University of Alberta

Health and Social Consequences of Caregiving for Family and Friend Caregivers of Older Adults

by

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Abstract

There is growing evidence of social and health consequences that threaten both adequacy of care and caregiver quality of life. Inconsistencies in empirical evidence and lack of an organizing framework have resulted in knowledge gaps in the types and extent of these consequences and of those at high risk of poor outcomes. The purpose of this research was to review systematically the current literature on the health and social consequences incurred by family/friend caregivers and to develop a taxonomy. Results indicated three broad categories of cost: physical health, mental/emotional health and social well-being. Certain characteristics of the caregiver, the care receiver, their relationship and the context and nature of care are all factors that can identify caregivers at high risk of experiencing health and social consequences. Results are discussed in terms of differential experiences by high risk caregivers, identification of knowledge gaps as well as implications of findings for stakeholders.

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Health and Social Consequences of Caregiving for Family and Friend Caregivers of Older Adults

Background

Family/friend caregivers are numerous and provide essential support to adults requiring assistance (Cranswick, 2003). In 2007, the number of Canadian caregivers aged 45 years and older assisting a senior with a long-term health condition was 2.7 million (Cranswick & Dosman, 2008). It is estimated that upwards of 70% of all care provided for ill or dying individuals in Canada is done by family caregivers (Romanow, 2002).

Furthermore, the need for caregivers is increasing so it is important to explore the impact of providing care and to understand the health and social consequences of caregiving. Several reasons underlie the increased demand for caregivers and the interest in understanding the caregiving situation. First, increasing life expectancy has resulted in a rising number of older adults with functional disabilities who depend on others for assistance (Barbosa, Figueiredo, Sousa, & Demain, 2011). Carriere and colleagues predicted that by 2031 the number of older adults in need of assistance could more than double (Carriere, Keefe, Legare, Lin, & Rowe, 2007). Second, demographic changes, including decline in fertility rates and aging of the baby boomers, have increased questions about the sustainability of family members to provide care for older adults (Barbosa et al., 2011; Carriere et al., 2007). A third reason for the increased importance of caregiving is social changes, such as increased participation of women in the labour force and the changing nature and extent of the family network. All of these have raised questions about the sustainability of family members to provide care for older adults (Carriere et al., 2007; Gaymu et al., 2010; Schulz & Martire, 2009).

Caregiving is becoming an increasingly important public health issue. Caregivers are an integral part of the health care system as costs and responsibility for care have been transferred from the public sector to the community (Bittman, Fisher, Hill, & Thomson, 2005; Fast, Williamson, & Keating, 1999). These entrenched and long standing policy approaches (noted by Pat Armstrong in Canada in the late 1990's) (Armstrong, 1996; Armstrong, 1999) along with demographic and social changes, define the current context in which a growing proportion of individuals are, or will be providing significant support to an ill, aging or disabled family member or friend (Habtu & Popovic, 2006; Ward-Griffin & Marshall, 2003). Caregiving labour is essential to the sustainability of the health and social care systems.

Researchers have also examined positive outcomes of caregiving, including a sense of fulfillment (Cohen, Colantonio, & Vernich, 2002), self-esteem (Nijboer et al., 1999) and other perceived benefits and positive outcomes of caregiving (Haley, 2003; Haley, LaMonde, Han, Narramore, & Schonwetter, 2001; Koerner, Kenyon & Shirai, 2009). While individuals may willingly provide care and support to close friends and family and derive satisfaction from doing so, caregiving can result in significant personal consequences to caregivers and their families (Lee & Gramotnev, 2007; Schulz & Martire, 2004). In a recent US report it was noted that, even compared to five years ago, caregiving is becoming a more emotional and financial hardship for some caregivers (National Alliance on Caregiving & American Association of Retired Persons, 2009). Caregivers in Canada face similar challenges as the population ages and individuals have more demands placed on them from employment, changes in family composition, and care responsibilities (Duxbury et al., 2009; Gaymu et al., 2010).

The negative consequences of caregiving are often associated with risk factors which can influence the magnitude and type of consequence experienced. It is important to note characteristics that may identify high risk caregivers or high risk groups to better understand the caregiving experience. For example, there is a significant body of literature on the gendered nature of caregiving. Previous research demonstrates that family/friend care is more likely to be provided by women than men (Cranswick, 2003; Cranswick, Fast, Frederick, Keating, & Perrier, 1999) and the care they provide is often more intense and time consuming than care provided by men (Health Canada, 2002; Pyper, 2006). Caregiver characteristics, as well as amount and type of care, are important factors to consider when reviewing the consequences of family/friend caregiving to identify those at highest risk of experiencing negative outcomes.

These consequences and risk factors have not been studied systematically,. Recent systematic reviews have demonstrated significant gaps in evidence-based approaches demonstrating the value of family/friend care (Hudson, Thomas, Trauer, Remedios, & Clarke, 2011). Furthermore, a comprehensive understanding of the psychological and social response to the family caregiver role is required to reduce the consequences experienced by caregivers. These types of consequences may have the greatest impact on a caregiver's well-being and potentially diminish a caregiver's ability to provide future care. Maintaining the health and well-being of family/friend caregivers is important for their quality of life and to prevent a gap between the family's care needs and the ability to provide care.

Purpose and Rationale

The purpose of this research is to review systematically the current literature on the health and social consequences incurred by family/friend caregivers and to develop a taxonomy. Caregiving is complex and multidimensional and should be studied holistically (Upton & Reed, 2006). The advantage of synthesizing knowledge regarding these consequences is to learn more about the entire experience of caregiving and associated consequences. O'Rourke and Tuokko (2000) commented on the state of research over a decade ago and why it is important to be systematic and holistic.

> One limitation of existing caregiving research is inordinate emphasis on single outcomes (e.g. burden). In other words, most studies focus on specific variables to the exclusion of other affective and physical health outcomes. Although informative, this research does little to disentangle the complex interrelation among negative outcomes and precipitating factors. (O'Rourke & Tuokko, 2000, p.390).

In more recent literature, researchers note that few studies on the impact of caregiving have looked at relationships between different types of outcomes such as both physical and mental health (Salter, Zetter, Foley, & Teasell, 2010).

There are several compelling reasons for undertaking a systematic review of the literature on consequences of care. The first reason is to help understand some of the inconsistencies and differences that exist within the findings. Second, is to increase our understanding of the potential outcomes of caregiving, rather than focusing on single outcomes or specific care situation. The third reason is to identify relevant risk factors to consider regarding characteristics of the caregiver and the care situation.

