of caregiver.

Practical steps to achieve this were noted only by Moules et al. (2018) who suggests that genograms, a pictorial or diagrammatic representation of connections, networks and relationships, could be used as a tool to capture AYAC family and significant others. This would only identify caregivers, not assess their needs. Martins et al. (2019) noted the lack of specific or validated questionnaires available for AYAC caregivers and highlighted that unmet need questionnaires for adults are not automatically transferable to AYA populations.

Shared experience

Both positive and negative caregivers needs and experiences were revealed to be comparable or interwoven with those of AYAC. Reassuring symmetry was demonstrated in preferences for support services (Goodall et al., 2012). Sharing the experience appeared to bring benefits. ‘*Keeping their world together’*, the core concept of Olsen and Harder (2009) model of AYA care, indicated that through integrating the cancer journey into everyday lives, at the same time as protecting the balance and harmony within the family network, caregiver needs were positively impacted. In contrast, rates of emotional distress associated with unmet needs were found to be comparable between parents and AYA (McCarthy et al., 2016). There was concordance of unmet needs for healthcare services (Sawyer et al., 2017), and information needs (McCarthy et al., 2018) with both linked to psychological distress. To address this negative impact, several papers concluded that a family-centred approach should be taken (McCarthy et al., 2016; Sawyer et al., 2017; McCarthy et al., 2018).

Discussion

The aim of this ScR was to examine the evidence relating to the psychosocial and social needs of the main caregivers of AYA undergoing treatment for cancer. The results demonstrate considerable heterogeneity of psychosocial and social needs experienced by caregivers of AYAC. However, themes generated enable examination of caregiver needs that relate specifically to this cohort of cancer patients. Regardless of characteristics, caregivers' needs are generated by their efforts to do their best in traumatic, worrying situations which impact every corner of life. The diagnosis and treatment of AYAC impacts caregivers' emotional wellbeing. HCPs need to be vigilant to this burden as it has potentially significant impact on health (Goren et al., 2014), caregivers may be less likely to verbalise their needs (Sharma et al., 2020) and may prioritise the emotional needs of the AYAC over theirs (Goodall et al., 2012).

Parents, particularly mothers, were identified as the largest characteristic group of caregivers. This is consistently acknowledged in the literature, and is unsurprising, given the natural dependency of minors at the lower end of the age range and overall developmental life stage of AYAC. The practical challenges of cancer, such as the impact of treatment on daily life, travelling to appointments and the reduced ability to attend education, study or work, may necessitate young people to return to the family home. In doing so they may lose economic independence. This new or resumed reliance on parents can impact on emerging independence and re-negotiation of identity (Pearce et al., 2020).

AYAC experience treatment in a period of physical, emotional and social liminality. A key element of this developmental life stage is the role of friends within social networks (Corey et al., 2008; Breuer et al., 2017). The importance of special friends to AYAC experiences is long established (Woodgate, 2006), and peer support features in the conceptualisation of age-appropriate care within the theme of social environment (Lea et al., 2018b). Given the developmental life stage of AYAC, friendships may well have developed into romantic relationships. This natural social transition creates alternative avenues for help bringing potential complexity within the social network and for HCPs providing care.

Evidence suggests that intimate relationships and sexual activity are common during AYAC treatment and linked to perceptions of identity (Rosenberg et al., 2017). Soanes and Gibson (2018) outline the importance of mobilising external resources to protect AYAC's adult identity. They observed that AYAC broadly allocate roles within their social network, noting that support provided by parents differed to that of partners and friends. While parents gave tangible, more practical help, emotional support came from partners in the form of an '*emotional anchor*' who played a key role in AYAC decision making and self-management.

It is important to consider that partners are also young people themselves. They are also transitioning through a developmental phase and require a different type of support than partners of other ages. Often within newly formed relationships, they too must face uncertainty, distress and frustration in commonly intense periods of treatment, largely unexpected and not predicted at this stage of life. They may have little experience or resilience to cope or manage in the situations they find themselves (Head and Iannarino, 2019).

Davies et al. (2019) highlighted the importance of education and advice to support the wellbeing of partners, delivered by HCPs. However Moules et al. (2018) suggests that HCPs can find themselves caught up in the disagreements generated by role negotiation, territorial disputes and rights and privileges to care. The implications for HCPs are complex. The literature suggests that they have a key role to support young people (both AYAC and their partners as caregivers) and parents to acknowledge and understand the impact of the situation on relationships. The impact on the partner in taking up this role cannot be underestimated. HCPs need to be cognisant of the potential conflicts and relationship dynamics. These are not fully articulated in the literature and need to be understood.

In relation to information requirements, parents attempt to balance their own needs with the changing autonomy of the young person, mindful perhaps of not only the immediate impact, but the threat to longer term existence and future hopes and dreams (Lewis et al., 2015). These different priorities and contrasting perspectives have been described as '*mirror images*' leading to tension and misunderstanding (Grinyer, 2009). This delicate balance of fulfilling the carer role, gathering information for self and acting as an advocate requires constant renegotiation throughout treatment and beyond. It takes strength, and caregivers need support to sustain their own needs and wellbeing (Bogetz et al., 2020). It is also dependent on factors such as existing patterns of communication, family adaptability and cohesion (Phillips-Salimi et al., 2014). Reflecting on the variation by caregiver characteristics (Martins et al., 2019), HCPs may introduce unconscious bias to information provision. HCPs must demonstrate awareness of the social network and its dynamics around the AYAC. Information provision must be respectful of the developmental life stage and consideration given to the who, what, when, where and how information is shared. As previously discussed, the presence of partners can bring further complexity and challenge.

Age-appropriate or specialist environments are frequently perceived as a key factor to the delivery of high quality experiences for AYAC's, with children's and adult settings or models of care depicted as inadequate or inappropriate (Lea et al., 2018b; Cable and Kelly, 2019; Peditto et al., 2020; McInally et al., 2021a). Care in a PTC is associated with clearer documentation of clinical processes and improvement in AYA quality of life (Fern et al., 2021). The ScR findings indicate that PoC can also impact the needs of caregivers. While the literature has provided some insight into the supportive culture of a unit for parents (Kelly et al., 2004), this warrants further research. It is also important to acknowledge that many AYAC treatments do not necessarily bring them to a specialist unit, therefore access to support for caregivers may require an alternative approach from services (McInally et al., 2021b).

The shared experience of caregivers and AYAC is not a new finding. Caregivers of any age group could be viewed as second order patients (Shilling et al., 2016). Given the developmental life stage of AYAC, reliance on caregivers, and the frequency of visits through treatment, Juth (2016) argues that caregivers are also 'treated' alongside the patient. The experience of parent and child are communal

(Head and Iannarino, 2019), shared and intertwined (Juth et al., 2015b), albeit with different reactions. Families are a key resource for AYAC and their function and resilience appear to be connected (Barakat et al., 2010; Lau et al., 2020). Although as with any life stressor, existing family strengths and relationships can impact caregiving roles and expectations (Reblin et al., 2019). Unmet needs do have an impact on both AYAC and parents, leading to distress and anxiety, impacting the wellbeing of caregivers (Sharma et al., 2020). The findings support existing evidence proposing the need to consider AYAC and their caregivers with a dyadic approach (Phillips-Salimi et al., 2014) which acknowledges their unique social ecology (Juth, 2016).

The ScR describes a wide range of approaches to the identification and measurement of needs. This finding supports existing evidence that the needs of carers of cancer patients are seldom assessed, and validated tools to assess their specific needs are lacking (Carey et al., 2012). Identifying appropriate methods, approaches, and the development of validated tools to do this effectively warrant further research. Comprehensive, holistic assessment of AYAC psychological and support needs are a now a standard element of AYAC care with specific, youth focused assessments well established in practice (Cargill et al., 2016; Patterson et al., 2018). Given the symmetry and shared experience of caregivers and AYAC, this potentially provides a platform on which to develop, with due consideration to heterogeneity of need, carer type and care setting. The roles, skills and knowledge of the HCPs in completing the assessment, and the service provision to meet any identified needs also require additional deliberation. This has significant resource implications, particularly for counselling and psychology provision given the high scores noted in relation to clinical indicators for intervention.

