Considerations regarding Incorporating a Cash-for-care Program in Ontario's Approach to Care for Older Adults

by

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Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

Ontario, like Canada more generally, has an aging population, which will exert further pressures on the approaches to providing care to older persons. Certain of these pressures are outlined, with the aid of population projections. Many developed countries, most of which have aging populations, have adopted various approaches to care provision for older adults, which differ from Ontario's approach in certain ways. Ariaans et al. (2021) developed a typology based on the approaches used in 25 OECD countries but did not include Canada or Ontario in the analysis. This thesis analyzes the care approach used in Ontario along the dimensions developed by Ariaans et al. (2021) to place it within the typology used by Ariaans et al. (2021). A measure used by Ariaans et al. (2021) is whether a cash-for-care program is included. Ontario's approach does not incorporate a cash-for-care program, whereas some other countries' approaches do include a cash-for-care program. A scoping review was performed to identify and report on the benefits and disbenefits of a cash-for-care program, identified in the literature, and five themes were revealed. A form of framework analysis was used for more detailed exploration of the gender engraining aspects of cash-for-care programs. The discussion has special relevance to any proposed intervention, such as introduction of a cash-for-care program, because women play a disproportionately large role as carers, both paid and unpaid, and as care recipients in long-term care homes, and may be adversely affected.

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Ethics Clearance

No primary data collection was done for this thesis, so ethics clearance was not required.

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Much of my work takes place in Etobicoke, which is part of the City of Toronto. The City of Toronto acknowledges that we are on the traditional territory of many nations including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples and is now home to many diverse First Nations, Inuit and Métis peoples.

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List of Abbreviations

ASR alone stage of retirement

C4LT care for the long term

CB_n nth Carer Benefit

CCRNC Canadian Research Network for Care in the Community

CDC Consumer-directed Care

CD_n nth Carer Disbenefit

CfC cash-for-care

CIHI Canadian Institute for Health Information

DP Direct Payment

FAO Financial Accountability Office of Ontario

IB Individual Budget

IBSEN Individual Budgets Evaluation Network

ILO International Labour Organization

IRPP Institute for Research on Public Policy

LTC long-term care

NIA National Institute on Ageing

NSW New South Wales

OECD Organization for Economic and Cooperative Development

PB Personal Budgets

PSWs Personal Support Worker(s)

RB_n nth Recipient Benefit

RCT Randomized Controlled Trial

RD_n nth Recipient Disbenefit

SB_n nth State Benefit

SD_n nth State Disbenefit

SHARE Survey of Health, Ageing and Retirement in Europe

StatsCan Statistics Canada

UK United Kingdom

US United States (of America)

Chapter 1 Thesis Overview

This thesis places Ontario's approach to care provision for older adults within a cluster in the six-cluster typology developed by Ariaans et al. (2021). From a scoping literature review, it lists the benefits and disbenefits of a cash-for-care (CfC) program. It describes how implementation of a CfC program could be gender engraining for women. It sets the discussion in the context of population aging, which does, and will continue to, have implications for care provision.

1.1 Background on long-term care (LTC) in Canada

Estabrooks et al. (2020) state the problem clearly: "Canada has failed to confront present and future financing of LTC" (Estabrooks et al., 2020, p.12) and "Canada has systematically failed to deal with the consequences of population trends in aging, dementia prevalence and fewer family caregivers for older adults" (Estabrooks et al. 2020, p.15). These statements are applicable to Ontario as well as Canada. Ontario depends to a significant extent on the federal government for financing. Systemic failure to provide care for older adults was revealed by the horrific consequences for older persons during the early stages of the global pandemic, which some would consider systematic failure (Estabrooks et al., 2020).

The appalling number of deaths in LTC homes in Canada during the first waves of the pandemic, highest proportionately among OECD comparators (CIHI, 2020) drew the attention of the public, the federal and provincial governments, including Ontario (Marrocco et al., 2021), and the military (Mialkowski, 2020), and raised concern regarding the safety of such homes. Lengthy waiting lists for admission to LTC homes (FAO, 2021) indicate that there is a mismatch between care demand and care capacity. In 2022, Ontario passed legislation to permit the transfer of LTC wait-listed individuals or those in hospital deemed suitable for LTC placement to LTC homes not selected by the individual or family and not necessarily close to their area of residence. In lieu of transfer, the individuals could be invoiced a daily fee exceeding what would be paid in a LTC home. This suggests that there are systemic failures in Ontario's approach to care for older adults, to which the politicians do not see a simple solution.

There is a sense that the public is also conflicted regarding how the problem should be addressed. The many deaths in LTC homes during the early waves of the pandemic apparently had little impact on the results of the 2022 elections in Ontario and Quebec. In both provinces, governments incumbent when the pandemic was declared were re-elected with increased majorities. Yet a survey by the National Institute on Ageing (NIA, 2021) found that only 26% or 1 in 4 Canadians thought that LTC homes in Canada were safe and upheld good standards for quality before the pandemic, and that only 13% of those 65 and older believed this to be true. Approximately 97% of people in Ontario and 98% of people in Quebec aged 65 and over state that they would do everything they possibly could to avoid entering LTC in their respective provinces (NIA, 2021) and 85% of all respondents would prefer to stay in their own homes for as long as they could (NIA 2021).

In 2019, before the pandemic, MacDonald et al. (2019) prepared a report projecting the future cost of LTC. They state, "between 2019 and 2050, our baseline projection indicates the

cost of public care in nursing homes and private homes will more than triple" (MacDonald et al. 2019, p.07) and "pressure on unpaid care provided by families will also increase ... by 2050, there will be approximately 120% more older adults using home care support ... our projections indicate there will be approximately 30% fewer close family members ... who would potentially be available to provide unpaid care" (MacDonald et al. (2019, p.07). They continue "The greater challenge, however, could well be increased pressure on Canadians who are providing unpaid care. The emotional, physical and financial stress reported by unpaid caregivers carries a cost... and our projections show the pressures will increase "(MacDonald et al. 2019, p.07), and that was before the emotional, physical, and financial stress of a global pandemic were contemplated.

Given the two areas of neglect mentioned in the quotations from Estabrooks et al. (2020), regarding financing and the consequences of population aging, it would require considerable optimism to believe that Ontario's approach to care for older adults will shortly address both those areas fully. Although Ontario's Ministry of Long-Term Care has announced significant increases in spending to provide additional LTC beds and increased labour hours with better compensation, a review of these plans by the Financial Accountability Office of Ontario (FAO) raises concerns that the number of LTC beds per 1,000 Ontarians aged 75 or older will reach its lowest level by fiscal 2029-2030 (FAO 2021, Figure 3-6, p.16). The projections in MacDonald et al. (2019) point to the magnitude of the challenges.

Wittenberg (2016) stated that there are three forms of care to be distinguished: unpaid care, publicly funded care, and privately purchased care services, which appears to distinguish care forms based on financing considerations. It seems more likely that the three forms of care listed by Wittenberg (2016) will be tried in different combinations, without fully acknowledging and addressing the two areas of neglect stated by Estabrooks et al. (2020). In this regard, cashfor-care (CfC) programs, of varying designs, are included in the care approaches of a number of OECD countries, and might be considered as a policy option for Ontario. Da Roit et al. (2016, p. 144) state that CfC programs "entail the provision of monetary transfers that enable recipients to receive care either through the purchase of services or the compensation of informal caregivers". Such programs "have various names and forms, including direct payments, care allowances, attendance allowances, individual budgets, personal budgets or self-directed care" (Da Roit et al. 2016, p. 144)¹. They may be useful in cost-containment, e.g., if they create a mechanism for greater "competition between care providers" or "the use of less expensive forms of care" (Da Roit et al. 2016, p. 160). In Chapter 3, the results of a scoping review performed to identify the

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¹ This footnote provides some examples of differences in the design of CfC programs. It is intended to provide information and does not purport to be a comprehensive list. All CfC programs, of which I am aware, provide a lower cash amount than the equivalent value of comparable care services delivered by the state or funded by the state and delivered privately. The determination of how much less than comparable in-kind care services is to be provided is not known. CfC programs may limit the carers to whom CfC payments may be made, e.g., France does not permit a payment to the spouse, and in England, programs typically do not permit payments to relatives living in the same household. The types of services for which CfC payments may be used may also be restricted, e.g., an approved schedule, frequently the case in England, or a broad range including domestic services. Oversight of the CfC payments may take differing forms. Columbo et al. (2011) suggest that France's CfC program is a model in this regard, in which CfC payments are written on an account that might be considered a state bank account, and so payees and payments can be tracked readily by the state,

benefits and disbenefits of CfC programs and considerations regarding incorporating CfC within Ontario's approach, are presented.

Women make an important contribution to the functioning of the care system, both through paid formal labour and unpaid care provision. Women in Canada spend an average of 3.0 hours per day on unpaid household care work, including caring for children or adult family members, chores, and other household duties, and men spend 2.4 hours per day doing the same tasks (Houle et al., 2017). Women are overrepresented in Canada's care economy, comprising 80% of workers in health occupations (Statistics Canada, 2019), which includes 90% of nurses, 75% of respiratory therapists, 80% of medical lab workers, and 90% of Personal Support Workers (PSWs) - who work in LTC homes and as a home care worker (Statistics Canada, 2016). Women also represent a significant proportion of care recipients. Women as a group live longer than men, and in Ontario LTC homes, more than 70% of residents are women (Luna, 2020). In discussing considerations regarding incorporating CfC benefits, it is important to give attention to the implications for women as care givers and care providers, as well as for care recipients.

1.2 Terminology and numbering

Care provision in Canada is a complex subject. There is not a single level of government that bears the full responsibility. Part of the reason for this is that care provision may combine elements of health care and social care. To the extent that the care is medically necessary health care, provincial and territorial governments are responsible for its provision. Nonetheless, the governments of the provinces and territories rely on funding from the federal government to help in financing health care, and the federal government may impose conditions to receive or remain eligible to receive funds, or on how the funds may be used. Moreover, there are areas of health care, which have not been deemed medically necessary, which some citizens may feel are necessary to their health or social well-being, and should be covered.

How a country or province provides support for and access to the mix of care forms identified by Wittenberg (2016) can differ greatly. Moreover, individuals' circumstances may differ, rendering some care forms unavailable.

To try to improve clarity, I have used the following terminology in this thesis. A country's or province's approach to care provision for older adults, will include care of all levels of intensity, whether provided with or without charge, and regardless of the setting in which it is delivered. It includes the three forms of care distinguished by Wittenberg (2016). Typology is discussed in Chapter 2 and refers to a method of classifying approaches used to deliver care. In Chapter 2 I used the six-cluster typology developed by Ariaans et al. (2021) to classify Ontario's approach to care provision for older adults, i.e., determine what type it is. I use system of care provision for older adults to refer to publicly financed care provision, i.e., what Wittenberg (2016) refers to as publicly funded care.

The system is a component of the approach. This use of the term is not consistent with how it is used by Ariaans et al. (2021), who appear to use the term system in the manner in which I have used the term approach. This proposed use of terms may seem a bit awkward, but it

serves a purpose. It provides a reminder of the broad ways in which care is delivered that are formal and informal, i.e., the approach, as well as the narrow ways in which we may think about care as being about the publicly financed component, concerning which financial data or information is more easily accessible, i.e., the system.

In Ontario, publicly financed care for older adults is provided mainly in LTC homes, to a lesser extent in institutions such as hospitals, and to some extent in home and community settings. It is difficult to obtain an exact breakdown of spending in the various areas. Government of Ontario (n.d.b) shows an estimate for total operating expense for fiscal year 2021-2022 of \$6.4 billion in respect of LTC. Government of Ontario (n.d.a) shows an estimate for fiscal 2021-2022 for Home and Community Support Services of \$3.3 billion, not all of which would relate to care for older adults. To provide a comparative perspective Ontario's projected spending on all programs in fiscal 2021-2022 is \$174 billion (Bethlenfalvy 2022, p. 165).

In thinking about providing care to older adults, it is important that the entire approach delivers services of adequate quality to those requiring them, on a timely basis, through accessible facilities, in a dignified manner, on a basis judged to be affordable, regardless of how the approach is financed. I refer to such care as "care for the long term", abbreviated as C4LT. More commonly, such care is referred to as long-term care, which may create confusion because LTC is used differently by different entities, and in some usages, may imply a more limited context or range of services. Where a narrower range is used in this thesis, it is specified. However, the broad definition of C4LT, has been used as well, on occasion, by other researchers, e.g., MacDonald et al. (2019) use the National Institute on Ageing (NIA) definition of LTC,

"Long-term care is the range of preventive and responsive care and supports, primarily for older adults, that may include assistance with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) provided by either not-for-profit and for-profit providers, or unpaid caregivers in settings that are not location specific and thus include designated buildings, or in home and community-based settings" (MacDonald et al., 2019, p.10).

Similarly, according to Columbo et al. (2011),

"Long-term care is the care for people needing support in many facets of living over a prolonged period of time. Typically, this refers to help with so-called activities of daily living (ADL), such as bathing, dressing, and getting in and out of bed, which are often performed by family, friends and lower-skilled caregivers or nurses." (Columbo et al., 2011, p. 37).

Because this thesis is concerned with considerations regarding benefits of CfC benefits, the use of the term "benefits" has the potential to be confusing. Da Roit et al. (2016) referred to both CfC programmes and CfC schemes, but did not explain how to differentiate between the two. To avoid using "schemes", which seems to convey different shades of meanings for English-speakers in Canada and North America than it does for English-speakers in England and the European continent, I have used the expression "cash-for-care programs", frequently abbreviated as CfC programs.

The discussion in some parts of this thesis is nuanced and complex. To try to provide clarity, sections and parts of sections are numbered as follows: $n_1.n_2.n_3.n_4$, where all n_i are positive integers, and n_1 refers to the chapter number, n_2 refers to a major section within a chapter, n_3 refers to a subsection within a major section, and n_4 refers to a division within a subsection. Numbers to the right of n_1 are only used when there are corresponding sections or parts thereof.

1.3 Thesis overview

1.3.1 Research agenda

For more than two decades I have been considering ways in which population aging will impact programs that comprise the social safety net, globally but primarily with respect to Canada. A few works are listed to provide a sense of the breadth of this research. Andrews (2007) assessed alternative methods of financing the Canadian health care system in view of population aging. My doctoral thesis (Andrews, 2008) examined the use of automatic balancing mechanisms within social security systems in four countries to provide sustainability and equity. Andrews (2014b) mapped the adequacy of care and support for the elderly in six developed countries. As well as the impact of population aging on social-safety-net programs, particular attention has been directed to the conditions faced by older women, especially those living in the alone stage of retirement (ASR), e.g., Curtis & Andrews (2020).

This thesis contributes to this research agenda in a number of ways. It situates Ontario's approach to care provision for older adults within the six-cluster typology of Ariaans et al. (2021), which may provide a better understanding of the context in which Ontario will make policy decisions, and the type of policy decisions, which Ontario would prefer or will be inclined, to make. A policy tool used by some countries, but not yet part of Ontario's approach is a CfC program. This thesis lists the benefits and disbenefits of CfC programs based on a scoping literature review. The thesis also examines how the implementation of CfC programs may be gender engraining for women. By reviewing and analyzing population projections for Ontario through 2043, the thesis shows that the population is projected to continue to age, and aging is projected to accelerate within certain older age groups. As such, the thesis provides a framework in which to understand how demographic pressures are likely to impact Ontario's approach to care, and how Ontario's policy responses regarding care are likely to unfold.

1.3.2 Outline

In the next subsection, the research questions investigated in this thesis are stated, accompanied by a brief overview of the methods used in the thesis. More detail regarding methods is included in the chapters.

In Chapter 2, demographic statistics are presented to indicate how pressures on the approach to care provision are likely to increase over the next two decades. To gain insight on the type of policy response, with respect to care provision, which Ontario may adopt to address such pressures, Ontario's approach is placed within the typology developed by Ariaans et al. (2021). That typology includes 25 OECD countries, but not Canada because of lack of complete data. The six clusters of the typology demonstrate differences in the way countries combine

public and private provision, make available supply, and regulate access, which result in different performance outcomes (Ariaans et al., 2021).

A policy tool used by many countries, but not yet by Ontario, is a CfC program. Given its use by other countries, it seems likely that Ontario would consider the possibility of implementing a CfC program. Based on a scoping literature review, Chapter 3 lists the benefits and disbenefits of a CfC program. If Ontario were inclined to implement a CfC program, it would likely emphasize the expected benefits. Chapter 3 presents the ones likely to be emphasized in such a situation.

Women are disproportionately represented in the approach to care provision, both through caring, both paid and unpaid, and as care recipients in LTC homes. Feminist scholars, e.g., Tronto (2013), suggest that discrimination towards women is a significant contributor to this situation. Accordingly, any policy intervention, such as implementation of a CfC program, which could be gender engraining, requires cautious consideration. Chapter 4 presents evidence from the literature regarding how a CfC program could be gender engraining. It also discusses aspects of policy design and implementation, which might help to mitigate the extent of gender engraining.

Chapter 5 summarizes the research, with respect to the research questions investigated. It discusses limitations and suggests some areas for further research.

This thesis may be somewhat unusual. It relies on publicly available information such as literature reviews and demographic projections, and does not conduct primary qualitative research. Moreover, it does not relate to an existing program in Ontario, or to one that was implemented in Ontario and that has been discontinued. Instead, it considers a future scenario with respect to a policy to implement a CfC program. In contemplating such a future, context plays an important role. Chapter 2 provides context regarding Ontario's approach to care provision in comparison to other approaches, to assist understanding regarding Ontario's preferred mix of policy options, e.g., publicly or privately delivered. Chapter 4 focuses on considerations with respect to gender engraining, because women are such an integral part of the context of provision, as currently structured. But shaping both the policy context and the gender context are pressures arising from population aging. Not only are such pressures relentless but as shown by the statistics in Chapter 2, they are accelerating. At the end of each of Chapters 2, 3, and 4, there is a section, which relates the material in the chapter to population aging. Whether an approach to provision of C4LT could meet the needs of all Ontarians is debatable, and is not considered in this thesis. But arguably, to consider whether an approach did meet the needs of Ontarians, one would consider the extent to which the approach was affordable and non discriminatory, and the care was accessible, of acceptable quality, and delivered in a way that preserved dignity. Possible interventions, such as a CFC program, would be assessed in relation to its satisfaction of such needs. Because such needs cross multiple disciplines such as health and social care, economics, finance, philosophy, political science, and actuarial science, this thesis has taken a multidisciplinary approach.

1.4 Methods overview

This section provides an overview of the methodological processes used in this thesis. Fuller details are presented in the chapters where they are used. The main research question is "what are the considerations and potential benefits regarding incorporating a cash-for-care program in Ontario's approach to care for older adults". To the best of the author's knowledge there is no proposal to implement a CfC program in Ontario. Consequently, any implementation would be in the future and the analysis is necessarily forward-looking. As such, the considerations pertain to a future care situation in Ontario. One significant occurrence that will affect the care-situation in Ontario is the aging of the population. The implementation of a CfC program has philosophic, economic, and health-care implications. As such this thesis takes a multidisciplinary approach.

The thesis takes a four-pronged approach to investigate the main research question. Because different countries take different approaches to LTC provision, with respect to items such as supply of and access to beds and services, the first prong is an analysis is to understand how the approach to care used by Ontario might be classified, in comparison to approaches used by other OECD countries. The supplementary research question for Chapter 2 is "where to place the approach to care provision for older adults currently used by Ontario, within a typology". Such a classification may provide insight regarding the nature of a CfC program, should the Ontario government decide to implement such a program. Using cluster analysis, Ariaans et al. (2021) developed a typology of LTC in OECD countries. Ariaans et al. (2021) identified nine distinct clusters, but because some clusters had only one country, they revised their analysis to produce six clusters. Canada was excluded from their analysis because of lack of data. From the information provided by Arianns et al. (2021), it is not possible to reproduce the cluster analysis. However, Ariaans et al. (2021) presented the statistical means of quantitative indicators developed from the six-cluster analysis. In Chapter 2, available Canadian data are obtained and compared to the means of the quantitative indicators, and a decision is made regarding which cluster most closely describes Ontario's approach to care for older adults. This is necessarily imprecise because as Ariaans et al. (2021) noted, complete Canadian data are not available. Ariaans et al. (2021) also used a word scale (low/medium /high) with respect to certain indicators. This descriptive terminology was also used as a check on the analysis based on comparison of quantitative information to means, and the decision reached regarding the cluster in which Ontario lies.

The second prong is to understand the benefits and disbenefits of a CfC program. Chapter 3 describes the literature review performed, following the methodology of Arksey & O'Malley (2005) for a scoping study, and incorporating some suggestions of Levac et al. (2010), and the results thereof. The supplementary research question addressed in Chapter 3 is "what benefits and disbenefits of incorporating a cash-for-care program in the approach to care provision for older adults have been identified in the literature, with primary focus on academic literature?". English-language academic literature published between January 1, 2010 and December 31, 2022 in CINAHL, PubMed, and Scopus was searched, yielding 573 articles, before removal of duplicates. Also, a limited search of grey literature was performed, which produced 1,798 items before any screening. After a screening process of the academic and grey literature identified, 44

articles were retained for analysis, regarding benefits and disbenefits of a CfC program. The analysis and process are presented in figures and tables. From a review of the benefits and disbenefits, five themes were identified and are discussed. Quantitative data were used in Chapter 2 to determine the cluster to which Ontario's approach belongs. Then the other countries within that cluster, as identified by Ariaans et al. (2021), were used to refine the literature search. As such, the methodological approach has some similarities to mixed-methods research.

Women, compared to men, provide a disproportionate share of care, both paid and unpaid, and are more likely to receive institutional care. The design and operation of LTC, and more broadly C4LT, has significant implications for women, as paid practitioners, unpaid carers, care recipients, and relatives of care recipients. The third prong examines special considerations regarding the nature of care and the way its provision is structured, which have special relevance for women. Some of the articles sourced for the scoping review in Chapter 3 contain relevant material. In order to take a systematic approach to reviewing those articles for Chapter 4, without performing another scoping review, a type of framework analysis was used. A framework consisting of five topics was developed, by reviewing a selection of 26 items from feminist scholarship, based on advice received from thesis committee members and additional hand searching. The supplementary research question for Chapter 4 is "what considerations are especially relevant to women who are care recipients or carers, regarding the implications of a cash-for-care program". The review of the articles from the scoping review in Chapter 3, supplemented by the additional 26 references used to construct the framework, resulted in 28 items for reporting and discussion in Chapter 4.

As noted, population aging will have a significant impact on many aspects pertaining to the care situation in Ontario. An older population, some of whom have progressive chronic conditions, will likely increase the demand for care, and the pool of family carers will also be aging and may become less capable of providing care. Increased care requirements will put pressure on budgets for beds and services. The analysis in Chapters 2, 3, and 4, described so far, is mainly descriptive or historical. Population aging means that policy formulation will take place in a dynamic and changing context. The fourth prong is to consider some impacts of population aging important to policy formulation regarding any potential CfC intervention. At the end of each of Chapters 2, 3, and 4, a subsection is included, which discusses "thinking about the future" in the context of population aging, and which draws on analysis presented earlier in the chapter. These subsections are conjectural and are based on possible future developments.

Chapter 2 Classifying Ontario's Approach

2.0 Introduction to typology

A typology is a method of classifying entities based on some set of characteristics. In the context of this thesis the entities are approaches to provision of LTC. A presumed benefit of creating a typology is that it helps to identify key similarities and differences among approaches, which can be helpful in understanding them, and may also be useful in considering how a specific approach may affect policy decisions. In the course of pursuing the broader research agenda referred to in Chapter 1, the research team² identified a paper written by Ariaans et al. (2021), which presents two typologies. In this chapter, Ontario's approach is classified using the six-cluster typology of Ariaans et al. (2021).