Differences such as definitions used and populations of caregivers and receivers studied make it challenging to build knowledge across care consequences. Several authors have commented on inconsistencies in the literature (Pinquart & Sorensen, 2003; Upton & Reed, 2006) which are found even within specific consequences such as caregiver depression. Some studies reported that caregivers experienced higher levels of depression than did non-caregivers (Bodnar & Kiecolt-Glaser, 1994; Vitaliano, Russo, Scanlan, & Greeno, 1996) while others did not find significant differences between caregivers and non-caregivers (Haley et al., 1995; Loomis & Booth, 1995). A meta-analysis of the health differences between caregivers and non-caregivers found only small to medium differences with respect to physical and psychological health in these two groups (Pinquart & Sorensen, 2003). The researchers concluded that other variables should be considered as well as study methodology taken into account. In addition, Connell and colleagues (Connell, Janevic, & Gallant, 2001) reviewed findings on caregiver health and found that some studies showed no disadvantage for physical health of caregivers while many did find effects on caregiver physical health. Also studies that compare caregivers to non-caregivers or to a sample of the general population may be problematic as they assume that the groups were equal to begin with (Beach, Schulz, Yee, & Jackson, 2000). An in-depth look across studies that takes into account source of research, study design and methods, and caregiver characteristics, for example, may help explain the inconsistencies and the reasons behind them. There is a need to identify consistent findings across studies and identify where the differences in the findings originate if possible.

Secondly, caregivers experience a variety of potential outcomes, however many studies focus on a single outcome in isolation (as noted in O'Rourke & Tuokko, 2000) and researchers agree on the need to look beyond single measures for consequences of care to include other dimensions or sources of costs (Navaie-Waliser et al., 2002). Some studies only take into account certain stressors or characteristics but not a range that may affect outcomes (Beach et al., 2000). Caregiver burden is a commonly studied single outcome and research on burden has been prolific since Zarit released the Caregiver Burden Scale in the early 1980's (Ohaeri, 2003). Changes in health are an often-studied outcome for family/friend caregivers. Evercare and the National Alliance for Caregivers (NAC) released a report in 2006 that looked at the health risks of caregiving for family/friend caregivers who were in poor health (Evercare & NAC, 2006). Similarly, Yamaki and colleagues compared the objective and subjective health status of female caregivers over age 60 who were supporting adults with disabilities at home to the health status of women in the general population (Yamaki, Hsieh, & Heller, 2009). Schulz and Beach (1999) studied caregiving as a risk factor for mortality in older spousal caregivers, while Savla and colleagues focused exclusively on mood in adult children caregivers (Savla, Almeida, Davey, & Zarit, 2008). Studies in this area also have focused mostly on a particular disorder, for example dementia, and provide information in relation to this particular care situation (Schofield et al., 1999). Researchers are suggesting that future research should be holistic and acknowledge the diversity of caregivers, care recipients, and their situations (Greenwood, Mackenzie, Cloud, & Wilson, 2008).

The current research focusing on specific care situations or outcomes results in a somewhat fragmented knowledge about the set of consequences that might be experienced by a caregiver and may mask other potential outcomes not apparent until the full experience of caregiving is considered. Moen and colleagues studied caregiver well-being (Moen, Robison, & Dempster-McClain, 1995); when psychological well-being was analyzed as a single outcome caregiving had no effect. On the other hand, when caregiver roles and resources were included, a picture of the complex relationship between caregiving and well-being emerged. An intervention study for caregivers of persons with Alzheimer's disease found no significant effects on caregiver burden (Ohaeri, 2003), however outcome indicators that included additional variables such as caregiver attitudes and knowledge show more positive outcomes. A handful of studies report multiple consequences of caregivers. The report "Caregiving in the US" by the NAC and the American Associated of Retired Persons (AARP) (2004) measured burden, physical strain, and emotional stress, while a different study of caregivers supporting adults with disability considered economic, health, and social consequences (Fast, Keating, & Yacyshyn, 2008). Mannion (2008) included psychological and physical effects of providing care for caregivers however did not include any effects on social well-being.

The third reason for this review addresses the idea that the experience of caregiving is complex and studying it across caregivers and situations will help to determine factors influencing the magnitude of consequences experienced by different groups of caregivers to older adults. Researchers identify vulnerable caregivers by focusing on caregiver characteristics as well as intensity and duration of care (Navaie-Waliser et al., 2002). Few researchers have studied the complex interactions among consequences for caregiver groups to determine if there are differences. Support for this holistic approach is evident in the review by Connell and colleagues which found that interventions for caregivers that were comprehensive and involved multiple components showed the most positive results compared to interventions which focused on single outcomes (Connell et al., 2001).

Importance and Contributions

As more individuals provide care for family members or friends, research on the consequences of caregiving will be increasingly important. Evidence shows that, in addition to an increase in the number of Canadian family/friend caregivers, the consequences for these caregivers are high. The first contribution of this work is to provide a comprehensive framework and taxonomy that includes all the domains of health and social consequences and a framework of the risk factors in this body of literature. Providing a framework and common language will facilitate communication and enable clearer and hopefully more evidence-based discussions among various stakeholders.

A current review of the literature is a contribution that will encourage discussions and planning at the policy level as decision makers will be able to consider several relevant factors and allow for a better understanding of the situation. Accurate and up-to-date information can help related systems be more effective and efficient.

Another contribution is to help service providers plan and deliver more appropriate support services for caregivers, as they will have a more complete understanding of the relevant factors. Caregiver associations and family support programs can use this information to initiate discussions regarding the most effective strategies or services to support caregivers in maintaining their own health and well-being. Caregiving in the community has been shown to help delay or prevent the use of nursing home care (Gibson & Houser, 2007), which is an important consideration for policy makers and health care providers and an example of the reliance on family/friend caregivers to reduce system costs. Supporting family/friend caregivers to provide the care they do will have an effect on the use of long term care and demands on the health care system for those needing care (Spillman & Long, 2007). However future work should place importance on maintaining the health and well-being of the caregiver.

A contribution to researchers is the taxonomy, which is a useful tool for studying interactions between consequences as well as to explore differences in the magnitude of effects between caregivers. The taxonomy diagram will be valuable for researchers in order to capture the whole picture of the caregiving experience and not focus in isolation on one consequence. In addition, the identification of knowledge gaps will highlight areas or specific consequences that could benefit from additional attention or further work. Caregiving for a family member or friend is a multi-faceted and complex experience and a better understanding of the consequences and risk factors will assist various stakeholders to be more focused in their actions.

Study Design

Scoping Review and Rationale

The aim of this project was to conduct a knowledge synthesis of the health and social consequences of family/friend caregiving. Knowledge synthesis is the integration of evidence from diverse knowledge sources to help inform knowledge users and decision makers. These types of syntheses are important for establishing the key messages from evidence in a research field prior to knowledge translation and to inform the design and conduct of new research (Grimshaw, 2008). Knowledge synthesis can include several different types of reviews: systematic reviews, meta-analysis reviews, literature reviews, and scoping reviews (See Appendix A for definitions).

A systematic review seeks systematically to search for, appraise and synthesize research evidence, adhering to the guidelines of the conduct of a review provided by organizations such as the Cochrane Collaboration or the National Health Service (NHS) Centre for Reviews and Dissemination (CRD). The strength of this type of review is its ability to draw together all known knowledge on a topic area. On the other hand, strict inclusion criteria can limit the application of this methodology (Grant & Booth, 2009).

A good systematic review is essential to a meta-analysis, which is a technique that combines statistically the results of quantitative studies to provide a more precise effect of the results (Grant & Booth, 2009). Meta-analysis in a review is appropriate when there are sufficiently similar quantitative findings to analyze such as numerical measures of effect. This method is therefore, not appropriate for the topic of this study where the findings do not include consistent measures.

