

# Policy delusions and dutiful daughters: Imagined versus real care integration for older people

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## Abstract

Policymakers advocate for integrated care as a solution to care fragmentation. In the case of older adults, informal carers (especially ‘dutiful daughters’) play a significant role in integrating and coordinating care. Ludlow and colleagues examine how the role of informal carers in integrating care across services and systems is reflected in policy (the blunt-end of the system) and the experiences of dutiful daughters (the sharp-end) in England and Australia. They present the findings from content analysis of key policy documents, as well as four case accounts of dutiful daughters. The authors found that unpaid carers, and the gender imbalance of caregiving, were largely invisible in the policy documents, accentuating the disconnect between policymakers’ vision for integrated care and the accomplishment of integration on the ground.

## Introduction

Care systems for older adults have many stakeholders, but in this chapter, we focus on two groups: those who formulate policy at the blunt-end and those who spend time making the system work at the sharp-end (Braithwaite et al. 2017; Hollnagel 2004). By examining care integration at these policy-making and frontline-doing ends of care systems, we compare and contrast the ways in which policymakers advocate for integrated care and the work unpaid carers (often daughters) do to achieve care coordination for older family members. We are particularly interested in attempts to create integrated care for older adults in England and Australia. In these two countries, formal care is provided to older adults by the healthcare system (e.g., hospitals, primary care), aged and/or social care systems (e.g., home care, residential care), and those service providers who work across the two systems (e.g., general practitioners, nurses and allied health professionals).

In this chapter we consider integrated care (also called ‘streamlined’, ‘seamless’, ‘coordinated’ and ‘joined up’ care) across care settings, services, specialities or systems. Care integration is a recurrent policy ambition, attempting to address discontinuities and fragmentation in caring systems (Coleman 2003; Rajan & McKee 2019). Various policy documents that intend to shape, structure, or influence care systems—White Papers, five-year plans and other authoritative, instrumental reports—speak of the need for integrated services; but we understand little about how integration is achieved via policy, in contrast to how it is achieved on the frontlines of the system.

Policymakers do not make a system work on the ground so much as they indicate how they would like it to be. Managers are one candidate group for making care systems operate smoothly, but they tend to work in silos (e.g., health regions, hospitals, care homes), and are often unable to integrate services across the care continuum due to a focus on their own responsibilities. Clinicians look after patients episodically; one person, condition or group of patients at a time, so they too are not a ready solution to integration (Hakek 2013). Aged care and social care workforces face systemic problems including staffing shortages, rigid routines and inadequate skill-mix that hinder care delivery (Ludlow et al. 2020a). This is not to say these professional groups do not have an important role to play in care coordination, but rather the fragmented and siloed nature of formal care systems impede professionals’ capacity to integrate care for older adults.

Turning the care system on its head, service users (i.e., patients, aged care clients or residents) may be better placed to ensure integration. This often requires a personal capacity that may not be available, especially for older people and those living with chronic conditions, functional limitations or diminished resources. Who looks after and integrates the care of those who have many needs, but less capacity to manage their condition or circumstances? The answer, resoundingly, is family members, who disproportionately do the work of looking after people in these categories.

## The role of family members in caregiving and care integration

Family members ‘bridge the gaps’ in care when older person’s care needs are unmet (Ludlow et al. 2020b; Puurveen et al. 2018). Bookman and Harrington (2007) referred to family caregivers as the ‘shadow workforce’, providing care in the home, healthcare institutions and the community, whilst being untrained, unpaid, and unrecognised members of the care workforce. They interviewed 50 US family caregivers, two-thirds of whom were women. Families spoke about inadequate coordination and

communication within and across healthcare institutions, a lack of continuity of care, a disconnect between community services, problems accessing information, and the difficulties dealing with the complexity of different systems. In a system described as “*uncoordinated, fragmented, bureaucratic, and often depersonalised*” (p. 1011), caregivers coordinated care, ensuring that their loved ones did not fall through the cracks. They did this by occupying various roles:

- Case manager: coordinating care and managing relationships across siloed providers;
- Patient advocate: arguing for and supporting patients when necessary care was not provided or when quality was poor;
- Medical record keeper: documenting and conveying important medical information and personal histories; and
- Paramedic: providing medical and personal care, monitoring diets and nutritional intake, and managing medications.

