

## **Abstract**

Young-onset dementia (YOD) affects individuals under 65 years of age, often leading to loss of employment and independence. Families provide increasing levels of care to family members with YOD, resulting in changes to their daily lives, including their occupational pursuits. This review examines evidence of the occupational implications for family members who provide care to a family with YOD to identify: (i) the influence and impact caregiving tasks and responsibilities have on employment, volunteering, and education, and (ii) caregiver, and caregiving situation factors associated with changes in employment, volunteering, and education. A scoping review was performed using eight electronic databases. Included articles were narratively synthesized using a thematic analysis. Sixteen studies met the inclusion criteria and were included for review. The over-arching (main) theme of ‘decision-making’ was identified, with family members required to make choices about their own occupational goals and roles to be able to provide care to family living with YOD. The outcomes of these decisions are dynamic and changeable across the caregiving trajectory. Three caregiving factors influence decision-making: 1) Implications of Combining Caregiving and Occupations, 2) Altered Identity 3) Strategies to Support Caregivers of Individuals Living with YOD. A fourth theme was also identified ‘Guidance for Researchers To Support Caregivers’. There is a scarce body of literature examining the influence caregiving has on occupational outcomes for the YOD caregiver population. Much of this work is descriptive and lacks focus on the implications, particularly long-term impacts. This review provides a foundational guide for future research and practices to support YOD family caregivers to obtain and sustain occupations.

## **Introduction**

An estimated 3.9 million individuals worldwide are living with young-onset dementia (YOD) (Hendriks et al., 2021), which refers to individuals who are diagnosed with symptoms of dementia prior to the age of 65. The presentation and aetiology of YOD is more diverse than dementia that occurs in later life, which may explain why many people experience delays in receiving a diagnosis (Loi, Cations, & Velakoulis, 2023). The causes of YOD may include, but are not limited to, Alzheimer's disease, frontal temporal dementia, vascular dementia, dementia with Lewy bodies, Huntington's disease, and Parkinson disease dementia (Hendriks et al., 2021; Rossor, Fox, Mummery, Schott, & Warren, 2010) plus dementia that arises secondary to other factors such as to brain injury or alcohol use (Loi, et al., 2023). Throughout this study, the term YOD refers to individuals diagnosed with any dementia under the age of 65 (Hendriks et al., 2021).

Problems at work are a common early sign of YOD (Ohman, Nygård, & Borell, 2001), which often lead to people losing their jobs (Evans, 2019) soon after diagnosis (Silvaggi et al., 2020). The personal, social and economic impact of YOD both on the individual and their families presents a major challenge (Roach, Keedy, Bea & Hope, 2009). As individuals with YOD transition from independent family members to dependents requiring care and support, so their family members transition to caregivers (Aspö, Visser, Kivipelto, Boström, & Cronfalk, 2023). For children growing up with a parent with YOD the experience can be confusing, distressing and have long-term impact (Sikes & Hall, 2017). Partners of people living with YOD take on both parenting roles (Gelman & Rhames, 2020), as well as being responsible for family finances (Kelley et al., 2020).

Studies of family caregiving for YOD do not always delineate findings based on relationship of the caregiver to the family member, making it difficult to determine if the experiences of adult children caregivers differ from those of spouses or partners. In this article, we define family caregivers as spouses, partners, young or adult children providing unpaid care and assistance to individuals living with acute or chronic illness or injury due to dementia (Kokorelias et al., 2020). While some previous research has reported positive impacts of caring for a family member with YOD, such as increased resilience (Kobiske & Bekhet, 2018; Pang & Lee, 2019) it is clear many family caregivers experience strain related to this role, and are at risk of poor quality of life outcomes (Baptista et al., 2016). Family caregivers are also in need of supportive interventions (Aplaon, Belchior, Gélinas, Bier, & Aboujaoudé, 2017), but lack support from health or social services (Barca, Thorsen, Engedal, Haugen, & Johannessen, 2014) and tend to underuse services that are available (Cations et al., 2017). These factors lead to an increased risk of emotional and psychological distress (e.g., (Hutchinson, Roberts, Kurrle, & Daly, 2016; Millenaar et al., 2014; Svanberg, Stott, & Spector, 2010)) among family caregivers of people living with YOD.

One major contributor to family caregiver stress is trying to balance paid occupation and unpaid family caregiving responsibilities (Bayly et al., 2021; Ikeda et al., 2021). Caring for someone with YOD often leads to reduced working hours (Fujihara, Inoue, Kubota, Yong, & Kondo, 2019) or academic productivity (Sikes & Hall, 2018). For some families, caregiving can cause “untold hardship and resentment” as individuals face the loss of income or having to give up their career (Bayly et al., 2021; Harris & Keady, 2004). There is limited information provided to families caring for YOD across the illness trajectory regarding long-term interventions or services that could support them. However, with increasing evidence about the occupational experiences of family caregivers of individuals with YOD (e.g., Flores et al., 2020; Rodrigues & Ilinca, 2021;

Sadavoy, Sajedinejad, Duxbury, & Chiu, 2021), it is possible to examine the impact caregiving has on their vocational occupations (i.e., employment, volunteering, and education).

