



## The psychological effects of caring for a family member with dementia

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# Psychological Impact of Caring for a Family Member with Dementia: An Integrative Review

## Abstract (194 words)

Informal caregivers play a key role in supporting and caring for family members with dementia. Caregiving is complex and may lead to psychological, physical, social and financial stress for caregivers. This review aimed to analyse existing literature with respect to the psychological impact of caring for a family member with dementia at home. A systematic database search of CINAHL Complete, ProQuest Health and Medical Collection and ProQuest Medline was undertaken. The search was restricted to the English language, peer reviewed and full text articles published from 2015 to 2020. Fourteen studies were included in the review and analysed thematically to generate four themes: 'the world shrinks', 'surrender to the unknown', 'robbed of the future' and 'torn between relief and guilt'. The findings offer valuable insights into the holistic experience of caring for a family member with revealing both positive and negative psychological effects of the role. Caregivers experienced isolation, parent-child like relationships, and relief/guilt when relocation to a nursing home becomes inevitable. These experiences result in caregiver stress, burden and anxiety. Nurses, other healthcare professionals and society need to actively engage in the development and delivery of interventions that address caregivers' psychological needs.

**Keywords:** Psychological impact or psychological effect or emotional impact, carers or caregivers or family members or relative or informal carers, dementia or Alzheimer's.

## **Background**

Dementia is a syndrome caused by a variety of conditions that affect the brain leading to problems with memory, language, understanding and judgement (Alzheimer's Society 2015). These conditions include Alzheimer's disease, vascular dementia, Lewy body dementia and frontotemporal dementia. According to the World Health Organization (WHO 2019), approximately 50 million people globally are living with dementia. More than 850,000 people in the United Kingdom [UK] are currently living with dementia and these figures are set to rise to one million by 2021, and two million by 2051 (Alzheimer's Society 2014). Luengo-Fernandez et al. (2015) reported that the health and social care costs associated with dementia almost match the combined cost of cancer, heart and stroke.

With the rising population comes the increasing need for caregivers for those diagnosed with dementia. Most caregivers provide informal care, which is defined as unpaid care provided by a relative or friend (Bremer et al. 2015). In the UK, there are over 700,000 informal carers for persons living with dementia (Lewis et al. 2014). Reports estimate the value of time given by informal carers to a person with dementia at approximately £12.4 billion a year for the UK (Lewis et al. 2014). Around 345,000 unpaid carers aged 16-64 in England, predominately women, have left employment to provide care to a loved one (Bremer et al. 2015). Leaving employment impacts financial status, as according to a Carers UK survey (2014) 30% of carers experiencing a decrease of £20,000 or more a year in household income.

Caregiving is complex and may lead to psychological, physical, social and financial stress for caregivers. Increased emphasis on psychological wellbeing has established that caregivers experience higher rates of psychological morbidity across Organisation for Economic Co-operation and Development (OECD) countries as compared to non-caregivers (OECD 2018, Rapp et al. 2018). Caregivers reported considerably higher levels of stress and depression, and poorer measures of subjective wellbeing than non-caregivers (Adams 2007). Caregivers were much more likely to report a poorer quality of life than comparable adults who do not care for family member (Thomas et al. 2015). Indeed, Cummins et al. (2007) found that family caregivers had the lowest levels of personal wellbeing or life satisfaction of any of demographic groups; including people who were unemployed or living alone.

Caregivers supporting people living with dementia are much more likely to experience poorer psychological than non-dementia caregivers (Stansfeld et al. 2014).

In 2015 the Prime Minister launched a policy paper 'Challenge on dementia 2020' whereby in 2020 there would be enhanced research and support for people with dementia, their family and carers. The policy highlighted the need for employers to have carer friendly policies and practice enabling carers to continue working along with caring (Department of Health [DOH] 2015). The policy also highlighted the need for carers to be made aware and offered the opportunity for respite, education, training and psychological support.