A traditional literature or narrative review is another common type of review which seeks to identify what has been accomplished previously, allowing for consolidation, for building on previous work, for summation, for avoiding duplication and for identifying omissions or gaps. A perceived weakness of the literature review is the lack of an explicit intent to maximize scope or analyse literature collected (Grant & Booth, 2009). The literature review may not involve comprehensive searching techniques and is limited in the analysis. An aim of this project was to assess the scope of the knowledge in this area, therefore a literature review is an inappropriate review type for this study.

After evaluating several different types of reviews used for knowledge synthesis, a scoping review was determined to be most appropriate for this project. A scoping review involves a level of analysis and organization of the findings above and beyond that of a literature review and is more comprehensive and systematic, while allowing for a body of literature that is more diverse than what is used in other types of analysis such as a meta-analysis.

Scoping reviews aim to determine the main concepts underpinning a research area, as well as the main sources and types of evidence available (Arksey & O'Malley, 2005; CRD, 2009; Grant & Booth, 2009). This type of review is generally conducted to examine the extent, range and nature of research in a particular field and produce a profile of the existing literature (Brien, Lorenzetti, Lewis, Kennedy, & Ghali, 2010). Scoping reviews are systematic, methodical and, through synthesis and analysis, can provide greater conceptual clarity (Davis, Drey, & Gould, 2009). Scoping reviews allow for a deeper understanding of how findings relate to each other and to the research question through identifying recurrent themes. Two reasons for undertaking a scoping review fit the purposes of this project: to summarize and disseminate research findings and identify gaps in the existing research literature (Arksey & O'Malley, 2005).

This scoping review provides a map of the literature on the health and social consequences of care for family/friend caregivers. The outcome is a taxonomy of these consequences. A taxonomy is a classification arranged in a hierarchical structure and, in this case, is used to organize the categories of consequences (Keating, Lero, Fast, Lucas, & Eales, 2012). The body of literature on consequences of family/friend care is complex as it includes a range of study types and sources of information. Study types include quantitative methods, qualitative methods as well as cross-sectional and longitudinal designs. A scoping review is especially useful where an area is complex because "it can provide a rigorous and transparent method for mapping areas of research" (Arksey &

O’Malley, 2005, p.30). This supports the appropriateness of this type of review for conceptualizing the consequences of caregiving to develop an organizing framework, a taxonomy.

Due to the exploratory, rather than explanatory, nature of this study and the intent to map the existing research and to look for recurring themes within the literature, a scoping review methodology was the most appropriate methodological fit.

Methodology

The methods for this project draw on a framework for conducting a scoping review developed by Arksey and O'Malley (2005) called the York Framework. Their framework formalizes five stages which had been widely used in previous approaches to scoping reviews. Prior to the introduction of this framework there were no set guidelines for conducting scoping reviews (Davis et al., 2009).

The five stages of the York framework are described below. Further discussion of these stages as they apply to this project follows in the subsequent methods section.

1. Identification of the research question: This step involves drawing on consultations with experts in this area as well as previous research.
2. Identification of relevant studies: To be comprehensive several literature sources are searched such as electronic databases, relevant organization websites and reference lists.
3. Selection of studies to include: The use of broad search terms in electronic databases may generate a large number of abstracts. In order to deal with the results clear inclusion and exclusion criteria are identified.
4. Extraction and charting of information and data within included studies: A multi-stage process is employed which involves extraction of information from individual articles. Extraction of information on study methodology and quality assessment of studies is conducted in this phase.
5. Analysis: The purpose of the final stage is to provide a structure to the literature that has been identified. When research objectives are broad and a large volume of literature is generated, a narrative synthesis is conducted to organize the findings into specific categories of consequences.

Identification of the Research Question and Objectives

This step involved drawing on consultations with Dr. Norah Keating and Dr. Janet Fast, who are researchers in the area of the costs and consequences of family and friend caregiving. Previous research by these researchers as well as other experts in the field was used to identify the research question and objectives of this study identified below.

The research question is: What are the health and social consequences of caregiving for family and friends who provide care to adults?

The objectives are as follows:

1. To determine the current state of knowledge about health and social consequences to family/friend caregivers.
2. Based on this knowledge, to develop a taxonomy of the main domains of these consequences.
3. To determine risk factors influencing the magnitude of consequences experienced by different groups of caregivers to older adults.

Search Strategy Details: Identification of Relevant Studies

In this study the search strategy was developed to capture the most relevant research in the large body of literature on health and social consequences of family/friend caregiving while keeping the search broad enough to be comprehensive. A research librarian was consulted for input on the appropriate search strategy, databases and terms used. Keywords were identified based on common terms used in this body of literature. For example, in addition to family or friend caregiver, ‘informal care’ is a term often used. Terms used to describe consequences that caregivers may experience included outcomes, costs, burden, and consequences. The goal was to conduct an inclusive rather than specific search (searching for example a specific method within a topic) of the literature; thus search terms were of necessity kept very broad. In larger databases terms for specific areas of consequence (such as physical, emotional, social, etc.) were used. Adding additional search terms for the larger databases ensured that the most relevant articles were identified while keeping the number of search results manageable. It was important in smaller databases not to restrict the search with terms that only mentioned specific consequences as the goal was to be comprehensive and to capture all types of health and social consequences. The search strategies are outlined in Appendix B. Table B1 was used in smaller databases and Table B2 in larger databases.

The source of findings was electronic databases comprising peer reviewed journals from a variety of disciplines. Restricting the search to this source ensured a variety of findings while still allowing for a manageable body of literature in terms of content and volume.

Searches were conducted across a range of bibliographic databases. Literature that addresses the consequences of caregiving is diverse. Information is available in databases for different disciplines such as psychology, family studies, nursing, sociology, medicine and gerontology. Small bibliographic databases using the search strategy in Table B1 included: Abstracts in Social Gerontology, Family Studies Abstracts, Gender Studies Database, SocINDEX with Full Text, and Sociological Abstracts. Large databases using the search strategy in Table B2 included: Academic Search Complete, CINAHL, Medline, PsycINFO, and SCOPUS. These are inclusive of databases which contain primarily health-focused articles and those which draw upon social science content.

Screening Process: Selection of Studies Included

Inclusion criteria. Literature was included if it provided data on the health and/or social consequences to family/friend caregivers of an adult over the age of 65 at home or in the community. These criteria identify a particular care situation while providing current and original evidence. Details and rationale for each criterion are provided below the list. Articles were included in the study if they addressed the following criteria:

- family and friend caregivers;
- care to adults over the age of 65 years;
- care recipients living in the community;
- health and/or social consequence to the caregiver;
- published since 1999;
- variety of study designs; and
- written in English.

For the purposes of this study, a family/friend caregiver was defined as an individual over 18 years of age who provided care or assistance to a family member, friend or neighbour who has a physical or mental disability, or is chronically ill, frail, or at the end of life (Duxbury et al., 2009; Health Canada, 2002). Other terms for caregivers were used as appropriate to capture all relevant literature, such as “informal caregiver”. Additional definitions of caregiver and care were found and were captured in the data extraction (refer to Appendix A for a list of definitions).