The concept of careers is starting to be applied to the experiences of people living with dementia and also their family members. When understood as navigating shifts in professional trajectory, encompassing changes in employment, roles, or sectors, requiring individuals to adapt and strategize for new opportunities, careers can be seen as charting the transitions experienced by people with YOD and their families. Additionally, career guidance professionals have the opportunity to involve and empower individuals living with dementia, as well as those assisting them, in acknowledging their transferable skills and experience, making informed career choices, and either maintaining their current employment or exploring alternative paid positions or unpaid engagements like voluntary work or community activities (Bolger et al., 2023). To inform this work requires an evidence base of when and how family caregivers of individuals living with YOD need or could benefit from opportunities to discuss their situation to make informed choices for themselves and their families.

We found no existing reviews examining the impact of family caregiving of individuals with YOD on occupation, such as education and employment. The scoping review presented in this paper aims to explore this gap. The objectives of this review are: (i) to identify the influence and impact caregiving tasks and responsibilities have on employment, volunteering, and education, and (ii) to identify caregiver, and caregiving situation factors associated with changes in employment, volunteering, and education.

## **Methods**

### *Design*

Scoping reviews are best suited to examining the range of literature available around a certain topic and identifying gaps within that literature (Arksey & O'Malley, 2005). This study followed the Arksey and O'Malley iterative six-stage approach (Arksey & O'Malley, 2005) as it has demonstrated rigour in various prior scoping studies, including those on caregiving (Hall, Rohatinsky, Holtslander, & Peacock, 2022; Lee, Chung, Meyer, & Dionne-Odom, 2022). The six stages are (i) Identifying the research question; (ii) Identifying relevant studies; (iii) Study selection; (iv) Charting the data; (v) Collating, summarising, and reporting the results, and (vi) Consulting with stakeholders.

We followed the PRISMA Extension for Scoping Reviews (PRISMA-ScR) statement (Tricco et al., 2018) reporting guidelines (see **Supplemental Material 1**). The protocol for this scoping review is registered (Blinded for Review) and is briefly described below. The present paper's aims deviated from the protocol as the aim of the research changed as we became more familiar with the existing literature. Upon reviewing the existing literature on the employment experiences of child caregivers (under the age of 18) to individuals with YOD we recognized a scarcity in the literature, thus, changing our original aims to consider caregiving broadly (i.e., spousal and child caregiving), rather than just on children.

*(1) Identifying the Research Question(s)*

We aimed to answer: 1) What do we know about the influence and impact caregiving tasks and responsibilities have on employment, volunteering, and education? 2) What caregiver, and caregiving, situational factors are associated with changes in employment, volunteering, and education? The research team drew upon the extensive experience of the researchers within the team conducting research in this domain (e.g., health services, dementia, cognitive impairment, occupational therapy, human rights, citizenship, and psychology) to inform the research questions.

For the purposes of this review, situational factors were operationalized and categorized by the authors in three ways: “caregiver factors” (such as physical health or psychological characteristics), “YOD factors” (such as psychological characteristics or functional level), and “other factors” (such as sociodemographic factors, social supports, and family functioning; Beach & Schulz, 2017; Burgener & Twigg, 2002).

### *(2) Identifying Relevant Studies*

To identify peer-reviewed literature, an informational specialist/librarian at [Blinded for Review] in Toronto searched Ageline, CINAHL, Embase, Ovid MEDLINE(R) (including Epub Ahead of Print, In-Process and Other Non-Indexed Citations, Ovid MEDLINE(R) Daily), Pubmed, OTSeeker, PeDRO, PsycINFO and Scopus on January 3, 2022. Prior to this, several search strategies were attempted to ensure we could capture all relevant literature to our topic. A sample of the search strategy is in **Supplemental Material 2**. The final search strategy was peer reviewed using Peer Review of Electronic Search Strategies guidelines (McGowan et al., 2016) and was intentionally broad to ensure articles were not excluded that may touch upon aspects of the research questions. EndNote X10 (Bramer, Milic, & Mast, 2017) managed bibliographic information of all references. To ensure a comprehensive review, we also reviewed the reference lists of all included articles in March 2022 to determine any articles that were missed while screening and analyzing the selected articles. Forward searching was conducted both in March 2022 and September 2022 to help capture any new articles (Levy & Ellis, 2006).