In related work, Wong-Cornall et al. (2017) conducted interviews with 13 family caregivers in New Zealand, the majority of whom were Maori women caring for older family members. Caregivers were found to promote continuity of care in three key ways: extending chronic care into the home through engagement and relationship building across a range of healthcare professionals, facilitating the transfer of information between providers, and managing care consistently and flexibly. Both Bookman and Harrington (2007) and Wong-Cornall et al. (2017) discussed a lack of acknowledgement from healthcare services and policymakers regarding the pivotal role family play in the care of older persons. They called for updated policy to better support caregivers, and a greater recognition of family caregivers as “*partners in an integrated model of care*” (Wong-Cornall et al 2017, p. 2).

## The gender imbalance in caregiving and other unpaid work

Global evidence shows that women do the majority of unpaid work in society, including caregiving (Ferrant & Thim 2019; International Labour Organization 2019). In England, Anne Oakley’s pioneering studies of domestic labour found that few men in heterosexual partnerships contributed to housework (Oakley 1974). Subsequent surveys have confirmed that these gender imbalances in domestic labour persist (Adjei & Brand 2018; Allan & Crow 2001). In the workplace there is ample global evidence that women are more likely to ‘put their work life on hold’ to raise children, and care for relatives, friends and neighbours (Boniol et al. 2019; PwC 2019; United Nations General Assembly 2019). Compared to men, they forgo promotions to a greater extent, need to take greater leave of absences, and ask for flexibility with work arrangements more frequently.

For 40 years, researchers have written about the ‘sandwich generation’ (Miller 1981), and the ‘women in the middle’ phenomenon (Boyd & Treas 1989) to describe how women bear most of the responsibility for the generation above them and the generation below. This literature (see also Bridges & Lynam 1993; Chisholm 1999; DeRigne & Ferrante 2012; Do et al. 2014; Doress-Worters 1994; Evans et al. 2016, 2019; Gillett & Crisp 2017; Huvent-Grelle et al., 2015; Raphael & Schlesinger 1994; Riley & Bowen 2005; Solberg et al. 2014; Steiner & Fletcher, 2017; Stephens, Franks & Townsend 1994) points out that women in their mid-years do more than their share of looking after ageing parents and children, regardless of family composition or living arrangement. Metaphors such as *juggling all the balls*, *herding cats*, and *being on a hamster wheel* are often used.

In seminal, highly cited work, Montgomery, Gonyea and Hooyman (Hooyman & Gonyea 1995, 1999; Montgomery et al. 1985) developed and articulated a feminist perspective on family care. They saw caring as a feminist issue, reinforced the fact that women were primary caregivers of older adults and children, noted the social context of caregiving, and critiqued long-term care policy. They did this at a time of markedly changing trends in the workforce, policy and population demographics. Against the context of the 1980s and 1990s and the rise of dual-income families, women were much more likely to be working and studying compared to past eras, while simultaneously caregiving and running the family home.

In Australia, 2018, females made up 71.8% of unpaid primary carers of older adults or people with a disability (Australian Bureau of Statistics 2019) and in the UK, 59% of people caring for a parent or older relative are women (Petrie & Kirkup 2018). Close female relatives, typically daughters, are disproportionately likely to be primary caregivers of older people (Grigoryeva 2017; Patterson & Margolis 2019; Szinovacz & Davey 2013), and so we focus here on the daughter's role as integrator-in-chief of care. Specifically, this chapter examines and contrasts how the care integration role of 'dutiful daughters' is reflected in policy and experienced in practice. We use the term 'dutiful' as recognition that the act of caregiving is often undertaken out of necessity (because of gaps in formal care) or expectation (societal norms). Care organisation can be challenging in a complex political context, due in part to multiple and competing narratives and the co-existence of a variety of mechanisms of governance, each influencing care in multiple and sometimes contradictory ways. Our chapter demonstrates significant tensions between policymakers' vision for integrated care and the actions of family members in integrating care for older adults. We reveal disparities in how unpaid carers and caring are valued, considered and understood at the sharp- and blunt-ends of care systems.