Limitations

There are several limitations acknowledged in this ScR. Firstly, no assessment of methodological quality was conducted (Levac et al., 2010). Secondly, limitations and exclusion criteria may have reduced the breadth of papers examined, therefore decreasing the understanding across countries, cultures, service provision and the perspectives of other caregivers such as siblings, grandparents or HCPs. Thirdly, the focus on caregiver needs of AYA undergoing treatment for cancer excludes the needs and experiences generated by survivorship or end of life care. This may have provided more depth and allowed consideration of variation throughout the cancer trajectory. Fourth, there was considerable variation across the studies both methodologically and, where tools or measures were utilised. The participant samples were small, with whites, females and mothers overwhelming represented. This does not make the findings generalisable across all caregiver characteristics. Fifth, the NICE (2014) quality standards provided a framework for the definition of need, however this was a tool for AYAC, therefore may not explicitly capture the needs of caregivers and may be open to misinterpretation. Finally, it is important to acknowledge that the ScR was completed prior to the COVID -19 pandemic. Restrictions implemented for infection control limited caregivers' physical access to loved ones, both at home and in hospital. The impact on needs is unknown.

Conclusion

The findings from this ScR support the need for greater exploration and understanding of psychosocial and social needs of caregivers of AYAC undergoing treatment. The developmental life stage of AYAC presents unique challenges for their caregivers and the HCPs providing support through treatment. Who and where the caregivers are appears to impact needs, with partners often overlooked, information needs generating conflict and place of care influencing the support experienced. Service provision to meet needs will need to incorporate a wide range of offers as one size will not fit all and preferences will vary. Bespoke assessment of caregiver needs is a significant area for future development, especially those of partners. Caregivers need help to fulfil their role, thus become better equipped to contribute to AYAC experiences positively.

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PART TWO

Examining the support and information needs of carers of adolescents and young adults with cancer: a secondary data analysis study

Abstract

Objective To complete secondary data analysis of the BRIGHTLIGHT carer questionnaire, the only multicentre, specific adolescent and young adult with cancer carer questionnaire performed in England. To explore the relationships between characteristics and information and support needs, focusing on the emotional and psychological wellbeing and support experienced for themselves.

Design Secondary data analysis of the BRIGHTLIGHT carer questionnaire using descriptive statistics and correlations of characteristic factors including relationship, gender, age, employment status and income with self-reported emotional and psychological wellbeing experiences.

Setting and participants The BRIGHTLIGHT cohort study was a prospective, longitudinal observation study which recruited 1114 young people between July 2012 and December 2014. Participants were recruited within four months of a cancer diagnosis from ninety-seven English National Health Service hospitals. The participants were asked to nominate their main caregiver to complete the BRIGHTLIGHT carer questionnaire. This generated 518 caregiver responses, 80% (n=415), were female, 92% (n=476) white, with parents or guardians the most represented relationship (86%, n=438).

Results Over half (51%, n=255) the respondents reported receiving information about their needs as a caregiver, with the majority finding this very or fairly helpful. Of those that had not received the information 80% (n=179), would have liked it. Responses showed caregivers reporting high levels of negative emotional and psychological wellbeing, with 91% (n=467) reporting symptoms of feeling depressed or anxious since the young person’s diagnosis, with 41% (n=208) always or often experiencing this emotion. Significant correlations were demonstrated between carer characteristics (parents, females, those unemployed or earning a below average wage and younger in age), emotional and psychological wellbeing and a summary score of ‘total distress’.

Conclusions Diagnosis of cancer in a young person negatively impacts on the emotional and psychological wellbeing of their main caregivers. The needs of caregivers are broad and multidimensional; however some characteristics present a higher likelihood to distress. When carer specific information is provided by health care professionals it is well received. The results offer health care professionals insight into caregiver needs, highlighting individual characteristics that may require more considered and individualised attention when providing information and support. Findings suggest future research should target caregiver information provision, signposting and support.

Introduction

Background

Adolescents and young adults with cancer (AYAC) are a group of patients that have a unique set of needs that require age appropriate, specialist care (Smith et al 2016). As a cohort in England they are defined by age (13-24years old), not malignancy (National Institute for Health and Care Excellence, 2005). Presenting with diverse, often rare tumour types, diagnosis in this age group accounts for less than 1% of all cancer diagnoses in the United Kingdom (Cancer Research UK, 2022).

Caregivers of cancer patients of any age can play a prominent and critical role both practically and psychosocially, however the personal demands of caregiving and impact on their relationships with both the patient and other loved ones can be significant (Goren et al., 2014). Each AYAC experiences their cancer treatment within a unique social ecology (Juth, 2016). Given the developmental life stage of AYAC, a cancer diagnosis impacts on evolving independence and developing identity (Pearce et al., 2020). This can present as challenge and create conflict, as together the caregiver and the AYAC renegotiate relationships and navigate the unfolding situation, against a backdrop of fluctuating autonomy (Grinyer, 2009; Kay et al., 2019; McInally et al., 2021a). This can create emotional, psychological and practical burdens for carers whose needs are rarely addressed or assessed and often remain unmet by services (Carey et al., 2012).

BRIGHTLIGHT was a mixed methods programme of research involving six, interlinked core projects designed to examine a single question: Do specialist services for teenagers and young adults with cancer add value? (Taylor et al., 2021). Centred on a prospective, longitudinal cohort of young people (n=1114), the programme explored a variety of elements of the AYAC specialism including the environment of care (Vindrola et al., 2016; Lea et al., 2018b), and desirable health care professional (HCPs) competencies (Taylor et al., 2016a). Bespoke metrics for levels of specialist care and disease severity were developed and a health economic analysis was undertaken to determine costs of specialist care (Taylor et al., 2019).

Patient and public involvement was extensive, with the voices of young people underpinning all elements of the programme (Taylor et al., 2011; Fern et al., 2013; Taylor et al., 2015b; Taylor et al., 2016c; Taylor et al., 2017; Taylor et al., 2018). This also included a novel, theatrical approach to dissemination in collaboration with a youth theatre group which enabled results to be made accessible to a larger, more diverse audience (Taylor et al., 2020b). Reported results to date include the impact of place of care on; caregiver information and support needs (Martins et al., 2019), quality-of-life outcomes across five time points in the three year period from diagnosis (Taylor et al., 2020a), associated survival and documentation of clinical processes of care (Taylor et al., 2019; Fern et al., 2021).

Objectives

The overall aim of the BRIGHTLIGHT Study was to determine whether or not specialist services for AYA with cancer added value, through a series of multiple-methods studies. The objective of this study was to complete secondary data analysis of the BRIGHTLIGHT carer questionnaire (BCQ) to explore the emotional and psychological wellbeing support and information needs of the main caregivers of AYAC undergoing treatment. Secondary outcomes were to identify any correlations between carer characteristics and their responses around emotional and psychological wellbeing support experienced. The analysis set out to answer the general hypothesis that there are no differences in the support and information needs of AYAC caregivers, when examined across the variable factors of characteristics.

Ethical approval for BRIGHTLIGHT was given by the London-Bloomsbury Research Ethics Committee in 2011 (ref. 11/LO/1718) and Research and Development Departments in each participating hospital. The BCQ was approved in a substantial amendment in 2012. A request was made to the BRIGHLIGHT team for permission and access to the BCQ data files to undertake secondary analysis which was granted, along with appropriate support in November 2019.

Ethical approval for the secondary data analysis was obtained following review by the University Science, Technology, Engineering and Mathematics Ethical Review Committee (Ref. ERN_19-1648). National Health Service (NHS) Health Research

Authority and Research Ethics Committee approvals were not required as the secondary data analysis was not considered research.

Methods

BRIGHTLIGHT study design

The BRIGHTLIGHT longitudinal cohort study was open between July 2012 and December 2014. AYAC were recruited from ninety-seven NHS Trusts across England and were eligible to participate if they were aged 13-24 at time of diagnosis, within four months of a cancer diagnosis and were diagnosed and treated in England. AYAC incapable of completing a survey (e.g. unconscious or severe mental incapacity), had recurrence of a previous cancer, receiving a custodial sentence, or anticipated not to be alive at six months after diagnosis, were not eligible. This resulted in consent of 1114 AYAC participants. This accounted for 20% of young people diagnosed during the recruitment period (Taylor et al., 2019). In the absence of a validated, patient experience survey for AYAC a bespoke survey was developed and validated which encompassed both cancer experience and age related issues (Taylor et al., 2015a). The study gathered data through the survey at five time points in the three years following the young person diagnosis (Figure 1).

During Survey 1, conducted face-to-face in their home, AYAC were asked to nominate their main carer, the person they perceived as providing the most care during periods of hospitalisation to complete the BCQ. Carer was defined by the BRIGHLIGHT protocol (pp. 22) as;

"…an adult who has provided physical and emotional support during their cancer treatment, e.g. parent/guardian, partner or close friend."