Nurses play a key role in dementia care as they must consider not only the person with dementia, but also familial caregivers (Nursing and Midwifery Council [NMC] 2018). Jenkins et al. (2016) state the nurse's role is to gain a clear understanding of caregivers' needs and signpost them to relevant groups that will provide help and guidance. The purpose of this literature review is to explore the psychological impact of caring for a family member with dementia within the home. It is anticipated that the review will update nurses' knowledge in this area and inform their practice when engaging with people with dementia and their carers (Winchester and Salji 2016).

## **Method**

### ***Search strategy***

A database search of CINAHL Complete, ProQuest Medline and ProQuest Health and Medical collection was undertaken. Key search words included 'carers or caregivers or family members or relatives or informal carers' and 'psychological impact or psychological effect or emotional impact' and 'dementia or Alzheimer's'. Limiters were applied to refine the search to literature published between January 2015 and February 2020, English language, full text, peer reviewed and academic journals.

### ***Study selection***

A PRISMA flow diagram (Moher et al. 2009) was used to guide the selection of relevant studies (Figure 1). A total of 231 papers were retrieved from the

database search, after duplicates were removed, 216 papers remained. The 216 papers were examined by title and/or abstract for eligibility in terms of study aim, sample and methods, with 186 being removed. The remaining 30 papers were read in full with 20 being excluded as they did not address the psychological impact on the carer but rather the person with dementia, related to end of life care, bereavement, Parkinson's disease and/or stroke. Consequently, 10 studies were selected for inclusion in the review. Four further studies were selected for inclusion following a search of the grey literature. Grey literature is considered an important source of information due to the uniqueness of the content published (Paez 2017). A total of 14 studies were included in the review.

### ***Synthesis and analysis***

Data analysis entailed reading and re-reading included studies with relevant sections of text being highlighted and code words assigned to these sections. Following this an inductive process was used to develop categories by combining codes.

Categories were further combined into four descriptive themes namely: 'the world shrinks', 'surrender to the unknown', 'robbed of the future' and 'torn between relief and guilt'.

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### **Findings**

#### **Description of included studies**

The review included ten qualitative studies (Chan et al. 2019, Hammar 2019, Kimuara et al. 2015, Lesko 2019, Moreno-Camara et al. 2019, Pini et al. 2018, Rayment et al. 2019, Tatangelo et al. 2018, Tuomola et al. 2016, Wijngaarden et al. 2018) and four quantitative studies (Fekete et al. 2017, Mukherjee et al. 2017, Nikzad-Terhune et al. 2019, Yu et al. 2015). An international perspective was represented with studies from the UK (2), Singapore (2), and one study from each New Zealand, Sweden, Brazil, Poland, Spain, India, China, Australia and Belgium.

#### **'The world shrinks'**

Although caring can be rewarding for some caregivers, it can also bring many

challenges mentally and physically. According to Pini et al. (2017), the loneliness experienced by caregivers (n=42) is caused by a range of circumstances, many of them out of their control. Caring for their relative with dementia impacted on caregiver relationships with others, reduced their networks and consequently led to feelings of isolation (Pini et al. 2017). For many caregivers, the world simply shrinks. **Social isolation among caregivers has been shown to be related to greater risk of psychological symptoms and burden as compared to non-caregivers (Tuomola et al. 2016).** Hammar et al. (2019) explored spouse caregivers' (n=9) experiences and reported that spouses longed to meet others in similar situations. Support groups were generally appreciated by most caregivers as it helped them feel like they were not alone and could exchange thoughts with others in similar circumstances (Hammar et al. 2019). However, Pini et al. (2017) found that support groups did not suit all caregivers with some being afraid to raise concerns in group sessions in case they were judged with respect to the care they provided. Individual sessions were often preferred, although Hammar et al. (2019) noted caregivers were unable to talk about themselves as human beings and their life journey, as nurse counsellor's training did not extend to such issues.