In the course of preparing the proposal, which was the precursor to this thesis, and the literature review performed in Chapter 3, four sources were reviewed that presented typologies relevant to care provision, namely Da Roit & Le Bihan (2010), Columbo et al. (2011), Campbell et al. (2016), and Le Bihan et al. (2019). These are summarized briefly for information purposes, and to provide an indication of why the use of the six-cluster typology of Ariaans et al. (2021) provides a more comprehensive treatment. Since the time of publication of the typology of Ariaans et al. (2021), two other papers of which I am aware were published regarding LTC typology, namely Fischer et al. (2022) and Suen et al. (2023). A brief summary of these papers is presented. Rather fortuitously both Da Roit & Le Bihan (2010) and Suen et al. (2023) represent their papers as systematic reviews, which comfortably bookends the time period pertaining to this thesis.

After classifying the approach of Ontario using the six-cluster typology of Ariaans et al. (2021), the chapter concludes with a section entitled "Thinking about the future", which discusses implications for policy in Ontario based on the information presented in this chapter. A similar section is included at the end of the next two chapters, which builds on the information presented in the chapter and preceding chapters.

2.1 Overview of seven papers

An overview of the seven identified papers, which discussed typologies, is presented in this section. The papers are discussed, in chronological order by publication date. They are presented as interesting information.

2.1.1 Da Roit & Le Bihan (2010)

Da Roit & Le Bihan (2010) examined CfC programs in six European countries (Austria, France, Germany, Italy, the Netherlands, and Sweden). Based on this examination, they proposed "a new typology of long-term care configurations ... based on the inclusiveness of the system, the role of cash-for-care schemes and their specific regulations, as well as the views of informal

² The research team consisted of Doug Andrews and Lori Curtis, Principal Investigators, and Karen El Hajj and Paul Stolee, Co-Investigators. The research was commissioned by the Canadian Institute of Actuaries, and has not yet been made publicly available.

care and the care work they require" (Da Roit & Le Bihan, 2010, p. 286). In this typology, there are the following three configurations.

- A persistent social service model Key characteristics include "making the plan more flexible with increasing differentiation of demand, and also more cost-effective", "care allowances are instruments through which free choice and the development of markets is introduced", "an attempt to bring care back to the family" (Da Roit & Le Bihan, 2010, p. 305).
- A LTC system based on a highly regulated CfC program Key characteristics include "development of a cash-for-care intervention that uses most of the public resources allocated to the policy towards elderly people (distinct from the health system)", "access, care management, and use of the benefit, are strictly regulated by social services", "an attempt to formalize and recognize informal care and to remove care from the family" (Da Roit & Le Bihan, 2010, p. 305).
- A LTC system based on little-regulated CfC transfers Key characteristics include "the cash-for-care system is the most important form of intervention in LTC", "limited regulatory capacity" (Da Roit & Le Bihan, 2010, p. 306).

Regardless of the configuration to which the analyzed countries belong, Da Roit & Le Bihan (2010) observed that although theoretically they are universal, i.e., providing support to all dependents regardless of income, practically they are not because of "their limited ability to cover (high) care needs, their explicit reliance on the care, organizational capacity, and monetary contributions provided by families, and their implicit reliance on an unregulated and low-quality care market" (Da Roit & Le Bihan, 2010, p. 306).

2.1.2 Columbo et al. (2011)

Columbo et al. (2011)³ have authored a lengthy book regarding LTC in OECD countries, which covered a breadth of topics such as cost, impact on family carers, public financing arrangements, and value. They discussed the multi-faceted nature of LTC systems, that systems are diverse and evolving, and presented many comparisons across multiple countries. Perhaps because of this diversity, and the range of possible comparisons, they refrained from specifying a typology. Nonetheless, in chapter 7, which focussed on the public financing arrangements, they used two criteria, which provided a way to cluster countries into three main groups (Columbo et al., 2011, p. 213). The criteria follow.

- "the scope of entitlement to long-term care benefits whether there is universal or means-tested entitlement to public funding; and
- whether LTC coverage is through a single system, or multiple benefits, services and programmes." (Columbo et al., 2011, p.215)

 The resulting clusters are as follows:
- A means-tested system
- Universal and comprehensive coverage within a single program

³ A very similar article, Columbo (2012), is occasionally cited in the literature rather than Columbo et al. (2011). For the purpose of this description the two are treated as interchangeable.

• A system with a mix.

These clusters are broad, and Colombo et al. (2011) identified a number of different approaches within the latter two clusters.

Within universal coverage within a single program, they identified the following three different approaches: tax-based models (Columbo et al., 2011, p. 220), e.g., Denmark, Norway, Sweden, and Finland; public long-term insurance models (Columbo et al., 2011, p. 220, 222), e.g., the Netherlands, Germany, Japan, Korea, and Luxembourg; personal care and nursing care through the health system (Columbo et al., 2011, p. 222), e.g., Belgium. Even though coverage is universal, there may be co-payments and maxima.

Within mixed systems, they identified the following variations: parallel universal schemes (Columbo et al., 2011, p. 224), e.g., Scotland, Italy, Czech Republic, and Poland; income related universal benefits (Columbo et al., 2011, pp. 223-225), e.g., Ireland, Australia, Austria, and France; mix of universal and means-tested (or no) benefits (Columbo et al., 2011, pp. 226-227), e.g., Greece, Switzerland, and Spain. Of particular relevance to Canada, Columbo et al. (2011) stated that many Canadian provinces fall into this later classification within mixed systems, because they provide universal coverage without charges for nursing services that are part of (required) home care but have income tests for admission to nursing care facilities, and in institutional LTC, health care services are provided without charges but accommodation charges are assessed but adjusted based on income (Columbo et al., 2011, pp. 226-227).

2.1.3 Campbell et al. (2016)

Perhaps one of the most widely discussed typologies is Esping-Andersen's three worlds of welfare capitalism, which provided a foundation for understanding the welfare state within capitalist societies. Esping-Andersen's three worlds are differentiated based on observations concerning the strength of the left (wing parties), the nature of organized labour, and the extent of commodification of the labour market within a country, and are as follows: Conservative, Liberal, and Social Democratic⁴ (Gingrich, 2015). Campbell et al. (2016) applied and extended Esping-Andersen's classification to seven countries, as follows: "Sweden in social democratic Northern Europe, Italy in familial Southern Europe, Germany in corporatist mid-continent, Australia, the US and England as quite different versions of the Anglo-Saxon 'residual' model, and Japan as the relatively new entry that shares aspects of all the other models" (Campbell et al., 2016, p. 47). They then compared these countries with respect to programs (institutional care, home and community-based care, cash allowances, administration), cost-control in LTC policy (limit access by controlling eligibility, limit access by means-testing, limit public spending and usage with higher out-of-pocket charges, modify the supply side, adjust the policy mix: cash over

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⁴ The foregoing is sufficient typological background to the discussion of the typology of Esping-Andersen. The following passage from Gingrich (2015, p. 72) provides greater general context "The Liberal world, which includes the Anglo-Saxon countries, provides meager benefits, producing little decommodification and encouraging citizens' reliance on the market. By contrast, the Social Democratic countries of Scandinavia produce ample decommodification, providing generous benefits extending across classes and crowding out market provision and empowering workers in the broader labor market. The Conservative welfare states of Continental Europe (and Japan), despite high spending, look to preserve the status of privileged groups and thus are less decommodifying."

services, adjust the policy mix: care at home over institutions, systematize LTC systems). In a subsequent chapter, Gori et al. (2016)⁵, investigated how resource allocation regarding older users of LTC in each country has changed, from the 1990s to the 2010s, which provided another dimension for comparison.

2.1.4 Le Bihan et al. (2019)

Le Bihan et al. (2019) examined how CfC programs within broader LTC policies have been used differently by countries to "envision, frame, and aim to condition informal care" (Le Bihan et al., 2019, p. 579), with specific attention to the role of family carers. The countries they examined and their placement within Esping-Andersen's terminology are as follows:

"Austria, Germany, and France represent the conservative welfare regimes. Italy and Spain are the strong familialistic variation of the conservative regime. Given the universalism and generosity of its LTC policies, the Netherlands has LTC features that resemble those of the social-democratic welfare regime. Finally, England is associated to the liberal welfare regime." (Le Bihan et al., 2019, p. 583)

This typology built on Leitner (2003), which specified four varieties of familialism, in discussing the caring function of the family. Leitner (2003, p. 358) defined familialistic policies as ones that "not only oblige (and at the same time: enable) the family to meet the care needs of its members, they also enforce the dependence of people in need of care on their family". He stated that defamilialism involves "not only taking away care responsibilities from the family" [but] "also reduces the extent to which the satisfaction of individual care needs is dependent on the individual's relation to the family" (Leitner, 2003, p. 358). The strength and explicitness of these familialistic or defamilialistic polices were used to create four varieties.

Le Bihan et al. (2019) used two criteria: extent of support for informal care (either supporting or no policy or no support), and care service policies (strong public/subsidized service development, market service development, or weak/no service development). This 2-by-3 combination provided six possible approaches labelled: optional familialism, optional familialism through the market, supported familialism, defamilialism, defamilialism through the market, and unsupported familialism (Le Bihan et al., 2019, p. 582). The first three are based on support for informal care and the last three on no policy or no support for informal carers. They illustrated how the different use of CfC programs may move a country from one approach to another; although, the move is not always in the same manner. In this regard, they concluded that "depending on the overall policy context, cash [for care] payments may entail familialization or defamilialization" (Le Bihan et al., 2019, p.593).

2.1.5 Ariaans et al. (2021)

Ariaans et al. (2021) provided a formal classification of care approaches in 25 OECD countries⁶, but did not include Canada (or Ontario) because data were missing on at least one

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⁵ Campbell et al. (2016) and Gori et al. (2016) are mainly the same group of authors, but their discussion is presented in the book in consecutive chapters. For brevity of discussion in this thesis, they have been presented under the heading Campbell et al. (2016).

⁶ The countries are listed in Chapter 3.

indicator or measure in the data source used. Ariaans et al. (2021) conducted 24 cluster analyses. Based on measures or indicators on the four dimensions of supply, public-private mix, access regulation, and performance, they used cluster analysis and suggested either a nine-cluster classification or a six-cluster classification. The nine-cluster analysis is based purely on methodology, whereas the six-cluster analysis used both methodological and content-based grounds. Although the nine-cluster classification may be more theoretically rigorous, it included clusters containing only one country. Consequently, for practical purposes, Ariaans et al. (2021) suggested using the six-cluster classification.

Ariaans et al. (2021, p. 610) stated that: supply indicators include "financial resources, staff and staffing levels, and bed intensity in institutional LTC". Public-private mix refers to the intensity of the three forms of care identified by Wittenberg (2016)⁷. Access regulation examines "barriers to access care, especially for groups with lower social status" such as meanstesting (Ariaans et al. (2021, p. 610).

Ariaans et al. (2021, p. 610) used a broad definition of LTC⁸, which they attributed to Columbo et al. (2011), namely:

"Range of services required by persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period of time on help with basic activities of daily living (ADL). This 'personal care' component is frequently provided in combination with help with basic medical services such as 'nursing care' (help with wound dressing, pain management, medication, health monitoring), as well as prevention, rehabilitation or services of palliative care. Long-term care services can also be combined with lower-level care related to "domestic help" or help with instrumental activities of daily living (IADL)." (Ariaans et al. 2021, p. 611)

Ariaans et al. (2021, p. 611) acknowledged that it can be difficult to apply this definition consistently because some "data were extremely limited", such as with respect to IADL, and because "quantitative comparative data is not available for many countries".

Ariaans et al. (2021, Table 1, p. 611) identified some measures or indicators used to assess the four dimensions, with respect to institutional LTC, on the six-cluster classification. Their work relied on data related to 2014 to 2016, in which 2016 might be considered the reference year. The measures or indicators are discussed in more detail in their paper, and are abbreviated for this description as: for supply, "expenditure, beds, recipients"; for public-private mix, "private expenditure, cash benefits"; for access regulation, "choice restrictions, choice home care, choice institutional care, choice cash, means-testing"; for performance, "life expectancy, self-perceived health" (Ariaans et al. 2021, Table 1, p. 611).

2.1.6 Fischer et al. (2022)

The foregoing typologies presented in this chapter appear to have been developed from examining existing systems. Fischer at al. (2022) developed a conceptual framework, and then analyzed three countries' systems, Germany, Japan, and South Korea, to illustrate how the conceptual framework could be applied. Before presenting their framework, Fischer et al. (2022)

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⁷ Wittenberg (2016) distinguished unpaid care, publicly funded care, and privately purchased care services, which appears to distinguish care forms based on financing considerations.

⁸ This is consistent with my definition of C4LT.

summarized the literature they reviewed⁹. Fischer et al. (2022, p.35) identified 17 typologies, of which¹⁰:

- five used quantitative methods, mostly cluster analysis, to group countries;
- most arrived at classifications using inductive reasoning based on observed characteristics, but three used deductive reasoning based on theoretical considerations;
- eleven used financing as the topic of consideration;
- eight are concerned with at least one aspect of regulation;
- seven included at least one criterion which is concerned with provision of LTC;
- six addressed aspects of integration or fragmentation of LTC systems, either with respect to coordination within a country or with other social protection schemes.

No attempt was made to assess quality; although, Fischer et al. (2022, p.37) stated "most typologies seem to select the criteria rather arbitrarily without clear theoretical considerations of how to differentiate among types".

In constructing their conceptual framework, Fischer et al. (2022) argued that the following three constitutive elements – service provision, financing, and regulation – are important dimensions, and as such they use them as the foundation of their typology. They also considered five different types of actors (i.e., the state, societal actors which are non-governmental public actors, private for-profit actors, private individual actors which include households, global actors). To simplify, they combined the private actors along the dimension of regulation. This resulted in 100 possible types, i.e., four types of regulation by five types of financing by five types of provision. They then suggested some simplification based on what has been observed and what they considered likely to be observed, and reduced the typologies to 22. These remaining typologies were four pure types (i.e., the same actor for regulation, financing, and provision) and 18 other types, which they considered plausible.

2.1.7 Suen et al. (2023)

Suen et al. (2023) performed a systematic review of studies that discussed typologies by searching databases Medline and EconLit as well as specific grey literature sources, and consultation with experts and relevant websites, for the date range – inception to July 9, 2020. They identified 14 aged care typologies – five applied to residential care, two to home care, and seven to mixed settings. Of these 14 typologies, five were considered as high quality, where quality was assessed based on the following five aspects, as well as on the risk of bias.

"(i) Is the typology information or data used to inform the typology development clearly reported? (ii) Are typology labels meaningful, i.e., allow understanding of the category? (iii) Is the typology presentation clear and readily understandable, i.e., provides enough detail to understand how to categorise information according to the typology? (iv)¹¹ Are

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⁹ There is little information provided regarding the constraints on the literature review. However, the article was first received for consideration of publication on March 12, 2021, so literature after that date (and likely some time before) would not have been included.

¹⁰ In the following list a typology may appear in more than one item, so totalling items does not add to 17.

¹¹ This item is referred to by this number in section 2.2.

categories mutually exclusive where each case can only be categorised into a single category? and (v) Can the typology presented be used across all cases illustrated in the paper?" (Suen et al., 2023, p. 3)

Other ways identified by Suen et al. (2023) to differentiate typologies included: the level of systems (e.g., national, regional, or provider) or the main aspect of organization, i.e., the setting and focus (e.g., financing, quality of care, provision of care, provision of services). For the five typologies considered by Suen et al. (2023) to be high quality, the reference, level, setting and focus are shown in Table 2-1.

Table 2-1 Level, Setting and Focus of High-quality Typologies Assessed by Suen et al. (2023)

| Reference | Levels | Setting and Focus |
|-------------------------|--------------|--|
| Kraus et al. (2010) | National | Funding in LTC |
| Lehning et al. (2012) | Regional and | Change in community aged care initiatives |
| | Providers | |
| Van Eenoo et al. (2018) | National and | Service provision in home care |
| | Providers | |
| Beeber et al. (2014) | Provider | Staff hours and services in residential care and |
| | | assisted living |
| Nusem et al. (2017) | Provider | Services in LTC |

Source: based on Tables 1, 2, and 3 in Suen et al. (2023)

2.1.8 Observations on this literature

On comparing the 14 typologies identified by Suen et al. (2023) to the 17 typologies identified by Fischer et al. (2022), I found that Fischer et al. (2022) counted two typologies within the paper by Kraus et al. (2010), whereas Suen et al. (2023) only counted this article as one typology. Among the remaining articles there were only four that appeared in both the literature review by Suen et al. (2023) and Fischer et al. (2022). This is quite surprising, given that both literature reviews covered a similar time-period, and especially because Suen et al. (2023) represented their review as a systematic one.

Moreover, with respect to the typologies discussed in this section, only two are reported by both Suen et al. (2023) and Fischer et al. (2022), namely Da Roit & Le Bihan (2010) and Columbo et al. (2011) or its comparable article, Columbo (2012). Suen et al. (2023, p.6) assessed Da Roit & Le Bihan (2010) to be of low quality and the quality of Columbo (2012) to be unclear. Campbell et al. (2016) is a book chapter not identified to describe typologies, so it may have been missed in a grey literature search. The article by Le Bihan et al. (2019) does not appear in Medline or EconLit, which may explain why it was not included by Suen et al. (2023) and possibly may have been outside the date range for Fischer et al. (2022)¹². The article by Ariaans et al. (2021) is certainly beyond the date range for Suen et al. (2023) and likely beyond the date range for Fischer et al. (2022) as well. This suggests that the number of relevant articles regarding typologies is closer to 30 than 14 or 17. Assuming that both sets of authors diligently followed a thorough search strategy, this illustrates the extent of the literature on this topic and

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¹² Fischer et al. (2022) do not specify the date range for their search.

how wide a net one must cast in order to capture it all. Since this thesis is focussed on CfC considerations, an attempt to summarize the complete literature with respect to typologies is considered out-of-scope.

Based on previous work and many years of experience examining international LTC approaches, and discussing them with colleagues (see for example, University of Southampton (2011); Andrews (2014a); Andrews (2014b))¹³, the following characteristics seem relevant in classifying approaches to LTC provision; although, this list may not be complete:

- Mix of responsibilities for providing care among individuals and families, governments (federal or lower level), or private sector providers,
- Covered services, e.g., only in institutional settings (and then fully or partially) or also provided outside an institution, or e.g., both health and social care or some limitations thereon.
- Payment for services, e.g., through general taxation, specific taxes or premiums, or at point of service delivery,
- Access to services, e.g., universal, means-tested, or needs-tested,
- Supply of services, e.g., adequate or some involve long waiting lists or some services are only available in certain locales.

Other items that might have been considered but were excluded include:

- Measures of service quality or service adequacy it is very hard to assess these matters without detailed measures or statistics. Since the objective is to classify approaches, one might begin with classification characteristics, as listed above, and treat assessment of how well entities within a classification perform as not relevant to how the approach is classified. In other words, there could be entities that fall into the same classification but have very different service quality or service adequacy.
- Cultural, ethnic, or religious factors as entities may not be culturally, ethnically, or religiously homogeneous, there could be difficulties in trying to classify by such factors.

Fischer et al. (2022) have argued that regulation is an important differentiator. I have not included it above as a separate item on the list; although arguably, it may be present in any of the listed categories. Fischer et al. (2022) have also proposed that the typology be focussed on actors, and a dominant actor is selected for each typology. In order to do this one must assess the actor who has the principal or dominant responsibility. Such an assessment hides the responsibilities of other actors. When I consider the complexity of finance-provision-regulation, the dimensions important to Fischer et al. (2022), I think a lot of information is lost by assigning a single actor designation, and as such the usefulness of the typology is reduced.

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¹³ In 2022, a report was prepared by Doug Andrews and Lori Curtis, Principal Investigators, and Paul Stolee and Karen El Hajj, Co-Investigators, for the Canadian Institute of Actuaries. entitled The Direction of Long-term Care in Canada, which requires translation into French before public release, which involved discussion regarding relevant characteristics of LTC, and some international comparisons. This discussion draws on that report.

As listed, the characteristics are descriptive; however, adding quantitative measures could also help, e.g., supply of beds on some per capita measure, such as for those age 65 or older, or level at which means-testing occurs. Another useful feature of a typology would be that it can be applied beyond the range of entities on which it has been developed, as opposed to being closed, i.e., limited to the entities analyzed. Theoretically, and metaphysically, a typology could be developed without reference to any entity's approach, as Fischer et al. (2022) purport to have done. In practice, most typologies are developed based on a selection of entities, which may limit their generalizability and comprehensiveness. On the other hand, a conceptual approach such as that of Fischer et al. (2022), which results in 100 possible types, would be very hard to apply and might have many empty types.

2.2 Application to Ontario

The approach to LTC provision in Ontario was not specified by any of the typologies described in the previous section, although Columbo et al. (2011) did make a reference to Canadian provinces. In this subsection the six-cluster typology of Ariaans et al. (2021) was used to classify Ontario's approach. Some of the reasons for selecting this typology follow.

The typology of Da Roit & Le Bihan (2010) was developed based on countries with CfC programs, but Ontario does not have a CfC program. Columbo et al. (2011) stated that many Canadian provinces have a mixed system, requiring charges for some services but not others. This is true of Ontario, e.g., care in LTC institutions, other than accommodation, is provided free at point-of-service, but there are accommodation charges, which may be reduced based on income. One would expect that within Campbell et al. (2016), Ontario's approach would be classified as Anglo-Saxon residual. Ontario has weak or no policy with respect to supporting family carers and services may be accessed through the market, which suggests that Ontario's approach is defamilialism through the market, on the typology of Le Bihan et al. (2019). If one were to consider only state-provided care, then Ontario's approach would belong to type 1 of Fischer et al. (2022), i.e., state regulated, stated financed, and state provided. However, such a narrow focus does not appear to capture the variation within the approach to care provision. Such classifications of Ontario's approach do place it within the typology, but do not appear to provide as much information regarding how policy decisions might be made as would one of the cluster classifications of Ariaans et al. (2021).

Ariaans et al. (2021) suggested that the six-cluster classification may be preferred to the nine-cluster classification because there are some clusters in the nine-cluster classification that only contain one or two countries. Although the code used by Ariaans et al. (2021) is not available for either of the two classifications, so further cluster analysis is not possible, Ariaans et al. (2021) have provided a table showing the means of quantitative indicators for the six-cluster analysis (Ariaans et al., 2021, Table 3, p. 614) and also have provided an overview of cluster labels and characteristics for the six-cluster LTC types (Ariaans et al., 2021, Table 4, p. 614). As such, it seemed appropriate to work with the six-cluster classification rather than the nine-cluster classification. The six clusters are labelled the residual public system, the private supply system, the public supply system, the evolving public supply system, the need-based supply system, and the evolving private need-based system (Ariaans et al., 2021).

Examining the six-cluster typology of Ariaans et al. (2021) with respect to the quality criteria identified by Suen et al (2023), I believe that all the criteria are satisfied, with the possible exception of (iv), which pertains to mutual exclusivity such that each case may belong to only one category. Within some clusters, there are certain countries that are very close together, i.e., forming the core of the cluster, but other countries that are farther away and approaching countries in another cluster. Picturesquely, I refer to such latter countries as being in the former countries' orbit, i.e., they belong to the assigned cluster but are at a distance from the core and approaching another cluster's orbit. Although each case (country) belongs to a distinct cluster, when one looks at Fig. 1 (Ariaans et al., 2021, p. 613), one observes that, first, the orbits of the need-based supply system and evolving private need-based system are close and that three countries (Slovakia, Slovenia, New Zealand) are on the outer reaches of those orbits, and second, to a much lesser extent, the orbits of the private supply system and evolving private supply system are close. Given the complexity of measuring and assessing so many indicators of a country's approach and the high likelihood that the approach is undergoing change and does not necessarily follow a strict and consistent rationale for each of its components, the potential for countries to lie on the outskirts of a cluster seems understandable and not a failing of the typology. Accordingly, on the criteria stated by Suen et al. (2023), I would consider the quality of Ariaans et al. (2021) six-cluster typology to be high.

Positioning the six-cluster typology of Ariaans et al. (2021) within Table 2-1, along with the other high-quality typologies identified by Suen et al. (2023), it would be national level, with focus on funding (i.e., expenditure) and provision. However, in Canada, LTC is primarily a provincial (i.e., regional) responsibility. So, by applying the typology to Ontario, I have used it in a regional context.