### *(3) Study Selection*

The searches for peer-reviewed literature yielded 10,032 studies for consideration and 7839 unique references (after duplicates were eliminated; see Figure 1). Authors (*Initials Blinded for Review*) independently conducted title scans and abstract reviews to assess eligibility against the inclusion

criteria. To be included, articles had to: include data from family caregivers of those with YOD; include YOD classification based on a clinical assessment rather than patient self-report (diagnosed); include individuals with YOD under 65, and mention employment and/or education among family caregivers in the results or discussion of the paper. Articles were excluded if they were a literature review or if the individual with YOD had cognitive deficits that may be due to a psychiatric condition. The first three authors (*Initials Blinded for Review*) then reviewed all potentially relevant full-text articles.

Grey literature and other non-peer reviewed works (e.g., theses), were included in the search and was searched by the information specialist and first author and reviewed by the research team from March 10-13, 2022. The search also included contacting agencies, such as Alzheimer's Societies, to obtain grey literature, which had to meet the same inclusion criteria as the peer-reviewed articles.

The PRISMA flow chart outlining our screening process is outlined in Figure 1.

Insert **Figure 1**.

#### (4) *Charting*

The research team used a consensus-based discussion to establish data extraction methods as a team at the beginning review and re-visited methods at the middle of the review (Colquhoun et al., 2014; Levac, Colquhoun, & O'Brien, 2010). All data were extracted in duplicate. The data were charted independently by *Initials Blinded for Review*, using a data extraction form and then compared. Data extraction included authorship, year of publication, geographical origin of study or article, type of article (e.g., original study, commentary paper), and description of the impact of caregiving on occupational effects. Members of the research team reviewed the abstracted data together through a series of bi-weekly meetings. Extracted data were recorded in an Excel

spreadsheet. The research team did not conduct a quality appraisal of included studies which is in line with scoping review guidelines (Arksey & O'Malley, 2005) as the goal of the was to identify and characterize available evidence rather than assess its methodological rigor.

#### *(5) Summarizing and Reporting the Results*

A thematic analysis was used to synthesise and categorise the included studies, such as to assist with the reporting of patterns within the extracted data (Braun & Clarke, 2020). In modifying Braun and Clarke's 6-step process (Braun & Clarke, 2006), four members of the research team (*Initials Blinded for Review*) reviewed the extracted data and came to meetings with written ideas about the Excel data. Unlike the traditional approach where data review might occur individually, our modification involved four team members independently reviewing the data and bringing written ideas to subsequent meetings. These notes informed the development of a code-book with key concepts, such as positive impact, negative impact, changes in identity, impact on finances. These codes were then applied to the method and discussion sections of each of the full-text articles by the first author (*Initials Blinded for Review*). While Braun and Clarke suggest generating initial codes directly from data, our modification involved first compiling written ideas into a code-book with predefined key concepts. NVivo 12 software was used to organize the coding process (Beekhuizen, 2007). The coded data were shared with the research team. Next, the authors met over a series of seven meetings to discuss patterns or themes across the studies. Over these meetings *Initials Blinded for Review* developed preliminary themes into main categories and sub-categories relevant for the aims of the scoping review. The first author created a lay summary report of our analysis that was presented to stakeholders below. While Braun and Clarke primarily focus on academic reporting, our modification prioritizes accessibility and dissemination of



findings to a broader audience, aligning with principles of knowledge translation and community engagement.

#### *(6) Consultation with Stakeholders*

The research team presented preliminary findings of the scoping review at a national conference that focused on gerontology. These activities involved sharing and discussing previously collected data at an existing forum without introducing new participants, interventions, or data collection procedures and thus research ethics was not required. Feedback from attendees was incorporated into the final reporting of the results. Next, we consulted a geriatrician, occupational therapist, and dementia health service researcher, known to the research team, each who have published at least two academic publications on caregiving and YOD. The first three authors presented the preliminary findings, informed by the conference, to them individually to gather their feedback (April 2022). Each individual was asked if our findings were consistent with their own understanding of the status of the literature and if applicable, clinical practice. These individuals made recommendations for the discussion section, which were incorporated into our final manuscript.

## **Results**

### *Overview: Characteristics of Studies*

The searches yielded a total of 7860 articles after the duplicates were removed. Of the 7860 records, 132 met the criteria for the full-text screen. As part of the full-text screen, articles were excluded if they did not stratify findings by caregivers to individuals with YOD, did not involve family caregivers of YOD, or did not examine caregiving experience. Sixteen studies were included for final review: two quantitative studies and 14 qualitative studies. No grey literature

was included. The two quantitative studies were both of a cross-sectional design. All, but one of the qualitative studies used interviews or focus groups. The remaining qualitative study used a survey (Stamou et al., 2021). While studies varied in their specific objectives, all were concerned with better understanding the experiences of spousal and/or child caregivers of individual with YOD. One of these studies focused on occupational experiences (Sikes & Hall, 2018). This study explored the a child's (6-31 years of age) educational career, as they cared for a parent with YOD (Sikes & Hall, 2018). The remaining studies were related to education or employment. Almost half of the articles came from North America (n=7/16, 44%). A summary of the 16 included studies is presented in **Table 1**.