Fekete and Szabo (2017) identified different patterns of psychological functioning and their correlates among caregivers (n=336) of patients with dementia. There were three distinct caregiver profiles, optimally functioning with positive outcomes and low levels of depression, sub-optimally with low levels of positive outcomes and increased depression, and poorly functioning with high levels of depression and low positive outcomes (Fekete and Szabo 2017). The optimally functioning group reported the most extended social network and lowest levels of loneliness. This suggests that those with higher levels of wellbeing can mobilise social networks more effectively (Fekete and Szabo 2017). On the other hand, the poorly functioning group were more isolated and lonelier.

Caregivers highlighted the need for informal social groups or places where they could go with their loved ones and be with others in similar situations. **Tatangelo et al. (2018) pointed to the importance of caregivers and their loved ones participating in social occasions such as going to a restaurant, without the fear of being embarrassed by behavioural problems associated with dementia.** However, the majority of caregivers have little or no energy left for socialising due to the

exhaustion of caring (Kimuara et al. 2015).

Moreno-Camara et al. (2019) reported that caregivers (n=82) felt tied down, like slaves of the care- recipient, and miss the freedom they once had and have lost by providing care. This is challenging for caregivers who have limited time but also have to be very selective of whom they socialise with based on the extent to which the friends' or family understand their situation (Kimuara et al. 2015). There is often a lack of support from other friends and family who do not understand the extent of caregiving role. This is often the main barrier as to why carers are reluctant to engage with previous social networks (Moreno-Camara et al. 2019). Friends and family may also become reluctant to visit as they are unable to deal with the day-to-day challenges of caring for a family member with dementia (Wijngaarden et al. 2018). Even when family or friends are open to socialising, caregivers found it hard to participate in social occasions due to difficulties managing the behavioural and psychological symptoms associated with dementia (Tatangelo et al. 2018).

### **'Surrender to the unknown'**

Many caregivers live with changes in mood and behaviour of the person with dementia, surrendering themselves to the unknown of the unpredictability and progressive nature of dementia (Wijngaarden et al. 2018). Caregivers who could deal with both the inevitable uncertainties of dementia and the gloomy existential moods these challenges bring such as anxieties, isolation and guilt seemed most capable of caring for a person with dementia (Wijngaarden et al. 2018). On the other hand, Lesko's (2019) study of 11 sibling caregivers found behavioural problems can be detrimental to the emotional well-being of caregivers. This was due to the impulsive and disruptive nature of behavioural disturbances, for example, keeping the caregiver awake all night, emotional outbursts and inappropriate social interactions (Lesko 2019). Furthermore, caregivers reported behavioural problems as a source of stress (Moreno-Camara et al.). Caregivers were placed in circumstances that required unexpected and instant attention which exacerbated their experience of stress. In Fekete and Szabo's (2017) study, more experienced caregivers developed more adaptive strategies to combat stress associated with caregiving. Additionally, Nikzad-Terhune et al. (2019) reported that behavioural problems play a vital role in moderating the relationship between onset of caregiver

stress and emotional health outcomes. Gradual onset is described as those who provided care prior to diagnosis. Caregivers in this group may have had the opportunity to develop personal strategies to effectively manage challenging situations better than those in abrupt onset groups. Those in abrupt onset group will have no experience of caregiving and may experience higher levels of depression, role overload and role captivity (Nikzad- Terhune et al. 2019).

Although some caregivers are more prepared than others, research demonstrated that caregivers require information about dementia. Moreno-Camara et al. (2019) reported carers need information at the time of dementia diagnosis but also throughout the journey of caring for the person with dementia. Family caregivers also raised the importance of training specifically to manage the person's with dementia behavioural symptoms. They needed to develop coping strategies to be psychologically prepared for each day being different (Rayment et al. 2019). Chan et al.'s (2019) study of 16 family caregivers reported that care recipients are all different and thus caregivers have to be mindful of the unique characteristics and preferences of their loved one. Therefore, training may be beneficial for learning coping strategies, but these may not be applicable to certain care recipients depending on their needs. Caregiver approaches require to be customised according to the needs of their loved one.