In comparing the items included in determining the six-cluster typology of Ariaans et al. (2021) to those listed in subsection 2.1.8, based on my experience, it is noteworthy that their typology includes some aspect of each of the relevant characteristics, as shown in Table 2-2.

Table 2-2 Matching of relevant characteristics and indicators in Ariaans et al. (2021)

| Relevant characteristic | Indicator in Ariaans et al. (2021) |
|-------------------------|--|
| Mix of responsibilities | Private expenditure; Cash benefit |
| Covered services | Included in index of choice restrictions |
| Payment for services | Means testing |
| Access to services | Choice restrictions |
| Supply of services | Expenditure; Beds; Recipients |

Another reason to work with the typology of Ariaans et al. (2021) is that it is recently published.

2.2.1 Placing Ontario within Ariaans et al. (2021) six-cluster typology

In their analysis, Ariaans et al. (2021) excluded Canada (and Ontario) "because data was missing on single indicators for the whole observation period" (Ariaans et al., 2021, p. 611). In this subsection data are presented, closely related to that used by Ariaans et al. (2021) in their

six-cluster analysis, in order to place the provision of LTC within Ontario, a province of Canada, within one of the six clusters in the typology. By so doing it is hoped that further analysis of Ontario may benefit from an analysis of related (similarly clustered) countries.

It was challenging to find data that corresponded completely to the data presented by Ariaans et al. (2021). Perhaps this is unsurprising since Ariaans et al. (2021) excluded Canada because there were some data missing. There were also some procedural questions because it was not completely clear from the article by Ariaans et al. (2021) how they proceeded, and it appeared in places that theoretical objectives may have had to be compromised because of lack of available information.

The values developed for Ontario related to institutional LTC as reported by provincial agencies or CIHI. In Table A-1 in Appendix A, the means of the indicators from Table 3 (Ariaans et al. 2021, p.614) for each of the six clusters are shown, followed by a figure in bold, derived for Ontario. At the end of Appendix A, there is an explanation of the derivation of the numbers for Ontario and the source of the data. Some of the indicators are complex, but have the advantage of reducing data to a single number, which facilitates comparisons. The indicators are described in Table 2-3¹⁴.

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¹⁴ Note in the ensuing discussion, numbers that refer to Ontario or Canada have been calculated or sourced by me, whereas numbers for other than Canada were presented in the paper by Ariaans et al. (2021).

Table 2-3 Description of indicator and how measured corresponding to Ariaans et al. (2021, Table 3, p. 614) and Table A-1 in Appendix A

| Indicator | Description of measure by Ariaans et al. (2021) |
|----------------------------------|--|
| Expenditure ¹ | LTC (health) expenditure per capita in US\$ of purchasing power |
| | parities. It includes all expenditure on body-related LTC, mainly on |
| | (basic) Activities of Daily Living (ADLs) such as bathing, dressing or |
| | eating. We did not include LTC (social) expenditure |
| Beds ² | The number of LTC beds per 1,000 population aged 65 and older. |
| Recipients ³ | The number of LTC recipients in institutions measured as the |
| | percentage of all people |
| Private expenditure ⁴ | The private (voluntary and out-of-pocket) expenditure as a percentage |
| _ | of total expenditure to measure public and private involvement in |
| | payments for care. |
| Cash benefit ⁵ | The availability of cash benefits as an approximation of formal and |
| | informal care provision. The cash benefit indicators may take the |
| | value 0, describing a system in which only in-kind benefits are |
| | available. If the use of cash benefits is bound to specific services and |
| | aids, the indicator is coded as 1, while unbound benefits, for which |
| | the use of the benefit is at the beneficiary's own discretion, are coded |
| | as 2. |
| Choice restrictions ⁶ | The indicators are choice of home-care provider (choice home care), |
| | choice of institutional care provider (choice institutional care), and |
| | choice between cash and in-kind benefits (choice cash), which are |
| | combined to create an index. This index may take values between 0 |
| | and 4, with 0 representing absolute freedom of choice and 4 strong |
| | restrictions. |
| Means-testing ⁷ | A country system was coded 0 if it applies no means-testing in LTC |
| | systems at the stage of LTC provision at all and 1 if means-testing |
| | takes place. |
| Life expectancy ⁸ | Life expectancy of people aged 65 and older in years. |
| Self-perceived | The percentage of the population who are 65 years and older and |
| health ⁹ | perceive their health as good or very good. |

The first point to note, in examining the data for Ontario in Table A-1 in Appendix A and the Table 3 information from Ariaans et al. (2021, p. 614), pertains to means-testing. Ontario requires a daily accommodation charge to be paid in LTC homes, which may be reduced for those with insufficient means. On this basis, Ontario belongs to either the need-based supply system or the evolving private need-based system. This is consistent with a description in Ariaans et al. (2021, p. 610) regarding a typology by Columbo et al. (2011) that "New Zealand and Canada are clustered with Greece, Spain, and Switzerland due to their universal but meanstested financing approach".

In their comparison of these two systems (need-based supply system and evolving private need-based system), Ariaans et al. (2021, p. 614) stated "the main difference [of the evolving

private need-based system] to the previous system type [need-based supply system] is low expenditure, but also provision of beds in residential care and the number of recipients of residential care are at a lower level". Examining these three measures¹⁵, expenditure for Ontario is 432.96 compared to 819.81 for need-based supply and 459.42 for evolving private need-based; beds for Ontario are 30 compared to 64.28 for need-based supply and 43.43 for evolving private need-based; recipients for Canada are 4.5 (Ontario is not shown separately in the data source) compared to 5.51 for need-based supply and 3.46 for evolving private need-based. On all these measures Ontario appeared to lie closer to the evolving private need-based system than to the need-based supply system.

The countries in the evolving private need-based system in the six-cluster grouping of Ariaans et al. (2021, p. 614) are Estonia, France, Israel, New Zealand, Spain, United Kingdom, and the United States. Given Canada's historical heritage of having developed many laws and practices based on the UK and its close geographical proximity to the US, which has a policy influence, it does not seem counter-intuitive that Ontario's approach would have similarities to the UK and the US.

For the purpose of further analysis, such as the grey literature search in Chapter 3, Ontario will be considered to be in the same cluster as the countries within the evolving private need-based system.

2.3 Thinking about the future, part 1

This research is being conducted within a broader research agenda of examining the impact of population aging on Canada's social safety net. Ontario's population is aging, as shown in Table 2-4, on three different population growth projections from the Ontario Ministry of Finance (2022), labelled Tables 2-4-1, 2-4-2, and 2-4-3. Table 2-4 shows that the size of the older aged population (65+) is increasing and its age distribution is changing, regardless of the growth projection. On all projections, the percentage of the population in Ontario aged 65 or older by 2043 will increase to more than 20%, and between 2023 and 2043, both the number of people and the percentage of the population aged 85 and older will increase. Note that the projected increase in the 85 and over population is larger between 2033 and 2043 than between 2023 and 2033, on all projections, i.e., one might describe this as accelerated aging among the oldest age group. These population projections suggest strongly that the need for care among older adults is likely to increase and the proportion of the population under age 65, who might be available to work as carers, will decline over the 20-year projection period.

A possible policy response might be to build more beds in LTC facilities and hire and train more care workers. The Government of Ontario tabled legislation in 2021 to increase spending on LTC, increase the number of beds by 30,000 (over a 10-year period) and the number of workers in that sector (FAO, 2021). The FAO (2021) analyzed the projected spending increases, bed-building plans, and staffing projections. The FAO (2021) expressed a number of concerns regarding the projections, including:

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¹⁵ Please refer to Table 2-3 for measurement units.

- if the spending commitments to LTC are met, the available spending for other health care sector programs will be able to grow by only an average annual rate of 1.6% over the six-year period (FAO, 2021, p. 6);
- there are risks that the forecast of the number of available beds will not be met, which include: beds temporarily out-of-service may not return (FAO, 2021, p.14), construction timelines may not be met (FAO, 2021, p. 15), and some beds with expiring licences may be taken out of service permanently (FAO, 2021, p. 15).

But even if the spending-construction-hiring projections are met, because of the aging of the population over the projection period, the number of beds per 1,000 people aged 75 and over will decline to 66 in 2029-30, the lowest number over the 20-year period commencing 2008-10 (FAO, 2021, p. 16, Figure 3-6)¹⁶.

Writing about Canada, MacDonald et al. (2019) projected strong increases in the need for care and significant shortages in care-supply, requiring large increases in caring by family and friends, e.g., they claim "between 2019 and 2050 ... the cost of public care in nursing homes and private homes will more than triple ... [and] by 2050, there will be approximately 120% more older adults using home care support ... [and] there will be approximately 30% fewer close family members – namely spouses and adult children – who could potentially be available to provide unpaid care" (MacDonald et al., 2019, p. 07). Although MacDonald et al. (2019) did not provide projections for Ontario, it is relatively safe to assume that Ontario, Canada's most populous province, will experience similar pressures.

Based on the analysis in this chapter, Ontario's approach is classified as an "evolving private need-based system". This might be rephrased, somewhat uncharitably, as "when taking action to address needs that are pressing, private sector approaches are preferred". This seems to be an accurate assessment of the situation in Ontario, with the current provincial government. From the earlier paragraphs in this section, it can be seen that needs are likely to increase, and may outpace the actions taken by the government regarding LTC spending, bed-supply, and staffing. A CfC program, in which care recipients, or possibly their carers, are offered cash, in lieu of provision of care services, is a private sector approach. It may be easier for the province to provide cash rather than to ensure that care services are available. As far as I can ascertain, all the other countries that fall within the "evolving private need-based system" do have some type of CfC program, at least in some of their constituencies. It seems likely that Ontario will consider the possibility of implementing a CfC program.

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¹⁶ In the year in which the projections were made 2018-2019 the number of beds per 1,000 Ontarians aged 75 or older was 73.

Table 2-4-1 Projected Population* Ontario Older Age Ranges¹⁷

| Age Group/Population Projection | 2023 # Millions | 2023 % | 2033 # Millions | 2033 | 2043 # Millions | 2043 % |
|---------------------------------|--------------------|-----------|--------------------|------|--------------------|-----------|
| 65-74 | 1.597 | 10.4 | 1.927 | 11.0 | 1.779 | 9.0 |
| 75-84 | .910 | 5.9 | 1.325 | 7.6 | 1.651 | 8.4 |
| 85+ | .364 | 2.4 | .563 | 3.2 | .897 | 4.6 |
| Total 65+ | 2.871 | 18.7 | 3.815 | 21.8 | 4.327 | 22.0 |

^{*} Reference population projection

Author's calculations based on projections from the Ontario Ministry of Finance (2022).

Table 2-4-2 Projected Population* Ontario Older Age Ranges

| Age Group/Population | 2023 # | 2023 | 2033 # | 2033 | 2043 # | 2043 |
|----------------------|----------|------|----------|------|----------|----------|
| Projection | Millions | % | Millions | % | Millions | % |
| 65-74 | 1.591 | 10.5 | 1.898 | 11.5 | 1.725 | 9.6 |
| 75-84 | .907 | 6.0 | 1.309 | 7.9 | 1.614 | 9.0 |
| 85+ | .364 | 2.4 | .558 | 3.4 | .881 | 4.9 |
| Total 65+ | 2.862 | 18.9 | 3.765 | 22.8 | 4.221 | 23.5 |

^{*} Low growth population projection

Author's calculations based on projections from the Ontario Ministry of Finance (2022).

Table 2-4-3 Projected Population* Ontario Older Age Ranges

| Age Group/Population | 2023 # | 2023 | 2033 # | 2033 | 2043 # | 2043 |
|----------------------|----------|------|----------|----------|----------|------|
| Projection | Millions | % | Millions | % | Millions | % |
| 65-74 | 1.603 | 10.3 | 1.955 | 10.5 | 1.834 | 8.5 |
| 75-84 | .912 | 5.8 | 1.342 | 7.2 | 1.688 | 7.8 |
| 85+ | .365 | 2.3 | .568 | 3.0 | .912 | 4.2 |
| Total 65+ | 2.880 | 18.4 | 3.865 | 20.7 | 4.434 | 20.5 |

^{*} High growth population projection

Author's calculations based on projections from the Ontario Ministry of Finance (2022).

¹⁷ The population projections were made by the Ontario Ministry of Finance. The reference population is the most likely, in its opinion. The other two provide a range of possible outcomes. The Ontario Ministry of Finance (2022, n.p.) stated in the section entitled Projection Results "In the reference scenario, population is projected to grow 43.6 per cent, or almost 6.6 million, over the next 24 years, from an estimated 15.1 million on July 1, 2022, to almost 21.7 million on July 1, 2046. ... In the low-growth scenario, the annual rate of population growth is projected to decline rapidly over the first five years of the projections, from 1.5 to 0.9 per cent by 2026–27, and then to slowly reach 0.8 per cent by 2046. In the high-growth scenario, the annual population growth rate is also projected to fall quickly over the first five projected years, from 4.9 to 1.8 per cent by 2026–27, and then to reach 1.6 per cent by 2046."

Chapter 3 Benefits and Disbenefits of Cash-for-Care

This chapter presents the process followed and the findings of a literature review performed to address the supplementary research question: "what benefits and disbenefits of incorporating a CfC program in the approach to care provision for older adults have been identified in the literature, with primary focus on academic literature?". It concludes with a subsection regarding thinking about the future, which builds on a similar subsection in Chapter 2 and the findings in this chapter.

3.1 Literature review methodology

There are many approaches to and types of literature reviews. Snyder (2019) discussed three approaches to literature reviews: systematic, semi-systematic, and integrative. Based on her discussion, the semi-systematic approach seemed best suited to this thesis, because it can use a systematic approach, without the strict restrictions placed on systematic reviews, and inform on the state of knowledge regarding the research topic (Snyder, 2019). Grant & Booth (2009) described 14 types of literature reviews and associated methodologies. Grant & Booth (2009, p. 101) state that a scoping review "aims to identify the nature and extent of research evidence" and attempts "to be systematic, transparent and replicable", which is consistent with the purposes of this literature review. The type of literature review performed in this chapter has been described as a scoping study by Arksey & O'Malley (2005), which I will refer to as a scoping review. Like a systematic review, it is systematic with respect to the process followed and the manner of presenting the results. It differs from a systematic review because it does not attempt any assessment of the quality of the findings in the literature. The methodology followed is as outlined by Arksey & O'Malley (2005) but modified in certain ways as suggested by Levac et al. (2010). An advantage of using the methodology of Arksey & O'Malley (2005) for a Master's thesis is that it can be performed independently by a single researcher, although it need not be. The following description of the process corresponds to the five stages identified by Arksey & O'Malley (2005), although the actual process followed was iterative and in places moved between stages.

3.1.1 Stage 1. Identifying the research question

The research question for the scoping review was: "what benefits and disbenefits of incorporating a CfC program in the approach to care provision for older adults have been identified in the literature, with primary focus on academic literature?"

3.1.2 Stage 2 Identifying relevant studies

The literature review is comprised of works published in the English language, and consists mainly of academic literature, supplemented by selected grey literature. The scope of the search was limited, using the following criteria to identify potentially relevant academic studies. These criteria were modified in respect of grey literature as explained in subsection 3.1.3.4.

- Only English language literature
- Published between January 1, 2010 and December 31, 2022. January 1, 2010 was selected as the starting point because it included the paper by Da Roit & Le Bihan

(2010)¹⁸ in the review and those authors stated in their paper that they did a systematic review of existing studies. December 31, 2022 was selected in order to constrain the literature reviewed to a set period. There were three papers that fell outside the date range that were included. Rummery (2009) was published in December 2009 and was included because it provided a comparative discussion of aspects of CfC programs in Austria, France, Italy, the Netherlands, UK, and the US, which are methodologically distinct from many of the included papers that are based on qualitative data regarding the UK. There was one paper published online in 2021 regarding Spain, namely Martinez-Lopez et al. (2023), which was not published in print until 2023, and is referred to by the 2023 date. Also, there was one paper in respect of Canada, namely Kelly et al. (2023), published in 2023, which was considered relevant, and it was included despite not meeting the inclusion criterion.

- In academic journals based on a search of the following databases: CINAHL, PubMed, Scopus. Before beginning the search, a meeting was held with Ms. Stapleton, Liaison Librarian, School of Public Health Sciences, Kinesiology and Health Sciences, at which we tested various search terms on different databases. She recommended that CINAHL be used rather than EMBASE, which had been proposed, because she thought it would provide a wider range for the search.
- In respect of experience in the 25 OECD countries for which a typology was identified by Ariaans et al. (2021), and in respect of Canada for additional relevance (hereinafter referred to as the 26 OECD countries). The 26 OECD countries are: Australia, Belgium, Canada, Czech Republic, Denmark, Estonia, Finland, France, Germany, Ireland, Israel, Japan, Korea, Latvia, Luxemburg, Netherlands, New Zealand, Norway, Poland, Slovakia, Slovenia, Spain, Sweden, Switzerland, United Kingdom, United States of America¹⁹.

3.1.3 Stage 3 Study selection

3.1.3.1 Search strings

After consultation with Ms. Stapleton, it was decided to limit the search strings to two combinations, in order to make the search as broad as possible, within the criteria already determined. Because the research question focuses on the benefits and disbenefits of CfC programs in the context of care provision for older adults, it was decided to create search strings to identify studies relating to CfC programs in the context of care provision for older adults. After removal of duplicates, and elimination of studies that did not meet the inclusion criteria or were otherwise irrelevant, based on a review of author-title-abstract, a review of the full text of qualifying studies was made to determine if the benefits and disbenefits of CfC programs are discussed. The specific search combinations used for each database are shown in Figure 3-1, along with the date of the search and the number of items found. They are of the following general construction, with the 1st and 2nd levels being connected by AND; although there are minor differences by search, primarily related to the requirements of the database:

1st level – older adults OR older person OR elderly OR geriatric OR older people OR long term care OR assisted living OR nursing homes OR palliative care OR social care

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¹⁸ The paper by Da Roit & Le Bihan (2010) presented a systematic review of CfC programs and a typology. Therefore, it was deemed foundational for this thesis. Although excluded from the papers selected for the thematic analysis in this chapter, it was summarized briefly in Chapter 2, regarding typologies.

¹⁹ Ariaans et al. (2021) list 11 OECD countries, including Canada, that were excluded because there was incomplete data. Subsequent to their cut-off date in 2019 for data receipt, two countries, Columbia and Costa Rica, have deposited their instruments of ratification. Hence, the current list of 38 OECD countries is accounted for.

2nd level – cash-for-care OR direct payments OR personal budgets OR direct financing

The items retrieved were loaded to the Covidence database on the University of Waterloo library site. There were 573 academic studies identified, of which 215 were identified as duplicates by Covidence.

3.1.3.2 Confirming review approach

Before proceeding to author-title-abstract screening, a comparison of the application of the screening criteria was performed by two reviewers (DA and PS). A selection of 20 items from the PubMed data were reviewed by both reviewers, using the inclusion/exclusion criteria. There were four items on which the two reviewers disagreed, resulting in a Kappa statistic of 0.6, which "represents intermediate to good agreement" (Celentano, & Szklo, 2019, p. 117). The reviewers discussed the disagreements and agreed to review an additional selection of 20 items from the PubMed data. The review of the second set of 20 items resulted in two disagreements for a Kappa statistic of 0.8, and a Kappa statistic of 0.7 in respect of all 40 items reviewed. According to Celentano, & Szklo (2019, p. 116-117) "Landis and Koch suggest that a kappa greater than 0.75 represents excellent agreement beyond chance, a kappa below 0.40 represents poor agreement, and a kappa of 0.40 to 0.75 represents intermediate to good agreement". It was decided that there was sufficient agreement on how the author-title-abstracts should be screened that I could perform the review independently.

3.1.3.3 Author-title-abstract screening of academic literature

Through an author-title-abstract screening of the 358 academic studies identified, using the exclusion criteria listed, 230 were identified as irrelevant, leaving 128 academic studies for full text screening. Of the 128 studies for which the full text was reviewed, 90 were excluded, and the results from the remaining 38 academic studies are reported herein. As noted, there were three studies included, despite not meeting the inclusion criteria.

3.1.3.4 Grey literature

The second source pertains to a selective review of grey literature. Godin et al. (2015) presented a case study illustrating four methods which they applied to do a systematic review of grey literature. They suggest that these methods could be applied, in full or in part, to other literature reviews. Since the ultimate aim of this thesis is to consider the benefits and disbenefits of a CfC program that might be incorporated in Ontario's approach to care provision for older adults, grey literature with respect to the countries, which have an approach that falls within the same type as that of Ontario as determined in Chapter 2, was performed. The relevant countries are: Estonia, France, Israel, New Zealand, Spain, United Kingdom, and the United States, as well as Canada.

The search strategy for the grey literature was developed in consultation with the librarian and sent to the Thesis Committee members for comment, before proceeding. It was different for Canada than for the other countries.

For the countries other than Canada, the OECD website was searched to identify international publications. On the OECD website, the search term "cash-for-care" was entered, and the results reviewed using the following inclusion criteria:

• concerns CfC in one of the eight countries of interest; and

- pertains to CfC for older persons; and
- was published on or after January 1, 2010; and
- is available in English.

Note that any grey literature retrieved, which was already included in the academic literature sourced, was classified as a duplicate and removed. The results are shown in Table 3-1, for the OECD database. Although the site estimated there were 77 items, on review there were only 36 items, and these were screened²⁰. In Table 3-1, the following terminology is used: "retrieved" means items produced by the search, "screened" means items screened for inclusion criteria, and "retained" means items included in the literature review, after reading the item to determine if it is relevant.

For Canada, a two-part search strategy of grey literature was used. First, the customized Google search engine on the Grey Literature - UW Public Health and Kinesiology Research guide was used to identify Canadian government publications, by entering the search term "cashfor-care". Items retrieved were reviewed and documented in Table 3-1, as described above. Using this approach five items were retrieved. Second, targeted website browsing on relevant Canadian organizations, including CIHI and StatsCan, was performed. To identify relevant Canadian organizations, "cash-for-care Canada" was entered into Google and the first 25 items listed were screened to identify up to five additional organizations (governmental and non-governmental) on which to perform a Google search. From this search, the following organizations were selected: Institute for Research on Public Policy (IRPP), Montreal Economic Institute, Canadian Occupational Safety. On the websites of the selected organizations including CIHI and StatsCan, the search term "cash-for-care" was entered. Only the first 25 items retrieved from each website were reviewed and documented in Table 3-1, as described above; although all retrievals were counted and reported. From this second approach, 1,757 items were retrieved.

After the screening of the grey literature was completed, and duplicates and irrelevant items excluded, there were 22 studies included for full text review. Sixteen studies were eliminated after full text review, and six studies extracted for inclusion in the review.

Table 3-1 summarizes the results of the grey literature search. It shows the number of studies retrieved from each source, the number excluded for each reason, and this information is summarized in the following sentences in this paragraph. The greatest number of references identified initially was from the Canadian Occupational Safety website (1,749 references). The search strategy had determined that only the first 25 references would be screened, so 1,724 references were not screened. Although the OECD website estimated that there were 77 references retrieved, a count indicated that there were only 36. After exclusion of six duplicates, title and abstract screening was applied to 68 studies and 46 were eliminated. The full text was reviewed for the remaining 22 studies and 16 were eliminated and 6 retained for this review. The 16 eliminated studies were added to the 90 eliminated studies from the full text review of the academic literature and the reason for exclusion added, for a total of 106 excluded studies, as shown in Figure 3-2.

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²⁰ This may have to do with the trade-off between speed of response and accuracy, incorporated in the algorithm. Other researchers have reported similar experiences.

3.1.3.5 Studies selected

There were 38 papers selected from the review of the academic literature and 6 references selected from the grey literature review for a total of 44 papers, on which the following review is based. Figure 3-2 summarizes the process to reduce the number of papers included in this review to 44, using the PRISMA reporting template from Covidence. It shows how the original 573 studies from the search of the three academic databases were combined with 1798 items from the grey literature search. Figure 3-1 shows the search strategy for the academic literature and Table 3-1 shows the search strategy for the grey literature. A title-abstract screen was applied to 426 studies, resulting in 276 studies being removed, and a review of the full text was performed on the remaining 150 studies. This screening eliminated 106 studies.