*Overview: Characteristics of Participants in the Included Studies*

Sample sizes across the studies ranged from 7 (Gelman & Rhames, 2020) - 233(Stamou et al., 2021). Fourteen studies (88%) included both male and female caregivers, while two included only female caregivers (wives;(Gelman & Rhames, 2020; Peyser, 2017)). Six of the 16 studies (40%) included children who provide care, with the youngest child being 6 years of age (Sikes & Hall, 2018). In the studies with spouses, one (6%) was limited to the experiences of individuals under 70 (Klink, 2013). Only one study required (child) caregiver participants to be in some form of education (i.e., at an elementary or high school, college or university studying for bachelors, masters or doctoral degrees) or in work following a college or university degree (6%; (Sikes & Hall, 2018)). The type of dementia experienced by the care recipients was not described, aside from three studies of family caregivers of individuals with young-onset Alzheimer's Disease (Ducharme et al., 2013; Wawrziczny, Antoine, Ducharme, Kergoat, & Pasquier, 2016; Wawrziczny, Pasquier, Ducharme, Kergoat, & Antoine, 2017). Half of the studies did not specify

the ethnicity of the caregivers. Of the eight studies that did report ethnicity, seven studies included Caucasian participants, and a seventh that included Chinese family caregivers (30). Two studies explicitly mentioned the lack of ethnic minority participants (Stamou et al., 2021; Svanberg et al., 2010).

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Insert Table 1 about here

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### *Thematic Analysis*

One overarching theme - decision-making - plus four major themes were identified. Caregivers make numerous decisions about their occupational situations across the caregiving trajectory. The outcomes of these decisions are dynamic and could change over time. Three caregiving factors (presented as major themes) influenced caregiver decision-making: 1) Implications of Combining Caregiving and Occupations, 2) Altered Identity 3) Strategies to Support Caregivers of Individuals Living with YOD. We also identified numerous suggestions that authors of the included literature made for future researchers (presented as major theme four).

#### Overarching Theme: Decision Making around Deciding Whether to Continue or Relinquish Occupations

This theme describes the decisions caregivers had to make about their choice to continue or relinquish occupations. The overarching theme of decision-making is intricately influenced by all three sub-themes, highlighting the multifaceted nature of their interconnections and the comprehensive impact on the decision-making process. For example, the caregiver role resulted in many caregivers distancing themselves from extracurricular activities (Allen et al., 2009; Cummings, 1997; Ducharme et al., 2013; García-Toro et al., 2020; Klink, 2013; Rosness, Mjørud,

& Engedal, 2011; Sikes & Hall, 2018; Wawrziczny et al., 2017), such as engaging in community activities (Ducharme et al., 2013), as well as education (high school and post-graduate education) (Gelman & Rhames, 2020; Sikes & Hall, 2018) and employment (Allen et al., 2009; García-Toro et al., 2020; Karie Ruckert Kobiske et al., 2019; Rosness et al., 2011; Stamou et al., 2021; Wawrziczny et al., 2017). Other caregivers, remained in employment or education, despite the demands of caregiving (Adams, 2006; Gelman & Rhames, 2020). We identified two sub-themes that influence the decision as to whether to continue or relinquish occupations: wages and financial considerations and the level of care required by the individual living with YOD. We describe these sub-themes below.

*Sub-Theme: Wages and Other Financial Considerations*

When a family member with YOD is no longer able to work, other family members are required to provide financial support for the family, which leads to many challenges and fears about the loss of income (Peyser, 2017). As individuals with YOD are often much younger than the typical age of retirement, the loss of employment is unexpected, forcing families to struggle with a sudden change in financial situation (Cummings, 1997; Peyser, 2017; Stamou et al., 2021). This can result in caregivers who were not previously employed, such as young adults with a parent with YOD or stay-at-home parents, to enter paid employment (Adams, 2006; Allen et al., 2009; Gelman & Rhames, 2020; Peyser, 2017). Some adult children make the decision to work in order to balance financially supporting their parent(s) and paying for education-related costs such as tuition (Gelman & Rhames, 2020; Peyser, 2017). Similarly, many caregivers who are already in employment make the decision to stay in the workplace, and take on additional employment (i.e., increased hours, a second job) to be able to support their family in a time of financial instability

(Peysner, 2017; Wawrziczny et al., 2016). Some caregivers have reported working for employers or organizations that did not treat them well, or paid them poorly, due to their need to overcome the loss of income (Allen et al., 2009). Being employed in a job with low pay, reduced work hours, and a lack of professional growth, can have long-term implications for the career prospects, and in turn, financial prospects, of partners and child caregivers in the future (Cummings, 1997; Peysner, 2017).