## Methods

Policy documents were sourced from Government websites in 2019 to understand how policymakers framed integration as a solution to fragmented care systems, and how they considered the role of unpaid carers and families in care integration. Selected policy documents included the more recent plans and strategies from each country; England's Five Year Forward View (NHS 2014), Next Steps on the NHS Five Year Forward View (NHS 2017), The NHS Long Term Plan (NHS 2019a) and Australia's Long Term National Health Plan (Australian Government, Department of Health 2019a). We also included national policy focused on integrated care (Australian Government, Department of Health 2019b; Health and Social Care Committee, House of Commons 2018; NHS 2019b, 2019c; Productivity Commission 2017). As each Australian State and Territory has its own Department of Health with responsibility for governing public health systems, we also included the most recent plans and strategies from each State and Territory as well as documents targeting integrated care (ACT Health 2018; Australian Government, Department of Health, 2019c; Government of South Australia 2017; Government of Western Australia, Department of Health 2015; Northern Territory Government 2018; NSW Health 2014, 2016, 2018; Queensland Government, The Department of Health 2019; Safer Care Victoria 2018; Victorian Government 2016). These policy documents are not exhaustive but were purposively selected to represent current strategic plans and targeted integrated care policy.

Automated content analysis was performed on the policy documents using Leximancer 4.5 (Smith & Humphreys 2006) to mine the text (of Australian and English documents separately) and create concept maps representing prominent concepts (smaller dots, or nodes), themes (larger circles) and their connections (lines between the nodes). Names of organisations, people and countries, function words

such as “the” and “it”, and numbers were excluded from the analysis. While Leximancer summarises the core components of a body of text, it does not provide context or nuanced meaning (e.g., negative and positive connotations). We therefore scrutinised the documents to understand how family, specifically daughters, were (or were not) implicated in integrated care policy or the strategic plan documents. We also looked at carer-specific policy for England and Australia to understand how these documents reflected and addressed gender in caregiving.

To explore how integrated care is experienced in practice, we examined four case accounts of informal care provided by daughters. These cases are illustrative, highlighting the kinds of work done, on the frontline, to integrate care. Two of the accounts were developed by two members of the author team through their engagement in a deliberative reflective writing task using auto-ethnography methods (Ellis, Adams & Bochner 2011). Each author wrote diary entries about the care of their parents which they shared in team meetings to compare experiences and identify themes of interest. The other two accounts were developed through discussions with a convenience sample of daughters that shared their stories of caring for their parents. We reviewed these stories in team meetings to identify common threads. The stories shared similar features, centred around two prominent characteristics: multi-generational caregiving and the guilt of seeking formal care support. These accounts were developed into two ‘composite narratives’ (Willis 2019). Composite narratives acknowledge the complexities of individuals’ experiences while delivering a cohesive account of a phenomenon (Willis 2019). Names and identifying details have been changed throughout. As a team we discussed the four case accounts, focussing on the role and contribution of the daughter in each, and comparing and contrasting the reported experiences with the findings from our policy analysis. These cases provide experiential narratives of everyday care integration challenges: we recognise that they are partial, and unique, but they are each, we contend, credible and illustrative of the matters at hand.

## Results

### Policy

*How policy frames integration as a solution to fragmented systems of care*

The concept maps resulting from the Leximancer analysis of England’s and Australia’s documentation on care integration policy and strategic plans are presented as Figures 1 and 2, respectively. These maps indicate recurring concepts and themes in policymakers’ intentions for integrated care systems.

**INSERT FIGURE 1 HERE**

**INSERT FIGURE 2 HERE**

Figures 1 and 2 demonstrate considerable overlap in England’s and Australia’s policy documents. Key foci include stakeholders (e.g., patients, staff), common conditions (e.g., cancer, diabetes), care services (e.g., community, primary), the use of data (e.g., evidence), support (e.g., funding) and organisation of care (e.g., private, public, local, national). Within both countries, integration is a key concept falling under the ‘care’ theme. Family members and unpaid carers are absent in the concept maps.

#### *The consideration of unpaid carers and families in England's policy*

We were unable to identify mention of unpaid carers or families in national government documents focused on integrated care (NHS 2019b, 2019c). Instead, these policies focus on the development of organisational forms (sustainability and transformation partnerships, integrated care systems, integrated care partnerships and accountable care organisations) through which integrated services will be planned and delivered. There is little idea about how integration is to be accomplished. The contribution of families and unpaid carers to care provision is invisible in these documents. Care work outside formal services is briefly mentioned in the Health and Social Care Committee, House of Commons' (2018) report on integrated care, in relation to understanding personalised networks of support and planning integration: *"patients' interactions with healthcare services account for only a fraction of their lives. The ability of patients to manage chronic conditions themselves is therefore critical to their health and wellbeing"* (p. 9). The supporting role of unpaid carers is mentioned, but again, what it comprises remains invisible.