The main reason for excluding a paper in the course of the full text review was that it did not present benefits or disbenefits of a CfC program (48 studies). The second most common reason for excluding studies was that the study pertained more to personalization, not to the benefits or disbenefits of a CfC program (21 studies).

Some judgement was exercised in classifying studies as being concerned with personalization, not benefits or disbenefits of CfC. Manthorpe & Stevens (2010) provided an overview of various ways in which personalization was defined in the UK. Personalization includes the use of a personal budget, i.e., a CfC program, which explains why these papers were initially included in the full text review. Since a main policy initiative of personalization is to provide the recipient with greater choice and control (Manthorpe & Stevens, 2010), if these were the only benefits identified, the paper was deemed to be discussing personalization, not the benefits or disbenefits of CfC programs, and was excluded. It would have been possible to include the personalization articles and state that benefits provided to recipients included increased choice and greater control. However, if there were no other benefits or disbenefits identified in the course of the full text review of these articles on personalization, they were excluded because the benefits of increased choice and greater control were well captured in the other literature.

3.1.4 Stage 4 Charting the data

The full text of the 44 papers was read and the relevant information extracted, which is shown in Tables 3-2 and 3-3. Table 3-2 describes the benefits and disbenefits in a few words for ease of presentation in a tabular format. Some further description of the types of experiences reported in the literature that have been aggregated within a single benefit or disbenefit is presented later. Table 3-3 reports the following information regarding the paper: author and publication date, brief overview of the aim of the paper, the country or countries in which it is in respect, brief description of the methods used, and list of benefits and disbenefits identified.

For convenience of reference in Table -3-2 and Table 3-3, the following notation is used: RBn refers to the nth benefit for the care recipient, RDn refers to the nth disbenefit for the care recipient, CBn refers to the nth benefit for the carer, CDn refers to the nth disbenefit for the carer, SBn refers to the nth benefit for the state (or funder), and SDn refers to the nth disbenefit for the state (or funder).

Figure 3-1 Search Documentation of Academic Literature

PubMed Search Strategy

Performed on February 8, 2023 by Doug Andrews

Retrieved 140 results

(older adults OR older people OR elderly OR geriatric OR older people OR long term care OR assisted living OR nursing homes OR palliative care OR "social care") AND ("cash for care" OR "direct payment*" OR "personal budget*" OR "direct financing") Filters: English, from 2010 – 2023

Scopus Search Strategy

Performed on February 9, 2023 by Doug Andrews

Retrieved 299 results

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(TITLE-ABS-KEY (("older adult*" OR "older people" OR "long term care" OR "palliative care" OR "assisted living" OR "nursing home*" OR "social care" OR caregiver* OR "care giver*" OR "carer*" OR "institutional care" OR aging OR ageing OR aged)) AND TITLE-ABS-KEY ("cash for care" OR "direct payment*" OR "direct financing" OR "personal budget*")) AND PUBYEAR > 2009 AND (LIMIT-TO (LANGUAGE, "English"))
```

CINAHL Search Strategy

Performed on February 23, 2023 by Doug Andrews

Retrieved 134 results