Consequently, giving up employment could result in a sense of dependency on welfare and other government social assistance (Ducharme et al., 2013). For example, a study by Ducharme et al., described a participant who initially chose to continue working for the income, but as this meant spending less time with their spouse, they ultimately decided to stay home and care for their spouse with YOD while receiving welfare payments (Ducharme et al., 2013).

#### *Sub-Theme: Level of Care Required*

Caregivers assisted with several categories of functional needs for their family members with YOD including medical decision-making and attending medical appointments (Adams, 2006; Gelman & Rhames, 2020; Pang & Lee, 2019), supervision of daily activities, (Adams, 2006; Allen et al., 2009; Gelman & Rhames, 2020; Svanberg et al., 2010) taking over daily tasks (e.g., cooking, financial management, cleaning) (Cummings, 1997; García-Toro et al., 2020; Gelman & Rhames, 2020; Karie Ruekert Kobiske et al., 2019; Pang & Lee, 2019; Peysner, 2017), managing behavioural and psychological symptoms (Ducharme et al., 2013; Sikes & Hall, 2018; Wawrziczny et al., 2016; Wawrziczny et al., 2017) and navigating the healthcare system (García-Toro et al., 2020). The severity of cognitive impairment among individuals living with YOD, resulted in caregivers

making the decision to adapt and prioritize caregiving duties (44). Many caregivers cited that they could not participate in paid work because they had full time caregiving responsibilities, that did not allow them time for employment (Allen et al., 2009; Ducharme et al., 2013; Pang & Lee, 2019; Peyser, 2017), or did not leave enough energy to engage in other activities, such as volunteering or working (Peyser, 2017). Similarly, in three articles spousal participants were also providing care to other dependents, such as their own children or parents, and thus, lacked the time to participate in other activities such as socialization or employment (Ducharme et al., 2013; Pang & Lee, 2019; Peyser, 2017). Child and young adult caregivers who were supporting a family member living with YOD frequently made the choice to use the scarce time they did have to provide further care for their parent, instead of their personal goals, such as higher education or career advancement (Cummings, 1997; Ducharme et al., 2013; Karie R Kobiske & Bekhet, 2018; Karie Ruckert Kobiske et al., 2019; Peyser, 2017). These choices were linked to diagnosable mental health problems, isolation, and depression among these individuals (Adams, 2006; Peyser, 2017). For caregivers in employment or education, the constant worry about their family member reduced their ability to focus on their work tasks, socialize with peers (Cummings, 1997; Ducharme et al., 2013; Karie Ruckert Kobiske et al., 2019; Peyser, 2017; Stamou et al., 2021) and set goals for their occupational and professional growth (Ducharme et al., 2013).

Some studies described that the level of care required by the individual living with YOD influenced caregivers' employment, in ways such as reducing working hours or changing jobs (Cummings, 1997; Ducharme et al., 2013; Karie R Kobiske & Bekhet, 2018; Karie Ruckert Kobiske et al., 2019; Peyser, 2017). However, sometimes making this decision meant that caregivers were focused on pursuing work opportunities with flexible work hours and health benefits (Cummings, 1997; Peyser, 2017), rather than selecting jobs based on their interests or aspirations. Such choices

often resulted in job dissatisfaction (Peysers, 2017) and lower self-esteem (Cummings, 1997; Ducharme et al., 2013) .

### Theme 1: Implications of Combining Caregiving and Occupations

Combining caregiving with other occupations resulted in practical (i.e., changes in outlook) and health related implications for the caregiver. For spousal caregivers in employment, the stress of the caregiving situation was ‘multiplied’ due to also becoming solely responsible for housework, childcare, and managing household finances (Adams, 2006; Allen et al., 2009; Gelman & Rhames, 2020). Balancing these multiple responsibilities often resulted in anger against the family member with YOD who was not in employment (Peysers, 2017). Caregivers also experienced guilt about not spending enough time with their family member with YOD, given the demands placed on them at work and home (Adams, 2006; Peysers, 2017). However, for some spousal caregivers, remaining in the workplace helped to reduce their stress, by providing respite from caregiving duties (Peysers, 2017). Similarly, adult-child caregivers reported that the distraction of school aided their ability to maintain their caregiving role (Svanberg et al., 2010).

The physical and emotional impact of caring for a parent with YOD on children and young adults’ educational careers was reported in two studies (13% of participants were aged from 6 to 31 [26,30]). Children trying to study reported being distracted and interrupted by their parent with YOD requesting assistance, information or support (Sikes & Hall, 2018; Svanberg et al., 2010). Moreover, as children began to recognize the progressive nature of YOD, many were faced with anticipatory grief. This increased their stress, impacted studying, as well as test writing, due to an inability to concentrate (Sikes & Hall, 2018). Child caregivers in both studies reported occasional

absences from school due to needing to supervise and provide care to their parent with YOD (Sikes & Hall, 2018; Svanberg et al., 2010).