In addition, Yu et al.'s (2015) survey of 200 patients with mild dementia and their caregivers demonstrated that behavioural and psychological symptoms of dementia [BPSD] were significantly associated with increased caregiver burden. Furthermore, as the severity of dementia increased BPSD so also did caregiver burden (Mukherjee et al. 2017). This study found that elation/euphoria were the only domains that were not associated with caregiver distress, as these BPSDs were seemingly cheerful and the care recipient appeared happy despite the condition (Mukherjee et al. 2017).

### **'Robbed of the future'**

Most caregivers reported feeling robbed of the future, as there is often a changing marital relationship, loss of intimacy and ultimately no future plans with their family member (Kimuara et al. 2015). Wijngaarden et al.'s (2018) study



found that a sense of distance and detachment was reported by caregivers but in some cases relationships changed in a positive way due to dementia. Caregivers also highlighted that their feelings of loneliness increased as the dementia progressed. Many caregivers wished for another illness, for a quicker death as they could not cope with dementia (Wijngaarden et al. 2018).

Hammar et al. (2019) found spouses described missing their partners as if they had already lost them. They were unable to share their life with the person they loved causing grief and frustration. Caregivers reported that they felt trapped in prospectless futures and struggled to watch other couples live happy lives together (Kimuara et al. 2015). Many spouses longed to hug and kiss their partner and to be intimate (Hammar et al. 2019). However, some caregivers noted that they were at risk of being accused of sexual abuse if the care-recipient did not recognise them (Tuomola et al. 2016). It was often very distressing for caregivers when their relative did not remember positive shared experiences (Pini et al. 2018). Relationship dynamics often changed for the worse and many noted the relationship had become like that of a parent-child (Pini et al. 2018). Tuomola et al.'s (2016) study exploring female spousal caregivers' experiences highlighted that many reported a sense of loneliness and loss of previous relationship with their partner. A new way of coping was to replace the relationship with something akin to parent-child as this allowed for feelings of affection to continue.

Lesko et al.'s (2019) study highlighted most caregivers worried about the future when the care recipient became more dependent and their ability as caregiver to manage. They raised the concern that they did not want the care recipient placed in a nursing home, as they did not want anyone to hurt or neglect their loved one (Lesko et al. 2019). Caregivers were also worried about their own future care needs (Chan et al. 2019). However, a minority of caregivers positively managed future changes by facing each challenge as it presented itself. This group accepted the inevitability of future health decline, accepting the inevitability of their loved one having to be placed in a nursing home (Chan et al. 2019).

### **'Torn between relief and guilt'**

Wijngaarden et al. (2018) found after years of providing care to a family member

with dementia, many caregivers reached a point where they could no longer cope. The physical and emotional burden of caregiving was reflective of increasing BPSD, conflict and domestic accidents. Moreno- Camara et al. (2019) reported that family caregivers needed respite services, however, limit their use because of social pressure and respect for the care recipient's preferences. Tatangelo et al.'s (2018) study of 24 family caregivers reported that caregivers needed time away from their caregiving role but, due to feelings of loyalty and obligation towards their loved ones, were reluctant to make use of respite services. Caregivers believed their needs had become irrelevant as belief patterns caused them to disregard their own health needs (Tatangelo et al. 2018). Many caregivers regard their caring role as their marital or natural duty that must be fulfilled, with little or no assistance from anyone. A reflection of the Asian context from Chan et al. (2019) also reinforces the caregiving role as a social obligation, highlighting self- sacrifice and self-neglect necessary within their role. Rayment et al. (2019) raised the importance and need for supporting caregivers in assisting them to challenge unhelpful belief patterns.