The need to better support unpaid carers is reflected in the NHS strategic policy plans (NHS 2014, 2017, 2019a), but the work that they do is not well specified. Once again, this renders the work invisible. These NHS documents focus on identifying who performs caring roles, so that they can be signposted to advise and support, paying attention to their health needs, educating them in the management of long-term conditions, providing help with crisis management, recognising their expertise and their carer role, and including them in planning care and partnership working. It is interesting to note that these interventions all serve to keep people in their caring role, with no alternatives on offer or an acknowledgement that unpaid carers might prefer not to care at all.

The 2014 Care Act assigns the wider responsibility of promoting unpaid carer wellbeing to local authorities, rather than providers of healthcare. Wellbeing is directed to supporting someone to continue in their caring role and may include supporting participation in activities (work, education, training, recreation) outside of their caring role. Wider carer policy such as the Carers Action Plan 2018-2020 (Department of Health and Social Care 2018) addresses the role of wider society, for instance, businesses are encouraged to offer flexible working. In all of England's documents, the gender of unpaid carers is not specified, and this omission obscures the structural gendered inequalities we highlighted earlier.

#### *The consideration of unpaid carers and families in Australia's policy*

We found no explicit reference to family members in Australia's national policies (Australian Government, Department of Health 2019a, 2019b; Productivity Commission 2017). Australian States and Territories each have a Bilateral Agreement with the Commonwealth Government on coordinated care reforms, in which integrated care is a key focus. Family members are only mentioned in the Northern Territory and Victorian documents, although details on how to involve unpaid carers in integrated care are non-existent.

At the State-level, New South Wales (NSW) and Victoria have policy documents on the topic of integrated care. The Victorian Clinical Council's Advice for Integrated Care outlines three recommendations, with no mention of the role of family members (Safer Care Victoria 2018). The NSW Health Integrated Care Strategy makes only brief mention of family members, regarding a Chronic Disease Management Program (NSW Health 2016). In comparison, the NSW Health Strategic Framework for Integrating Care considers family members throughout, for example, in its definition of integrated care, and in its vision: *"Integrating care—organized by, with, and for people, families and carers"* (NSW Health 2018, p. 8). As part of this framework, the first of four key aims is to *"improved experiences for people, families and unpaid carers"*

(NSW Health 2018, p. 5). Intended outcomes for this aim include involving family members in the co-design of care services and their involvement in decision-making and care planning.

Strategic plans for each Australian State and Territory were more likely to make reference to family members and unpaid carers than national policy (ACT Health 2018; Australian Government, Department of Health 2019b; Government of South Australia 2017; Government of Western Australia, Department of Health 2015; Northern Territory Government 2018; NSW Health 2014; Queensland Government, The Department of Health 2018; Victorian Government 2016). The strategic plans outlined the need to: engage families in care services and decision-making, consider family members' views, make health information accessible for families, and improve communication. Despite the consideration of the family in care planning, engagement and outcomes, families are consistently referenced in conjunction with other stakeholders, i.e., *"the individual and their family and carers"* (Government of Western Australia, Department of Health 2015, p. 10). Reference to family members is largely superficial with little information on how to involve unpaid carers in integrated care. Moreover, the role of family and unpaid carers as integrators of care, and their unpaid work, is not acknowledged in any of the documents.

Turning to carer-specific Federal policies and reports, the National Carer Recognition Act (2010) aims to *"increase recognition and awareness of carers and to acknowledge the valuable contribution they make to society"* (Australian Government 2016, p. 2). Carers are those who provide personal care, support and assistance to other individuals, including people who are "frail and aged", outside contracted or formal volunteer work. The Act states that *"carers should be considered as partners with other care providers"* (Australian Government 2016, p. 3). The Australian Royal Commission into Aged Care Quality and Safety's recent background paper, Carers of Older Australians (Commonwealth of Australia 2019) details the role of unpaid family caregivers; the diversity of carers; support services for carers; the rewards of caregiving (e.g., strengthening relationships and development of new skills); and the detrimental effects of caregiving (e.g., lower social wellbeing, depression/anxiety, deterioration of health, financial strain, and loss of income). Australia's national carer-specific policy largely fails to acknowledge the gender imbalance of unpaid family carers. Of the documents cited, only the Royal Commission's background paper recognises the fact that the majority of unpaid carers are women, particularly daughters.

### Case accounts

Overall, the policy documents from England and Australia reflect 'work-as-imagined' (Hollnagel 2015). If things went well, care systems would be more integrated, care would be joined up, and service users would not fall through the cracks. However, the challenge lies with implementation, i.e., making the system work ('work-as-done'). To understand this, we turn to the lived experiences of daughters-as-carers, which we describe as 'dutiful daughters'. The following case accounts are of daughters who provide care for older parents and other family members. The first two are English cases, the second two, Australian. These cases serve as illustrations, drawn from experience, of the implementation challenges.