Figure 1 Pictorial representation of data collection administration (replicated with permission from www.brightlightstudy.com).

Nominated caregivers independently completed the BCQ while the AYAC was engaged with the interviewer. If more than one carer was nominated or present, they were asked to complete it together through discussion and provide consensual responses. Alternatively, a paper questionnaire was left for the caregiver with a stamped addressed envelope to return upon completion. No reminders were sent. Return of the questionnaire was considered informed consent. There were no personal identifiers on the questionnaire, but the respondents were able to provide their contact number/email address if they wished to be involved in any future research. There were no exclusion criteria for BCQ completion save the young person's consent and their participation in the initial interview. Further details on processes for BRIGHTLIGHT recruitment and data collection methods are reported in detail by Taylor et al. (2016b), Kenten et al. (2017) and Taylor et al. (2019).

BRIGHTLIGHT carer questionnaire

In the absence of an existing unmet needs questionnaire for caregivers of AYA with cancer, the BCQ was developed specifically for the BRIGHTLIGHT study based on instruments developed for use with carers of adults with cancer (McIllmurray et al., 2001; Hodgkinson et al., 2007; Buscemi et al., 2010; Ream et al., 2013). Content validity was established through consultation with HCPs working with AYAC, experts in survey methodology and an appropriate parent group (Martins et al., 2019).

The BCQ was eight pages long and consisted of fifteen multi answer items, utilizing a four point Likert scale for responses (very good – very poor, very easy - very difficult, very helpful – not at all helpful, always – never). The BCQ included the following five sections;

1. Your information needs
2. The cancer treatment centre and contact with health professionals
3. You and your relationship with the young person
4. Completing practical tasks and the need for support
5. About yourself

Questions 10, 13, and 15 produced a response relating to amount of support needed defined on three levels (usually, sometimes, never had the support I need). With the final section ‘about yourself’ eliciting sociodemographic information regarding relationship to young person, whether they resided together, employment and academic attainment, marital status, household income, age, gender and ethnicity. A copy of the survey is freely available under license, https://xip.uclb.com/i/healthcare_tools/brightlight_carer.html

Previous analysis of the BCQ included review the dataset to determine if exposure to AYAC specialist care settings impacted on caregiver information and support needs. Results showed no difference between place of care and amount of support received, significantly more satisfaction was reported if care was all received in specialist settings, and no contact with specialised services resulted in fewer specific services for carers (Martins et al., 2019). Given this context derived from the original analysis, place of care was not explored in the data analysis for this report where the focus was on the emotional and psychological wellbeing support and information experienced by caregiver. The items of the BCQ which constitute the secondary data analysis are shown in Table 1.

Table 1 Items of BCQ analysed

Section of BCQ	Question number	Question	Item to analyse
1. Your information needs	Q1	Since the young person's diagnosis, have you been provided with each of the following types of information?	e) my needs as a carer/partner g) support service for carers/partner
	Q2	Would you like to have received the following types of information?	
	Q3	How helpful or unhelpful did you find each of the following types of information?	
	Q5	In your view, how good or poor was the information provided to you by health and social care professionals (HCP) responsible for the young person's treatment?	a) The amount of written information supplied b) The amount of verbal information supplied c) Timing at which you received the information d) The detail of the information given to you e) How understandable the information was to you
2. The cancer treatment centre and contact with health professionals	Q7	How good or poor have you found each of the following?	e) the time given by HCP to listen to my views or concerns h) Access to HCP i) The friendliness of HCP
	Q8	For each of the following things, how helpful or unhelpful were the HCP responsible for the young person's care and treatment?	a) Putting me in touch with other parent/carers who care for young people with cancer b) directing me to parent/carer support groups d) directing me to sources of support of support from charitable organisations
3. You and your relationship with the young person	Q9	How often, if at all, have you experienced the following things since the young person's diagnosis?	a) feeling tired b) feeling sad c) feeling lonely d) difficulty finding time for myself e) feeling angry f) feeling unable to help g) feeling guilty h) feeling depressed or anxious
	Q10	To what extent, if at all, do you feel you have had the support you need when you have experienced the following things?	

Statistical methods

Data from the completed BCQ were stored on an NHS server after manual entry into SPSS (version 22) by the BRIGHTLIGHT team. The dataset contained no identifiable details and was linked only to anonymised young people generated data through a unique study number. The dataset was password protected and once authority granted from the BRIGHTLIGHT team, the data file was transferred and stored in a secure, online University data sharing repository and the password supplied by telephone. Data analysis was performed using SPSS version 25 software.

Descriptive statistics including frequency, percentage and mean were used to categorise carer characteristics within the dataset. To enable comparisons and simplify data analysis, characteristic factors were collapsed down, grouped and/or dichotomised to create new variables. Outliers were included and allocated to groupings with a best fit to avoid bias. Valid percentages are reported to adjust for missing data (Kang, 2013). Questions posed by the BCQ were answered with yes / no, or with a Likert scale response. Hence nonparametric tests were applied as no real statistical assumptions could be made about the data.

Cronbach's Alpha was performed to assess the construct reliability of the summary score of individual elements of question 9 assessing emotional and psychological wellbeing (Table 1). This was then applied to a Pivot table to explore the non-parametric correlations between variables including characteristics of caregivers and their emotional and psychological wellbeing using Spearman's Rank Order (Dogde, 2008). Anovas were applied to predict outcomes based on dependent characteristic variables. Bonferroni calculations were performed to adjust for multiple testing.

Results

A total of 518 caregivers returned the BCQ originally. After cleaning, the final sample used for this analysis was 516 due to missing values. The findings will be presented in three sections; caregiver characteristics, information needs and emotional and psychological wellbeing.

Caregiver characteristics

A summary of caregiver characteristics is shown in Table 2. The majority were female (80.4%, n=415), white (92.4%, n=476) and with a mean age of 45.8 years. Parents or guardians were the most represented relationship (85.9% n=438), with the preponderance of caregivers living with the AYAC at the point of survey completion (94.9%, n=487).

Table 2 Summary of caregiver characteristics

Caregiver characteristics [a]		Frequency, n (%)
Gender	Male	100 (19.4)
	Female	415 (80.4)
Age, years	17-24	42 (8.2)
	25-34	26 (5.1)
	35-44	102 (20.0)
	45-54	260 (51.0)
	55-64	73 (14.3)
	≥ 65	7 (1.4)
Age at last birthday, years	Mean 45.80	
	Median 47	
	Range 66	
	Percentiles 25 = 42	
	50 = 47	
	75 = 52	
	Standard Deviation 10.5	
Relationship	Parent / Guardian	438 (85.9)
	Partner / Peer	72 (14.1)
Employment status	In employment (full time, part time or self-employed)	353 (68.5)
	Unemployed or Sick leave	162 (31.5)
Income [b]	Below average	231 (46.4)
	Above average	226 (45.4)
	Don't know	41 (8.2)
Ethnic group	White	476 (92.4)
	Other	39 (7.6)
Residing with Young person	Yes	487 (94.9)
	No	26 (5.1)

[a] Missing data where numbers are less than 516, valid percentages given

[b] Median average household income in the UK financial year ending 2019 was £29,600 (Office for National Statistics, 2020)

Information needs

Following the AYAC diagnosis, half of the respondents had been given information about their needs as a caregiver, with the majority (94%, n=211) finding this very or fairly helpful. Of those that had not received this type of information 80% (n=179) would have liked it. Nearly two thirds (61%, n=309) of caregivers were provided with information about support services for caregivers, with the majority, finding this very

(49.3%, n=134) or fairly helpful (45.2%, n=123). Of those not receiving this specific information, 82% (n=146) would have liked it. HCPs were considered by 41% (n=208) very or fairly helpful in putting caregivers in touch with others in the same situation and directing caregivers to parent/carer support groups (n=209). Highlighting the support from charitable organisations was helpful for 64% (n=327) of respondents (Table 3).