```
((( "older adult*" OR "older person" OR elderly OR geriatric* OR "older people" OR "long term care" OR "palliative care" OR "assisted living" OR "nursing home*" OR "social care" OR caregiver* OR "care giver*" OR "carer*" OR "institutional care" OR aging OR ageing OR aged ))) AND(( "cash for care" OR "direct payment*" OR "direct financing" OR "personal budget*")))
```

Limited 01012010 to 31122022 English Journal articles

Total of 573 results retrieved before removal of duplicates

Table 3-1 Grey Literature Results

| Date | Database | Search Strategy | # of items retrieved | # of duplicates | # of items screened | # of items retained |
|----------|---|--|---|--------------------|--|--|
| 12/06/23 | UW Public Health and Kinesiology Research guide | Enter "cash-for-care" | 5 Exclude 1 irrelevant ^c | 1 ^b | 3 ^d | 3 |
| 13/06/23 | StatsCan | Enter "cash-for- care" and enter cash-for-care | 0 | | 0 | 0 |
| 13/06/23 | СІНІ | Enter "cash-for- care" and enter cash-for-care | 0 | | 0 | 0 |
| 13/06/23 | Institute for Research on Public Policy | Enter "cash-for-care" | 4 | 4 ^b | 0 | 0 |
| 13/06/23 | Montreal Economic Institute | Enter "cash-for-care" | 4 | | 4 ^d | 1 ^e |
| 13/06/23 | Canadian Occupat- ional Safety | Enter "cash-for-care" | 1,749 Exclude 1,724a Only screen first 25 - Exclude 24 irrelevantc | | 1 ^d | 1 |
| 14/06/23 | OECD | Enter "cash-for-care" | 77 (site estimate - actually 36) Exclude 21 irrelevant ^c | 1 ^b | 6 of which were chapters of same report | 1° 3 chapters of same report retained but reported as single reference |

Total items retrieved (5+4+4+1749+36=1,798)

a Not screened (1724), leaving 74 before removal of duplicates

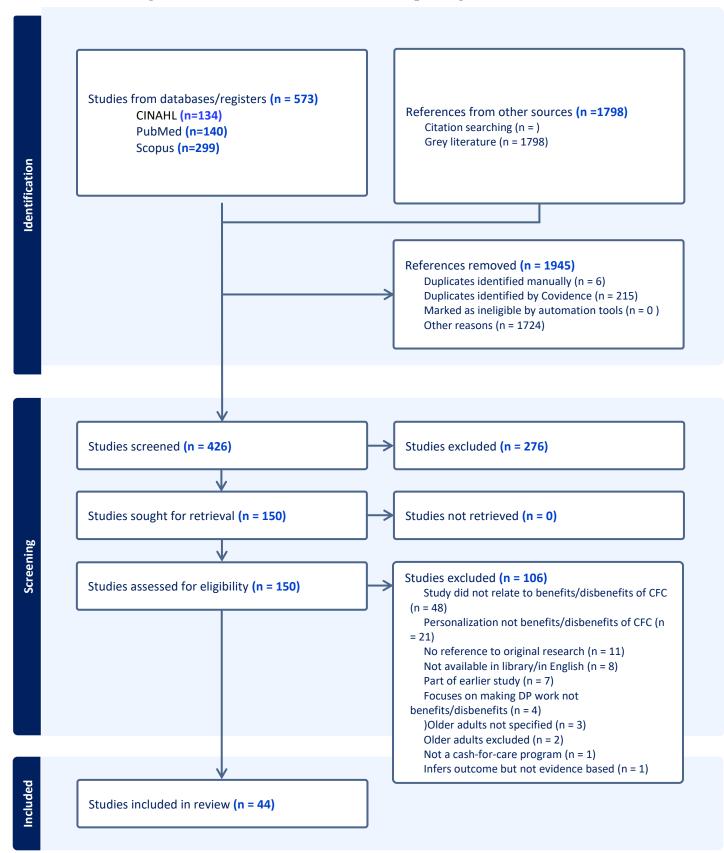
b Duplicates excluded (1+4+1=6), leaving 68 for title and abstract screening

c Irrelevant excluded based on title and abstract screening (1+24+21=46), leaving 22 for full text review

d Full text review (3+4+1+14=22)

e Excluded through full text review (4-1+14-1=16), leaving 6 included in review

Figure 3-2 Search Overview PRISMA Reporting Format



It is important to note that what might be considered a benefit for one party might be considered a disbenefit for another party. In this regard, benefits and disbenefits were considered primarily from the perspective of the care recipient, unless the paper identified the benefit or disbenefit to be in respect of the carer. There may also be benefits or disbenefits for the state which provides the CfC program. Typically, this was not the focus of the discussion in the extracted papers, so there may be some additional benefits or disbenefits for the state not reported herein. A brief discussion of the benefits and disbenefits to the state is presented in subsection 3.2.6.

Table 3-2 Summary of Benefits and Disbenefits by Beneficiary

| Beneficiary\(dis)Benefit | Benefits | Disbenefit |
|--------------------------|--|---|
| Recipient | RB1 [30] - Increased choice RB2 [30] - Greater control RB3 [10] - More continuity RB4 [2] - More cost effective RB5 [22] - Enhance social capital RB6 [5] - Improve prevention/treatment | RD1 [7] - Gender engraining RD2 [3] - Greater isolation RD3 [8] - Inadequate budget RD4 [9] - Powerless/Fear/Frustration RD5 [21] - Bureaucracy RD6 [15] - Lacks transparency RD7 [4] - Tension between professionals RD8 [10] - Complex to manage budget RD9 [8] - Decline in quality RD10 [5] - Cost increases/added fees RD11 [8] - Reinforces inequities RD12 [9] - Lack of market responsiveness |
| Carer | CB1 [12] - Enhance quality of life CB2 [12] - Support family carers | CD1 [7] - Decline in quality of life CD2 [8] - Administration stressful |
| State | SB1 [1] – Improve universal access SB2 [7] – Cost savings SB3[4] – More efficient service mix SB4[3] - Substitutes formal care for informal care | SD1[4] – Introduce consumerism into welfare SD2 [1] – Unethical to place care responsibility on recipients SD3 [1] – Not cost-effective for older adults SD4 [3] – Substitutes formal care for informal care |

[n] shows that n is the number of papers reporting that benefit or disbenefit

Table 3-3 Summary of Papers

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|------------------------------|---|--|---|-----------------------|-------------------------|-------------------|---------------------|-------------------|---------------------------|
| Albertini & Pavolini (2017) | Incorporate the stratification perspective into LTC systems | Denmark, Germany, France, Italy | Analysis of SHARE data from waves 1 and 2 for four countries | | RD11 | | | | |
| Arksey & Baxter (2012) | Report new empirical research, which takes a longitudinal perspective, about the use of Direct Payments | England | Interviews with subsample of 30 individuals from 98 who talked about direct payments in at least one interview, longitudinal study of three successive interviews 2007-2009 | RB1, RB2, RB3 | RD5, RD6, RD8 | CB1, CB2 | | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|------------------------|--|-----------|--|-----------------------|-------------------------------|-------------------|---------------------|---------------------|---------------------------|
| Arntz & Thomsen (2011) | Evaluate the effects of a Consumer-Directed home Care program compared with the standard home care program of the German LTC insurance | Germany | RCT based on field experiment data across six sites between 2004-2008 | RB1, RB2, RB5 | | | | SB2, SB3, SB4 | SD4 |
| Baxter et al. (2011) | Analytic framework used to consider how the widespread introduction of Personal Budgets is likely to affect the market for social care | England | Analysis based in economic theory and face-to-face semi- structured interviews in 2007 with a commis- sioning manager and managers of eight home care agencies in each of four local authorities | RB1, RB2, RB3 | RD6, RD7, RD9, RD12 | | | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|-----------------------|---|----------------------------------|--|----------------------------------|-------------------------------|-------------------|---------------------|-------------------|---------------------------|
| Bradley et al. (2021) | Describe Self-Direction (SD) approaches across four countries – successful strategies, unresolved questions, and recommendations | Australia, England, NZ, US | Shared experiences at conference in 2019 by people from these countries who are SD, providers and caregivers who support people who are SD, advocates, fiscal agents and public managers who administer SD | RB1, RB2, RB5 | | | | | |
| Cash et al. (2017) | Integrative literature review on relationships between community aged care recipients, family carers and care providers under Consumer- Directed Care | US, UK, Australia | Integrative literature review of seven databases and grey literature between 1998 and 2014 | RB1, RB2, RB3, RB5, RB6 | | CB1 | | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|-----------------------|--|---|---|-----------------------|-------------------------------|-------------------|---------------------------|-------------------|---------------------------|
| Columbo et al. (2011) | Provides an overview of LTC in various OECD countries including general info (chapter 1), family care (chapter 4), undervaluing of workers (Chapter 5) | Germany, Nether- lands, US, UK, Spain, Korea, France, Israel | Grey literature reporting experiences from observation and research | RB1, RB2, RB5 | RD5, RD9, RD12 | CB1, CB2 | CD1, CD2 | SB2, SB4 | SD1, SD4 |
| Coyle (2011) | Report on the use of Personal Budgets in three early intervention (mental health) teams | England | Interviews with seven individuals from a mental health trust in north-west England on two occasions, two focus groups | RB1, RB2, RB5 | RD2, RD5, RD11 | | | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|----------------------|---|-----------|--|-----------------------|-------------------------------|-------------------|---------------------|-------------------|---------------------------|
| Damant et al. (2020) | Explore the experiences of care home residents and their families offered a Direct Payment, in terms of choice, control and consumer power, using model designed to explore frictions/conflicts on (i) inequality, (ii) relationship between private and public care services, and (iii) power relationships re service users and paid carers | England | Semi- structured interviews with eight care home residents and 26 family members in a trailblazers' pilot for residential care between 2015-2016 | RB5 | RD5, RD11, RD12 | | CD2 | | |
| Day et al. (2018) | Explore the experiences of older people receiving home care package support following the introduction of Consumer-Directed Care (CDC) in Australia | Australia | 19 interviews, 25 responses to paper survey, from 2 service providers in NSW, following CDC introduction in July 2015 | RB1, RB2 | RD4, RD5, RD6, RD12 | | | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|---------------------|--|------------------------------|--|-----------------------|-------------------------------|-------------------|---------------------------|-------------------|---------------------------|
| Dudova (2022) | Investigate what happens in Czech Republic when money in the form of a Cash-For-Care benefit enters family relationships | Czech Republic | Compares two case studies based on interviews with children caring for parents (between 2012-2016) and parents caring for children (in 2012) | | RD1 | | | | |
| Flood (2017) | Present insights from two countries regarding funding options for home care and LTC | Germany, Nether- lands | Grey literature reporting experiences from observation and research | RB2 | RD1, RD9 | | | SB2 | |
| Flood et al. (2021) | Research report to produce policy recommendations regard LTC, which investigates cash- for-care | Germany, Nether- lands | Grey literature reporting experiences from observation and research | RB1, RB2 | RD1, RD5 | CB2 | CD1, CD2 | SB2, SB3 | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|------------------------------|--|-----------|---|----------------------------------|-------------------------------|-------------------|---------------------|-------------------|---------------------------|
| Griffiths & Ainsworth (2013) | Investigate the experiences of seeking to obtain and use Direct Payments of people who experience mental illness and their carers | England | Telephone semi- structured interviews with 12 people with experience of mental illness and 9 carers | RB1, RB2, RB3, RB5, RB6 | RD3, RD4, RD5, RD6 | CB1 | CD2 | | |
| Hamilton et al. (2016) | Explore within the field of mental health, whether Personal Budgets are providing an effective mechanism for users to exercise greater power, choice and control | England | Interviews with 52 service users with mental health problems and 28 mental health practitioners, conducted in three local authorities between 2010-2013 | RB1, RB2 | RD4, RD5, RD6 | | | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|----------------------|---|-----------|---|-----------------------|-------------------------|-------------------|---------------------|-------------------|---------------------------|
| Irvine et al. (2017) | Investigate the experiences with Personalisation of people from Chinese backgrounds | England | Interviews in English, Cantonese, Mandarin, of 26 physically disabled people from Chinese backgrounds who lived in England, were aged between 18 and 70, and received social care, and two subsequent focus groups of 14 of above. Study conducted 2012-2013. | RB1, RB2, RB3 | RD5, RD8 | | | | |
| Jones et al. (2014) | Evaluate the impact and outcomes of Individual Budgets on carers | England | Interviews with 129 carers in 9 pilot IBSEN sites between 2007-2008 | | | CB1 | | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|---------------------|---|-----------|---|--------------------------|-------------------------------|-------------------|---------------------------|-------------------|---------------------------|
| Kelly et al. (2023) | Describe the role of agency providers in Direct Funded home care in Canada and consider potential equity implications | Canada | Online focus groups with 56 DF home care clients and families in Alta & Manitoba, conducted between 2021-2022 | RB1, RB2, RB3, RB5 | RD5, RD10, RD11 | | | | |
| Lamura (2014) | Present best practices in home care in Italy | Italy | Grey literature reporting experiences from observation and research | | | CB2 | CD1 | SB2 | |
| Larkin (2015) | Explore the experiences of carers and the effects on the carer–service user relationship, of Personalisation | England | Semi- structured interviews with 23 carers from 11 local authorities, between 2011-2012 | RB5 | RD5, RD8, RD9 | CB1, CB2 | CD2 | SB4 | SD4 |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|-------------------------|---|-----------|---|-----------------------|-------------------------|-------------------|---------------------|-------------------|---------------------------|
| Larsen et al. (2013) | Describe approaches to introducing Personal Budgets to people with severe and enduring mental health needs, and identify facilitators or barriers | England | Semi- structured interviews with 58 participants in four local authorities regarding PB for those with mental health needs, between 2010-2011 | | RD7 | | | | |
| Laybourne et al. (2016) | Examine the experiences of Direct Payments for people living with dementia | England | Interviews with nine social care practitioners and with seven Suitable People (re DP and dementia) across five local authorities, in study approved 2011 | RB6 | RD6 | CB1 | | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|----------------------------|--|-----------|---|-----------------------|---------------------------------------|-------------------|---------------------|-------------------|---------------------------|
| Locke & West (2018) | Describe findings from a study commissioned by a local authority to explore older people's views of Direct Payments | England | Semi-structured interviews with 24 older people receiving DP or managed care packages, in a local authority, conducted in 2016 | RB1, RB2 | RD5, RD6, RD8, RD10 | | | | SD2 |
| Manthorpe & Stevens (2010) | Examine the possible impact of Personalization of social care on older people living in rural areas and those supporting them in formal and informal roles | England | Semi-structured interviews with 33 individuals working with older people aged 75 or older in rural communities, conducted in 2008 | RB1, RB2, RB5 | RD4, RD5, RD9, RD10, RD12 | | | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|-------------------------------------|---|---------------------|---|-----------------------|-------------------------------|-------------------|---------------------------|-------------------|---------------------------|
| Martinez- Lopez et al. (2023) | Presents an analysis of the impact of Cash-For-Care on carers in Spain | Spain | Case study based on a sample of 256 question-naires from a survey of 5,697 caregivers from 2009-2014, followed by 10 semi-structured interviews, conducted in 2014-2015, in respect of the Region of Murcia | | RD1, RD11 | | | | |
| McGuigan et al. (2016) | Examine the impact of Direct Payments on service users in a large trust in Northern Ireland | Northern Ireland | Interviews with 2 recipients of DP and 28 informal carers with experience in implementing a DP | RB1, RB2, RB5 | RD6 | CB2 | | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|---------------------|---|--------------------------------|---|----------------------------------|--|-------------------|---------------------|-------------------|---------------------------|
| Micai et al. (2022) | Review evidence on use of Personal Budgets (PB) in mental health and intellectual disability contexts; summarize the recent research on interventions, outcomes, and cost-effectiveness of PB with such beneficiaries | UK, US, Italy, Australia | Systematic literature review based on articles in PubMed and PsycINFO published between April 1, 2013 and September 15, 2021 | RB1, RB2, RB4, RB5, RB6 | RD3, RD4, RD5, RD6, RD8, RD9 | CB1, CB2 | | SB2 | |
| Moran et al. (2012) | Report the findings of an evaluation of the impact and outcomes of Individual Budgets (IB) for carers | England | Structured interviews with 129 carers, and semistructured interviews with 13 carers of older people and 11 carers of people with learning disabilities. All interviews conducted 2007-2008. | RB1, RB5 | | CB1 | CD2 | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|---------------------|--|-----------|---|--------------------------|--------------------------|-------------------|---------------------|-------------------|---------------------------|
| Moran et al. (2013) | Report on the impact and outcomes for older people of the recent English Individual Budget (IB) pilot projects (IBSEN) | England | RCT - surveys, structured interviews with 263 older people, and semi- structured interviews with 130 older and disabled people (or their proxies) conducted during 2007. Analysis of data regarding older people, from semi- structured interviews of senior social work staff leading IB pilot in 13 IBSEN pilot sites, conducted in | RB1, RB2, RB3, RB5 | RD3, RD5, RD6, RD8 | CB1, CB2 | CD2 | | |
| | | | conducted in 2006-2007. | | | | | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|-------------------------------|--|---------------------|--|----------------------------------|---|-------------------|---------------------|-------------------|---------------------------|
| Morgan & Zechner (2022) | Compare Cash-For- Care programs supporting older people with health- related social care needs in England and Finland, and their informal carers | England, Finland | Analysis through familialism lens | RB1, RB2 | RD1, RD3, RD10, RD11, RD12 | CB2 | | | |
| Needham (2013) | Look at the limitations of the market in relation to individual purchase of private goods, using Personal Budgets (PB) | England | Multi-method approach, combines framing of PB advocates, with national evaluation data from the National Personal Budget survey, and 123 responses to a survey of day centre workers, sent out in 2012 | RB1, RB2, RB3, RB4, RB5 | RD2, RD3, RD4, RD5, RD6, RD8, RD9, RD10, RD12 | CB2 | | SB1 | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|----------------------|---|-----------|---|-----------------------|----------------------------------|-------------------|---------------------------|-------------------|---------------------------|
| Netten et al. (2012) | Measure out- comes of Individual Budgets, and describe the effects found and how they varied between and within service user group | England | RCT – 959 included in final sample, of whom 510 were in the IB group | RB5 | RD4 | | | | |
| Norrie et al. (2014) | Report on the introduction of individual Personal Budgets for older people and people with mental health problems in one local authority in 2011 | England | Interviews on PB with seven older people and carers, and with seven people with mental health problems, from a single urban, affluent local authority. Study conducted in 2011. | RB1, RB2, RB5 | RD3, RD5, RD6, RD7, RD8 | | | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|------------------|---|-----------|---|--------------------------|-------------------------------|-------------------|---------------------------|-------------------|---------------------------|
| Rodrigues (2020) | Understand how Direct Payments (DP) impact caring relationships and the decisions of older users of care and their perceived satisfaction | England | Semi-structured interviews with 24 DP holders, aged 60 and older, from three local authorities in Greater London area, conducted in 2013. | RB1, RB2, RB3, RB5 | RD4, RD9, RD11, RD12 | | | | SD1 |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|-------------|-------------------------------------|-----------|------------------------|-----------------------|-------------------------|-------------------|---------------------|-------------------|---------------------------|
| Rodrigues & | Examine early | England | Combines | RB1 | RD2, | | | | SD1 |
| Glendinning | evidence on: the | | two studies | | RD4, | | | | |
| (2015) | commissioning and | | based on | | RD8, | | | | |
| | contracting of | | interviews. | | RD12 | | | | |
| | home care services | | The first was | | | | | | |
| | by local authorities and individual | | conducted in | | | | | | |
| | | | three local | | | | | | |
| | older people; and | | authorities | | | | | | |
| | the experiences and | | between | | | | | | |
| | outcomes for | | 2011-2012, | | | | | | |
| | individual older | | and included | | | | | | |
| | people using home | | interviews, | | | | | | |
| | care services | | with senior | | | | | | |
| | | | managers and | | | | | | |
| | | | 18 older | | | | | | |
| | | | persons, as | | | | | | |
| | | | well as focus | | | | | | |
| | | | groups with | | | | | | |
| | | | frontline staff. | | | | | | |
| | | | The second | | | | | | |
| | | | involved | | | | | | |
| | | | interviews | | | | | | |
| | | | with 24 | | | | | | |
| | | | people who | | | | | | |
| | | | had opted for | | | | | | |
| | | | a Personal | | | | | | |
| | | | Budget, and | | | | | | |
| | | | was | | | | | | |
| | | | conducted in | | | | | | |
| | | | 2013. | | | | | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|----------------------|---|---|--|-----------------------|------------------------------|-------------------|---------------------|-------------------|---------------------------|
| Rummery (2009) | Comparative literature review and policy analysis of the role of policy development and outcomes in Cash- For-Care programs | Austria, France, Italy, Nether- lands, UK, US | Comparative analysis | RB1, RB2, RB5 | RD1, RD3, RD5, RD11 | CB1 | CD1 | | |
| Schmid et al. (2012) | Examine the association of welfare state policies and the gendered organisation of intergenerational support to older parents | Austria, Belgium, Denmark, France, Germany, Greece, Italy, the Nether- lands, Spain, Sweden, Switzer- land, Czech Republic, Ireland, Poland | Analysis of SHARE data, from wave 1 (collected in 2004/2005 for 11 countries) and wave 2 (collected in 2006/2007 for 14 countries) based on interviews of people 50 and older who were not in an institution and their partners. | | RD1 | | | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|-------------------|---|-----------|---|--------------------------|-------------------------------|-------------------|---------------------------|-------------------|---------------------------|
| Tew et al. (2015) | Develop an 'ideal type' model of Personal Budgets (PBs) for people with mental health difficulties and compare it to the reported experiences | England | Interviews with 53 people with serious mental health difficulties who had accessed PBs, from three local authorities. Majority of participants interviewed on two or three occasions during 18 month period in 2012-2013. | RB2, RB3, RB5, RB6 | RD6 | | | | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|---------------------|---|-----------|---|-----------------------|-------------------------------|-------------------|---------------------------|-------------------|---------------------------|
| Welch et al. (2022) | Report on Personal Budgets (PBs) and integrative care | England | Interviews with 8 organizational representatives, 23 PBs holders, and 3 service providers. Fourteen service providers completed an online survey and 42 personal health budget support plans were collected. All data collected during 2015-2016. | RB1, RB2, RB5 | RD5 | | | | |
| Wilson (2021) | Report on cash-for- care option | Canada | Grey literature reporting experiences from observation and research | RB1, RB2 | | CB2 | CD1 | SB3 | |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|-------------------------------------|---|------------------------------|--|-----------------------|-------------------------------|-------------------|---------------------------|-------------------|---------------------------|
| Wittevrongel & Faubert (2022) | Insights from two countries on how cash-for-care could improve home care | Germany, Nether- lands | Grey literature reporting experiences from observation and research | RB1, RB2, RB5 | | CB2 | CD1 | SB2, SB3 | |
| Woolham & Benton (2013) | Consider the costs and benefits of Personal Budgets (PBs) to local authority Social Services Departments, and to people using PBs | England | Quantitative analysis based on a single local authority, comparing data for 378 traditional service users and 180 PB holders. For comparison purposes, package costs were defined to be those at June 1, 2009. | | | | | | SD3 |

| Paper | Overview/Aim | Countries | Methods and Population | Recipient Benefits | Recipient Dis- benefits | Carer Benefits | Carer Dis- benefits | State Benefits | Dis- benefits State |
|-----------------------|---|-----------|--|-----------------------|----------------------------------|-------------------|---------------------|-------------------|---------------------------|
| Woolham et al. (2017) | Compare outcomes of older Direct Payment users and those receiving care via a managed personal budget | England | Postal survey with 339 respondents, aged 75 or older, from three Councils with Adult Social Services Responsibilities. Survey conducted in 2013. | RB1, RB2 | RD5, RD6 | | | | |
| Woolham et al. (2018) | Report on the impact of a Personal Budget on the role of unpaid carers of older budget holders | England | Postal survey of 1500 unpaid carers, semistructured interviews with 31 carers. | RB1, RB2 | RD3, RD5, RD6, RD7, RD8 | CB1 | CD1, CD2 | | SD1 |

3.1.5 Stage 5 Collating, summarizing and reporting the results

There were several components to this stage, which might be labelled collation, summarization, and reporting. Levac et al. (2010) have suggested some ways in which the methodology of Arksey & O'Malley (2005) might be advanced. They recommended revising stage five to have three distinct steps "analyzing the data, reporting results, and applying meaning to the results" and that "analysis (otherwise referred to as collating and summarizing) should involve a descriptive numerical summary and a thematic analysis" (Levac et al. 2010, p. 6).

Collation of the benefits and disbenefits identified across all papers is presented in Table 3-2, where the number n in [n] shows the number of papers in which that benefit or disbenefit was identified.

For each paper, Table 3-3 presents a summary of which specific benefits or disbenefits were identified.

To identify themes, all benefits or disbenefits that were reported 10 or more times were examined to see if they shared common or similar content with any other benefits or disbenefits. Table 3-4 shows how the various benefits and disbenefits for the recipient or the carers were categorized to identify five themes, and shows the number of papers in which those benefits and disbenefits were reported. Only CB12, support family carers, was reported in more than 10 papers, but was not included in the themes, because it did not have any other benefits or disbenefits, with which it shared similarities. The five themes are as follows: choice and control; quality of life; gender engraining and inequity enforcing; administrative concerns; amount and fees. These themes, along with elaboration on the benefits and disbenefits included in the themes, are discussed briefly in the next section which presents the results of this review. To identify a specific CfC program, capitals are used, e.g., Individual Budgets, Direct Payments, or Consumer Directed Care²¹. Gender engraining is a significant topic, which is discussed further in Chapter 4.

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²¹ Individual Budgets and Direct Payments were names of programs used in England. Consumer Directed Care is how Australia refers to its programs. In Scotland, the term Self Directed Support is used. To try to enhance readability, I have avoided using these terms, unless they are included in a direct quotation.

Table 3-4 Benefits/Disbenefits Categorized to Identify Themes

| Benefits/Disbenefits | Number of Papers | Theme |
|-----------------------------|------------------|--|
| RB1 | 30 | Choice and Control |
| RB2 | 30 | |
| RB5 | 22 | Quality of Life |
| CB1 | 12 | |
| CD1 | 7 | |
| RD1 | 7 | Gender Engraining and Inequity Enforcing |
| RD11 | 8 | |
| RD4 | 9 | Administrative Concerns |
| RD5 | 21 | |
| RD6 | 15 | |
| RD8 | 10 | |
| CD2 | 8 | |
| RD3 | 8 | Amount and Fees |
| RD10 | 5 | |

3.2 Results

3.2.1 Theme 1: Choice and control

A theme that occurred in most of the selected articles is that CfC programs are designed to provide the recipient with choice and control, which is considered to be a benefit for the recipient. FitzGerald Murphy & Kelly (2019, p. e42) reported that choice "is an undeniable, predominant theme in the literature". A historical explanation for the prominence of choice and control is that CfC arose in response to the call by disabled persons to have greater independence and power over their care, and has expanded into care for other individuals. Much of the literature in English refers to the UK, which has experimented with various designs, under variously named programs, in attempting to provide individuals with greater choice and control²².

Examples of uses of choice and control related to: the care services acquired (Day et al., 2018), including not only direct personal care but indirect services such as gardening; from whom the services are acquired (Bradley et al., 2021); the characteristics of carers hired, e.g., culturally, ethnically, linguistically aligned (Irvine et al., 2017); use of family members (Damant et al., 2020), which may be important for some, including disabled persons, or use of non family members (Arksey & Baxter, 2012) in order to lighten the family's caring duties; and flexibility to vary the arrangements regarding service delivery (Woolham et al., 2017).

Where continuity of carer is mentioned as a benefit, it appeared to occur in conjunction with both choice and control (viz., Arksey & Baxter, 2012; Baxter et al., 2011). Only Tew et al. (2015) identified continuity and control, without listing choice; this may be because they studied

²² For more historical context, see, e.g., Rodrigues & Glendinning (2015), Rummery (2009), and Manthorpe & Stevens (2010).

recovery among those people living with mental health difficulties, in which control and empowerment were emphasized.

Although considerable literature lists choice and control as benefits of CfC programs, one might reasonably ask do recipients want those characteristics or ultimately do they want care, perhaps of high quality and delivered in a dignified manner on a timely basis. In other words, choice and control through CfC programs may be listed as benefits, compared to the manner in which care was delivered prior to the change to CfC, if such (prior) care lacked the desired quality, attentiveness, and timeliness (Rodrigues, 2020). Cash et al. (2017) observed that CfC programs are most successful when they begin with a discussion of a care plan which takes account of care preferences, goals and aspirations that have been missing. Locke & West (2018, p. 221) stated "For most of the participants who had moved to DPs [Direct Payments] from an LA [local authority] managed care package, the choice was a reflection of the difficulty they had with the timing of visits, constantly changing care staff and lack of control that they felt they had over their care." Woolham et al. (2017, p. 972) concluded "direct payment users appreciated the flexibility, choice, empowerment and control offered by direct payments; however, it was also apparent that these things were usually seen not as a 'good in themselves' or in the abstract, but as a practical means of enabling care and support to be provided in particular ways."

This question may be especially pertinent with respect to older adults, which are the population of interest in this thesis. Moran et al. (2013) analyzed data gathered regarding Individual Budgets for working-aged people and older people. They found "Analysis of data on outcomes, collected six months after the offer of an IB [Individual Budget], showed poorer results for older people, compared to younger IB holders." (Moran et al., 2013, p. 835) and concluded "Together these findings suggest no objective collective benefits of IBs for older people, and no benefit to public finances either." (Moran et al., 2013, p. 835). Rodrigues & Glendinning (2015, p. 651) in reviewing the literature reported that relatively few older people elected Direct Payments and cited a statistic from the Quality Care Commission 2010 that "by 2009 still only 3.6 per cent of older people receiving publicly-funded care had this in the form of direct payments" (Rodrigues & Glendinning, 2015, p. 651). Rummery, 2009, p. 643) reported "take-up among older people, ethnic minorities and learning disabled adults remains comparatively low".

3.2.2 Theme 2: Quality of life

The literature contained multiple references to enhanced social capital and improved quality of life for the recipient. The programs referenced occur in various countries, and countries often used a different name to describe their program. The details of the programs are not relevant to this discussion regarding the theme of quality of life, but the different program names are presented for accuracy of reference, e.g., Arntz & Thomsen (2011) with respect to Consumer Directed Home Care in Germany, Bradley et al. (2021) with respect to Self-Direction in Australia, England, New Zealand, and the United States, Cash et al. (2017) with respect to Consumer Directed Care in the United States, the United Kingdom, and Australia, Kelly et al. (2023) in respect of Direct Funded home care in Canada, and in respect of the cash-for-care programs in England (Damant et al., 2020 re Direct Payment; Manthorpe & Stevens (2010) re Personalisation; Netten et al., 2012 re Individual Budgets). Some excerpts from the literature show the range of satisfaction, which is an indicator of quality of life:

- "Being a direct employer was seen as a key element in explaining higher satisfaction rates for direct payment holders. People who employed their personal assistants directly rather than through a care agency got better continuity, greater control and an enhanced quality of life" (Needham, 2013, p. 4)
- "an access to economic capital which enabled them to have a better quality of day-to-day life" (Tew et al., 2015, p. 190-191)
- and more lyrically, "'I wanted to be a song writer, and now I'm writing my own lyrics." (Bradley et al., 2021, p. 299).

Self-reported satisfaction may indicate enhanced psychological quality of life, but not be a good indicator of physical well-being, as evidenced by the following citation from Columbo et al. (2011). Reporting on CfC in Israel, Columbo et al. (2011, p.50) stated, "Beneficiaries in the cash-for-care scheme have shown greater satisfaction but decreased well-being, compared to individuals receiving in-kind benefits." On the other hand, reporting on changes after the introduction of CfC in Germany, Wittevrongel & Faubert (2022, p. 2) stated "greater self-determination leads to more independence, better health, and better adjustment to increased care needs", which suggests that both psychological quality of life and physical well-being have been enhanced.