#### *Case account 1: The mobilization of my mother (UK)*

Mum (80 years) needed to see a dentist (May 2019). She had moved to Brighton a few years ago but had kept her dentist in Guildford, and travelled up there by train for appointments. After a stroke (2017), she moved into a care home and could not travel independently so had not seen the dentist. I sent an email

to her friends in Guildford to see who might be able to help with transport. A couple of friends rang Mum and offered help. They hatched a plan. Anna (50 years) was going to drive to Brighton, pick up Mum, drive her to Guildford, take Mum to the dentist and then take her to Maureen's house. Maureen (71 years) cared for her husband before she died so had a bed downstairs that Mum could sleep in. Mum planned to stay there a few days then get a lift back to Brighton.

I saw a number of problems with the plan. Mum had underestimated her physical support needs and it was very unlikely that Maureen was going to be able to care for her without injury to one or both of them, for example, getting her in and out of a domestic bed. I knew Mum could get in and out of a car but is in a lot of pain and tires very easy, so I wasn't sure if she could tolerate the journey. Also, no one had thought to check if the dental surgery had steps leading up to it and so Mum might get there and not be able to get in the building. There had been no thought given to her complicated medication regimen and Mum had not discussed her plans with the care home.

I had to undo the plan—and felt horrible about it. It was hard to discuss this in advance with Mum because of the mismatch between what is possible and what she believes is possible. I raised concerns about feasibility and she scoffed at them. I talked to the care home's lead nurse, Lucy, who agreed with my concerns and that her telling Mum "no" would hold more weight than my doing so. I contacted the friends who had agreed to help and I explained that the plan would not go ahead. I cancelled the dentist's appointment.

That closed the door to one problem and opened another. I still needed to work out how Mum could get to see a dentist and also, was there a way to still get her to Guildford? Clearly she had been looking forward to being back there again and seeing her old friends. I didn't know why the care home didn't have dental health as part of its remit, but it seemed to be something that wouldn't otherwise get sorted out. Once I had found a dentist, made an appointment and got the registration forms, the home arranged her appointment.

#### *Case account 2: On creams and responsibility (UK)*

Dad (80+ years) has an itchy back and has been scratching. There is dried blood under his fingernails as evidence of his successful scraping of the areas he can reach. After a phone call to the GP, and a complicated excursion to see a dermatologist, he is prescribed some cream to treat the rash. The rash is un-named and ill-diagnosed, but we have established a medical solution. The instructions are that the cream should be liberally applied four times a day and ideally "allowed to soak in" before covering.

Dad sits in an upholstered armchair for 14-16 hours a day, mobilising very occasionally to toilet. He eats, sleeps, and watches TV from the chair, wrapped in a dressing gown and a blanket because, having lost considerable weight over recent years, he constantly feels cold. The central heating thermostat is turned up to the maximum even in summer, so the environment is not conducive to skin cooling at the best of times. However, there is a more pressing and insurmountable problem. Who will apply the cream? The carers from the social care agency say they are not allowed to touch the cream because it is prescribed medicine. This makes it a healthcare intervention. They are responsible for meals and personal care (washing and dressing), but this expansion of their duties is a step too far. Taking them at their word, I relay this to the GP, and suggest that the District Nurse team may need to step in.

After three phone calls to different parts of the care system, the answer comes: The District Nurses "do not apply creams". We are at an impasse. I send another ever-despairing email to the GP stating the facts:



Cream has been prescribed. The itch persists. No one can apply the remedy. She sends one of her usual empathetic and shocked responses, copying in the relevant members of the health and social care team and this produces a care miracle. The agency carers will, prompted by the GP, apply the cream. Whether they will do this on their often-perfunctory visits remains to be seen, but this feels like a victory. After all, Dad has been scratching his back for about eight weeks.