The difference between a formal caregiver and a family/friend caregiver lies in their theoretical and practical background, but above all it relates to their motivations. Care provided by a formal or paid caregiver has different characteristics, such as financial compensation and scheduled hours, as compared to care provided by a family member or friend. The professional caregiver's motivation is of an occupational kind, whereas a family caregiver is in a position which he or she may not have chosen freely and which constitutes an additional role related to the illness of a loved one (Falchero, 2008).

The focus was on care provided to older adults rather than care to children or young adults in order to capture the consequences of care for family/friend caregivers rather than for parents of children specifically. There is also a large body of literature for care to children with disabilities compared to regular child care as it presents different issues as well (Brehaut et al., 2004; Gerhardt et al., 2003; O’Connell, Bailey, & Pearee, 2003). The age 65 was used as it is the most commonly used cut-off to identify older adults.

Excluding articles that dealt with care to recipients who were in acute care settings or hospitals, assisted living, long term care or nursing home or residential palliative or hospice care was also an important distinction as this presented a different care situation (e.g. in hospital may be due to an accident or short term event). When a care recipient moves to residential care the caregiver enters a new phase of caregiving (Aneshensel, Pearly, Mullan, Zarit, & Whitlach, 1995; Davies & Nolan, 2004; Nolan, Grant, & Keady, 1996), and they experience a new set of factors such as financial stressors, sharing care responsibilities with formal care providers and a changing caregiver role (Nikzad-Terhune, Anderson, Newcomer, & Gaugler, 2010).

Articles that did not provide specific information on the health and/or social consequences of caregiving to family/ friend care providers were excluded. Sources that dealt with economic costs only were excluded. Articles that did not provide information at the individual caregiver level were not included.

Material published since 1999 was included. This allowed for findings to be relevant and appropriate for current care situations, while still accounting for a large body of literature. A review done in 1999 was very broad and included both economic and health and social consequences of caregiving. The current scoping review does not replicate the previous study however it provided information and background for research in this area so literature was included if it was published since 1999.

A variety of study types (qualitative, quantitative, mixed methods, etc.) was included provided that they were published since 1999 and offered measurable data. Results were also limited by publication type (if possible) to include journals and exclude books, book reviews, and conference proceedings. The types of documents that were not included include conference presentations, editorials or commentaries, informational newsletters or pamphlets, and review articles since they did not provide any new original data. Theses and books were excluded due to length and time constraints of this project. Intervention studies were excluded as the literature on caregiver interventions is a separate body of literature and reviews have been done to examine the effectiveness of interventions on reducing caregiving consequences (Van Houtven, Voils, & Weinberger, 2011).

Sources that were in a language other than English were not included in this review due to time constraints and translation cost. Of the English abstracts from non-English articles 33 were included for full text review based on information from the abstract. However, only 2 studies included information on the age of the care recipient while the rest used the term elderly or senior. Of the 33 articles 8 were in Spanish, 9 were in Portuguese and 7 were in Japanese. Other languages included French (3), German (2), and one each in Korean, Dutch, Czech, Italian and Slovenian.

References were organized using EndNote® reference manager software. Initial search results were imported into EndNote® or entered manually. Title and abstract review was done in EndNote®, and references were sorted into included or excluded files. When information contained in the title or abstract was not sufficient to determine inclusion, the source was included for review of the full text article. A final complete list of references was updated throughout the process to indicate those articles that were included, those that were excluded and a brief explanation of why for future information.

The stages of the screening process followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) and are presented below.

1. Identification of references: The total number of references is identified.
2. Removal of duplicates: The first step includes the removal of duplicate references.
3. Screening: The initial review of references and tracking of exclusion reason.
4. Abstract review: The next phase involves screening the remaining abstracts for relevance and eligibility.
5. Full text review: After full text review articles were selected for inclusion in the study.

Data Extraction and Charting: Extraction and Charting of Information and Data within Included Studies

Data extraction or charting was done by a primary reviewer (S. Lucas) with random checks by several reviewers using the developed data extraction table to ensure the criteria were clear. The reviewers assessed whether changes to the inclusion or exclusion criteria were needed. The data extraction table found in Appendix C was initially piloted with multiple references. This piloting was done to ensure the data extraction tool was comprehensive and captured all relevant information within the identified categories. The data extraction table and pilot results were also reviewed by a professor with extensive experience doing systematic reviews to ensure that the data extraction tool was appropriate. The main categories of the data extraction table were:

- Reference source: author, year, title, journal.
- Study details: country, objectives, caregiver details/definition, care recipient details, sample characteristics, theoretical framework, study methods/ procedures, source of data, details on measures/instruments, reliability/validity, analysis.
- Domains of consequences: physical health, mental/emotional health, social well-being, other.
- Additional details: gender differences, magnitude or risk factors, future research, strengths and limitations of the study, recommendations, and comments.

Consequences of caregiving were tracked in order to determine the appropriate domains and sub-categories. Domains identified in previous work were used initially to track the information while additions and/or refinements were expected. All areas and types of consequences cited in the studies were included in the data extraction table. Focusing on the descriptive nature of the material in the charting phase allowed for the identification of additional categories and themes of consequences present in the literature. Creation of these a priori sub-categories provided a structure to the findings and a clearer way of describing the literature (Brien et al., 2010) and informing the development of the taxonomy.

Some additional information was gathered, such as the magnitude of the consequences if available and noting any significant risk factors for consequences of caregiving. Capturing this information also was helpful when looking at the differences between domains of consequences of care.

Analysis: Narrative Synthesis

Narrative synthesis is a useful analytic method for reviews such as this as it provides flexibility and ease of handling a wide range of different types of evidence (Mays, Pope, & Popay, 2005). Narrative synthesis is inherently a more subjective process than meta-analysis, therefore the approach in this study benefitted from a predetermined guideline/framework for analysis and techniques to assess the robustness of the synthesis conclusions and findings.

Guidance for conducting narrative syntheses was developed by the Economic and Social Research Council (ESRC) Methods Program (Popay et al., 2006; Rodgers et al., 2009). Three main steps in conducting a narrative synthesis are: a) developing a preliminary synthesis of the findings of included studies; b) exploring relationships in the findings; and c) assessing robustness of the synthesis produced. The guidance identifies a number of specific tools and techniques that can be used during these steps and the choice of tools depends on the type of evidence included (CRD, 2009; Popay et al., 2006; Rodgers et al., 2009). The steps of the narrative synthesis guidance as undertaken for this review are outlined in Figure 1 and described in the following text.