There was less literature regarding the experiences of carers under CfC programs, but the benefit described by carers was enhanced quality of life, e.g., being more involved in activities of their choice, having greater control, being able to arrange time off (Moran et al., 2012), having a better relationship with the care recipient and spending fewer hours in caring (Jones et al., 2014), more freedom, happier and healthier (Larkin, 2015), greater flexibility especially for those in an informal care role (Laybourne et al., 2016), having assistance with care duties (Griffiths & Ainsworth, 2013), and a feeling that for the first time the care they had been providing was recognized (Cash et al., 2017).

Although both Rummery et al. (2009) and Woolham et al. (2018) reported enhanced quality of life for carers, they also reported reductions in quality of life for carers, which is a disbenefit. Rummery et al. (2009) mentioned that inserting cash into the care relationship provides power and control, which could provide conditions for potential abuse of the carer. Woolham et al. (2018) reported that some carers felt the payment of a Direct Payment to the recipient affected the carer's ability to maintain a social life outside their carer role. Columbo et al. (2011) suggested that it may be important to distinguish between whether the CfC benefit is paid directly to the carer, i.e., a carer's allowance, or indirectly through the care recipient, and further with respect to the carer's allowance whether the state philosophy regarding eligibility is universal, based on need, or means-tested. Where the carer's allowance is paid directly, within a needs-based system, such as in the Nordic European countries of Denmark, Finland, Norway, and Sweden, the payment creates a formal employment relationship with employment protections, which may enhance carer self-worth. Wittevrongel & Faubert (2022) indicated that both the amount of the CfC benefit and the extent of market regulation may be important to the carer's quality of life. In Germany, where the CfC payment is made to the recipient, who in turn hires the carer, and the amount of the benefit is less than the equivalent cost of in-kind care services, and where the care-employment is unregulated, informal carers may be employed on

unfavourable terms to themselves (Wittevrongel & Faubert, 2022), which one might expect to reduce quality of life of the carer.

3.2.3 Theme 3: Gender engraining and inequity reinforcing

Six papers (Dudova, 2022; Flood, 2017; Flood et al., 2021; Martinez-Lopez et al., 2023; Morgan & Zechner, 2022; Schmid et al., 2012) listed gender engraining as a disbenefit. By gender engraining, I refer to outcomes that result in, or that continue, men dominating or oppressing women, or which create, or promulgate, unequal or disadvantageous consequences or results for women. I have listed gender engraining as a recipient disbenefit because I do not believe that an enlightened recipient would wish to construct or engage in a gender engraining situation, especially if there were non gender engraining approaches available. Although I have listed it as a recipient disbenefit, it pertains to the whole care relationship, so it might have been listed as a carer disbenefit as well. A number of other papers, which were excluded for review in this chapter, discussed caring and CfC from a feminist perspective. In order to provide a fuller consideration of this broad and important topic with respect to the disbenefits for both the recipient and the carer, I have discussed it in detail in Chapter 4.

Dudova (2022) reported on a cash allowance in the Czech Republic that was paid to children in respect of caring for parent(s). They observed that daughters treated the allowance as the money of the parents and did not claim it, whereas sons treated the allowance as a means to purchase care services for the parents, obviating them of the need to render such care themselves.

Flood (2017) identified the possibility that the introduction of a CfC program could impact women's participation in the workforce. Flood et al. (2021, p. 13) explained that introduction of CfC might "encourage more working-age women to provide more informal care, this could reduce their participation in formal employment and, in the longer run, reduce their lifetime income-earning potential".

Martinez-Lopez et al. (2023) reported on the effect of the Autonomy and Dependence Law in Spain, which they claimed reinforced the Spanish tradition of treating LTC as a familial responsibility assigned to women. Summarizing the results of their survey into four clusters²³, they reported that within the first two clusters there are 55.2% of caregivers, who are poor women, inactive or unemployed, and that the majority of caregivers in each cluster used the CfC as the main basic income (Martinez-Lopez et al., 2023, p. 1959, Table 3).

Morgan & Zechner (2022) used a familialist lens to analyze CfC programs in England and Finland. Within the traditional family in those countries, informal caregiving is predominantly done by family members who are women, and is considered gender engraining. However, if the CfC programs were able to produce a context of supported or optional familialism, then they would not be considered gender engraining. Because of the means-tested nature of social care in England, the low level of payments, and the tax structure, they argued that the CfC program does not lead to supported familialism, but rather to entrenching traditional

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²³ The four clusters of carers with labels in quotation marks, and with the percentage in the cluster shown in parentheses, are as follows: "poor inactive with cohabitation" (28.1%); "poor unemployed caring someone else" (27.1%); "working with economic resources" (26.2%); "elderly illiterate with cohabitation" (18.6%) (Martinez-Lopez et al., 2023, p. 1959. Table 3).

family roles. Whereas in Finland, Morgan & Zechner (2022) argued the CfC programs have a much stronger appearance of supported or optional familialism. However, Morgan & Zechner (2022, p.11) observed that "when it is placed in the context of other aspects of Finnish long-term care policies, the outcome differs". The context included stricter targeting of "both institutional and home care provision ... [and] ... decreasing availability of public services and insufficient budgeting" (Morgan & Zechner, 2022, p. 11). They concluded "Finnish reforms and austerity measures are arguably forcing individuals to undertake informal care... municipality budget restrictions mean that some applicants who meet the needs-test for ICA [Informal Care Allowance] are not receiving it" (Morgan & Zechner, 2022, p. 11).

Schmid et al. (2012) analyzed data with respect to 14 European countries, with differing extents of familialism. They examined the support for their three research questions, all of which pertained to gender differences and gender inequalities of intergenerational support to older parents within welfare policies. They reported their findings for the group of countries; although, there are differences by individual country. Here I report only their findings with respect to CfC programs. "Generally, welfare states policies were associated with daughters' and sons' sporadic support but only with daughters' involvement in intensive support." (Schmid et al., 2012, p. 47); however, "Our results thus fail to confirm the hypothesis that cash payments actually provide an incentive for children in general." (Schmid et al., 2012, p. 47). Overall, they concluded "welfare state policies seem to affect daughters more strongly than sons ...[they] promote such support from daughters... to a lesser degree, by providing cash-for-care payments...[and] therefore appear to strengthen the gendered organisation of intergenerational support." (Schmid et al., 2012, p. 48).

Gender inequities and caring responsibilities are discussed in greater detail in Chapter 4. The literature also identified other inequities that may be reinforced by CfC programs.

Albertini & Pavolini (2017) used data from waves 1 and 2 of the Survey of Health, Ageing and Retirement in Europe (SHARE) for four countries (Denmark, France, Germany, Italy) and analyzed the impact of service provision of CfC allowances. They concluded that "systems that are mainly based on care services provision (Denmark and France) ...not only grant higher coverage of LTC services but also ensure that access to formal care is equally distributed along the income distribution." (Albertini & Pavolini, 2017, p. 519). Further "both in Germany and Italy [based on cash-for-care programs] individuals' income is positively correlated with the likelihood of receiving formal care." (Albertini & Pavolini, 2017, p. 519).

Coyle (2011) reported that some professional public service workers felt that providing different levels of cash allowances [Individual Recovery Budgets] to different recipients violated the ethos of fairness and equity.

Kelly et al. (2023) studied Direct Funded home care in the Canadian provinces of Alberta and Manitoba, and reported a number of positive and satisfactory outcomes, but noted that decisions in policy design can create barriers, which may result in inequities especially for "low-income individuals, those with limited social supports, and clients with limited English" (Kelly et al., 2023, p. 10).

As well as being gender engraining, CfC which became, for some persons, a main basic income in the Spanish context, as described by Martinez-Lopez et al. (2023), reinforced inequities. Martinez-Lopez et al. (2023) stated that in the Spanish economy post 2006 (when the law was introduced), which was scarred by lack of formal employment opportunities, in which the dominant welfare philosophy regarding care provision responsibility was that the state is subordinate to the family, the inactive and unemployed were encouraged to engage in care relationships to receive CfC income. Because the level of this income was low and did not qualify the individual for social security credit, a consequence of accepting CfC was that carers remained outside the formal employment sector and poverty was entrenched.

In addition to the gender inequities within traditional-family care-sharing responsibilities, Morgan & Zechner (2022) found that the eligibility criteria for CfC receipt and the programs' administration in both Finland and England reinforced inequity across income groups with low income individuals and families being disadvantaged. In Finland "because the rules are more likely to exclude them from using the scheme...[and]...in England where low income family members live together they are prevented from being employed to provide care using the adult's direct payment" (Morgan & Zechner, 2022, p. 14).

Rodrigues (2020) observed that for those recipients of a Direct Payment used to purchase carer services [personal assistants], many of the personal assistants were from ethnic minorities, which may be due to a continuing exercise of power over minorities. Rodrigues (2020) reported a few instances of carer abuse among those interviewed, possibly arising because the employer-recipient had power over the carer. Rodrigues (2020) also observed symbolic gift exchanges that arose through the reciprocal nature of the care relationship, for which the concomitant power dynamic was unclear. The practice of reciprocal gift exchanges reported in Direct Payment arrangements could be interpreted as mutually reciprocal, or it might be construed as a way in which the employer-recipient created indirect power.

As well as the gender engraining disadvantages of CfC discussed by Rummery (2009), the "marketized, consumerist mechanism...is likely to create and exacerbate social divisions already apparent between different social groups" (Rummery, 2009, p. 642-643). In other words, market mechanisms are likely advantageous to those with strong market positions and disadvantageous for those in weak market positions, reinforcing inequities, e.g., in the UK "take-up among older people, ethnic minorities and learning disabled adults remains comparatively low" (Rummery, 2009, p. 643). Although the impact of CfC and power relationships is underexplored, Rummery (2009) suggested that in capitalist societies money is a form of power and one controlling the money can exert influence, which might result in abuse.

3.2.4 Theme 4: Administrative concerns

There were a number of disbenefits identified, which may not necessarily be inherent to CfC programs, but rather may relate to the way in which the specific programs were implemented and administered. This subsection describes some of the recurring disbenefits that may be related to administration.

Bureaucracy was frequently cited in many different countries²⁴, e.g., England (Arksey & Baxter, 2012; Columbo et al., 2011; Damant et al. 2020; Flood et al., 2021; Griffiths & Ainsworth, 2013; Hamilton et al., 2016; Irvine et al., 2017; Larkin, 2015; Locke & West. 2018; Manthorpe & Stevens, 2010; Moran et al., 2013; Needham, 2013; Norrie et al., 2014; Welch et al., 2022; Woolham et al. (2017); Woolham et al., 2018), Australia (Day et al., 2018), Canada (Kelly et al., 2023), Germany and the Netherlands (Flood et al., 2021) and in studies involving multiple countries, such as Micai et al. (2022) in respect of UK, US, Italy, and Australia, Rummery (2009) in respect of Austria, France, Italy, the Netherlands, UK, and the US, and Columbo et al. (2011) in respect of Germany, the Netherlands, US, UK, Spain, Korea, **France**, and **Israel**. This may not be surprising when one recognizes that in a CfC program, money is being provided to some recipient to arrange the services; and the party granting the funds may perceive some fiduciary or other responsibility to ensure the funds have been used as intended. Where intended may be defined by law or regulation.

A related concern expressed by recipients, which may be a manifestation or the result of bureaucracy, was the complexity involved in managing the budget within the rule-bound and reporting framework (Arksey & Baxter, 2012; Irvine et al., 2017; Larkin, 2015; Locke & West, 2018; Micai et al., 2022; Moran et al., 2013; Needham, 2013; Norrie et al., 2014; Rodrigues & Glendinning, 2015; Woolham et al., 2018). In a number of cases, carers became involved in the program's management, and they reported that the administration was stressful (Damant et al. 2020; Griffiths & Ainsworth, 2013; Larkin, 2015; Moran et al., 2012; Moran et al., 2013; Woolham et al., 2018), which is a disbenefit. Moreover Locke & West (2018) argued that in an age of austerity, CfC programs are designed as a way to managing waning budgets, not as a way to provide care, and administrative rules and quality decline accompanied such management.

Possibly directly related to the bureaucracy and administration were the reports by recipients of a lack of transparency regarding how the program operated (Arksey & Baxter, 2012; Baxter et al., 2011; Day et al., 2018; Griffiths & Ainsworth, 2013; Hamilton et al., 2016; Locke & West, 2018; McGuigan et al., 2016; Micai et al. 2022; Moran et al., 2013; Needham, 2013; Norrie et al., 2014; Tew et al., 2015; Woolham et al., 2017); Woolham et al., 2018). Taking all of these various disbenefits into account, it is not surprising that a number of recipients reported feelings of powerlessness, fear regarding what might happen, and frustration (Day et al., 2018; Griffiths & Ainsworth, 2013; Manthorpe & Stevens, 2010; Micai et al. 2022; Needham, 2013; Netten et al., 2012; Rodrigues, 2020; Rodrigues & Glendinning, 2015).

3.2.5 Theme 5: Amount and fees

The amount of the CfC allowance, while not an inherent disbenefit of CfC programs, can be a disbenefit, if it is inadequate, as reported in eight papers (Griffiths & Ainsworth, 2013; Micai et al. 2022; Moran et al., 2013; Morgan & Zechner, 2022; Needham, 2013; Norrie et al., 2014; Rummery, 2009; Woolham et al., 2018). In addition, five papers reported that those receiving CfC allowances encountered fees or charges for some services, which they would not have incurred, if they received services instead of an allowance (Kelly et al, 2023; Locke & West, 2018; Manthorpe & Stevens, 2010; Morgan & Zechner, 2022; Needham, 2013). For

²⁴ Countries are listed in bold in this paragraph for ease of reading.

example, individuals in Alberta and Manitoba reported that the hourly rates charged by care agencies were higher than the rate on which the CfC program was calculated (Kelly et al., 2023, p. 6). Needham (2013) examined the practice behind the theory that CfC recipients would pool their budgets to maintain day care centres. She found that this did not occur and that day care services were closed, operated with a reduced menu of services, or raised the fees for their services. Some respondents interviewed by Manthorpe & Stevens (2010) expressed concerns regarding the higher costs of delivering services and recruiting workers in rural areas, resulting in higher costs being borne by rural recipients purchasing care themselves.

3.2.6 Benefits and Disbenefits for the State

The research methods used mainly in the selected papers, which are based on information gathered from interviews with recipients, carers, or administrators or on an analysis of data sets, are not as likely to identify potential benefits and disbenefits for the state; as would say, interviews with policy makers regarding what their desired outcomes were, and what obstacles the implementation of such programs were encountered. For completeness of the discussion regarding benefits and disbenefits, those for the state are described herein. The next paragraph lists benefits and the subsequent remaining paragraphs of this subsection discuss disbenefits, with some caveats.

Expanding CfC programs to all those in need of social care, e.g., older persons or persons with mental health issues, increased universal access to the methods of delivery of social care services (Needham, 2013). Depending on how the CfC programs were implemented, there were opportunities for cost savings, e.g., if the amount of the CfC allowance was less costly that the services which would have been delivered otherwise (Arntz & Thomsen, 2011; Columbo et al., 2011; Flood, 2017; Flood et al., 2021; Lamura, 2014; Micai et al., 2022; Wittevrongel & Faubert, 2022); although the analysis by Needham et al. (2013) indicated that Personal Budgets were not cost-effective for older adults. When the recipient is enabled to purchase the services judged most desirable, there may be a more efficient service mix (Arntz & Thomsen, 2011; Flood et al., 2021; Wilson, 2021; Wittevrongel & Faubert, 2022).

There may be philosophical concerns regarding CfC programs, depending on what the responsibility of the state is viewed as being for the care of its people. There is the issue of whether it is appropriate to introduce a consumerist model into social welfare, which may undermine public service provision (Columbo et al., 2011; Rodrigues, 2020; Rodrigues & Glendinning, 2015; Woolham et al. 2018), as well as the ethical issue of moving the responsibilities for acquiring social care to the care recipients (Locke & West. 2018). These are both disbenefits at a policy, i.e., state, level. A consequence of the implementation of a CfC program may be that it substitutes formal care for informal care provision (Arntz & Thomsen, 2011; Columbo et al., 2011; Larkin, 2015). As Columbo et al. (2011) stated this might be viewed as a benefit or a disbenefit, depending on what the specific policy objectives are with respect to specific groups, e.g., substituting formal care might provide some relief to unpaid carers, a benefit, but might introduce structures for abuse of power by a recipient-employer over a carer, a disbenefit.

One of the philosophical underpinnings of the consumerist model is that in a market economy, the market can be expected to respond to the needs of individuals enabled to purchase services they desire. Given the range and nature of social care services, and the presence of family members and others willing to provide unpaid care, there may be impediments to the market operating efficiently. Evidence that this may be the case are reports that there was a decline in quality of services delivered and available in some regions (Baxter et al., 2011; Columbo et al., 2011; Flood, 2017; Larkin, 2015; Manthorpe & Stevens, 2010; Micai et al. 2022; Needham, 2013; Rodrigues, 2020), and that the market was not responsive to the needs of some recipients in certain regions, where turnover concerns were expressed (Baxter et al., 2011; Columbo et al., 2011; Damant et al. 2020; Day et al., 2018; Manthorpe & Stevens, 2010; Morgan & Zechner, 2022; Needham, 2013; Rodrigues, 2020; Rodrigues & Glendinning, 2015).

3.3 Thinking about the future, part 2

Thinking about the future, part 1 ended with the observation that Ontario would likely consider the possibility of implementing a CfC program, because of the care needs accompanying demographic change, which will likely outpace the ability of the government to respond fully to these needs. Some of the benefits discussed in this chapter could be used to generate support for a CfC program. For Ontario, the potential that a CfC program might provide cost-savings would be viewed positively. In Chapter 2, projections that care costs might triple (MacDonald et al., 2019) and concerns that planned supply may not keep up with projected care needs and will depress the budget available for other health care sector programs (FAO, 2021), would create an environment conducive to the provincial government considering programs that offered cost savings.

Undoubtedly there would be some advocates of market-oriented economies that would see a benefit in substituting cash for state-provided care.

There would likely be care recipients who would see a benefit in receiving cash to arrange their care, rather than receiving state-provided care, especially if there are waiting lists for state-provided care, and if its provision seems bureaucratic. The main benefits of CfC programs reported by recipients are greater choice and control. Even though older adults were found to have lower take-up of direct payments (Rodrigues & Glendinning, 2015; Rummery, 2009), if service provision deteriorates, having the ability to choose and control the care providers may be viewed as an improvement, or a lesser evil.

Some carers might also see an opportunity to enhance their quality of life. MacDonald et al. 2019) projected that family members would need to increase their caring activities by 40%. If a CfC program provided a way to compensate family members for some of this care, which otherwise would be unpaid, it might be viewed as beneficial.

These are the types of arguments one might expect to be advanced regarding the positive aspects of implementing a CfC program.

Chapter 4 Considerations Relating to Women Care Recipients and Carers

Chapter 3 has provided an answer to the main research question, which is "what are the considerations and potential benefits regarding incorporating a cash-for-care program in Ontario's approach to care provision for older adults". The supplementary research question, addressed in this chapter, is "what considerations are especially relevant to women who are care recipients or carers, regarding the implications of a cash-for-care program".

In discussing considerations regarding incorporating a CfC program, it is important to give attention to the implications for women, because of the disproportionately large role that women play within the approach to care provision, not only in delivering care in paid and unpaid roles, but as residents within LTC homes. As such, any changes to the care approach, such as implementing a CfC program, could have disproportionately large consequences for women. If such changes could be gender engraining, as will be discussed in this chapter, it is important to consider the roles women play in providing care and how they might be affected by any changes.

Women make an important contribution to the functioning of the care system, both through paid formal labour and unpaid care provision. Women in Canada spend an average of 3.0 hours per day on unpaid household care work, including caring for children or adult family members, chores, and other household duties, and men spend 2.4 hours per day doing the same tasks (Houle et al., 2017). Women are overrepresented in Canada's care economy, comprising 80% of workers in health occupations (Statistics Canada, 2019), which includes 90% of nurses, 75% of respiratory therapists, 80% of medical lab workers, and 90% of PSWs - who work in LTC homes and in home care (Statistics Canada, 2016). Women also represent a significant proportion of care recipients. Women as a group live longer than men. In Ontario LTC homes, more than 70% of residents are women (Luna, 2020).

As reported in Chapter 3, important benefits of CfC programs are the choice and control they provide the care recipient. Many Western countries have market-oriented economic philosophies, in which consumer choice and control are hallmarks of well-performing markets. CfC programs are consistent with such an economic philosophy.

Chapter 3 contains a preliminary discussion regarding the potential for CfC programs to be gender engraining, a disbenefit. This is a significant topic, which is multifaceted, for which comprehensive treatment is not possible in such a short space. This chapter will investigate whether there are issues regarding the market context in which women receive or provide care, whether paid or unpaid, which may result in gender engraining outcomes. In other words, is there anything about care, with respect to the context in which women are situated, and/or is there anything in the way that markets are configured, which may result in gender engraining outcomes? Gender engraining outcomes are ones that result in, or that continue, men dominating or oppressing women, or which create, or promulgate, unequal or disadvantageous outcomes for women.

The next section provides a description of the methods used. The following section discusses the results of the analysis. The final section in this chapter, entitled "Thinking about the future, part 3", uses the material in this chapter to build on the "thinking about the future"

sections of previous chapters in the context of an aging population. It presents some guidance regarding the design and implementation of a CfC program, which is mindful of considerations regarding women's position in relation to care.

4.1 Methodological Approach

One systematic method to investigate the supplementary research question would be to perform a scoping review, similar to what was done in Chapter 3. Given the existence of an extensive multidisciplinary feminist scholarship, such an approach could be quite time consuming and labour-intensive. An alternative approach was developed for the chapter, which is rigorous with some potential loss of comprehensiveness. The approach commenced by receiving guidance regarding some relevant feminist literature, and then reviewing that literature and related literature "snowballed" therefrom. The purpose of this first review was to identify topics in which feminist scholars have pointed to aspects, relevant to care, that may be considered gender engraining. Such topics were used to construct a framework for examining the available literature from the scoping review in Chapter 3.

Frameworks may be developed in different ways to serve varying purposes. Spencer et al. (2003) discussed how a framework might be developed and used in research involving qualitative evaluation, and specified four guiding principles around which a framework is based.

"research should be:

- **contributory** in advancing wider knowledge or understanding;
- **defensible in design** by providing a research strategy which can address the evaluation questions posed;
- **rigorous in conduct** through the systematic and transparent collection, analysis and interpretation of qualitative data,
- a credible claim through offering well-founded and plausible arguments about the significance of the data generated." (Spencer et al., 2003, p. 6²⁵)

The methodological approach in this chapter has many similarities to this guidance; although, it is somewhat unusual in that the only qualitative data are derived from literature reviews. To develop the framework, I first investigated an alternative research question "are there characteristics of the nature of care, or of the market context in which women care recipients and carers are situated, which may have gender engraining outcomes?", using a limited selection of feminist literature. As a result of this review, certain topics in the literature were used as the framework, for evaluation of additional literature, which was identified in the literature search in Chapter 3 or was hand-searched. The additional literature was screened and analyzed to answer the supplementary research question, stated in the first paragraph of this chapter.

4.1.1 Identification of topics

As the research question investigates gender engraining outcomes, feminist scholarship was a logical starting point for investigation. Given the extent of the feminist literature that might be relevant, potential sources were identified by thesis committee members. Reading these sources served to identify additional sources. In June 2022, Dr. Fulfer provided a reading list, which she had used in Winter 2022 when she taught PHIL 673/675 concerning care ethics. This

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²⁵ Bolding appears in the original text.

reading list, presented in Figure B-1 in Appendix B, provided an introduction to some of the main authors writing about care ethics from a feminist perspective, such as Tronto and Kittay. Dr. Curtis identified Waring and Folbre as feminist economists. A review of these suggested authors and sources provided a gateway to others, and led to reading books rather than excerpts, which provided a better understanding of feminist perspectives on care.

Five topics were identified that I considered might provide a useful framework for review and screening of additional literature, in respect of gender engraining, namely: care is relational, care work is intimate, familialism, value of women's work, and migrant workers. The latter three may seem rather obvious, e.g., because of the way in which the family does not provide equal rights to all members, or because the inequity in pay for women has been well documented, as has discriminatory treatment to migrant workers, and such discriminations may be magnified by gender. The first two regarding care may be less apparent at first glance. Most feminist theorists would take these as starting points, e.g., Engster & Hamington (2015), and assigning a care responsibility to women seems quite common.

4.1.2 Selection of studies

The literature reviewed to identify the topics to form the framework included 26 items. These were added to the items identified in the literature review in Chapter 3, namely the 573 items from the review of CINAHL, PubMed, and Scopus, and the 1,798 items identified by the grey literature search, for a grand total of 2,397 items. See Figure 4-1.

In performing the scoping review described in Chapter 3, there were certain articles, which presented feminist concerns and also identified benefits and disbenefits of CfC. As such those articles were included in the review in Chapter 3. However, there were also some articles, which presented feminist concerns regarding care, but did not identify benefits and disbenefits of CfC and were excluded from the review in Chapter 3. A list of such references was maintained while performing the scoping review for Chapter 3.

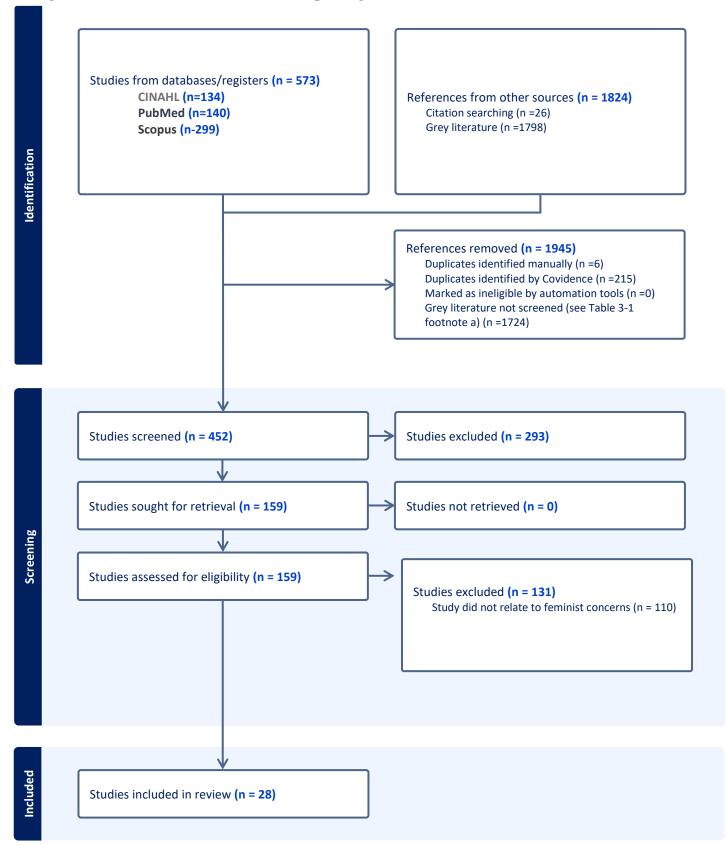
The inclusion/exclusion criteria were as identified in Chapter 3, with the added inclusion requirement that the study discussed issues that might be gender engraining, or which might result in inequitable treatment of women, or pertained to the five topics. After removal of duplicates and other irrelevant items, 159 studies were identified for author-title-abstract screening, which screened out 131 studies. A full text review of the remaining 28 studies was performed. There were six publications included, which did not fall within the date range of 2010 to 2022: four were seminal or foundational works (Folbre, 2006; Folbre, 2001; Kittay, 1999; Waring, 2004), Rummery (2009) that was published in December 2009 and included relevant material, and Martinez-Lopez et al. (2023) that was published online in 2021 but did not appear in print until 2023. The papers were charted to show how many times each paper mentioned one or more of the five topics, which is shown in Table 4-1 in square brackets. The process followed is shown in PRISMA reporting format in Figure 4-1.

Table 4-1 Summary of Included Literature by Topic

| Authors | Source | Type of Work | Care is Re- lational [11] | Care Work is Intimate [9] | Familialism | Value of Women's Work [14] | Migrant Workers |
|---------------------------------|----------------------------|-----------------|------------------------------------|------------------------------------|-------------|-------------------------------------|--------------------|
| Bertogg & Strauss (2020) | excluded in scoping review | academic paper | | | X | | |
| Boris & Parrenas (2010) | hand searched | book | X | X | X | X | X |
| Columbo et al. (2011) | included in scoping review | grey literature | | | X | X | X |
| Da Roit & Le Bihan (2010) | excluded in scoping review | academic paper | | | X | | X |
| Da Roit & Moreno-Fuentes (2019) | excluded in scoping review | academic paper | | | х | | X |
| Dudova (2022) | included in scoping review | academic paper | | | X | | |
| Engster & Hamington (2015) | PHIL 673/675 reading list | book chapter | X | X | | | |
| FitzGerald (2022) | hand searched | book | X | X | | X | X |
| Flood et al. (2021) | included in scoping review | grey literature | | | | х | X |
| Folbre (2006) | hand searched | academic paper | Х | Х | | Х | |
| Folbre (2001) | hand searched | book | Х | х | Х | х | |
| Frericks et al. (2014) | excluded in scoping review | | | | Х | | |
| Gallo & Scrinzi (2016) | excluded in scoping review | academic paper | | | Х | X | X |

| Authors | Source | Type of Work | Care is Re- lational [11] | Care Work is Intimate [9] | Familialism | Value of Women's Work [14] | Migrant Workers |
|--|----------------------------|----------------|------------------------------------|------------------------------------|-------------|-------------------------------------|--------------------|
| Keating et al. (2021) | hand searched | academic paper | X | | | | |
| Kittay (1999) | PHIL 673/675 reading list | book | X | х | X | X | |
| Le Bihan, Da Roit, & Sopadzhiyan (2019) | excluded in scoping review | academic paper | | | X | | Х |
| MacDonald & Charlesworth (2021) | excluded in scoping review | academic paper | | | | X | |
| Martinez-Lopez et al. (2023) | included in scoping review | academic paper | | | X | X | |
| Morgan & Zechner (2022) | included in scoping review | academic paper | | | Х | | |
| Muller (2019) | hand searched | academic paper | X | | | X | |