Nevertheless, caregivers often experienced a sense of relief when healthcare professionals recommended relocation of the person with dementia to a nursing home (Wijngaarden et al. 2019). Many caregivers felt guilty, labelling themselves as egoists who placed their need for respite before the person with dementia. Asian culture perceived placement in a nursing home as failure as adult children were expected to care for their ageing parents (Chan et al. 2019). Caregivers in other cultures also considered placement in nursing homes as 'putting away' or abandoning their loved one (Wijngaarden et al. 2019). There may also be friction between the caregiver and nursing home staff where it is perceived that staff lacked expertise or competence to care for the person with dementia (Wijngaarden et al. 2019). Similarly, respite or day care staff would contact the caregiver to clarify care needs of the person with dementia or ask for solutions when their behaviour became challenging (Hammar et al. 2019), resulting in caregivers being too worried to socialise in case they could not be reached. This predisposed to caregivers becoming depressed as they just wanted to give up, many wishing for relocation to a nursing home or worse case death of the care recipient (Rayment et al. 2019). The caregivers felt that stress led to other health issues including memory problems, irritation and fatigue making it difficult for them to care. To reduce caregiver burden,

Chan et al. (2019) pointed to the importance of caregivers needing to 'recharge' with respite being highlighted as a time to focus on the caregivers' own needs having a positive effect on mental health (Tatangelo et al. 2018).

## **Discussion**

This review focused on the psychological impact on the holistic experience of caring for a family member with dementia. The included studies provided valuable insights into the diverse range of feelings, emotions and needs that caregivers experience. A diagnosis of dementia had the potential to make a positive contribution to the relationship between the caregiver and their family member, contributing to a stronger relationship and strengthening family ties (van Wezel et al. 2016).

However, the progressive health decline of the person with dementia, their loss of competency to undertake daily activities, behavioural change such as physical or verbal aggression, and loss of intimacy had a huge negative impact on the relationship between the caregiver and their family member, resulting in a parent-child like relationship. Negative perceptions of the caregiving relationship was further compounded lack of support from other family members and social isolation from both family and friends. The increasing demands of caring for a family member with dementia were such that caregivers tended to restrict their interactions with family and friends, sacrificed their interests and hobbies, gave up or reduced their employment predisposing to yet greater loneliness and social isolation. Caregivers therefore tended to lose or set aside their meaning in life and hopes for the future, presenting opportunities for psychological health problems to emerge.

Opportunities to enhance family cohesion, the presence of enduring friendships as well as appropriate support from nurses, other healthcare professionals and voluntary organisations have the potential to enhance the psychological wellbeing of family caregivers. Nurses have a central role in educating caregivers, as well as advocating on their behalf to ensure that they receive access to quality care and support for themselves and their family member living with dementia. Education programmes are important in helping caregivers understand and manage their family member's needs and behaviours, thereby enhancing the caring experience.

Promoting the sharing caregiving tasks with family or formal caregivers can reduce caregiver stress and exhaustion, with some time being used by the caregiver to

engage in other activities that they enjoy. Access to formal care support such as home care, day care services, respite care or nursing home care, together with positive experiences with formal care, are perceived as very positive by caregivers, as long as formal care providers are considered to have the knowledge and skills (dignity, compassion, security, communication) to care for the family member with dementia (Yu et al. 2018). Such supports are crucial not only to maintaining and enhancing the psychological wellbeing of family caregivers, but also to improve their quality of life and that of the person with dementia.

## **Conclusion**

To conclude, this literature review elucidates upon the negative psychological impact for caregivers of caring for a family member with dementia with respect to social isolation, BSPD, imagining the future for the caregiver and the person with dementia, and nursing home relocation. Social isolation is associated with the BSPD as the caregiver became physically and mentally exhausted, and unable to socialise with family or friends. Family and friends were also reluctant to spend time with the caregiver as they did not know how to cope with the behaviour from the care recipient. BSPD is further linked with caregiver fears for the future as if behavioural symptoms gradually get worse, the caregiver knows that their future life and that of the care recipient will change. This may lead to nursing home placements as caregivers are unable to cope with the burden of caring. Relocation to the nursing home comes with relief but also guilt for the caregiver. A minority of studies pointed to caregivers having a positive outlook for the future and taking every day as it comes. Yet the review points to the need for nurses, other healthcare professionals and policy makers to be cognisant of the psychological wellbeing of caregivers and to work collaboratively to address psychological needs.