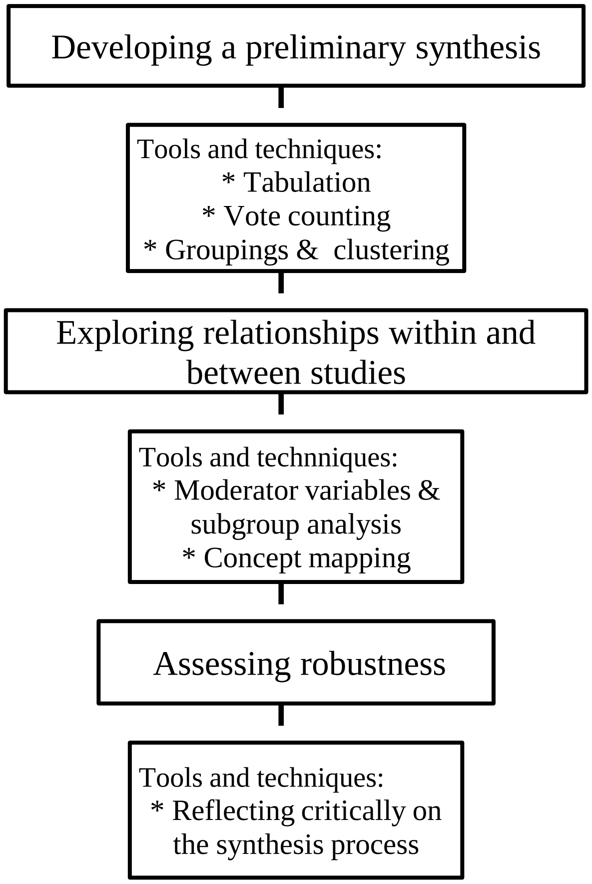

Figure 1. Narrative synthesis process. Adapted from: “Testing methodological guidance on the conduct of narrative synthesis in systematic reviews: effectiveness of interventions to promote smoke alarm ownership and function,” by M. Rodgers, A. Sowden, M. Petticrew, L. Arai, H. Roberts, N. Britten, … J. Popay, 2009, *Evaluation*, 15, p.52.

The first step of creating a preliminary synthesis of findings involved categorizing the findings about consequences into the main domains experienced by family/friend caregivers. The tools and techniques used in the preliminary synthesis included: tabulation, vote counting, and grouping and clustering. Tabulation was used to present data visually and involves extracting data from the primary studies in tabular form. The table was especially useful in creating an initial description of the included studies and provided details on the country of origin, sample characteristics, study design and methods, and health and social consequences. The results of the tabulation were useful for the preliminary synthesis and provided a reference tool for further elements in the synthesis process.

Vote counting involved calculating the frequency with which different types of consequences appeared across included studies and was a useful way of producing an initial identification of the sub-categories of consequences across the included studies. Caution is often urged when using vote counting as the interpretation is complex (Hedges & Olkin, 1985, as cited in Rodgers et al., 2009). However it proved to be a useful descriptive tool along with other analysis techniques.

Grouping and clustering involved looking at the tables to determine the presence of dominant groups or clusters of consequences, by which the subsequent synthesis could be organized. Through grouping it became apparent that there were three main domains of consequences for caregivers: physical health, mental/emotional health and social well-being, as well as sub-categories of consequences within these domains.

The dominant consequence types that emerged from the analysis, which reflect the ways in which consequences have been characterised in research studies to date, were organized into domains and sub-domains or categories. Once the findings were tabulated, counted and grouped using the described tools and techniques, the next step was the development of a taxonomy which identified the main domains of health and social consequences as well as the sub-categories that were prevalent within the domains

Exploring the relationships within and between studies was the second step guided by the narrative synthesis. At this stage the goal was to move beyond identifying, listing, tabulation and counting results to explore relationships within and across the included studies (Rodgers et al., 2009). The tools and techniques used in this stage involved identifying moderator variables, examining differences between sub-group, and concept mapping.

Moderator variables are any variables which can be expected to influence or be associated with the health and social well-being of caregivers. In this stage it was helpful to identify the variables or factors that had an effect on the groups of consequences identified in the first step. Once the individual risk factors were identified they were grouped by the source of the characteristics, such as a characteristic of the caregiver, the care recipient, the relationship between the two, or the nature of the caregiving situation. Given consistent findings, described earlier, that gender is a contributing factor in the consequences of caregiving, differences in consequences by gender of the caregiver and the care recipient were tracked during data extraction and examined in this step.

Concept mapping was used to create a visual diagram of the concepts, in this case, the risk factors, and to group them by source of characteristic identified via the previous tool. This allowed for a visual representation of the hierarchical relationships between the risk factor itself and the source such as female gender of the caregiver. A subsequent analysis was completed to identify relationships between the groups of risk factors and the domains of consequences identified in the preliminary synthesis.

The final element of the narrative synthesis involved assessing the robustness of the synthesis. The analysis of relationships described above should lead to an overall assessment of the strength of the evidence (Rodgers et al., 2009). The credibility of a synthesis depends on the quality and quantity of the evidence base on which it is built, as well as the method of synthesis and the clarity/transparency of its description (CRD, 2009). The technique employed at this stage was to reflect critically on the synthesis process. This was done by reviewing the methodology of the synthesis used and reflecting on its appropriateness for the review and body of knowledge. The validity of the use of guidance presented by the ESRC programme was presented at the beginning of the analysis section justifying it as an appropriate synthesis method. This method has also been adopted by the CRD as the method for narrative synthesis in their guide to systematic reviews (CRD, 2009). The CRD provides research-based evidence on conducting systematic reviews and is highly regarded in the United Kingdom and internationally.

Assessing the robustness of the synthesis also considers the generalizability of the evidence used. Evidence was obtained predominantly from cross-sectional survey studies presented in peer reviewed journals that included representative samples. Several of the tools and techniques were used in conjunction to identify the domains of consequences and the risk factors, thus providing confidence in the findings of the narrative analysis.

Findings

Search Results

The screening process and number of included references at each stage was tracked following these five stages of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) as presented in Figure 2. Details for each step are outlined below:

1. Identification of references: The total number of references identified through database searches was 12,880.
2. Removal of duplicates: The first step included the removal of 5743 duplicate references leaving 7137 titles.
3. Screening: The initial review included 7137 references and exclusion was based on type of document (for example: review) and content in reference title. Based on the title, references were either included for further review or excluded based on the pre-determined criteria. In this stage, the reason for exclusion was tracked in a spreadsheet and 4166 titles were excluded.
4. Abstract review: The next phase involved screening the remaining 2971 abstracts for relevance and eligibility. When information contained in the title or abstract was not sufficient to determine inclusion, the full text was reviewed. Following the abstract review 912 references were included for full text review.
5. Full text review: After full text review of the 912 articles, 49 articles were selected for inclusion in the study. The age of the care recipient was available in the full text at this point and resulted in a significant reduction in the numbers of included articles. In this type of review, it is not uncommon to retrieve a large number of irrelevant studies, therefore only a small proportion of results are included for further review (CRD, 2009; Arksey & O'Malley, 2005).