*Case account 3: Will the guilt ever ease? (Australia)*

Over the years, Jen (60 years) has held many caregiving roles: mother, aunt, wife and grandmother. The most difficult caregiving role that she has faced has been that of daughter. When Jen's mum Elizabeth was 68 years old she lost her husband. Widowed and lonely, she moved into the granny flat on Jen's property. For the first ten years of living with her daughter, Elizabeth was very independent. That eleventh year, over the space of a couple of months, things started to change. Cooking became too much of an effort for Elizabeth, so Jen prepared her meals for her. The vacuuming hurt Elizabeth's back, so Jen took on this job. Shopping was tiring for Elizabeth, so Jen added this to her list of errands. Within six months, Elizabeth was dependent on Jen for most of her domestic care. Looking back, Jen sees that these changes were the early signs of her mother's dementia, however, at the time, Elizabeth's diminishing ability to care for herself was put down to tiredness as a result of ageing.

Fast forward three more years and Elizabeth and Jen were living with Elizabeth's diagnosis of dementia. Elizabeth could no longer complete simple everyday tasks, she was often confused, and she relied heavily on Jen. Elizabeth needed Jen to drive her to all of her doctors' appointments, requiring Jen to leave work early or take an extended lunch break. During these appointments, Elizabeth often had no idea why she was visiting the doctor and when she was reminded, she played down her symptoms. Jen became her mother's advocate; explaining the reality of Elizabeth's health conditions, which was often not in line with how Elizabeth perceived her ailments. Jen would ask the doctors questions on behalf of her mum and would need to re-explain to Elizabeth what the doctor was saying. Without Jen's input, Elizabeth would not have received the medical care she needed. Jen was struggling to manage full time work, care for her mother, and look after her grandson.

For two more years, Jen agonised about putting her mother into a care home. On the days where it all got too much and she revisited the idea of nursing home care, she kept telling herself, "it's not time yet" or "I can handle it". Eventually the day came when Elizabeth started living in a formal care home, a day that broke Jen's heart. The guilt was overwhelming; she felt as though she had failed her mother. Although Elizabeth never said anything to Jen about it, Jen could sense the resentment burning inside her mother when visiting her. Not matter how many times her co-workers, friends and family reassured her that she had made the right decision, she asked herself—had she put her mum into care too early? Couldn't she have held out a little longer? She wondered: will the guilt ever ease?

*Case account 4: Multigenerational caregiving (Australia)*

Helen (56 years) lives with her husband, Cam, one of her three adult children, Jessie, her four-year-old grandson, Brydon, and her mother-in-law Adelita. Brydon was born when Jessie was 19 years old. Helen took leave from her job as an accountant in order to help care for Brydon. This was supposed to be a temporarily leave of absence, however, Helen decided she couldn't go back to work until Brydon started school. She is helping raise Brydon; looking after him on weekdays so that Jessie can finish her university degree.

Helen's mother-in-law, Adelita, has arthritis which limits her ability to venture out on her own. Throughout the week, Helen runs errands for her mother-in-law, including picking up her prescription medication and buying groceries. She drives Adelita to all of her physiotherapy and doctors' appointments—on average, twice a week with her various health problems. Adelita was born in Spain and although her English is good, it is her second language. Helen needs to sit in on Adelita's appointments to help facilitate conversations between Adelita and the doctor.

Last year, Helen's father, Richard, was diagnosed with dementia which has progressed quicker than anyone was expecting. Her mother, Anne, has taken on the role of primary caregiver for Richard, who now needs daily care. Helen has taken on yet another caring role—looking after her mother. As Anne's time is consumed by looking after Richard, she neglects herself. Helen has to remind her mother to look after her own health. She also provides emotional support to Anne; speaking with her on the phone twice a day and visiting her most afternoons. Anne doesn't drive and since Richard's driver's license was cancelled, the responsibility fell on Helen to fill this role.

Helen has always prided herself in being the glue that holds her household, and her family, together. Lately though, she feels as if she is unravelling. With the extra duties of caring for her own parents, she has been feeling extremely overwhelmed with life. She stays awake most nights thinking about the tasks that lay ahead in the upcoming days, worrying about each of her loved ones. Recently she visited her doctor who prescribed medication to help with her sleep troubles. Helen is finding that every day feels like a struggle—there is no down-time, no chance of a holiday, no relief, and absolutely no time to get sick. If Helen isn't there to look after everyone, to coordinate everyone's lives, to support her family, then who will?