Table 3 Information needs and signposting for own needs as caregivers

Question Number	Item	Frequency, n (%)						
		Total responses[a]	yes	no	Not applicable	Very helpful	Fairly helpful	Not helpful
1 e)	Provided with information about my needs as a caregiver	502	255 (50.8%)	247 (49.8)				
2 e)	If not provided, would you have liked to have received	224	179 (79.9%)	45 (20.1)				
3 e)	If provided, how helpful or unhelpful	223				119 (53.4)	92 (41.3)	12 (5.4)
1 g)	Provided with Information about support services for caregivers	504	309 (61.3)	195 (38.7)				
2 g)	If not provided, would you have liked to have received	179	146 (81.6)	33 (18.4)				
3 g)	If provided, how helpful or unhelpful	272				134 (49.3)	123 (45.2)	15 (5.5)
8 a)	Putting me in touch with other caregivers	512			149 (29.1)	70 (13.7)	138 (27.0)	155 (30.2)
8 b)	Directing me to caregiver support groups	509			116 (22.8)	68 (13.4)	141 (27.7)	184 (36.1)
8 d)	Directing me to support from charitable organisations	512			82 (16.0)	173 (33.8)	154 (30.1)	103 (20.1)

[a] Missing data where numbers are less than 516, valid percentages given.

Overall, the majority of respondents felt that the amount of information, whether written (90%, n=460), or verbal (94%, n=479) and the timing of the information provided (91%, n=462), was very or fairly good. Information was reported as understandable by 94% (n=480) of caregivers. HCPs were seen as good at giving time (87%, n=445), being accessible (91%, n=464), and friendly (98%, n=506) towards caregivers (Table 4). It was noted that the ‘not applicable’ item for question 8 (Table 3), in response to the role of HCPs in directing to alternative sources of support was higher in range (16 to 29%), than the same ‘not applicable’ item (range 6 to 9%), for question 5 items concerning information provision (Table 4).

Table 4 Delivery of information and opinions of HCPs

Question number	Item	Frequency, n (%)					
		Total responses[a]	Very good	Fairly good	Fairly poor	Very poor	Not applicable
5 a)	Amount of written information supplied	514	283 (55.1)	177 (34.4)	34 (6.6)	11 (2.1)	9 (1.8)
5 b)	Amount of verbal information supplied	513	305 (59.5)	174 (33.9)	22 (4.3)	6 (1.2)	6 (1.2)
5 c)	Timing of information	513	264 (51.5)	198 (38.6)	29 (5.7)	14 (2.7)	8 (1.6)
5 d)	Detail of information	513	276 (53.8)	193 (37.6)	26 (5.1)	12 (2.3)	6 (1.2)
5 e)	How understandable the information was	515	281 (54.6)	199 (38.6)	17 (3.3)	9 (1.7)	9 (1.7)
7 e)	Time given by HCP to listen to caregiver views & concerns	511	282 (55.2)	163 (31.9)	36 (7.0)	11 (2.2)	19 (3.7)
7 h)	Access to HCP	513	264 (51.5)	200 (39.0)	30 (5.8)	7 (1.4)	12 (2.3)
7 i)	Friendliness of HCP	513	418 (81.0)	88 (17.2)	3 (0.6)	3 (0.6)	1 (0.1)

[a] Missing data where numbers are less than 516, valid percentages given

Emotional and psychological wellbeing

Responses showed caregivers reporting always or often feeling tired (65%, n=331), sad (59%, n=301), unable to help (42%, n=215), guilty (33%, n=168), angry (31%, n=157) and lonely (27%, n=139), with almost half (45%, n=230) having difficulty finding time for themselves. Symptoms of feeling depressed or anxious were reported by 92% (n=467) of respondents, with 41% (n=208) always or often experiencing these emotions since the AYAC diagnosis. In relation to the extent of support needed when feeling these emotions there was very little variation. On average, 80% felt they usually or sometimes had the support that they needed to address these feelings (Table 5).

Table 5 Caregivers emotional and psychological ‘distress’ experience and support provision

		Frequency, n (%)							
		Question 9 How often experienced since young person’s diagnosis?				Question 10 Did you feel you had the support you needed?			
Question	Item	Total responses[a]	Always / often	Sometimes / rarely	Never	Total responses[a]	Usually	Sometimes	Never
a)	Feeling tired	512	331 (64.6)	164 (32.1)	17 (3.3)	467	190 (40.7)	198 (42.4)	79 (16.9)
b)	Feeling sad	513	301 (58.6)	207 (40.4)	5 (1.0)	460	211 (45.9)	170 (37.0)	79 (17.2)
c)	Feeling lonely	509	139 (27.3)	259 (50.9)	111 (21.8)	439	196 (44.6)	161 (36.7)	82 (18.7)
d)	Difficulty finding time for myself	510	230 (45.1)	228 (44.8)	52 (10.2)	447	170 (38.0)	185 (41.4)	92 (20.6)
e)	Feeling angry	511	157 (30.7)	272 (53.3)	82 (16.0)	439	183 (41.7)	170 (38.7)	86 (19.6)
f)	Feeling unable to help	511	215 (42.1)	254 (49.7)	42 (8.2)	447	189 (42.3)	177 (39.6)	81 (18.1)
g)	Feeling guilty	512	168 (32.8)	239 (46.7)	105 (20.5)	437	189 (43.2)	157 (35.9)	91 (20.8)
h)	Feeling depressed or anxious	513	208 (40.6)	259 (50.5)	46 (9.0)	450	181 (40.2)	179 (39.8)	90 (20.0)

[a] Missing data where numbers are less than 516, valid percentages given.

A construct was generated for ‘Distress’ using the summary score of the responses to all 8 items of question 9. Internal consistency checks with Cronbach’s Alpha showed this to be reliable ($\alpha = 0.84$), therefore established as a fair grouping to explore the self-reported emotional and psychological wellbeing of participants. This was labelled as ‘Total Distress’. Spearman’s Rank Order correlations were conducted to assess the relationships between a range of characteristics and ‘Total Distress’. Being a parent was associated with increased emotions of tiredness and sadness ($p < 0.01$), feeling guilty, more total distress and finding it harder to find time for themselves ($p < 0.05$). Female caregivers were associated with more tiredness, sadness, feelings of anger and guilt, depression/anxiety and reported more total distress than males ($p < 0.01$). There was a significant relationship between being unemployed or earning a below average income, and feeling more lonely, depressed/anxious, hard to find time for themselves and more total distress ($p < 0.01$). Younger caregivers were significantly associated with feelings of anger and guilt ($p < 0.05$), (Table 6)

Table 6 Spearman's Rank Order Correlations between characteristics, emotional & psychological wellbeing and total distress (*p<.05. **p<.01.)

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13
1 Relationship													
2 Gender	-.18** [-.27, -.10]												
3 Age	-.56** [-.63, -.50]	-.08 [-.17, .00]											
4 Employment	-.05 [-.14, .04]	.04 [-.05, .12]	.08 [-.01, .16]										
5 Total household income	.01 [.-.08, .09]	-.05 [-.14, .04]	.07 [-.02, .16]	-.04 [-.12, .05]									
6 Tired (Q9a)	-.12** [-.21, -0.3]	.13** [.05, .22]	-.02 [-.11, .07]	.05 [-.04, .13]	-.05 [-.13, .04]								
7 Sad (Q9b)	-.12** [-.20, -.03]	.16** [.07, .24]	.01 [-.08, .09]	.04 [-.04, .13]	-.07 [-.15, .02]	.30** [.21, .37]							
8 Lonely (Q9c)	-.06 [-.15, .02]	.07 [-.01, .16]	-.01 [-.10, .08]	.06 [-.03, .14]	-.20** [-.29, -.12]	.33** [.25, .41]	.58** [.51, .64]						
9 Time for myself (Q9d)	-.11* [-.19, -.02]	.08 [-.01, .17]	.02 [-.06, .11]	.12** [.04, .21]	-.14 [-.23, -.05]	.54** [.47, .60]	.29** [.20, .37]	.40** [.32, .47]					
10 Angry (Q9e)	-.06 [-.14, .03]	.12** [.03, .20]	-.11* [-.20, -.030]	.02 [-.07, .11]	-.06 [-.14, .03]	.29** [.20, .37]	.46** [.39, .53]	.50** [.43, .57]	.30** [.22, .38]				
11 Helpless (Q9f)	.01 [-.07, .10]	.05 [-.04, .13]	-.08 [-.16, .01]	.02 [-.07, .10]	-.03 [-.12, .06]	.25** [.16, .33]	.40** [.32, .47]	.41** [.33, .48]	.20** [.11, .28]	.47** [.39, .54]			
12 Guilty (Q9g)	-.11* [-.19, -.02]	.20** [.11, .28]	-.10* [-.19, -.01]	.01 [-.07, .10]	-.07 [-.16, .02]	.22** [.14, .30]	.40** [.32, .47]	.46** [.38, .53]	.27** [.18, .35]	.58** [.52, .64]	.48** [.41, .55]		
13 Depressed or Anxious (Q9h)	-.06 [-.15, .03]	.13** [.05, .22]	-.01 [-.10, .08]	.14** [.05, .22]	-.06 [-.14, .03]	.33** [.24, .40]	.55** [.48, .61]	.57** [.50, .63]	.34** [.26, .42]	.50** [.43, .57]	.47** [.40, .54]	.48** [.40, .54]	
14 Total Distress	-.12* [-.20, -.21]	.16** [.07, .24]	-.05 [-.14, .04]	.08 [-.01, .16]	-.15** [-.24, -.06]	.56** [.49, .62]	.68** [.62, .73]	.77** [.73, .81]	.59** [.53, .65]	.75** [.70, .79]	.65** [.59, .70]	.72** [.67, .76]	.75** [.70, .79]