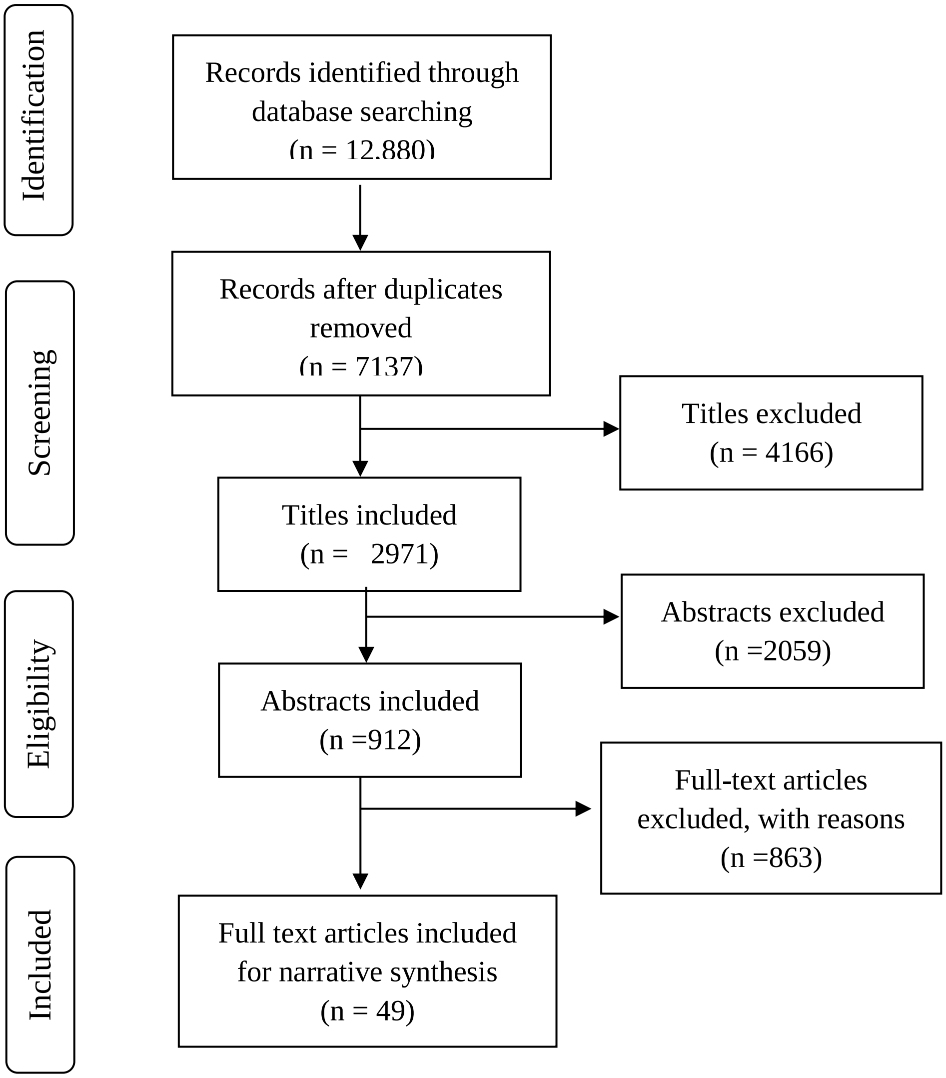

Figure 2. Screening process flow diagram. Adapted from "*P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement," by D. Moher, A. Liberati, J. Tetzlaff, D.G. Altman, and The PRISMA Group, 2009, *PLoS Medicine*, *6*, p. 3.

Description of Included Literature

The final 49 studies included in the scoping review consisted of international literature published from 1999 to 2012. Forty percent of the studies were conducted in North America (14 in the United States, 6 in Canada), 30% (15/49) from Asia (including 8 from Japan), 24% (12/49) in European countries, one study from Australia and one from Central America. The final group of studies comprised 45 quantitative and 4 qualitative studies. The qualitative studies of interviews with caregivers had samples sizes ranging from 5 to 29 caregivers. The quantitative studies were predominantly large scale survey studies with representative samples. A variety of caregiver and care receiver groups was studied.

Information for each article was tracked through tabulation. The columns of the table obtained information on the first author, year of publication, country of origin, characteristics of the study sample, caregiver details, care recipient details, study design and the source of the data. Details of the characteristics for each study are shown in Appendix D.

Main Domains and Sub-Categories of Consequences

The systematic review of the international literature on the health and social consequences of care for caregivers to older adults highlighted three broad domains of consequences: physical health; mental and emotional health; and social well-being. Results showed substantial evidence of consequences in each domain. Thirty-one of the 49 articles contained consequences to physical health, 42 for mental and emotional health and 31 articles for social well-being. Through narrative synthesis, specifically grouping, three main domains of consequences were identified for caregivers: physical health, mental/emotional health and social well-being, comprised of smaller categories of consequences within these domains. Figure 3 represents the taxonomy of health and social consequences of care to family/friend caregivers based on the results of this review. The number of articles containing information on each sub-domain is identified in Figure 3.

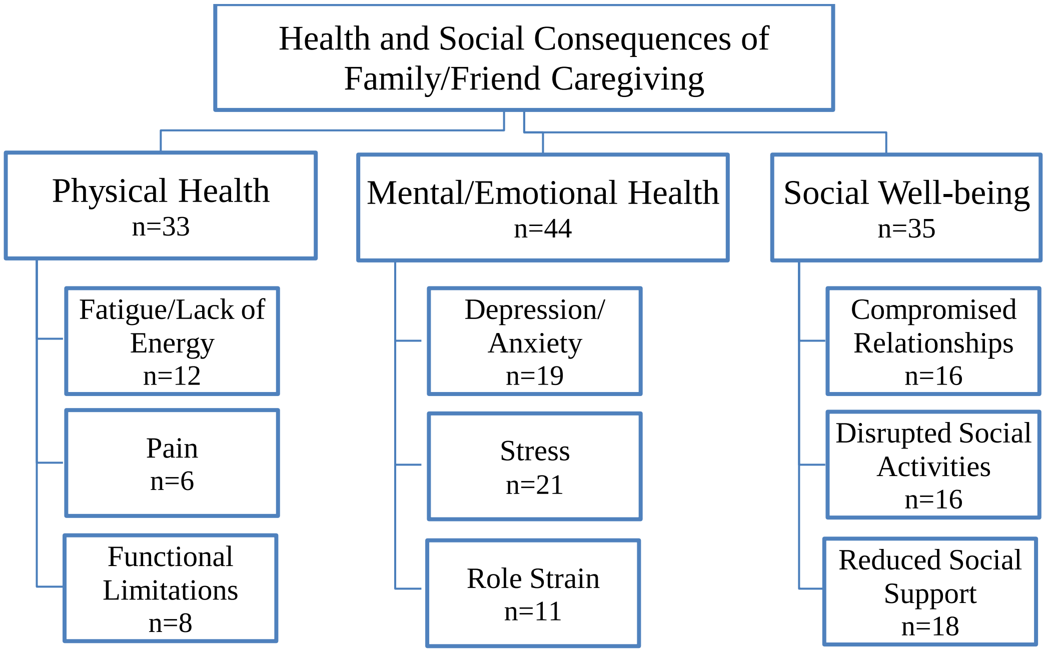

Figure 3. Taxonomy of the health and social consequences of family and friend caregiving.

Physical health consequences. Thirty-three of the 49 articles included in the review focused on consequences of caregiving to a caregiver's physical health. The literature reviewed on physical health consequences included a variety of study types from large scale, population-based surveys to convenience samples to qualitative interviews in countries across the world. There were some inconsistencies in findings that resulted from differences in sampling and some findings may be country- or context-specific. The following provides an overview of the most common findings in the literature with in this domain, and then each sub-category is explored.