| Ranci & Arlotti (2019) | excluded in scoping review | academic paper | | | | | X |
| Rodrigues (2020) | included in scoping review | academic paper | Х | х | | | |
| Rummery (2009) | included in scoping review | academic paper | | | X | X | Х |
| Schmid et al. (2012) | included in scoping review | academic paper | | | X | | |
| Strauss (2021) | excluded in scoping review | academic paper | | | x | | |
| Tanner et al. (2018) | excluded in scoping review | academic paper | Х | X | | | |
| Tronto (2013) | PHIL 673/675 reading list | book | X | X | Х | X | X |

Figure 4-1 Search Overview PRISMA Reporting Format – Considerations for Women



4.2 Characteristics of the nature of care or context and of market structure

Based on the initial review of the literature sources outlined above and cited where they appear in this chapter, the following topics were identified as providing a suitable framework for a review of the additional literature, with respect to gender engraining in care: care is relational; care work involves intimacy; familialism; what is the value of women's work; issues in using migrant care workers. They are discussed in turn. The first three relate to the nature of care work and the context in which women are situated. The latter two relate to the structure of markets, within which women work. The 28 papers are shown in Table 4-1, along with information regarding the authors and date of publication, the source, the type of literature, and the number of papers in which the topic was mentioned (i.e., n occurrences are shown as [n]).

4.2.1.1 Nature of care or context: Care is relational

When one thinks about caring for an older person, an infant, or a person with sickness, the relational aspect of care is apparent from the care-receiver/caregiver roles. What may be less apparent is that within our lifespan most people have both care-receiving and caregiving roles. Tronto (2013) argued that even the self-described fully autonomous man, is receiving care of some sort, such as the care that goes into the preparation of food consumed. As such, we are all care-receivers and caregivers, in some capacity, and we may play both of those roles in relation to ourselves and others throughout any given day.

Viewed from such a care perspective we are relational beings (FitzGerald 2022; Kittay, 1999). As relational beings we are dependent and therefore vulnerable. As FitzGerald (2022, p.110) stated, "our embodied well-being and our very identities are vulnerable and shaped by the shifting and unequal relations that comprise our lives". "Providing care is highly personal and emotionally challenging, and largely hidden from, or ignored by, others in society" (Keating et al., 2021, p.616). All three of these factors – the personal nature, the emotional challenge, and the hidden nature – make the setting of a fair market value difficult. Citing the experiences of a care worker in the German elder care sector, Muller (2019, p.4) concluded "care emerges as a complex but also relational process, as a relationship based on interaction, continuity and knowledge". Describing the care of a child with a disability, Kittay (1999, p. 157) wrote "this caring labor so infused with the relationship, has enhanced the relationship and has made it as solid as the bonds of motherhood". Engster & Hamington (2015, pp. 1-2) stated that care ethics requires a recognition of context, and "a more complete understanding of persons and actions enmeshed in relationships and situated in their environment".

Tanner et al. (2018) used what they described as a capability approach, in combination with interviews to analyze care in the context of self-funding. They stated, "the centrality of relationships means that their decision-making is entwined in considerations about others" (Tanner et al., 2018, p. 276). Moreover, they found that care decisions are complex and relational, and often are taken when those needing care are less capable of decision-making. They reported, "Outcomes or well-being depend not just on functioning, in the sense of having access to and being able to manage care, but on a range of psychological and emotional factors that influence participants' attitudes and experiences in respect of self-funding." (Tanner et al., 2018, p. 276). They concluded that an understanding of the complex dynamics of a care

relationship "takes account of the significance of relational factors that influence individual reasoning and decision-making" (Tanner at al., 2018, p. 278).

Traditional economics is more suited to counting transactions, items produced, and goods consumed, than it is to measuring the value of relationships. The acts of feeding and toileting might be priced, as they are when performed by an employed PSW. But the 24-hour on-call availability or the loving tenderness of care delivery, which may arise through a longstanding marriage or partnership relationship, may have greater value to the care recipient than what a market would apply. Such characteristics of care relationships may make what are deemed "fairly-priced CfC benefits", an inadequate representation of the full value of the care relationship. Moreover, often care occurs, within relationships based on marriage or family connections. Kittay (1999, p. 111) described the nonfungible nature of care, in which "who²⁶ does the caring is frequently as important as the care itself", and the who is part of the assessment of quality of care. Kittay (1999, p. 111) referring to dependency work stated, "so much of this work involves affective bonds and is infused with social meaning, it is likely to remain so". Kittay (1999, p. 111) continued, regarding nonfungibility, "this is especially true when dependency work is familial and unpaid, but can be significant even when the dependency work is paid" As such, an approach to valuing care based on market values may be gender engraining.

4.2.1.2 Nature of care or context: Care work involves intimacy

Closely related to the relational nature of care work is that care for older adults often involves intimacy. This may relate to tasks associated with touching and cleaning private areas but also extends to the emotional connections, which may develop between the care recipient and the carer. These emotional connections may be especially strong, and longstanding, between the care recipient and a caring spouse or other family member, but they may also develop between a care recipient and a carer who is not a family member. Ibarra in Boris & Parrenas (2010, pp. 117-118) described the "deep alliances" formed by Mexican immigrant women carers with the care recipient, which may also extend to the recipient's family, wherein "relationships of deep alliance imply that workers commit to stay and care until the end and put their own lives at the service of another for a protracted and undetermined amount of time".

End-of-life care, and care for older adults, can frequently require such care, and may involve extremely deep and complex emotions. Such emotions arise in both the care recipient and in the carers. Emotions may be rationalized, but they seldom provide an uncomplicated and logically consistent way of explaining courses of action, especially involving death and the longstanding partnership and family relationships, which death concludes. Although Kortes-Miller (2018) has correctly concluded, in a book so-named, that "talking about death won't kill you", such conversations are difficult and emotional for most people, especially those with whom we have shared life experiences. Emotions arise if the conversation is held, and also may arise in thinking about end-of-life and the conversations, which may be too difficult emotionally to have. Ibarra in Boris & Parrenas (2010, p.129) reported that in such situations, time, which is

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²⁶ Italics in the original.

an important component of care, takes on a different meaning, "thus, workers no longer function by the rationality of time around the wage".

Regarding the findings from interviews with carers participating in a CfC situation (i.e., Direct Payments), Rodrigues (2020) reported that emotional bonds are created between the care recipient and the carer, regardless of whether an agency employed the carer, or the care recipient employed the carer. For example, a care recipient using an agency acknowledged "the rapport they developed, even if detached, contributed to an improved experience of receiving care of an intimate nature" (Rodrigues, 2020, p. 1480), and a care recipient who hired a carer directly, developed, "close caring relationships that involved feelings of concern for their carers, viewing them as friends or kinlike, even though they had not previously known them" (Rodrigues, 2020, p. 1480).

Within such a context, normal market pricing may not be the only factors in the determination of the amount of CfC payment a carer would accept to provide care. Ibarra in Boris & Parrenas (2010, p.130) reported that the carers were "adamant that their love and compassion are not part of the wage". Ibarra in Boris & Parrenas (2010, p.118) interviewed a Mexicana carer who was not related to the care recipient, who stated, "My reward is not money". One can imagine that between spouses or partners and some family members, there would be a willingness to provide care even though the CfC benefit seemed inadequate. There might be an expectation on the part of the care recipient, real or perceived (by the carer), that there was a right to receive care from a spouse, partner, or family member despite the amount of the CfC payment. Such non-market forces, i.e., "the affective bonds" as Kittay (1999) called them, may engrain gender outcomes.

Without conflating care for older persons with sex work²⁷, it is worth noting the findings of Hoang in Boris & Parrenas (2010, p.180) regarding different tiers of sex-workers in Vietnam, some of whom were able to "capitalize on and engage in expressive and repressive emotional labor". A similar parallel might exist between a care recipient and a carer in which the recipient's emotions might be used to extract care beyond what is compensated by a CfC payment.

Moreover, the alternative to a CfC payment may be receipt of services, e.g., in a nursing home. As Ibarra stated in Boris & Parrenas (2010, p.119), nursing homes are thought by many to prioritize bodily care and ignore emotional needs, to represent cruelty and dehumanization and perhaps elder abuse, and to crystallize a loss of independence. When such perceptions of nursing home care are included in an assessment of an alternative to a CfC payment, nursing home care may be undervalued. This may result in the selection of home care with a CfC benefit, which may be gender engraining.

4.2.1.3 Nature of care or context: Familialism

There is no single universal category into which all families fall. Nonetheless, the idea that the family has a role in social service provision is longstanding, transnational and cross-cultural. Kittay (1999, p. 30) stated "whatever dependency work we pay for today has, at some time, been done by women as part of their familial duty". In 1978, Moroney (1978, p.212) writing about the

²⁷ Although there is a literature describing ways in which sex work involves caring and is care work, e.g., Bernstein (2010).

US stated a widespread belief regarding the family's role within the welfare state: "most social welfare programs developed on the premise that the family and the neighboring environment constituted the first line of responsibility when individuals' self-maintaining capacities were impaired or threatened. It was expected that families would support these members until the situation became overwhelming ".

Since 1978, many countries, especially those in the OECD, have developed policies for state-provided care so that the family is not the individual's only line of support. The extent of these policies differs by country and within countries, e.g., in Canada much care-support policy is a provincial or territorial responsibility. Although a government may set a standard for care provision, the extent to which families and individual family members within families, are accepting of the responsibility for care provision, borne by the state rather than the family, is unknown but likely varies across countries.

Ranci & Arlotti (2019) analyzed why an innovative home care program in Italy, which promoted a shift away from heavy reliance on care provided by family members and immigrant women, to more professional, formalized care arrangements, encountered low take-up rates. They concluded that two factors contributed to the low take-up: "dominant, economically advantageous care arrangements, largely sustained by established welfare schemes, have a significant impact on policy implementation"; and "policy change requires a long-term perspective and major public investment to counter adaptive behaviour that is deeply rooted in the existing institutional framework" (Ranci & Arlotti, 2019, pp. 573-574). Using data from the 2014-2015 release of the SHARE²⁸, Strauss (2021) analyzed the impact on volunteerism by women aged 50 or older, from two perspectives. Where the general orientation within a country regarding the responsibility of family members to act as carers is high, such as in countries in southern and eastern Europe, volunteerism is low; despite implementation of programs to support family carers. In countries marked by higher participation of women in labour markets, such as the Scandinavian countries, volunteerism is higher and increased when more generous care policies were implemented. The results of Ranci & Arlotti (2019) and Strauss (2021) support the notion that a standard or policy set by the state may not be adopted, at all or uniformly, by individuals or within families, which may make it difficult to change practices that are gender engraining.

Bertogg & Strauss (2020) analyzed data for 17 European countries, using SHARE Release 6.0.0, Wave 6, regarding the role of the spouse or partner in elder caring and found five distinct approaches: solo-caregiving, shared informally, shared formally, outsourced informally, outsourced formally. All approaches were used in all countries; however, solo-caregiving is the most common approach in all countries and women are more likely to engage in solo-caregiving than are men.

Schmid et al. (2012) also analyzed data from the SHARE. They examined the association of three types of policies, (professional service provision, CfC programs, and imposing legal obligations to provide support), and the gendered organisation of support to older parents. They found that: "daughters provided somewhat more sporadic and much more intensive support than sons throughout Europe"; and "both legal obligations and cash-for-care schemes were also

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²⁸ SHARE is an acronym for Survey of Health, Ageing and Retirement in Europe.

accompanied by a more unequal distribution of involvement in intensive support at the expense of women" (Schmid et al, 2012, p. 39). This demonstrated how deeply gender roles are engrained in existing family care practices.

Frericks et al. (2014) analyzed the degree to which welfare policies regarding family care for seniors represented social risks for caring family members, in three countries (Denmark, Germany, the Netherlands), all of which have CfC programs. In all three countries the frail care recipient may chose a family member as a care provider and receive support in respect of this care provision. They found differences in the degree to which the program implementation supported family care²⁹, which in turn resulted in differences in the "legal situation as well as the quality and level of social citizenship for family caregivers" (Frericks et al., 2014, p. 74).

Morgan & Zechner (2022) examined the role of family carers within the CfC programs in England and Finland. They concluded that there is "an overarching tendency to familialise or refamilialise the activity of caring for older people, exacerbated by austerity-related politics" (Morgan & Zechner, 2022, p. 1). Given the roles traditionally assigned women within families, such familialization or refamilialization is likely to be gender engraining.

Le Bihan et al. (2019) outlined literature in the familialism and defamilialism debate, and proposed a new typology comprised of six types of familialism depending on the extent of the informal care polices and the strength of care service policies (Le Bihan et al., 2019, p.582, Table 1). In these configurations, CfC programs are "key [and] can be framed as instruments of (supported) familialism, insofar as they financially foster care and, at the same time, as more or less intended instruments to foster (specific forms of) market care" (Le Bihan et al., 2019, p.583). In other words, CfC programs encourage familialism, by providing some monetary encouragement to family members to provide care, which removes the responsibility for delivering such care by the state. Da Roit & Moreno-Fuentes (2019, p. 608) presented France as an example of how caring in LTC is framed as a family responsibility. Family members may assess the situation as one of providing the care on an unpaid basis versus providing the care with some remuneration, rather than assessing the situation as the state paying for the delivery of appropriate care services versus compensating family members to deliver those services. Or as Dudova (2022) found in the cash allowance program in Czech Republic, male children may view a CfC payment as compensation, whereas female children may perceive the allowance as belonging to their parents. If so, family carers may be unlikely to demand or receive fair market value from a CfC program, resulting in a situation that is gender engraining.

4.2.2.1 Market structure: What is the value of women's work

Although the heading of this subsection appears to have meaning, it implies that there is some type of work that can be distinctly classified as "women's work". Such a notion is in itself gender engraining. However, it is reinforced by care markets, in which a large portion of activity is not counted in the economic statistics because it is unpaid, and it is performed by women.

Tronto (2013, p.115) stated "from an economist's standpoint, the limits of markets are twofold: markets are not good at pricing public goods, and markets cannot take into effect

²⁹ To emphasize this difference, Frericks et al. (2014) referred to "semi-formal family care" in Germany and the Netherlands and "formal family care" in Denmark.

'externalities'". She stated that even if these problems could be addressed, there are concerns that "grow out of the nature of care itself, and out of the nature of market thinking" (Tronto, 2013, p. 116). As well as the two limitations of markets cited by Tronto (2013, p. 115), which Folbre (2001) addressed under subheadings "Buying Care" (Folbre, 2001, p. 48) and "Spillovers and Side Effects" (Folbre, 2001, p. 49), Folbre (2001, pp. 51-52) discussed a third limitation "Care as Commodity". Therein she stated, "the quantity and quality of care work depend heavily on cultural values of love, obligation, and reciprocity – values that are seldom adequately rewarded in the marketplace" (Folbre, 2001, p. 51).

The International Labour Organization (ILO) has been studying the impact of not counting unpaid care. According to Addati (2021, p. 150) "care work, including unpaid care work, is vital to humanity and to economies. However, it remains unrecognised, unvalued and unaccounted for in decision-making." To provide an indicator of the inadequacy of traditional market measures of the care market, consider the following statistics cited by Addati (2021) regarding the extent of unpaid care, and as such the misleading nature of traditional market measures:

- "Looking at unpaid care work in particular, the ILO estimates that in 2018, 16.4 billion hours were spent in unpaid care work every day. This is equivalent to 2.0 billion people working eight hours per day with no remuneration." (Addati, 2021, p. 151)
- "Were such services to be valued on the basis of an hourly minimum wage, they would amount to 9 per cent of global GDP." (Addati, 2021, p. 151)
- "In 2018, 606 million women, as against only 41 million men, were either unavailable for employment or not seeking a job due to unpaid care work. These 647 million women and men who are full-time unpaid carers represent the largest pool of participants lost to the labour market across the world." (Addati, 2021, p. 151)

According to Tronto (2013, p. 68) to say that care is women's work is "to say that the current construction of masculinity and femininity permit men to avoid having to take, or to think about, the responsibilities for the caring tasks assigned to women". On such a construction, (productive) work that is counted in the economy is performed in the public sphere, which is the traditional sphere of men, and (reproductive) work, which is predominantly the work of women and is performed in the private sphere, is not counted. Waring (2004) observed that what gets counted in the formal economy tends to be important to what men do, and much of what women do that is enabling is not counted. For example, in the Canadian census of agriculture, "a woman whose hours of work on the farming venture would be the equivalent to a full-time paid worker, but who works in an unpaid capacity, is utterly invisible both as a producer and a consumer" (Waring, 2004, p. 108).

Ibarra in Boris & Parrenas (2010, p. 118) stated that "a classic argument in the domestic labor literature is that it is personalism on the job – close personal relations between employer and employee – that allows employers to continually add tasks and exploit workers". Domestic work and care work are most commonly done by women. Taking place within the home, even if there is a CfC payment, such work will be undervalued and the conditions exploitative, according to the personalism argument.

Boris & Klein in Boris & Parrenas (2010, p. 188) provided a history of the development of law in the US regarding home care work and elder companionship, and how the law "refused to recognize the home as a workplace", wherein much work that women do, occurs. Their account of history regarding New York, suggested a number of factors which contributed to the undervaluing of work done predominantly by women. It included the lack of clear delineation among domestic work, home care work, volunteer care, and services expected of families (Boris & Klein, 2010, p. 194); and action by the state to support care being done in home by independent contractors, as a way to undermine the collective bargaining power of employed social care workers (Boris & Klein, 2010, p. 195). They concluded "such struggles over definition underscore the complexity of both domestic and care work – and their continuing entanglement under a political economy that expects intimate labor on the cheap" (Boris & Klein, 2010, p. 200). In France, where its CfC program is a policy priority, which is lauded for the "optimisation of public expenditure and readability of public action" (Columbo et al., 2011, p. 50), the spouse is not entitled to receive payment under the CfC program. As more care is provided, on average, by women spouses than male spouses, there is another indication of the (lack of) value placed on women's work.

Even if women receive some compensation for care work, say through a CfC program, they may incur large opportunity costs through not working in more highly paid employment. Such foregone opportunity costs are not counted in the economy. In Spain, which has a CfC program, the payments received do not qualify for social security contributions or social security eligibility, placing care workers in a precarious position (Martinez-Lopez et al., 2023). But even if social security contributions and eligibility were attributed to paid care work, as they are in France, there may be opportunity costs in respect of social security through the higher wages of alternative employment, which are foregone.

Even in the public sphere, where men and women perform similar work, women are compensated less than men, i.e., the gender pay gap (Ciminelli et al., 2021; Pelletier et al., 2019). Or as Waring (2004, p. 162) bluntly stated "within the labour force, the exploitation of women is reproduced by way of lower pay, lower status, fewer benefits, and less job security". In other words, it is accepted that women's work is of lesser value than men's work. Hence, care work, which is largely performed by women, is viewed as having less value than work which men do. As MacDonald and Charlesworth (2021, p. 481) observed "caring work is imbued with the status of 'not quite' work". According to Folbre (2006, p. 186) "women's segregation in caring jobs helps explain the persistence of gender differences in pay".

Although care work may be performed in the public sphere, much care work is performed privately, e.g., in homes. As such it is often unprotected by labour and employment law and under-scrutinized by regulators. In such circumstances, even though workers may be compensated through CfC programs, they may lack other protections, which has been the case in Australia (Macdonald & Charlesworth, 2021).

Rummery (2009) analyzed CfC programs in six countries (Austria, France, Italy, the Netherlands, UK, and the USA) and concluded:

"Care work, whether paid or unpaid, is still overwhelmingly the responsibility of women in all six schemes. Perhaps because of the overarching policy objective of cost

containment, in all schemes the actual value of payments to users has been deliberately set low (even in the comparatively expensive Netherlands scheme), which has had the result of reinforcing gendered inequalities: if routed as 'wages' to previously unpaid carers, they have the result of 'trapping' women into gendered expectations of care while at the same time not adequately compensating them for the value of that care; if routed as actual wages to formal carers, they still have the result of 'trapping' women into underpaid and under-regulated employment, with poor prospects for formalized skills and training development or employment protection." (Rummery, 2009, p. 642)

Muller (2019) made the even more fundamental argument that it is inherent to capitalist societies to undervalue care work. She provided some history on the development of Marxist-feminist scholarship including: the separation of the production and reproduction spheres, which are typically assigned to men and women respectively; and the concept of double free labor that produces surplus value and ignores the need for care. She added to the analysis of capitalism and care's position therein, by introducing the concept of abjection, which "literally means degraded or rejected" (Muller, 2019, p.5). Following her line of analysis, she observed that:

- "As a basic mode or tendency in capitalism, value abjection results in an overall devaluation and exteriorization of care, thereby defining care as unpaid work" (Muller, 2019, p. 6)
- "Patriarchal capitalism thus relies and builds on care work, but requires that specific elements of care to be structured as abject, unpaid, and invisible" (Muller, 2019, p. 8); and
- the conclusion that "the care system appears to be built on the premise that care is unpaid work" (Muller, 2019, p. 8).

Hence market values created regarding a CfC program are likely to result in engraining gender. Previously unpaid work is likely to be undervalued and work that is perceived as "women's work" will be undervalued.

4.2.2.2 Market structure: Migrant care workers

Italy has a strong familial culture and a CfC program. Interestingly though care has been largely outsourced to migrant workers. Gallo & Scrinzi (2016, p. 370) cited the following statistics: "In 2011 nearly 900,000 workers were employed in the Italian care sector: 72 per cent of domestic/care workers were migrants, with women making up 88 per cent (Caritas, 2012). The increase in migrant care labour has been both demand-induced and policy-constructed (Andall, 2000; Cangiano et al., 2009; Sciortino, 2004)."

Immigrant employment is not limited to Italy. According to Da Roit & Le Bihan, 2010), "A private care sector not controlled by social and labor regulations has clearly emerged in Italy, Austria, and Germany. According to recent estimates, there are currently between 650,000 and 800,000 (i.e., 5.5% to 7% of the population aged sixty-five and older) immigrant care workers in Italy (Da Roit and Castegnaro 2004; Mesini, Pasquinelli, and Rusmini 2006), between 10,000 and 40,000 in Austria (Streissler 2004), and 100,000 in Germany (Theobald 2009). In these countries, the tasks that families hand over to paid care workers are based on the availability of both funds and relatively cheap and undocumented immigrant labor." (Da Roit & Le Bihan, 2010, p. 302)

Gallo & Scrinzi (2016, p. 378) reported on qualitative research conducted in Italy and stated, "the outsourcing of elderly care labour to migrant workers is central to reproducing hegemonic masculinity in so far as our male informants are able to withdraw from the 'dirty work' associated with daily physical care". Discussing the US, Boris & Klein in Boris & Parrenas (2010, p. 187) stated "some scholars point to the stigma of the labor and the exploitation of this predominantly African American, Latina, and immigrant female workforce and thereby emphasize the cultural ways that linking such women with dirty tasks maintain dominant power relations". In situations of dominant power, the less powerful, i.e., migrant women, are unlikely to receive fair treatment. Even if migrant women were able to bargain from a position of equivalent power, the description of the work as "dirty" carries the connotation that it is base or lowly. As such the fair compensation for such work is likely to be deemed to be lower (than work done by others, such as non migrants or men).

Crossman et al. (2021) reported significant wage gaps in Canada for new and recent immigrants aged 25 to 54, compared to Canadian-born counterparts, for both men and women. In its 2019 report the Ontario Caregivers Organization reported that 45% of caregivers were born outside Canada or their parents were born outside Canada (The Change Foundation, 2019). According to survey information, PSWs in Ontario are more likely to be from visible minorities than the average worker, 42% compared to 23% (CRNCC, 2010, Tables 3 and 4); although being a member of a visible minority is not an indicator of being an immigrant, many in visible minority groups have immigrated. Sinha (2013) reported that in 2012,

"an estimated 54% of caregivers were women. Although the median number of caregiving hours was similar between men and women (3 and 4 hours per week, respectively), women were more likely than their male counterparts to spend 20 or more hours per week on caregiving tasks (17% versus 11%). Meanwhile, men were more likely than women to spend less than one hour per week providing care (29% versus 23%)." Sinha (2013, p. 10)

Da Roit & Le Bihan (2010, pp. 302-303) offered three reasons why CfC programs have contributed to the development of the market of migrant care workers: "immigrants can provide twenty-four-hour care, which would not be available from social services or would be too expensive; the arrangements offer better incomes to these caregivers than they could earn in their home countries; the gray market reduces the pressure of the increasing demand for social services". In discussing the Canadian context, Flood (2021, p. 17) identified a fourth reason why migrant caregivers may remain in situations where they are exploited and their services are undercompensated, "because their chances of remaining in Canada depend on the goodwill of their employers, with whom they are in a particularly intimate relationship".

4.2.3 The framework and the supplementary research question

Spencer et al. (2003) indicated that it is good practice to review the framework in light of further research. This subsection presents a brief summary of the relevant points, which lend support for the hypothesis that "there may be characteristics of the nature of care, or of the market context in which women care recipients and carers are situated, which may have gender engraining outcomes". The review of 26 items led to the development of the five topics used to construct the framework for the subsequent literature review. In light of the results of the further

literature review, presented in this section, there is strong support for the importance of the topics that formed the framework.

The results presented provide considerations regarding why the implications of a CfC program may be gender engraining for women. These considerations provide an answer to the supplementary research question presented in the first paragraph of this chapter. A brief summary follows.

Care is relational and involves intimacy and emotion. It is often performed for a relative or family member. It is not uncommon within families to expect that other members will provide some care voluntarily. This expectation is often more strongly held, in respect of women family members, and especially by men.

Within most economies, greater monetary value is attached to: productive work than to reproductive work; work done in the public sphere rather than in the private domain; and work done by men compared to work done by women. Much care work is performed on an unpaid basis, especially by women.

Migrant workers tend to be paid less than domestic born workers, at least for some period after immigration, and are often employed in jobs to which a lower monetary value is assigned, such as care work. Such jobs may be perceived by the migrant worker as paying better than the employment available in their country of origin and they need to work for pay.

CfC is a market-oriented program. For all of the reasons above, carers, whether traditionally unpaid or employed, are likely to be in an inferior market position to demand a fair wage for their work. Because the majority of care workers are women, and this seems unlikely to change, the implementation of a CfC program is likely to be gender engraining.

4.3 Thinking about the future, part 3

Part 1 concluded that Ontario might consider the possibility of implementing a CfC program in response to supply-side pressures to meet care needs, which will be increasing due to changing demographics. Part 2 presented the benefits that would likely be touted of implementing a CfC program. In Part 3, consideration is given to whether a CfC program would likely be gender engraining. At the time of writing, there is no formal CfC program proposal of which I am aware, so this discussion is somewhat general and conjectural³⁰.

In this chapter, characteristics of the nature and context of care and market structure were examined, and reasons suggested why women in the care market are likely to accept less than the fair value of their care services. Hence, if a CfC program has any hope of avoiding being gender engraining, it must offer fair payments. In determining fair payment, one might consider lost opportunity cost, in a "fair" employment market, i.e., one in which there were no gender pay gap, and other labour practices applicable to formal employment such as social security contributions (i.e., Canada Pension Plan) and paid time-off, were present. This is a big ask. A number of