A one-way ANOVA was conducted on characteristics with the strongest associations to compare their effect on total distress. Due to multiple testing Bonferroni post hoc testing was conducted with a corrected significant cut off (p = 0.017). The characteristic with the highest significant difference in total distress was between gender [F(1,497) = 12.40, p = <0.001], with females having a higher mean score (M = 25.31, SD = 6.13) than males (M = 23.34, SD = 5.89). Similar significant differences were found for relationship (F(1,493) = 7.57, p = 0.006], with parents/guardians having a higher mean score (M = 25.64, SD = 6.01) than partners/peers (M = 23.47, SD = 6.66), and for household income [F(2,480) = 6.78, p = 0,001] with those in receipt of a below average household income with a higher mean score (M = 26.31, SD = 6.09) than those earning above average (M = 24.20, SD = 5.90), (Table 7).

Table 7 ANOVA

	Total distress			
Measure	Mean	Standard Deviation	F	significance
Gender	25.31	6.16	12.40	<.001
Female	25.31	6.13		
Male	23.34	5.89		
Relationship	25.33	6.15	7.57	.006
Parent /Guardian	25.64	6.01		
Partner/Peer	23.47	6.66		
Household Income	25.28	6.17	6.78	.001
Below average	26.31	6.09		
Above average	24.20	5.85		
Don’t know	25.63	7.38		

Discussion

Cancer caregivers in general report inadequate provision of support, unmet needs and can experience unmanaged distress (Ugalde et al., 2021). Caregivers of AYAC are currently understudied (Mikrut et al., 2019), with little research examining their unique experiences (McInally et al., 2021a), and the emotions and distress associated with AYAC (Hodgson et al., 2021). The objective of the secondary data analysis was to explore the wellbeing support and information needs of carers in relation to their characteristics. There were significant differences in need across a range of characteristics therefore refuting the general hypothesis posed for analysis. The majority of participants identified as white mothers and were living with the AYAC. This demographic picture reflects other studies, where mothers are consistently identified as the main source of caregiving support to AYAC (Grinyer, 2002; Goodall et al., 2012; Mikrut et al., 2019).

Information provision and decision-making processes have been noted to generate conflict with caregivers (Day, 2016; Darabos et al., 2021). Young people’s evolving independence, changing legal entitlement at 18, and the potentially fluctuating influence of the illness trajectory on decision making abilities and desires to be engaged, can create circumstances in which caregivers can feel excluded and uninformed (Grinyer, 2003). Unmet information needs of caregivers can range from general advice and information to fulfil the caregiver role (Stevens et al., 2018) to specific medical and treatment information (McCarthy et al., 2018; Hart et al., 2020). However, there is some evidence that unmet information needs are not universally experienced, with many caregivers satisfied with information provision (McCarthy et al., 2016; Martins et al., 2019).

The analysis in this current study also found this divergence. Overall, participants reported high levels of satisfaction with information provision including the types and amounts of information, its timing and delivery by HCPs. Friendly staff directed caregivers to a variety of sources of support relating specifically to their own caregiving needs which the majority found helpful. While this is reassuring and may reflect HCPs having a better understanding of caregiver needs, improvements in the communication of information or good signposting to specific caregiving services, nearly half of the participants reported not receiving this type of information. Fundamentally for these participants, HCPs may not have even enquired after or acknowledged their needs as caregivers. Given the heterogeneity of caregiver needs, support services may not be possible or cannot be delivered in a way that can be individualised to the caregiver. AYAC services may not themselves have provision, or access to specific caregiving information or help. HCPs may not have an awareness of specific services and therefore not be able to signpost appropriately to external providers. This may be particularly relevant for caregivers accessing services outside of specialist units, where specific skills, knowledge and information are often centralised (Lea et al., 2019; Lea et al., 2021; McInally et al., 2021b).

There were higher ‘not applicable’ rates for items about the role of the HCPs in directing caregivers to sources of specific support than other elements in the BCQ. One interpretation is that caregivers did not perceive it was a HCPs role, in contrast with information provision more clinically focused on the AYAC treatment. Caregivers may not have expected HCPs to provide information relating to their own needs. Caregivers may have sought or found alternative sources of support independently of HCPs. The Internet is an ever-growing source of information, integral to young people who are pervasive technology users. Digital health interventions for AYAC are a growing area aiming to address both psychosocial and health information needs (Devine et al., 2018). AYAC report using communication platforms, entertainment sites, social media, and a variety of websites to discover information and support (Lea et al., 2018a). It would be relatively easy for AYAC caregivers to engage with these types of resources to meet their own information and support needs.

Searching, accessing, and engaging with online information and resources can have powerful emotional consequences (Lea et al., 2018a). There is also a risk caregivers could be misinformed of confused due to the lack of quality standards for online information (Weeks et al., 2019). Warner et al. (2020) explored young adult cancer carers' use of social media for support, highlighting convenience when balancing caring with daily lives. They identified positive consequences, (being able to update others on the patient's situation, connecting with others, etc.), alongside negative consequences, (misinformation, uncomfortable responses), to posting experiences online, identifying the need for further research in this area. While caregivers may take these steps, it does not remove the need to access experienced HCPs and factually correct quality information. It must also be acknowledged that not all caregivers will have access to alternative sources due to language, knowledge and skills gaps, digital literacy, poverty, or socioeconomic factors.

Direction towards charitable support was 20% higher than all other item responses in the analysis relating to experiences of signposting by HCPs to sources of support. Charities are known to be a major source of support for caregivers (Jolliffe et al., 2019), and the philanthropic stakeholder endeavour in AYAC services has heightened public awareness around cancer in young people generally (Cable and Kelly, 2019). Caregivers may already have knowledge around information resources outside the traditional hospital sources or have more awareness to ask specifically for this. Specialist units enable natural access to peer support and information sharing from other caregivers that doesn’t require formal facilitation from HCPs. They may also display information such as posters or leaflets, from a variety of sources for people to access directly.

Caregivers identity may also play a role in how, or indeed if, they access support for themselves. Waters et al. (2021) qualitative inquiry examining cancer caregiving during young adulthood (range 18-39 years, majority 38% 25-29 years), found participants did not identity as caregivers. These young caregivers saw their caring responsibilities as an extension of the relationship they had with the patient. Whilst the study explored experiences of caring for a cancer patient, not specifically AYACs, the findings are relevant to the development of support and information for caregivers. Partners of AYAC may not identify with the definitions commonly used and therefore may need signposting to support opportunities and resources articulated differently.

The negative impact of AYAC on caregivers emotional and psychological wellbeing was high across all participants in this study. Feelings of depression or anxiety were reported by nine out of 10 participants. The construct of total distress generated significant results for key characteristics of gender, relationship and household income. While these findings were self-reported and not formally measured or assessed with validated psychological tools, they demonstrate the negative wellbeing consequences for caregivers. This is in keeping with the literature. For cancer caregivers across the age spectrum, emotional distress has been shown to have the greatest impact on unmet supportive care needs (Baudry et al., 2019). The burden and suffering described by AYAC caregivers and families with unmet needs

(Grinyer, 2002; Barling et al., 2013), is more recently consolidated by evidence demonstrating high levels of post-traumatic stress (PTSS) and psychological distress in caregivers (McCarthy et al., 2016; Sawyer et al., 2017; McCarthy et al., 2018). In this current study, parents were found to experience a statistically significant range of negative emotions and overall total distress. Parental distress is commonly cited as being comparably higher in AYAC than other cancer populations (Mikrut et al., 2019). Sharma et al. (2020) proposed that parental distress transferred from the '*contagion of distress*' felt by the AYAC as they too tried to navigate the cancer experience alongside them. This supports the work of Juth et al. (2015a) who found caregivers reported higher levels of posttraumatic stress symptoms (PTSD) than AYAC.