Within the broad domain of physical health, researchers found that caregivers reported poorer self-rated physical health when compared to matched groups of non-caregivers in two similar studies. Caregivers of a disabled spouse (Beach et al., 2000) and caregivers in a sample from Israel (Soskolne, Halevy-Levin, & Ben-Yehuda, 2007) reported poorer health outcomes compared to non-caregivers.

Findings from studies presented a range of proportions of caregivers who reported consequences to their physical health. A majority (65.6%) of US family caregivers of older adults with cognitive impairment or dementia reported poor physical health (Fisher et al., 2011). In other US studies, 31% of family caregivers to older adults dying at home reported that their health was fair or poor (Townsend, Ishler, Shapiro, Pitorak, & Matthews, 2010) and 22% of caregivers to community-dwelling memory-impaired seniors said their health was fair to not good at all (Chumbler, Grimm, Cody, & Beck, 2003). When caregivers to disabled older family members in Korea were asked to self-rate their health, 18.7% said it was poor, 46.3% said it was fair and 35% indicated that their physical health was good (Lee, Yoon, & Kropf, 2007). Results of the National Long Term Care Survey (NLTCS) in the USA found that 47.6% of all caregivers reported some to very much physical health difficulty from caregiving activities (Rubin & White-Means, 2009). Using nationally representative data of adults over 45 years of age, Suwal found that 13.6 – 16.1% of family caregivers to older adults in Canada reported that their health was directly negatively affected by caregiving (Suwal, 2010). These two large scale North American studies are some of the few that ask caregivers about the effect that providing care has on their physical health. Although there is a range of percentages of caregivers who report poor health, it is a dominant consequence experienced by caregivers of older adults.

Many studies compare physical health status in different groups of caregivers based on variables such as place of residence or cultural group. Almost 20% of rural caregivers and 9% of urban caregivers in Poland indicated that caregiving always or often had a negative effect on their physical health (Bien, Wojszel, & Sikorska-Simmons, 2007). This is one of the few studies that asked caregivers directly if their physical health was affected by their caregiving responsibilities. When comparing Korean and Japanese caregivers, Rhee and Lee (2001) found that 23.2% of Korean caregivers reported being unhealthy, while only 10.1% of Japanese caregivers said they were unhealthy.

Three other studies presented the number of caregivers who reported good health rather than those who experience poor health. Egbert and colleagues (Egbert, Dellmann-Jenkins, Smith, Coeling, & Johnson, 2008) found that 69% of caregivers reported very good or excellent health in the past month. The majority of caregivers in a study on care to people with dementia and diabetes reported that their health was at least good (Feil, Lukman, Simon, Walston, & Vickrey, 2011). Similarly, Schwarz and Dunphy (2003) found that 68% of caregivers to older adults with heart failure reported good to excellent health. Although not reported in these studies, it would appear that there were still up to 30% of the samples reporting less than good physical health which was not inconsistent with other evidence.

Findings in this domain reflect different ways that certain consequences are measured or conceptualized and different study characteristics (sample size, study design, etc.). For example, one study asked caregivers to report their health over the last month (Egbert et al., 2008), while another study was longitudinal over several years (Beach et al., 2000). It is also difficult to compare across samples as some are small studies with convenience samples (Schwarz & Dunphy, 2003), or use qualitative methods (Feil et al., 2011) and some are representative samples with over 1000 respondents (Beach et al., 2000; Lee et al., 2007; Suwal, 2010).

Another method for assessing caregivers' overall physical health was to inquire about physical health symptoms as opposed to asking respondents to rate their general overall health. More than half (54%) of caregivers of elderly in Japan indicate that they experience physical health problems (Imaiso, Tsukasaki, & Okoshi, 2012). Ho and colleagues (Ho, Chan, Woo, Chong, & Sham, 2009) found that both male and female caregivers in their large scale comparative population-based study experienced significantly more health symptoms than non-caregivers. US spousal caregivers reported significantly more health symptoms than comparable non-caregivers (4.88 vs. 3.73) (Wallsten, 2000). A longitudinal study of 195 spousal and child carers of disabled people over 65 in Spain found caregivers reported 3.2 – 3.8 physical symptoms (Llacer, Zunzunegui, Gutierrez-

Cuadra, Beland, & Zarit, 2002). Physical health symptoms included weight loss, headaches, and dizziness, as consequences experienced by caregivers.

When asked to report their perceived level of physical health, caregivers across countries and care situations reported poor health, although the proportion of caregivers reporting a poor or fair health status varied by study. Research findings that reported physical health symptoms of caregivers consistently found that caregivers experienced more problems than non-caregivers. Regardless of how researchers measure physical health, caregivers likely experience some aspects of poor health.

The next step addresses the sub-categories that comprise the domain of caregiver physical health: feelings of fatigue and lack of energy; physical pain; and functional limitations due to caregiving activities.

Fatigue/lack of energy. This sub-category of fatigue and lack of energy includes feeling tired and exhausted, experiencing a lack of/or disrupted sleep, and low energy levels. Research findings from twelve studies on this sub-category suggest that caregivers suffer from fatigue, disrupted sleep and low energy levels.

Using the 1999 NLTCS data, Rubin and White-Means (2009) found that 44.7% of all caregivers reported being exhausted at bedtime. In a qualitative study, caregivers reported being tired and fatigued due to providing care when talking about their experience of caregiving to older adults living at home (Efraimsson, Hoglund, & Sandman, 2001).

Caregivers' sleep patterns are affected by caregiving as reported in several studies and range from 12% to 22% of caregivers reporting sleep is affected. For example sleep interruptions were experienced by 22% of all caregivers in the NLTCS national survey in the USA (Rubin & White-Means, 2009). Between 12 – 15% of family caregivers in a Canadian study of adults over 45 reported changing their sleep patterns due to care responsibilities (Suwal, 2010). In general, sleep was affected for caregivers of adults over age 75 in Scotland (Jarvis, Worth, & Porter, 2006) and caregivers in a cross-sectional community-based study in Hong Kong reported experiencing more trouble with sleep than non-caregivers (Ho et al., 2009).

Another physical health consequence that caregivers report is low energy levels. Caregivers of frail older adults indicated a loss of energy due to caregiving responsibilities (Aggar, Ronaldson, & Cameron, 2011). Miura and colleagues surveyed family caregivers in Japan and found that they scored lower than the general population with respect to energy (Miura, Arai, & Yamasaki, 2005). Similarly when compared to non-caregivers, caregivers in Hong Kong reported lower energy levels (Ho et al., 2009).

Pain. This sub-category includes reports of experiencing physical pain by caregivers and was captured in six articles. Pain is captured by asking about the magnitude of pain that caregivers experience and includes indicators of types of pain such as back pain and headaches.