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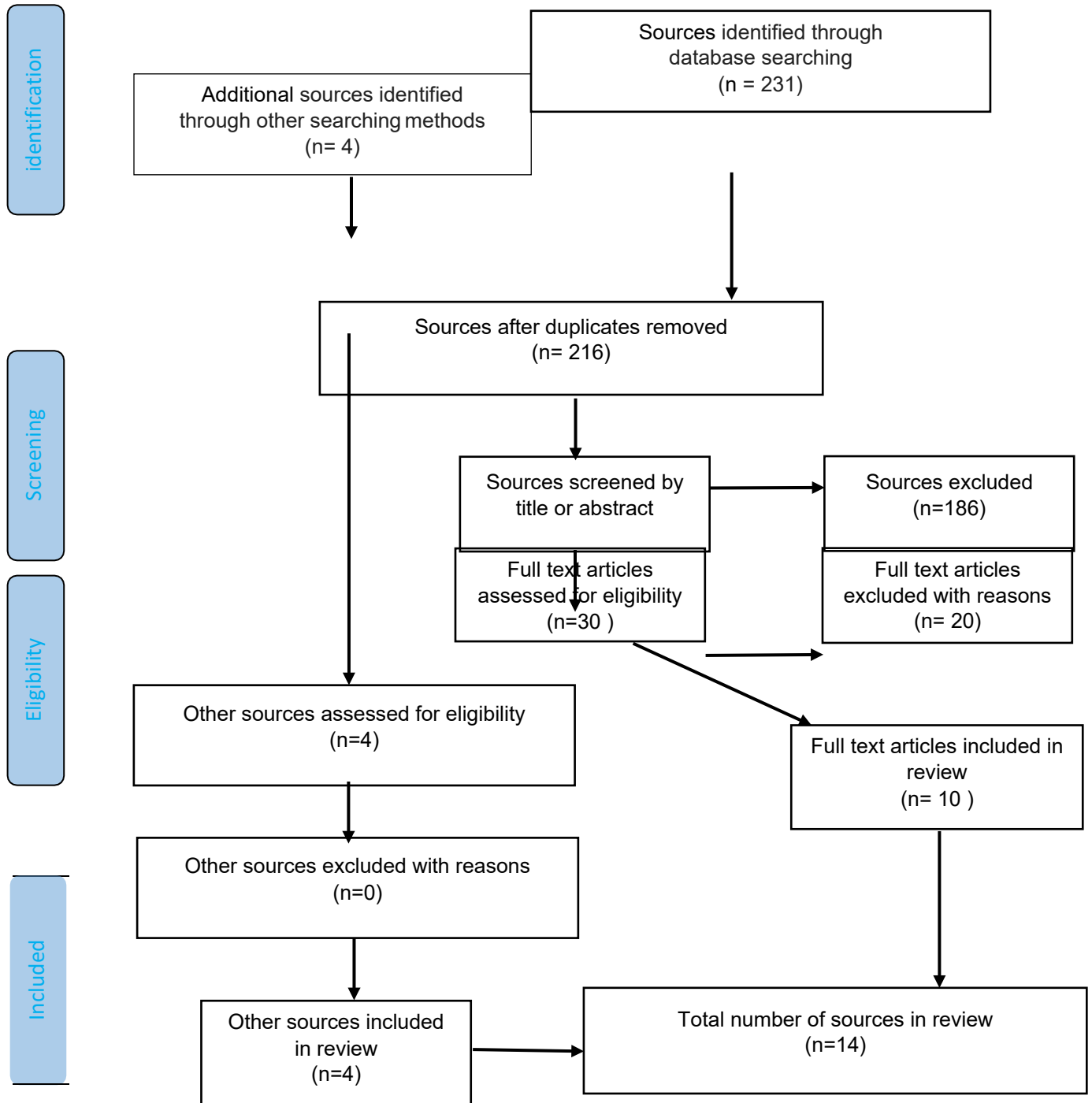
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**Figure 1: PRISMA diagram**



(Moher *et al.* 2009)