#### *The experiences and contributions of daughters across case accounts*

Viewed together, the case accounts of daughters' experiences highlight the vital role that daughters play in coordinating care for older family members. Daughters are at the front-line, keeping older people healthy and living well. They are averting the disasters that would likely occur if the only support on offer was provided by fragmented formal care systems. In these narratives, the peripheral role that formal agencies play in maintaining health and wellbeing of each older person is striking. Without integration work by daughters, the care on offer would not fully meet the needs of the individual older person. Daughters do this work in addition to carrying out the paid and unpaid work of their other roles and responsibilities in life. Echoing the findings from the research studies we presented earlier in this chapter, daughters were found to organise care across siloed services, advocate for older adults' needs, provide domestic services and emotionally support their parents. The role of caregiving was found to have negative effects on emotional, mental and physical wellbeing of daughters, resulting in stress, frustration, sleeping problems, and feelings of immense guilt. This finding aligns with the Australian Royal Commission into Aged Care Quality and Safety's background paper on Carers of Older Australians (Commonwealth of Australia 2019).

#### Concluding comments

Rosalyn Carter, former first lady of the United States of America, said *"There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver"*. We think she mostly meant women.

This chapter set out to examine and contrast how care integration is imagined in policy and experienced in practice. We found a wealth of policy that asserts the need for care to be integrated and that sets out high-level visions for care systems and associated organisational forms to enable this to happen. For the most part however, we found that written policy neglects the role of family caregivers as integrators of care, and in particular the gender imbalance in caregiving. In a select number of documents, recommendations were put forward that unpaid carers should be identified, supported, and their caring role preserved, however, minimal detail was provided on how to achieve this. Our findings highlight the need for policymakers, managers, leaders and dutiful daughters to work cohesively to create integrated care for older adults on an ongoing basis.

The unpaid work that women do to integrate care is largely invisible, highlighting inadequacies of formal models of integrated care set out in current health, social and aged care policy. To formally acknowledge this silent workforce potentially shatters assumptions that women are, and will continue, to be ‘naturally’ caring and responsible for the welfare of others at any cost. In our case accounts, daughters were often unsupported in their attempts to integrate care (although other family members sometimes helped with care tasks). Reflecting on the stress of the family carer role, Bartlett and Brannelly note:

*“Caring for and about a person with dementia who lives at home is a shared responsibility. The changing and progressive nature of the condition and the multifaceted complexities of care it entails makes a single source of support inadequate. It is like expecting a lone parent to care single-handedly for a child with multiple disabilities”* (Bartlett & Brannelly 2019, p. 116).

We echo these conclusions. If the responsibility for care and its integration is held by a single family member, these gendered patterns of work will persist. Our policy analysis suggests that the perceived responsibility of health and other care services is to support family members to continue in their caring role, and to respond and adapt to the individual circumstances in which they find themselves. In contrast, previous research and our case accounts of dutiful daughters suggest that persistent structural inequalities should be the focus of policy (and formal services’) attention. Future developments in policy and practice need to focus on who is doing the integrating and ensure that unpaid carers are offered real choice in whether or not they continue in the caring role.

Responding to a growing recognition of the social, political and economic circumstances of people’s lives in determining their health, Bridges and Lynam (1993) highlighted the contribution that front-line nurses could make to tackling the structural gender inequalities of family care for older people. We support Bridges and Lynam’s (1993) conclusions that care providers have a legitimate role in highlighting and helping to tackle some of the structural forces that underpin gender inequalities. However, a quarter of a century on, we see no evidence in policy that health and social care services are seen to have such a role.

We have shown the gap between the way care integration is imagined in policy and experienced by those providing everyday care for older people. Across both England’s and Australia’s policy documents, there was a lack of recognition or consideration for the unpaid work family caregivers, particularly daughters, do to coordinate and integrate care for family members. Policy provides minimal detail on how to support these caregivers in their roles, nor does it advocate for alternative care arrangements to reduce the burden experienced by family caregivers. Previous research, and the four illustrative case accounts of dutiful daughters we examined, highlight the magnitude of unpaid, invisible work women do to care for their parents, parents-in-law, children and grandchildren, often simultaneously, while also undertaking paid work. Comparing this to our analysis of policy documents, we reveal the disconnect between how

policymakers recommend integrated care *should* be achieved, and how dutiful daughters (and other family carers) struggle to *actually* achieve integration on the front-lines of care.