³⁰ Although, it appears that a form of CfC program has been tried for persons in Ontario with autism. See https://www.ontario.ca/page/ontario-autism-program-interim-one-time-funding.

countries' CfC programs are purposely structured to offer less than the comparable in-kind services, e.g., in Spain (Martinez-Lopez et al., 2023).

According to a recent survey, 96% of Canadians aged 65 or older want to age at home and live independently for as long as possible (NIA, 2021). An individual who needs care to remain able to age at home requires that there are carers available to provide in-home care, and typically requires family members to provide some care. Hence, a condition for a viable CfC program is that it permits family carers to be compensated. In some countries' programs this is permitted, e.g., Germany; however, others impose limits, e.g., France, which excludes payments to a spouse (Da Roit & Le Bihan, 2010). Moreover, it is important that care work be defined broadly, e.g., to include such duties as window cleaning and grocery shopping, in order to recognize the extent of the work associated with maintaining the care recipient at home. Griffiths & Ainsworth (2013) reported there were beneficial outcomes if local authorities were flexible and innovative regarding the services for which direct payments could be used. Although it seems likely that women will continue to provide more care than men do, on average, the design features described in this paragraph and the previous one would help to reduce somewhat the burden on women.

Regardless of the foregoing design considerations, unless there are adequate resources available to provide needed care services for the population, there is potential for inequitable allocation of resources, which will favour the privileged and disadvantage the vulnerable. In such circumstances, women, and especially immigrant women, are susceptible to being engaged on conditions that are gender engraining. Migrant workers, the population requiring care, and the province, may permit migrant care workers to work for less than fair market wages for all of the three reasons cited by Da Roit & Le Bihan (2010) and the additional reason provided by Flood (2021). Migrant women may be inclined to accept care work on terms that are gender engraining, as has been the case in Italy (Gallo & Scrinzi, 2016).

There are conditions in Ontario, which would contribute to a CfC program being gender engraining, such as the following. Care services are not keeping pace with care demand, resulting in those with more wealth being in a preferred position to bid for services. The population in Canada is growing rapidly, mainly by immigration³¹, recently passing 40 million, and this growth pattern applies to Ontario as well. Taken in combination, these factors may lead to privileged families employing migrant women in care roles, in the informal economy. Not only is this gender engraining, but it may also reinforce ethnic and racial discrimination.

If a CfC program leads to more care services being provided at home through a combination of family carers and others, then those without family supports or who cannot afford to hire carers may become dependent on the state. For a number of reasons, including the

18% and Filipino at 14% being the two larger component groups (CRNCC, 2010).

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³¹ It is worth noting that many in Canada's population currently and in the future will be racialized. According to the 2021 census (Statistics Canada, 2022a), the top three birth-countries for immigrants, with percent of immigrants in parentheses, are India (18.6%), Philippines (11.4%), and China (8.9%). Visible minorities have long been workers in the care industry. In a 2009 survey of Ontario PSW, 42% self-identified as from a visible minority, with Black at

norm for men to marry younger women and that, on average, men's life expectancy is shorter than women's, women are more likely to experience a period of isolation near the end-of-life, referred to by Curtis & Andrews (2020) as the alone stage of retirement (ASR). Using 2016 Census data, Curtis & Andrews (2020) showed that there are more than twice as many older women living alone than older men (Curtis & Andrews, 2020, p. 10, Table 2B) and that among single households, poverty rates are high, but even higher for single women than for single men (Curtis & Andrews, 2020, p. 11, Table 2). Any measure which furthers, or does not contribute to addressing, the poverty and isolation associated with the period of the ASR, may be considered gender engraining.

Chapter 5 Concluding Remarks

The first section in this chapter provides a summary of the research questions, methods used, and results of the research. The second section lists the contributions made by this thesis. The third section discusses limitations. The fourth section outlines some other areas for further research. The last section provides a brief conclusion.

5.1 Summary of research questions, methods, and results

The main research question was "what are the considerations and potential benefits regarding incorporating a CfC program in Ontario's approach to care for older adults". In Chapter 3, a scoping literature review focused on the supplementary research question, "what benefits and disbenefits of incorporating a CfC program in the approach to care provision for older adults have been identified in the literature, with primary focus on academic literature?". The academic literature searched was drawn from articles published between January 1, 2010 and December 31, 2022 in the following databases: CINAHL, PubMed, and Scopus. The search of academic literature identified 573 studies. After screening, 38 academic papers were included in the review. This included three papers that were slightly outside the date range but were considered relevant to the research question.

In addition to the academic literature, a selective review of grey literature was performed. Part of the selection process was to consider literature published regarding countries which followed the same approach as Ontario, as determined from the six-cluster typology of Ariaans et al. (2021). In order to identify the countries in the cluster in which Ontario's approach is situated, an analysis was performed in Chapter 2, which answered the supplementary research question, "where to place the approach to care provision for older adults currently used by Ontario, within a typology". Ontario's approach was classified as an evolving private need-based system in the six-cluster grouping, in which Estonia, France, Israel, New Zealand, Spain, United Kingdom, and the United States were included by Ariaans et al. (2021, p. 614). The grey literature search identified 1,798 items. After screening, six studies were included in the review.

From the review of the 44 studies, benefits and disbenefits in respect of the care recipient, the carer, and the state, were identified. There were six benefits and 12 disbenefits identified in respect of the recipient, two benefits and two disbenefits identified in respect of the carer, and four benefits and four disbenefits identified in respect of the state. On considering the benefits and disbenefits, five themes were identified which involved more than one benefit or disbenefit. The five themes were categorized as: choice and control, quality of life, gender engraining and inequity enforcing, administrative concerns, and amount and fees. Choice and control may be considered the dominant theme, as it appeared in 30 of the papers. It would appear to be the primary beneficial basis for implementing a CfC program. However, with respect to care for older persons, choice and control may be a next best option, when there is dissatisfaction with quality care delivery, when what is desired, i.e., the best option, is quality care provided on an as-needed basis (Woolham et., 2017). None of the other themes included only benefits. Quality of life was identified as being a benefit for the care recipient in 22 papers and for the carer in 12 papers; however, there were seven papers that identified a diminishment of quality of life for the carer. The other three themes only included disbenefits.

Because women play a disproportionately large role in the care approach, not only in paid and unpaid care capacities, but also within the care-recipient population in care homes, and because one of the themes was gender engraining and inequity enforcing, a significant disbenefit, another supplementary research question was investigated. Namely, "what considerations are especially relevant to women who are care recipients or carers, regarding the implications of a CfC program". In lieu of performing another scoping review using a new search strategy, a type of framework analysis was used, as discussed by Spencer et al. (2003). A framework consisting of five topics was developed, by reviewing a selection of 26 items from feminist scholarship, based on advice received from thesis committee members and additional hand searching. The five topics identified were: care is relational, care work is intimate, familialism, value of women's work, and migrant workers. The framework was used to examine the items identified in the literature review of Chapter 3, combined with the 26 items used to identify the topics. These items were screened using the inclusion/exclusion criteria identified in Chapter 3, with the added inclusion requirement that the study discuss issues that might be gender engraining, or which might result in inequitable treatment of women, or that pertained to the five topics. After screening, a full text review was performed of 28 studies, which included six studies outside the date range considered relevant. After reviewing the literature within the framework of the five topics, it was concluded that carers, whether traditionally unpaid or employed, are likely to be in an inferior market position to demand a fair wage for their work. Because the majority of care workers are women, and this seems unlikely to change, the implementation of a CfC program is likely to be gender engraining.

One of the significant forces that will exert pressure on the approach to LTC is population aging. Based on calculations using population projections from the Ontario Ministry of Finance (2022), presented in Chapter 2, the percentage of the population in Ontario aged 65 or older by 2043 will increase to more than 20%. Between 2023 and 2043, both the number of people and the percentage of the population aged 85 and older will increase. Moreover, the projected increase in the 85 and over population is larger between 2033 and 2043 than between 2023 and 2033, on all projections, i.e., one might describe this as accelerated aging among the oldest age group. These population projections suggest strongly that the need for care among older adults is likely to increase and the proportion of the population under age 65, who might be available to work as carers, will decline over the 20-year projection period.

Ontario does not currently have a CfC program. However, in response to pressures on the approach resulting from population aging, it seems likely that a CfC program would be considered. CFC programs have been implemented by a number of countries within the cluster in which Ontario's approach lies (Ariaans et al., 2021). The primary beneficial basis for implementing CfC is greater choice and control for care recipients. Access to quality care, on a timely basis, may become challenging, because of the likely increase in demand due to accelerated aging among older adults. Care recipients may feel they would be better able to satisfy their care needs if they received cash through a CfC program, rather than having to wait for the benefits to which they are entitled to be made available. As such there may be a situation in which the province wishes to implement a CfC program, and this meets with the support, perhaps grudging, of older persons, especially those in need of care.

A benefit of CfC for the state, identified in the literature review, is cost savings. This typically occurs because the CfC program is designed to offer less cash to the care recipient than would be the comparable cost if the care were arranged and paid for by the state. Within the cluster in which Ontario lies, evolving private need-based system, the province might rely on the private sector to deliver care to meet the needs of those seeking care, who have received cash through a CfC program to purchase care. Such a combination of significantly increased demand for care due to population aging, combined with care purchasers with funds from a CfC program that are less than the cost of care if provided, may have negative outcomes. In a market with private care providers seeking to make, and possibly maximize, profits, many of those seeking care may not have their care needs satisfied with the funds provided. As well as the group who cannot afford to have their needs satisfied, there is potential that some in need of care will supplement the CfC payment with their own funds and purchase the required care, engraining inequity between those who can afford to pay and those who cannot. Another likely outcome is that there will be additional pressure placed on carers, who are primarily women, and female family members, to deliver the care, which is required but has not been purchased. Such circumstances are likely to be gender engraining.

5.2 Contributions

This thesis makes four contributions that are relevant to public health sciences. First, it situates Ontario's approach to care provision within the six-cluster typology of Ariaans et al. (2021). This may be helpful to researchers trying to understand the context in which Ontario makes policy decisions regarding care, and the types of policy decisions that may be preferred.

Second, this thesis lists the benefits and disbenefits of a CfC program, from the perspectives of care recipients, carers, and the state, resulting from a scoping literature review. This information may be a helpful resource should Ontario, or other provinces or countries, consider implementing a CfC program.

Third, the thesis discusses five aspects of care provision, which if not properly considered and addressed may lead to care policies, such as the implementation of a CfC program, being gender engraining and reinforcing inequity.

Fourth, the thesis highlights the projected demographic changes, which are likely to exert pressures on the approach to care provision. Awareness of how the demographics are projected to change, may enable policymakers to act proactively to mitigate the negative consequences that such change may render, if not addressed. Moreover, by alerting the public to the changing demographics, future planning, on an individual or family basis, may occur, resulting in better preparedness and a smoother transition.

5.3 Limitations

There are a number of limitations with the research approach. The data used is publicly available and has been assumed to be correct. No attempt has been made to verify its accuracy. Ariaans et al. (2021) noted that all the necessary data for Canada were not available. Best efforts have been made to find the required data, but for some data points, data at a slightly different

date or data in respect of Canada rather than Ontario, may have been used. It is possible that this may have affected the results.

One major difference between a systematic review and a scoping review is that a systematic review includes some assessment of the quality of the studies reviewed. No attempt has been made to assess the quality of the literature used in Chapter 3, i.e., it is a scoping review, or in Chapter 4. Much of the literature was based on qualitative research. As such, the information reported may be from a limited sample that is not completely representative, or may contain bias. If the literature lacks quality, is incomplete, or biased, it may have affected some of the results.

It is possible that relevant literature was not retrieved, because the searches in Chapters 3 and 4 were limited to certain databases, and limited by exclusion and inclusion criteria. For example, there may be relevant literature published outside the date range, or in a language other than English. Moreover, no claim is made that all relevant literature has been included. In all the literature searches used in this thesis, some criteria were used that limited the literature included. As such, it is not claimed that the reviews of the literature presented represent a complete, comprehensive, and balanced review of the relevant literature. As such, another researcher might choose to adopt a different search strategy and approach to reviewing the relevant literature and might produce a review with differing perspectives, analysis, and emphasis. what may be the case over the next two decades, it must be recognized that much can change over such a time period. Population projections have been presented on various assumptions (most likely, low, and high), but may prove inaccurate, if experience differs significantly from the underlying assumptions, e.g., if Ontario were to change dramatically its policy with respect to immigration. Moreover, it has been assumed that Ontario's approach, classified as an evolving private need-based system, will persist. However, this approach could be changed by a subsequent government.

Culture and accepted practice are important factors why the context may include discriminatory or inequitable outcomes or practices, such as gender or age discrimination. It is possible to change culture and accepted practices. It is hoped that discriminatory outcomes or practices will be eliminated, but this thesis does not assume changes will occur, which is a possible limitation.

5.4 Areas for future research

There are many possible areas for future research and many researchers working in various areas regarding LTC policy. Only five areas are listed here, but that is not to suggest that this list is comprehensive or is limited to the most important areas. Rather, these areas have been selected because they are of interest to me, have far-reaching implications, and have relevance to some topics discussed in this thesis. The descriptions in the following subsections are merely outlines of the research area, not abstracts or research proposals. There may be many different avenues within an area that could be researched.

5.4.1 Consider other approaches

Having situated Ontario's approach within the six-cluster typology of Ariaans et al. (2021), researchers are well positioned to consider whether this is the most suitable cluster for the future well-being of Ontarians. It also provides a guide for considerations of how any proposed policy interventions would be consistent with the cluster in which Ontario is situated or which might move Ontario's approach to another cluster (which might be viewed as desirable or undesirable depending on the objectives and the method of assessment).

5.4.2 Health human resource considerations

The projections in Chapter 2 suggest that the demand for care will increase significantly as the population ages. This effect will be especially pronounced after 2030, as the large babyboom cohort attains age 85. The Ontario government has acknowledged a need for increased LTC bed supply and has committed to increase the supply by 30,000 beds by 2028-29 (FAO, 2021). However, on the analysis of FAO (2021), "the Province's plan to add 30,000 beds by 2028-29 will likely not be sufficient to keep pace with the growing demand for long-term care from Ontario's growing and aging population". Moreover, committing to and spending on building beds, is only one aspect of supply. To deliver quality care requires sufficient trained staff to provide the care required by those assigned to the beds. FAO (2021) raised concerns that the Province's plans to hire nurses and PSWs would not be met over the period ending 2024-25. The Province's projections for redeveloped beds increases significantly from 13,461 in 2024-25 to 30,701 in 2028-2029. Such an increase in beds will require a significant increase in hiring and training of staff.

The foregoing analysis relates to care in LTC homes. A significant amount of care is delivered by families and others, outside of LTC homes, much on an unpaid basis. The population projections indicate an aging population, which is likely to result in increased care requirements. They also suggest that care recipients' family carers may also be aging and therefore may become less able to provide care. MacDonald et al. (2019, p. 07) projected that by 2050 there will be a large increase in demand for care, "approximately 120% more older adults using home care support" accompanied by a large decline in care provision "approximately 30% fewer close family members – namely, spouses and adult children - who would potentially be available to provide unpaid care".

It will be important to research the projected needs for care and the type of health human resources needed to satisfy those needs; to consider the development of plans to hire and train such individuals; and to provide sufficient support to families and others who are delivering care outside LTC homes.

A related issue, for families facing care needs in excess of their abilities to satisfy them, is that they may hire helpers to provide care. Canada's population is expected to grow in the coming decades, largely as a result of immigration. There is potential for domestic and care help to be provided by immigrant women. Such a pattern has occurred in other countries, such as Italy and Germany (Da Roit & Le Bihan, 2010). This combination of demand-supply dynamics has the potential to result in inequitable treatment of women, and to be further gender engraining.

5.4.3 Cash-for-care and basic income

This subsection continues to delve into the population dynamics discussed in subsection 5.4.2. In the event that beds in LTC homes are insufficient to meet demands, those needing care may rely on family members and others to deliver care on an unpaid basis, or to purchase care from private providers or individuals, such as immigrant women. One group that is very vulnerable in such circumstances are those requiring care who are not admitted to LTC homes, and who lack a family-friend network of carers, and who find the cost of purchased care beyond their means. A significant component of this group are women living in the ASR (Curtis & Andrews, 2020). This is another way in which women may be disadvantaged and their disadvantage further engrained.

As discussed in this thesis, a CfC program is a possible intervention that may be adopted. But as introduced in many countries, the amount of the CfC benefit is less than the value of the equivalent care if the state were responsible for paying for its provision. The group mentioned in the previous paragraph, i.e., those who require care, lack a network of unpaid carers, and find private carers expensive, may see a CfC program as desirable. It would provide additional income to assist with the expenses of care purchasing. In this respect CfC would be a form of income support for those with inadequate incomes, rather than a program to deliver care on a more flexible basis.

Another aspect of CfC as a type of income support or basic income program was reported by Martinez-Lopez (2023) in respect of Spain. Poor carers treated the CfC programs as their basic income. In the potential dynamics outlined, some immigrant women may find that payments received from care recipients who receive a CfC program payment, are their main or only source of income. This may be poverty engraining, in addition to gender engraining.

There is ongoing research regarding basic income plans. It is important that such research clearly distinguishes between basic income plans implemented for that purpose and other income-type programs, such as CfC, which might become a basic income plan for some, with negative consequences.

5.4.4 Implementing a care ethic

Tronto (2013) has advocated replacing the work ethic by a care ethic. In a care ethic, the role that care plays throughout our lifetimes and daily activities would be recognized and acknowledged, as would the responsibility for care resting with all who are capable of providing it, not just women.

Subsection 5.4.2 has outlined how the demand for care, both paid and unpaid, will likely increase. One possible avenue to accommodate some of the increased care needs is through making paid employment, i.e., work, more flexible, e.g., in terms of place of employment, working hours, or job sharing. During the earlier stages of the COVID-19 pandemic, many found working from home a more manageable way to balance and share work and care responsibilities; albeit the forced closure of schools, which added further duties – primarily to women - of children's education, is not an example to be followed. Another area in which more flexible

working arrangements might be investigated, would be working beyond a set retirement age such as age 65, on a part-time or contractual basis.

In a context in which work arrangements were made more flexible to help families manage care requirements more easily, the introduction of a CfC program, which could be paid to family carers, might have beneficial outcomes. There are many avenues of research regarding how to change from a work ethic to a care ethic, which could be investigated. Such avenues include researching barriers to change, and how they may be removed or overcome.

5.4.5 Complex systems

The provision of quality LTC on a universally accessible basis to the population of Ontario, whose size and needs for care are projected to change over time, is an example of a complex system. As such, it could be beneficial to investigate how to apply advantageously research from sustainability and complex system theory. Holling (2001) has contributed to complexity theory by describing the phases and processes of sustainability and development of self-adaptive complex systems. Franzke et al. (2022) discussed tipping points within complex systems, and the potential for uncoupling, in which the system leaves its current state and typically enters a less desirable state. Tipping points may not be readily apparent, and are more easily determined with a historical perspective. To suggest the utility of complex system theory for social science research, and specifically research regarding C4LT, two examples of possible tipping points are presented. They are relevant to the care approach in Ontario in the face of population aging.

It has been reported that the fertility rate in India dropped below the replacement rate in 2019 (Buchholz, 2023). If this situation persists, or the fertility rate drops further below the replacement rate, in conjunction with the continuance of below replacement fertility rates in other countries, including most developed countries, the world's population is projected to level and decline. As well, the world's population will be aging, which will likely be accompanied by increased care demand. A country-specific strategy of hiring immigrant workers to meet care demand may be sustainable at the country-level, in a world in which the population is increasing. It is unlikely to be sustainable in a world in which the population is declining and care needs are increasing in the world's most populous country. Hence, India's fertility rate falling below replacement level might be a tipping point.

I would suggest that when Ontario's over age 85 population begins to increase rapidly, after 2030, that may present a tipping point for Ontario's LTC approach. Care demands are likely to rise in a non-linear way. Non-linearity of demands will have implications not just for LTC budgets, but health and other budgets. Budgetary health pressures in Ontario are likely to have repercussions for federal transfers and intergovernmental dealings.

Positively, Holling (2001) stated that human systems are distinguished by their capacities for foresight, communication, and technology. Research on how complex system theory may be applied to the provision of C4LT in Ontario, may help us bolster all three of these capacities.

5.5 Conclusion

This thesis has provided a list of considerations regarding introducing a CfC program, which may be helpful in considering policy options and outcomes. It outlines ways in which care provision, and the introduction of a CfC program, could be gender engraining and inequity reinforcing. Demographic projections suggest strongly that the approach to care will undergo extreme pressures in the next two decades, with respect to demand for care, and in respect of supply of carers, both paid and unpaid. The thesis situates Ontario's approach to care as an evolving private need-based system. Policymakers and citizens may wish to consider whether this approach is best suited to meet the needs of Ontarians, and the potential implications for care provision if this approach is maintained. All of the foregoing point to other areas for future research, which may have long-lasting implications for care policy, quality of life, inclusion, inequality, and dignity of Ontarians.

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Appendix A Data to Place Ontario in Ariaans et al. (2021) Typology

Table A-1 is based on Table 3 (Ariaans et al., 2021, p.614). The numbered footnotes in the first column refer to how Ariaans et al. (2021) define the item (see corresponding numbering and description in Table 2-2). The lettered footnotes in the last column refer to how the data for Ontario was derived. For Ariaans et al. (2021), the target year for the indicators was 2016.

Table A-1 Means of quantitative indicators of six LTC types in Ariaans et al. (2021) and Ontario

| Indicator/Type | Residual public systems | Private supply system | Public supply system | Evolving public supply system | Need- based supply system | Evolving private Need-based system | Ontario |
|---------------------------------------|-------------------------------|-----------------------------|----------------------------|-------------------------------|------------------------------------|------------------------------------|-----------------------|
| Expenditure ¹ | 161.82 | 811.33 | 1369.15 | 603.97 | 819.81 | 459.42 | 432.96 ^a |
| Beds ² | 21.76 | 56.33 | 53.21 | 24.28 | 64.28 | 43.43 | 30 ^b |
| Recipients ³ | 1.18 | 4.4 | 4.16 | 2.63 | 5.51 | 3.46 | 4.5° |
| Private expenditure ⁴ | 5.77 | 23.94 | 10.49 | 18.17 | 11.81 | 24.25 | 19.9 ^d |
| Cash benefit ⁵ | 1.67 | 2 | 0.25 | 0 | 1.57 | 0.86 | 0 e |
| Choice restrictions ⁶ | 1 | 1 | 3 | 2 | 0.57 | 2.29 | 3.3 ^f |
| Means-testing ⁷ | 0 | 0 | 0 | 0 | 1 | 1 | 1 ^g |
| Life expectancy ⁸ | 17.49 | 19.84 | 19.93 | 21.06 | 19.90 | 20.15 | 21.03 ^h |
| Self-perceived health ⁹ | 16.08 | 42.73 | 63.43 | 22.68 | 49.99 | 52.88 | 45.9 ⁱ |

Based on Table 3 (Ariaans et al. 2021, p.614)

Data Gathered for Ontario – lettering refers to item in last column

- a. Table 2-2 FAO estimates for 2021-22 shows total expenditure of \$7,925 millions (FAO, 2021, Table 2). Adjust by population projection 2021 of 14,826,276 (Statistics Canada, 2022c, Table 2). Purchasing power parity of \$1 CDN is \$.81 USD³². Converted expenditure per capita = 432.96.
- b. Ontario had 30 beds per 1,000 people aged 65 or older at March 31, 2021 (CIHI, 2021).
- c. 4.5% living in nursing homes, chronic care or long-term care hospitals (Statistics Canada, n.d., Box 2)
- d. Table 2-2 FAO estimates for 2021-22 shows resident expenditures of \$1,580 millions out of total expenditure of \$7,925 millions or 19.9% voluntary and out-of-pocket (FAO, 2021, Table 2-2).

³² https://www.pppsalaryconverter.com/

- e. The availability of cash benefits (cash benefit) as an approximation of formal and informal care provision. The cash benefit indicators may take the value 0, describing a system in which only in-kind benefits are available. If the use of cash benefits is bound to specific services and aids, the indicator is coded as 1, while unbound benefits, for which the use of the benefit is at the beneficiary's own discretion, are coded as 2. 0 Decision: Ontario 0 no cash for care benefits.
- f. *Decision:* Choice home care 4; choice institutional care in theory choice but due to waiting lists, limited 2; choice cash 4. Index 3.3.
- g. Accommodation charges are based on ability to make payment, code as 1.
- h. 21.03 is the life expectancy in years of people aged 65 or older for the reference period 2015-2017 for Ontario, both sexes (Statistics Canada, 2023).
- i. For Ontario in 2016, 45.9% of the population who are 65 years and older and perceived their health as good or very good (Statistics Canada, 2022b).

Appendix B Care Ethics Reading List

Figure B-1 Reading List Developed by Associate Professor Katy Fulfer for Offering of PHIL 673/675 in Winter 2022

- 1. Jan 14: Feminist Care Ethics
 - a. "Introduction" to *Care Ethics and Political Theory*, Engster and Hamington (pp. 1-8, stop at "The Editors" section)
 - b. Bahn, Cohen, and Rodgers, "A Feminist Perspective on COVID-19 and the Value of Care Work Globally" (5 pages)
- 2. Jan 21: The Origins of "Care Ethics" in Philosophy
 - a. Gilligan, "Moral Orientation and Moral Development" (15 pages)
 - b. Ruddick, "Maternal Thinking" (26 pages)
- 3. Jan 28: Confucian Ethics and Care
 - a. Li, "The Confucian Concept of Jen and the Feminist Ethics of Care: A Comparative Study" (20 pages)
 - b. Yuan, "Ethics of Can and Concept of *Jen*: A Reply to Chenyang Li (23 pages)
- 4. Feb. 4: Justice and Care
 - a. Held, "The Meshing of Care and Justice" (5 pages)
 - b. Narayan, "Colonialism and its Others: Considerations on Rights and Care Discourses" (8 pages)
 - c. Kittay, *Love's Labor*, Chapter 4 "The Benefits and Burdens of Social Cooperation" (14 pages)
- 5. Feb. 11: Democracy and Care
 - a. Hamington, "Jane Addams and a Politics of Embodied Care" (17 pages)
 - b. Tronto, "There is an Alternative: *Homines Curans* and the Limits of Neoliberalism" (18 pages)
- 6. Feb. 25: Care Work
 - a. Tronto, "The Nanny Question in Feminism" (18 pages)
 - b. Weir, "The Universal Caregiver: Imagining Women's Liberation in the New Millennium" (23 pages)
- 7. March 4: Care in Black Feminist Thought
 - a. Collins, *Black Feminist Thought* Chapter 8, "Black Women and Motherhood" (28 pages) and pp. 262-271 from Chapter 11, "Black Feminist Epistemology" (10 pages)
- 8. March 11: African Ethics and Care Ethics
 - a. Metz, "The Western Ethic of Care or an Afro-Communitarian Ethic? Specifying the Right Relational Morality" (16 pages)
 - b. Gouws and van Zyl, "Towards a Feminist Ethics of *Ubuntu*: Bridging Rights and *Ubuntu*" (22 pages)
- 9. March 18: Care and Solidarity
 - a. Cherry, "Solidarity Care: How to Take Care of Each Other in Times of Struggle" (12 pages)

- b. Gould, "Recognition *in* Redistribution: Care and Diversity in Global Justice" (13 pages)
- 10. April 1: Care and COVID-10
 - a. Baxter, "A Hitchhiker's Guide to Caring for an Older Person Before and During Coronoavirus-19" (11 pages)
 - b. Quinlan and Singh, "COVID-19 and the Paradox of Visibility: Domestic Violence and Feminist Caring Labor in Canadian Shelters" (11 pages)
 - c. (*Recommended*) Tomkins, "Where is Boris Johnson? When and Why It Matters When Leaders Show Up During a Crisis" (12 pages)