Taking on the caregiver role was not always regarded as negative, as some children described their role as caregiver as helping them to “become a better person”(Svanberg et al., 2010, pg. 742). For a few child caregivers, participating in caregiving actually contributed to their desire to participate in volunteer activities to help other individuals with dementia, such as through dementia support groups or not-for-profit organizations (Klink, 2013; Svanberg et al., 2010). Some post-graduate aged child caregivers described how experiencing caring for someone with dementia, resulted in them changing their academic interests, such as becoming interested in studying neuroscience to better understand the disease and (Sikes & Hall, 2018). While the specific activities associated with volunteering were not described by the included studies, volunteering was viewed as helping spousal caregivers develop an overall sense of acceptance and accomplishment (Klink, 2013).

## Theme 2: Altered Identity

Whilst all studies spoke of the love and commitment caregivers had for their family member with YOD, many described how caregivers experienced a change in self-identity. All studies spoke of the identity of spouses and children using the term ‘caregiver’. Some studies (47%) referred to a loss of a former identity of caregivers (Allen et al., 2009; Cummings, 1997; Ducharme et al., 2013; Klink, 2013; Peyser, 2017; Sikes & Hall, 2018; Svanberg et al., 2010). For spousal caregivers, the caregiving identity replaced their primary identity as a spouse (Cummings, 1997; Ducharme et al., 2013; Klink, 2013; Peyser, 2017), whereby they reported not feeling “young anymore” (Ducharme et al., 2013, pg.638) or more like “roommates” than partners (Peyser, 2017, pg.139). The transition for a spouse from a partner to a caregiver may lead to fatigue and psychological distress as



caregivers fail to prioritize their own emotional needs and strategies for coping with stress (Cummings, 1997; Ducharme et al., 2013; Klink, 2013; Peyser, 2017). To cope with changes in identity from a spouse to a caregiver (Cummings, 1997), some spousal caregivers frequently reflected on their life prior to their spouse's diagnosis of YOD (Peyser, 2017).

Children of parents with YOD reported that taking on the caregiver role resulted in an altered identity that was more 'mature' and grown up than their childhood peers (Svanberg et al., 2010). Other children reported that their identity became closely linked to being the child of a parent with YOD (Sikes & Hall, 2018), whereas others felt that they had to take on the parental role that their parent (in this example, father) used to hold (Allen et al., 2009). Changes to their own identity, were perceived as a sense of loss of a typical childhood for young children (Sikes & Hall, 2018; Svanberg et al., 2010), as they felt they could no longer take part in fun, social events, which were previously enjoyed together by the parent and child (Allen et al., 2009).

### Theme 3: Strategies to Support Caregivers of Individuals Living with YOD

Several recommendations to address the needs of children and spouses caring for a family member with YOD were made by the authors of the papers reviewed here – see **Table 2**. Below we outline the recommendations in terms of the following sub-themes. Participants in the consultation exercise of this scoping review (stage VI) supported these recommendations.

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Insert Table 2 about here

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*Sub-theme 3a: Psychosocial Support to caregivers*

Family members take on responsibility for decision-making in the care of the family member living with YOD as well as decisions concerning their own occupations. Some studies noted that increased psychosocial support can assist caregivers in their decision-making, by helping them normalize and recognize feelings, such as resentment (Allen et al., 2009), due to changes in family dynamics and responsibilities (García-Toro et al., 2020; Stamou et al., 2021). Moreover, this support should be offered to all family members and not just the primary caregiver (García-Toro et al., 2020). One study noted that psychosocial support should continue to be offered, even after the individual with YOD passes away, to help caregivers cope with the evolving changes in family dynamics (García-Toro et al., 2020). Differences emerged as to who should provide this support including other family members (García-Toro et al., 2020), social workers or other professions (Allen et al., 2009). Regardless of who is offering the support, it is important that the symptoms of young onset dementia are recognized early to for families to access support (García-Toro et al., 2020; Svanberg et al., 2010). Moreover, services must be open to understanding the range of emotions that caregivers may feel (Gelman & Rhames, 2020). Recommendations included further research examining longitudinal effects of psychosocial training (Cummings, 1997) and how this training may support acceptance of the changes that occur following a YOD diagnosis (Klink, 2013).