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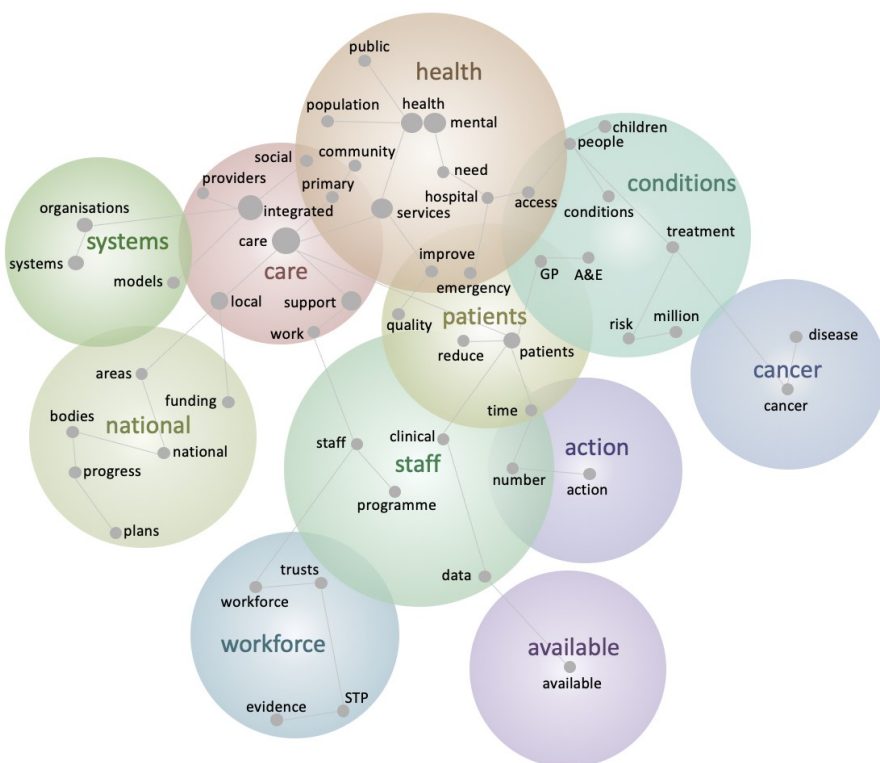


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## Figures

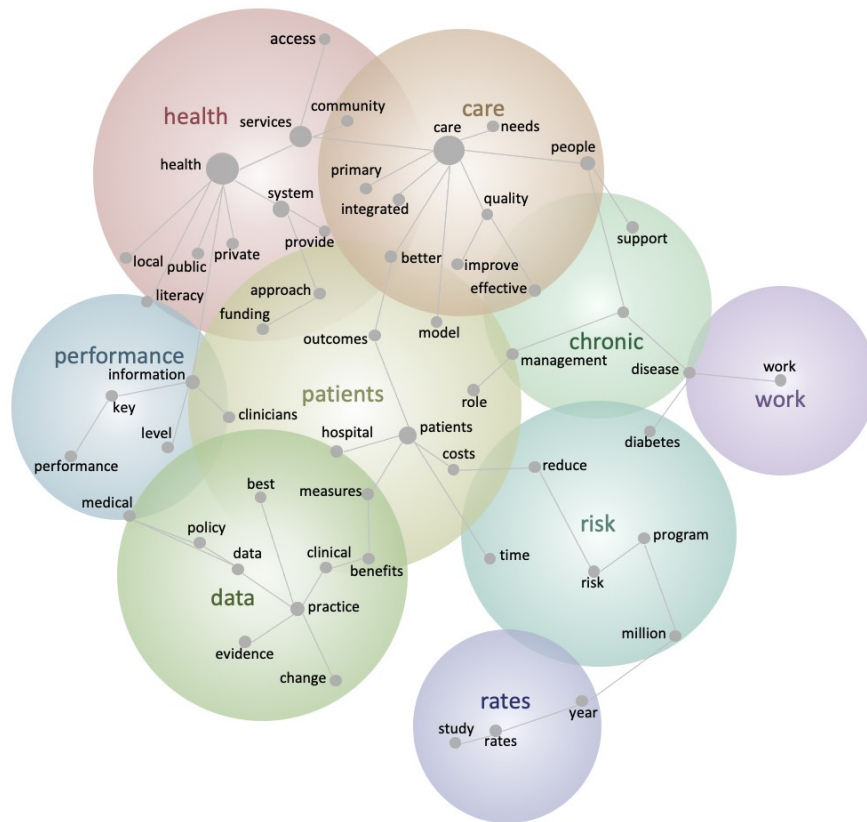
Figure 1 England's policy documentation



Source: Authors' conceptualization, developed using Leximancer (Smith & Humphreys 2006).

Note: A&E = Accident and Emergency; GP = General Practitioner; STP = Sustainability and Transformation

Figure 2 Australia's policy documentation



Source: Authors' conceptualization, developed using Leximancer (Smith & Humphreys 2006).

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