Gender was also found to be statistically significant, with females reporting more total distress than males. This needs to be interpreted with caution. Participants were largely female, so this may be generalisable where women are more likely to be the main caregiver, but not to a general population. Future studies should focus on the male experience as both fathers and partners. Caregiving is historically a female role, with the majority of cancer caregiving studies, regardless of patient age, showing a bias towards woman as caregivers. However consideration of theoretically driven vulnerable caregiver subgroups also requires further investigation generally (Kim et al., 2019). The social construction of families is increasingly complex and intersectional, for example the growing numbers of same sex parents, and AYAC in same sex relationships. This may also have implications on AYAC caregiving experiences, and HCPs positioned to support them.

Within this study, younger caregivers were statistically significantly more angry and guilty than older caregivers. Lund et al. (2015) found that younger caregivers (aged

18-39 years) reported the highest levels of problems and unmet needs. Baudry et al. (2019) identified that younger caregivers (less than 50 years) were more at risk of unmet support needs, surmising that they are less equipped to deal with negative life experiences and associated emotional responses. In this data analysis, 14% (n=72) of participants identified as partners or peers. Exploring, forming and engaging in romantic relationships is a key developmental task and plays a major role in young people’s lives, with first romantic relationships occurring typically around the age of 14-15 years (Gonzalez Aviles et al., 2021). Although young people’s experiences will vary, a first or new relationship has been shown to both positively and negatively influence wellbeing (Gomez-Lopez et al., 2019). In relation to AYAC, emotional support from partners is seen by AYAC as a positive aspect of being in a relationship (Robertson et al., 2016), however, there is a paucity of data relating to the wellbeing needs of partners of AYAC who more than likely will be young people themselves. While tentative assumptions can be drawn, more research is needed to understand the implications of this.

Significant associations related to financial status; unemployment and those receiving a below average household income and negative emotional and psychological wellbeing were found. Not a new finding, as illness is known to be expensive and carries expected and unexpected costs (Grinyer, 2003). The financial burden for adult cancer patients has been categorised as: financial toxicity (direct costs), treatment related out of pocket expenses (transport, parking, accommodation) and indirect costs (loss of income) (McNeil et al., 2019). In literature pertaining to the AYAC cohort it has been demonstrated that caregivers also experience this adverse financial impact, a stressful burden with significant and lasting effects. These are compounded for families with lower financial reserves who are substantially financially disadvantaged for prolonged periods following AYAC treatment ending (McNeil et al., 2019; Salsman et al., 2021). Financial advice is frequently reported as an area of unmet need during treatment (McCarthy et al., 2016; Stevens et al., 2018) and when treatment ends (Wakefield et al., 2013). Support for this unmet need can itself bring additional frustrations and stressors. Given the life stage of AYAC, challenges related to access and related bureaucracy to income support can occur (Grinyer, 2002; McNeil et al., 2019). In countries where health care is not free at the point of access, or there is inadequate insurance coverage, additional distress can be exerted (Salsman et al., 2021).

Encouragingly, on average 80% of participants in this study felt they had support to address their emotional and psychological wellbeing. However, it is important to note that the source(s) of this support were not identified. Caregivers may have access to a huge variety of formal and informal support services that meet individual preferences. Many caregivers will be supported by existing social networks of friends, families and communities, others will rely on support from HCPs. Contact with HCPs in relation to accessibility, friendliness and time given to listen to caregiver views and concerns rated highly in the results. This is a positive finding. Previous work has explored characteristics, attributes and competencies required to establish successful therapeutic relationships between HCPs and AYACs (Gibson et al., 2012; Vindrola et al., 2016; Taylor et al., 2016a). However these studies largely focused on the perspectives of AYACs or HCPs and their role(s) in the social organisation of AYAC cancer care (Lea et al., 2019). The impact of HCPs skills and attributes in relation to AYAC caregivers’ perspectives warrants more focused attention.

Implications for practice & research

HCPs should attempt to consider caregivers needs individually and provide or signpost to support where available. For busy HCPs balancing the many demands on their time, at the very least there should be acknowledgment of the impact of caregiving on individuals, and prioritisation of those with characteristics shown to be more at risk. HCPs can facilitate caregivers to identify their own support mechanisms, and guide where appropriate to sources of reliable and quality information. Where possible, HCPs should explore individual caregiving support needs and facilitate access or referral. One element of this is understanding the criteria for eligibility of formal support.

Research considering the needs of those caregivers who traditionally may not have been heard or were invisible, particularly men, fathers, same sex and heterosexual partners of AYAC is indicated. Methods to support the identification and assessment of caregivers needs alongside the development of caregiver focussed resources and support is also required. The positive responses of many participants in this analysis suggests that good practice exists in England, but the shape and scope require further enquiry. The dissemination of these could enhance the experiences of other caregivers. HCPs may be best placed to deliver caregiver support, but this requires further investigation given the increasing pressures on care provision which inevitably prioritises patient care (Martins et al., 2019). Caregivers as stakeholders need to be involved in the design and implementation of any future research, given the heterogeneity of needs identified.

Strengths & Limitations

There are several limitations to this study. Notably, the sample are largely white females, predominantly identifying as mothers, which limits generalisability to men, fathers, partners and other ethnic groups. Recruiting nominated carers may have resulted in a range of opinions but may also have polarised who was deemed as the main caregiver. Selection may have been on the basis of availability in the home at point of Survey 1, or so not to add to any existing disharmony or perceived status. That said, completion of the BCQ may have been seen as quite light involvement and completed when the AYAC was being interviewed.

Given the limited research examining AYAC caregivers, the BRIGHLIGHT team designed the BCQ by adapting adult caregiving questionnaires (McIllmurray et al., 2001; Hodgkinson et al., 2007; Buscemi et al., 2010; Ream et al., 2013). Content validity was confirmed using a variety of experts, (HCPs, survey methodology and parents), arguably a little narrow (Martins et al., 2019). The items in the BCQ related to information needs and support services lacked specificity. These broad and general questions were potentially open to interpretation and therefore responses may have lacked precision. The design and layout of the BCQ could be perceived as complicated, as responses to initial items could exclude future items. There was only one single option for free text responses throughout the BCQ, which may have restricted the reporting of feelings, perceptions, and experiences of caregivers. The items relating to emotional and psychological wellbeing are self-reported and do not include a validated psychometric measure. Nonetheless, overall the survey instrument was broad and identified areas for future research.

The statistical analysis was limited by the structure of the instrument. Missing data was corrected transparently, however broad groupings and responses were dichotomised into categories which may have diluted the nuances in individual responses. Associations and correlations do not show causality; therefore it is important to acknowledge that the results indicate relationships and implications can only be inferred. The construct of ‘Total Distress’ as an indicator of emotional wellbeing is not formally recognised or validated, or a clinical measure. Despite this, it proved useful as a mechanism to explore the data and identify future avenues for research.

The data were originally collected between July 2012 and December 2014 (Taylor et al., 2019), and arguably no longer contemporary. This is particularly pertinent given the impact of the COVID-19 pandemic on the experiences of patients with cancer, caregivers and HCPs. Psychological distress associated with fears related to virus susceptibility, uncertainty, disruptions in access to HCPs and information are emerging in the general cancer population (Edge et al., 2021). Population based studies in children and young people (0-24 years), in England during the first wave of the COVID-19 pandemic have observed significant reductions in number of cancer diagnoses with increases in critical care admissions. The reduction in incidence was particularly apparent in young people (Saatci et al., 2022). While the underlying reasons for this phenomenon are undoubtedly complex, the impact on caregiver’s emotional and psychological wellbeing may equally be significant. Once diagnosed, access to patients in hospital was limited. Concerns about infection control and public health measures regarding avoiding unnecessary social contact, may have compromised caregiving role allocation, and levels of support. Visiting restrictions formally enforced in health care settings, or informally in the families own homes, will undoubtable have contributed to emotional distress and limited opportunities for connections to support for all involved.