#### *Sub-Theme 3b: Increase of Health Education*

In efforts to increase an understanding of YOD for families and in society more broadly, more public health education has been urged for in a few studies (Klink, 2013; Karie Ruekert Kobiske et al., 2019; Pang & Lee, 2019; Stamou et al., 2021; Wawrziczny et al., 2017). Moreover, healthcare providers are encouraged to liaise with family caregivers of individuals with YOD to

understand what content is required and subsequent resources for informational and emotional support (Stamou et al., 2021; Wawrziczny et al., 2017). This could include support and guidance to assist family members when making decisions about their work and education.

## **Discussion**

This review aimed to provide a synthesis of the literature on the occupational implications of providing care to a family member with YOD. Family caregiver decision-making about the occupations they continue to pursue or relinquish was identified as an overarching topic. The existing research suggests that the decisions caregivers make about work and the impact of balancing occupations and caregiving are context-specific and influenced by 1) Implications of Combining Caregiving and Occupations, 2) Altered Identity, and 3) Strategies to Support Caregivers of Individuals Living with YOD. Results can inform careers guidance but also help to understand the role transitions and support decision-making.

Decisions were contextualized within financial considerations, as well as the level of care required by their family member with YOD. Studies (Adams, 2006; Allen et al., 2009; Gelman & Rhames, 2020) reported on the changes caregivers make if they wish to remain employed, including working fewer hours (to spend more time caregiving) or more hours (to increase income) or imposing requirements that limited possible career paths (e.g., to have access to healthcare or other benefits). In some cases, child caregivers had to choose between caregiving duties, financially supporting their families through work, and maintaining their education. Existing studies have highlighted that in comparison to adult children caregivers who take on caregiving roles later in life (e.g., to a parent diagnosed with late onset Alzheimer's disease), these cumulative worries subsequently impact the well-being and the mental health of young caregivers which can affect

their future outcomes (Cree, 2003; D’Amen, Socci, & Santini, 2021; Stamatopoulos, 2018). For example, young caregivers may lack the informational and economic resources regarding services that can support their well-being and help them sustain caregiving over time. As with previous research examining decision-making by caregivers of family members with late-onset dementia, decision-making can evolve over time (Kokorelias, Gignac, Naglie, Rittenberg, & Cameron, 2021). However, in the case of YOD the decision-making process may begin earlier in life. Therefore, longitudinal studies could help fill a particularly noteworthy gap in understanding the influence of decision-making on long-term occupational outcomes and how decisions change over time for family caregivers of individuals with YOD. Such information could help agencies and clinicians better understand how to support caregivers of individuals with YOD at different phases of the caregiving trajectory with decisions about their own occupational pursuits.

Our review found that caregivers reported not only additional roles but an altered identity as they attempt to balance caregiving and other occupations. For example, spouses noted the loss of an intimate relationship and their identity as a romantic partner, whereas children reported trying to maintain their childhood identity. Both children and spouses feel great responsibility for and commitment to their family member with YOD in addition to the responsibilities they have as a student, or parent and/or employee. The notion of role conflicts as caregivers try to balance these multiple identities and roles has been reported in other research examining family caregiving and employment (Neubert, König, Mietzner, & Brettschneider, 2021; Sakka et al., 2019; Stephens, Franks, & Atienza, 1997).

These earlier studies also show that concerns over financial strain are often correlated with a lower caregiver well-being and quality of life (Coen, O’Boyle, Coakley, & Lawlor, 2002). However, our review suggests that caregivers must make difficult decisions to reduce working hours or give up

their job as their family's need for care increases, even when experiencing major financial strain. Given that many individuals assuming the caregiving role for family members living with YOD are younger (children or young adults), taking on these roles can have life-long financial consequences. Using programs that offer social and financial support, as well as workplace support programs that offer flexibility, such as remote work and altered work hours, may be especially relevant and helpful for YOD caregivers. Child caregivers could also benefit from specific support to help them learn how to balance caregiving and their other occupations, such as education, to limit the long-term financial effects caregiving may have. Such support can include assigned school counselors to provide emotional support (Rush & Akos, 2007) and advocacy for the accommodations children may need to remain in education (Siskowski, 2006).

Lastly, much of the YOD caregiving literature included in this review involved homogeneous groups of caregivers in terms of ethnicity, country of employment, gender, and residing in urban areas, limiting the generalisability of the findings. Moreover, only one study on child caregivers included young children (Sikes & Hall, 2018), suggesting that there is a gap in our knowledge surrounding the experiences and occupational well-being of caregivers who assume the caregiving role very early in life. The studies on child caregivers also did not consider findings within the context of the different ages of the children. Thus, future research should emphasise comparisons between different aged caregivers and the potential impacts on educational and other occupational outcomes. Similarly, all studies included heteronormative spousal relationships, necessitating the need for researchers to consider unique family structures such as same-sex relationships (Peysers, 2017) or hybrid families. Researchers are therefore encouraged to expand this field of research through the recruitment of diverse caregivers, through appropriate wording on recruitment posters (e.g., not labeling them as caregivers or kin-families), offering compensation for participation,

having translators to recruit caregivers with different first languages, and fostering strong partnerships with community organizations where family caregivers may be found (e.g., schools) (Amador, Travis, McAuley, Bernard, & McCutcheon, 2006; Dilworth-Anderson, Moon, & Aranda, 2020). Such strategies are particularly useful for exploring and capturing occupational experiences and outcomes that may be overlooked by limitations in samples.