Despite these limitations, this secondary data analysis study utilised a data set generated by the recruitment of a large number of caregivers as part of the first national prospective cohort study of newly diagnosed AYAC in England (Taylor et al., 2019). The AYAC participants were a broadly representative sample of newly diagnosed cancer patients, spanning the defined English age range (13-24 years). Caregiver's experiences therefore reflected the developmental life stage of this cohort and the support experienced across levels of specialist care and disease severity. Response rates were good (62%), which has previously been attributed to the extensive patient and public involvement (Martins et al., 2019). The BCQ was written in English, but a helpline provided translation for caregivers which may have facilitated participation and completion, therefore removing some communication barriers. The need to better understand the support and emotional wellbeing of caregivers has been identified as requiring further attention (McCarthy et al., 2016; Sawyer et al., 2017; McCarthy et al., 2018; Davies et al., 2019; Martins et al., 2019), and this analysis will offer a further layer to the literature around the experiences of caregivers of AYAC.

Conclusion

The secondary data analysis results identified caregivers of AYAC have a wide range of needs. The emotional and psychological wellbeing of caregivers of AYAC can be negatively affected by the experience of being alongside and available to AYAC. Some characteristics seem to be associated with a higher propensity to distress than others. While parents, particularly woman, made up the majority of caregivers, the partners of AYAC acting as main caregivers may have unique needs requiring careful consideration. Levels of household income also appear to impact on levels of distress.

Caregivers have specific information and wellbeing needs which HCPs must acknowledge, signpost to support and/or encourage self-directed interrogation of resources. Experiences relating to specific caregiving targeted information were variable, although when provided or accessed there were high levels of satisfaction. HCPs have a role to play engaging with caregivers and assessing any unmet needs. This may reduce feelings of worry and distress. While these findings offer some insights, particularly factors or characteristics that are more likely to be present in those experiencing most distress, further research is needed to better understand the specific help and support required by caregivers.

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PART THREE

Reflective report

Introduction

Reflection is a cornerstone of professional nursing practice and integral to the Nursing and Midwifery Council revalidation process (Nursing & Midwifery Council, 2018). Reflective practice in nursing is a cognitive skill, demanding conscious effort to consider a clinical incident or situation alongside individual beliefs, values, and practice. This enables learning which develops knowledge and ultimately can be incorporated into improving patient care (Patel and Metersky, 2021). I consciously use reflection in a variety of ways to learn from my professional and personal experiences. Translating this experience for formal reflective writing presents a new learning opportunity. Writing slows our thought processes and focuses our attention on what we are trying to express (Bassot, 2016). Investing time in this process enabled me to link ideas together, broaden and deepen my understanding of approaches towards my Masters in Clinical Health Research (MRes) studies, support decisions made during my thesis project and consider implications for future learning.

Background

The work of Alan Peshkin (1988) serves as a model to guide my reflection. An American anthropologist, Peshkin describes his realisation that positive and negative sensations and feelings experienced during his research on educational establishments had the potential to *“filter, skew, shape, block, transform, construe, and misconstrue what transpires from the outset of a research project to its culmination in a written statement”* (Peshkin, 1988, p. 17). Being meaningfully attentive to his subjectivity through a range of sources, such as belief and value systems, experiences of environment or place, and relationships, Peshkin was able to identify his perceived Subjective I's at that point in time. He proposed that this brought validity and rigour to his qualitative research. This approach has been explored in the literature in relation to rigour in qualitative research (Bradbury-Jones, 2007a), Doctoral research experience (Bradbury-Jones, 2007b), teaching and education professional practice (Savage, 2007) and nursing students learning in clinical practice (Bradbury-Jones et al., 2009; Bradbury-Jones et al., 2010).

Limitations

Peshkin's work argues that a systematic approach is required to seek subjectivity, recording sensations as they occurred, reviewing and auditing field work or notes while research is actively in progress (Peshkin, 1988). I adapted the approach as a reflective model, and reflected 'on' doing research, not 'in' research. Although I knew I had to submit a reflective report, I did not keep a journal through my MRes experience, a key piece of learning for my future. I relied on my understanding through a significant experience of reflective practice to shape my thinking and realise my Subjective I's. However, I acknowledge that I have considered my thoughts and feelings over a period defined by formal learning, opposed to a specific incident, a more traditional starting point to nursing reflection. Bradbury-Jones et al. (2009) postulate that reflective practice is underpinned by a questioning spirit and perplexity. I concur that these have been key drivers in the generation of my subjective I's through reflection on supervision notes, conversations with both personal and professional acquaintances and periods of contemplation.

Ultimately, I was inspired by the notion of the subjective I's. Despite identified tensions relating to assessment of personal reflections (Bradbury-Jones et al., 2009), I feel comfortable with the potential personal exposure required to demonstrate learning. After all, this is a subjective process and therefore there is no right way to search for I’s, and no correct I’s to disclose or names to assign (Bradbury-Jones et al., 2010; Bradbury-Jones, 2013). I feel adoption of its principles provide an adequate reflective framework in the context of this report.

Subjective I’s

My subjective I’s are presented in Figure 1.

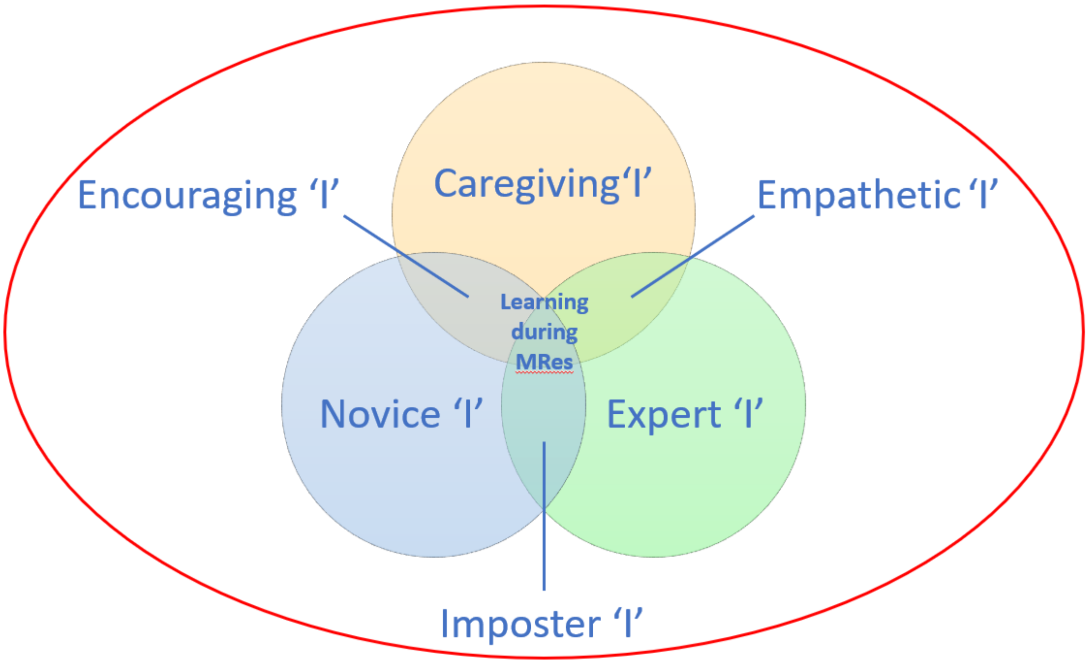

Figure 1 My Subjective I’s

I acknowledge, like Savage (2007), my use of the principles to shed light on my experiences and illuminate my reflections in the written word, these are ‘Intrinsic Subjectives’. Reflecting on my studies, these represent aspects of my whole, reflective being. I am unique, shaped by complex contextual, societal and historical factors (Bradbury-Jones, 2013). I brought all of myself to the MRes but realise that my I’s are fluid. A different subset may emerge in an alternative set of conditions in the future, which Peshkin (1988) describes as ‘Situational Subjectives’. Application of this approach, indeed any reflection, is an ongoing process, never a completed activity (Bradbury-Jones, 2013).

Peshkin (1988) notes that the I's can be contrary and do not have to reconcile each other. Savage (2007) explores the overlap of his I's, how they appease yet broaden his approach to teaching music in a more tolerant and inclusive way. As my reflections evolved, I found that it was the interplay between my initial I's that generated my most powerful moments of subjective realisation. As Bradbury-Jones et al. (2009) observed, the power of the approach in revealing 'hidden' aspects of self-awareness was both striking and surprising. The corollary of which was nursing students' enhanced learning, and I hope to demonstrate my own.

I acknowledge COVID-19 and its impact on my Subjective I's. Its influence is demonstrated by the red circle in the diagram. Every corner of my life was impacted by the pandemic declared in March 2020, a point in time midway through my MRes journey. As a senior nurse working in a large organisation providing acute care, my psychological and emotional wellbeing suffered because of multiple redeployment periods, including time in COVID Intensive care. I am not alone in this (Maben et al., 2022). This presented me with my own 'wicked problem' in relation to COVID and its complexity and impact on nurses' ability to practice reflection (Patel and Metersky, 2021). However, I feel that application of the principles of Peshkin has provided me with a foundation to unpick my experiences and make sense of them, in relation to my learning.

The *Expert I*

I am very proud of being a nurse, having worked in the speciality of adolescent and young adult cancer care for two decades. At the start of my MRes I was Regional

Lead Nurse, responsible for development, implementation, and improvement of services. I line managed a large multidisciplinary team and had professional responsibility for nurses funded by a charity but employed in NHS organisations external to my own. Additional postgraduate teaching on the specialism, heled me to gain national reputation as an expert in the field. I freely chose to undertake post graduate study to enhance my clinical expertise, develop my academic thinking and contribute to the evidence base.

While my *Expert I* gave me credibility and practical insight into the area of care I was hoping to influence, this became a huge barrier, particularly when undertaking the scoping review. Understanding the existing literature base is one of the first and most important steps in research (Moule et al., 2018). Numerous approaches to reviewing the literature exist. All provide a systematic approach to identifying a body of evidence and choice of review type must be applicable to the topics being explored (Booth et al., 2016). Arksey and O'Malley (2005) outline a five-stage methodological framework for conducting a scoping review study, identifying its strengths as a tool to broadly illustrate the field of interest and identify gaps in the evidence base.

It was exceptionally difficult to switch off my expert reality, focus on the literatures findings and identify themes. I kept allowing my lived experiences of the specialism cloud, and potentially bias, the evidence generated by the review. I had to continually return to my aims and objectives to remind and guide me to articulate the papers findings and identify the gaps, not what I imagined they described. However, with support from supervisors and engaging more deeply with the checklist and explanation developed by (Tricco et al., 2018) I was able to quieten *Expert I* and complete the review.

The *Novice I*

I began my MRes journey fully cognisant I was starting something new. Looking back at my application I had made statements such as *'I am excited to learn more and curious as to how this will shape my own research plans'* and *'I am enthusiastic to… develop my research knowledge and experience'.* I was passionate to learn and saw the MRes as an *'…essential step on a much longer clinical academic career journey'*. The *Novice I* soon appeared as I commenced taught modules and realised how much I had to learn and how challenged I was. I felt completely out of my depth, panicky and was despondent at times. These emotions continued, particularly in relation to the secondary data analysis and the requirement to apply newly learnt quantitative skills, such as SPSS and interpretation of statistics. The research *Novice I* was the antithesis of my clinical *Expert I*. I was conscious of my limited abilities, was very task orientated and felt inadequate in my early stages of learning, abstract by comparison to my clinical nursing practice, in which I perceived myself to be excellent (Benner, 1984).

The pandemic necessitated a leave of absence from my studies. Not having to give thought to my academic endeavours, despite the pressures of the new clinical skills I was rapidly acquiring during redeployment, I was caught off guard at the relief I felt from the permission to pause. I stumbled across a post on Twitter which referenced an essay by Schwartz (2008) on the importance of stupidity in scientific research. The realisation that the feelings I had about the daunting tasks, difficulties, and failure to foresee let alone solve problems, were in fact hiding a strength, was very powerful. I began to accept that I was experiencing what Schwartz (2008, p. 1771) described as *"a very big transition: from learning what other people once discovered to making your own discoveries",* identifying my *Novice I*, I was bracing for the challenges of learning, now and in the future, these were not feelings be ashamed of.

The *Caregiving I*

As a mother of two children under 12 years, a wife, daughter, daughter-in-law, and sister I feel love for my close family and take immense pleasure from caring for them, perhaps as no surprise being a nurse after all. Carving out time for learning alongside work and logistics of family life made me feel constantly guilty and overwhelmed. This subjective I was the first that I identified, but generally the one I now recognise I tend to place last. I was struck by the similarities of my *Caregiver I* and the *Wizard I* of Bradbury-Jones (2007b). I found her descriptions of family compromise, tension and competing demands validating. My experiences through COVID have been a catalyst to reprioritise the demands on my time, and my newfound awareness of my *Caregiving I* provided perspective on plans for future learning. I have decided that I will not undertake further academic study unless I have dedicated time in my week for this.

The *Imposter I*

In the clashing of my *Expert* and *Novice I*'s, I found my *Imposter I*. Feelings of doubt in my own abilities, nervously anticipating that someone would call me out as a fraud are not uncommon. This *I* historically haunts me from time to time in all aspects of my life. Imposter Syndrome is a well-recognised and widely discussed phenomenon whereby individuals, generally high achieving professionals, fail to acknowledge or accept successes as their own doing (Bravata et al., 2020b). In healthcare settings, the COVID response may have increased responsibilities and reduced supervision. This will potentially have negative implications for those who consistently question their professional legitimacy (Bravata et al., 2020a). No wonder that this *I* appeared at this juncture.

In relation to my learning, my *Imposter I* was most keenly felt as I had been a local investigator for the BRIGHTLIGHT Study (reference LO/11/1718), and actively involved in its recruitment. To then be gifted with the opportunity to perform secondary data analysis on data that I knew, first hand, had presented recruitment challenges (Taylor et al., 2018), was overwhelming. I felt pressure to perform as an honorary part of the study team whose decade of work was finally coming to fruition. I wanted to deliver something meaningful with impact and answers for the specialist community, but ultimately the AYA and their caregivers. Using this fear as a driver, I courageously discussed this with the study team, thus acknowledging this Subjective I. I took comfort that prominent researchers in the field also felt pressured by the responsibility and constantly questioned their actions. I learnt to share feelings in a safe space and not make assumptions about my perceived eminence in others.

The *Empathetic I*

This *I* was my most profound realisation and came to me as an epiphany. I was washing up, a mundane task most befitting of my *Caregiver I*. When suddenly it struck me that I was a caregiver, the very topic I was researching and that I could and should empathise with it. This astonished me in three ways. Firstly, as a mother to consider ill-health in your children can be breath-taking. Secondly, I had always managed to corral this type of thinking in my clinical practice. I was once told that when I had children I wouldn't be able to do what I did. I had seen that as a challenge and realised I had locked away that thought and associated emotions so it wouldn't surface and impact my *Expert I*. Thirdly, my supervisor had suggested I allow time to think, not just to read and write and I had not appreciated its significance.

I spent time unpacking this complexity, and the meaning of caregiving and families but often packing it away again, not giving it the time it perhaps needed. This caught up with me during my redeployment to a family liaison role on a ward in the first wave. Tasked with calling next of kin to update with patients, often rapidly deteriorating progress, was exhausting. I was shocked by the huge variation in family dynamics, reactions and attitudes towards their relatives' outcomes, often at odds with my own had I been in their shoes. For my learning, I see that allowing my *Empathetic I* some space brings some valuable ideas. Just sitting with thoughts can generate growth of ideas and consideration of alternative perspectives, providing enlightenment in academic endeavours.

The *Encouraging I*

I enjoy supporting others to develop and taken immense satisfaction from mentoring and teaching in both formal and informal settings. I champion the work of others, sometimes at the detriment of my own. Being asked to share my clinical academic journey alongside peers at a European research meeting at the University hugely challenged my *Novice* and *Imposter I*. To be perceived as competent enough to share my work so far in that forum was a huge boost and I gained much from the networking and learning opportunity it created. However, it was the overlap with my *Caregiving I* that generated the insight into this I. My children see I am applying myself, setting an example to them, that you can achieve anything if you put your mind to it. They want to be ‘as clever as mummy’. Adults in my social circles have said I inspire them to do more, learn more or try something new. Others saw my *Encouraging I* before I did.

Conclusion

Completing this reflective element of my thesis has been a worthwhile opportunity personally and professionally. Use of Peshkin's model made it more than an academic piece of writing. The self-awareness I have found through its principles has enhanced my learning during this period of study. I have experienced negative thoughts and emotions and made mistakes. Nevertheless analysis through the lens of my Subjective I's has brought acceptance, generating a newfound confidence. I recognise the positive implications of engaging fully with supervision to guide and temper me, the benefits of journaling and allowing myself time to consider perspectives and their impact on the iterative process of learning. Acceptance of this, realisation and recognition of the pride I feel in completing this thesis despite a global pandemic and many of life's challenges, provides a strong foundation for next steps on my clinical academic journey.

Perhaps aspiring to a Doctorate is an option worth considering…

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