While many caregivers in the included studies reported increases in stress while trying to balance occupations and caregiving, others reported that caregiving resulted in a greater desire to volunteer or opened new academic pursuits. Moreover, by focusing mostly on spousal caregivers, the important role children play in caring for a parent with YOD and the implications this can have for their occupational outcomes may have been overlooked. Most studies were cross-sectional and qualitative in nature. Future studies examining long term impacts of caring for a family member with YOD are needed to inform our understanding of the occupational changes and decision making that take place across the caregiving trajectory

Limitations identified in the included studies point to areas for future research. The two quantitative studies lacked longitudinal data, with experiences only captured at one point in time, which does not account for variations in experiences due the dementia progression and the length of time the family member had been in the caregiving role (Karie Ruekert Kobiske et al., 2019). The qualitative studies also lacked a longitudinal perspective and sample characteristics that limited generalisability to other settings (Allen et al., 2009; García-Toro et al., 2020; Gelman & Rhames, 2020; Klink, 2013; Pang & Lee, 2019; Peyser, 2017; Stamou et al., 2021; Svanberg et al., 2010; Wawrziczny et al., 2016; Wawrziczny et al., 2017). For example, due to participant ages, gender (Allen et al., 2009), race (Svanberg et al., 2010) or only including people living in urban settings [(García-Toro et al., 2020; Gelman & Rhames, 2020)). In light of these limitations,

longitudinal research exploring the impact of YOD progression on the caregiving trajectory is recommended (Cummings, 1997; Karie Ruekert Kobiske et al., 2019). Extending research to include diverse genders, ethnicity, religion, socio-economic statuses and same-sex relationships (Peysers, 2017). Likewise research should engage all members of the household to understand variations in household dynamics and the impact on occupation of all members (Ducharme et al., 2013; Peysers, 2017). Future research is also encouraged exploring quality of life and mental health, especially depression, including the impact of staying in or leaving work or education (Rosness et al., 2011).

The reviewed studies emphasised that the experience of being a child and witnessing a parent live with YOD can have profound effects on childhood development (Gelman & Rhames, 2020). This necessitates that the parents without cognitive impairment increase the support they provide to their children. However, more research is needed to best understand how the nature of this support should evolve across childhood development (Gelman & Rhames, 2020). Similarly, future research is also encouraged to consider the challenges and impact of different subtypes of dementia in relation to the experiences of children living with YOD (Svanberg et al., 2010).

### *Limitations*

The limitations of this review must be noted. Firstly, literature reviews are inherently biased by the quality of the included studies (Elkins, Herbert, Moseley, Sherrington, & Maher, 2010), and this review is no exception, particularly as most articles did not focus on the impact caregiving has on occupations as the primary outcome. Our findings, however, must be viewed with the understanding that most of the reviewed studies were not specifically examining the impact of caregiving on occupations. As consistent with scoping review methodologies, we did not assess

the quality of the included studies, however we noted that many articles had small or inadequate sample sizes to promote the generalizability and transferability of findings. Thus, recommendations from the articles should be considered with caution (Tricco et al., 2018). Moreover, some relevant articles were possibly missed, as only English-language articles published between January 1<sup>st</sup> 1990 and September 1<sup>st</sup> 2022 were included, resulting in a cultural bias as we could only draw conclusions regarding the cultures included in the review. To mitigate the risk of potentially missing articles, our search strategy was comprehensive, peer-reviewed and guided by an information science specialist. Nonetheless, this review provides valuable information to guide a more in-depth understanding of caregivers to individuals with YOD's occupational outcomes and experiences.

## **Conclusion**

Spousal and child caregivers are often responsible for meeting the health and psychosocial needs of adults living with YOD (Bannon et al., 2022). This scoping review suggests that due to their caregiving role, family caregivers to individuals with YOD must make decisions about whether to relinquish or continue with occupations, such as work, volunteering, and education. These decisions are often influenced by wages and financial considerations and the level of care the care recipient requires. Whereas some research found that trying to balance other occupations with caregiving was stressful, others noted positive aspects such as newfound interests motivated by their caregiving role. Future studies should examine the long-term consequences of caregiving on occupations with diverse groups of caregivers, especially those who start at a young age. Future studies can address this knowledge gap to broaden our understanding of the long-term impact of



caring for a family member with YOD, such that appropriate psychosocial and other support can be provided by welfare institutions and professionals.

Accepted version

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