Men and women primary caregivers for elderly care recipients in Hong Kong, reported more physical pain than non-caregivers (Ho et al., 2009). Two studies using QualityMetric's SF™ health survey which is a 36 item questionnaire (commonly referred to as the SF-36) (QualityMetric, 2012) (Ware et al., 2007) found that caregivers reported bodily pain with scores ranging from 83.08 (in family caregivers of hip-fractured elderly in Taiwan) (Shyu, Chen, Liang, & Tseng, 2012) to 54.12 (among family caregivers of impaired elderly in Japan) (Miura et al., 2005). A higher score indicates better physical health, or in this case less bodily pain. In qualitative interviews, family caregivers in Belize reported experiencing physical pain such as back pain and headaches (Vroman & Morency, 2011).

Functional limitations. A functional limitation refers to a caregiver's ability or inability to perform activities of daily living (ADL) and/or instrumental activities of daily living (IADL) (Fisher et al., 2011) (see Appendix A for definitions). A total of eight articles reported findings on the functional limitations experienced by caregivers.

Four studies found that caregivers had more difficulty performing ADLs and more limited physical functioning than non-caregivers (Ho et al., 2009; Soskolne et al., 2007; Wallsten, 2000). Researchers found that in a sample of 234 older couples, caregivers experienced more difficulty performing ADLs than did non-caregivers (10.59 ADL difficulties in caregivers vs. 7.16 in non-caregivers) (Wallsten, 2000). Shyu and colleagues reported that normal activities and work were affected by physical health problems for family caregivers of hip-fractured elderly (score of 77.59 for the role physical scale on the SF-36) (Shyu et al., 2012). Male caregivers had worse role physical functioning scores than male non-caregivers (74.03 vs. 84.74), similar results were found in female caregivers (68.34) compared to female non-caregivers (84.84) (Ho et al., 2009). Although these studies use different measures, the findings are consistent across multiple countries and caregiving characteristics reporting that caregivers suffer more functional limitations than non-caregivers.

Three studies reported scores ranging from 70.35 in a smaller sample of family caregivers for impaired elderly in Japan (Miura et al., 2005) to 86.11 on physical functioning in family caregivers of hip-fractured elders in Taiwan (Shyu et al., 2012) indicating a range from below normal to within normal as compared to the general population. Physical functioning was assessed by asking caregivers about their ability to perform vigorous activity, moderate activity, lift groceries, climb stairs, bend/kneel, and walk/bathe/dress. Both male and female caregivers had worse physical functioning scores than their non-caregiving counterparts (Ho et al., 2009).

One study of 75 US family caregivers to older adults with heart failure approached the consequence from a different perspective (Schwarz & Dunphy, 2003). Researchers asked caregivers if they experienced physical limitations or disabilities that prevented them from providing care. Sixty five percent of caregiver’s reported that they did not have limitations or disabilities preventing them from providing care (Schwarz & Dunphy, 2003). This was a small, convenience sample study using a different measure than previously mentioned studies so the findings are not directly comparable and should be interpreted with caution as there is no way to tell if caregiving limitations are care-related or were pre-existing. This limitation is common in this body of literature in cross-sectional research.

A similar small, convenience sample study indicated that caregivers suffered fewer consequences than non-caregivers. In a study of Taiwanese female caregivers aged 40 – 65 who provided daily support for at least 2 hours, Lo (2009) reported fewer problems with physical activity than non-caregivers. These surprising findings may be attributable to the sample being limited to middle aged caregivers, or the fact that caregivers were recruited from small businesses such as coffee shops and public areas in southern Taiwan.

Overall, there are consistent findings that caregivers report negative effects on their physical health and suffer poorer physical health in general. While some studies approach self-rated health from different perspectives, the research provides strong support for including poor physical health as a consequence of caregiving. Caregivers consistently report feeling fatigued, having low energy, being in pain, and the majority of studies also support the findings that caregivers suffer from functional limitations in their everyday life.

Mental/emotional health consequences. Results of studies that reported global measures of mental health are addressed first in this section. Next, the main sub-categories of mental and emotional consequences are addressed: depression/anxiety, stress and role strain. Overall, consequences to mental and emotional health were included in 44 of the total 49 articles in this review.

Caregivers consistently report experiencing consequences for their mental and emotional health related to their caregiving role. In a cross-sectional community based study conducted in China, researchers found that female caregivers had lower emotional and mental health scores than non-caregivers (Ho et al., 2009). Similarly in Asia, Miura et al. (2005) reported that caregivers for impaired elderly had scores of 60.80 on the mental health scale of the SF-36, while family caregivers of hip-fractured older adults reported a score of 67.94 on the same scale (Shyu et al., 2012). These findings indicate worse mental health than the mean of 50 for the general population (Ware et al., 2007). The mental health scale includes items such as feeling nervous, down in the dumps, feeling calm and peaceful, downhearted and depressed, and happy.

Overall mental/emotional health consequences included 12-22% of caregivers reported that caregiving had a negative effect on their emotional well-being (Bien et al., 2007), 25 % of caregivers experienced emotional difficulty Rubin & White-Means, 2009), 30% reported that their emotional well-being suffered as a result of caring (Jarvis et al., 2006) and 40.4% felt that it was more than they could handle (Rubin & White-Means, 2009).

Findings are consistent in reporting that caregivers suffer overall mental and emotional health consequences. There are three sub-categories of the most commonly experienced consequences within this domain: caregivers identified depression or depressive symptoms and anxiety; stress; and role strain.

Depression/anxiety. Depression and anxiety were the two most common mental health conditions addressed in the caregiving literature and were identified as consequences in nineteen articles. They are grouped together in this sub-category because both are clinical diagnoses. Comparison studies show higher levels of depression in caregivers compared to non-caregivers. Using the Caregiver Health Effects Study (CHES) in the USA, Beach et al. (2000) found that caregivers reported a greater number of depressive symptoms than non-caregivers at both time 1 and time 2 of the longitudinal study. In another longitudinal study of primary family caregivers in Belgium, the depression rate (30%) was higher in caregivers of relatives with dementia than in the control group (Schoenmakers, Buntix, & De Lepeleire, 2009; Schoenmakers, De Lepeleire, Ylieff, Fontaine, & Buntix, 2004). Studies in both Israel and Hong Kong found that caregivers had higher levels of depression compared to non-caregivers (Ho et al., 2009; Soskolne et al., 2007).

Rozario and colleagues found that 15 – 18% of female caregivers met the threshold for clinical depression (a score of 16 on the Centre for Epidemiological Studies – Depression Scale {CES-D}) (Rozario, Chadiha, Proctor, & Morrow-Howell, 2008; Rozario & DeRienzis, 2008). Two Japanese studies found that caregivers experienced depression (Izawa, Hasegawa, Enoki, Iguch, & Kuzuya, 2010; Kuzuya et al., 2006) while 40% of American caregivers reported depressive symptoms (Fisher et al., 2011). In Japan, just over half of caregivers (53.5%) had low depression (score of 0-5), 46.5% had a score of 6 or higher and 12.5% reported a score of 11 or higher indicating high levels of depression (Izawa et al., 2010) and over time the average level of depression in primary family caregivers got worse (Sugihara, Sugisawa, Nakatani, & Hougham, 2004).

Two articles included in the review provided a different perspective of depression in caregivers. Schwarz and Dunphy (2003) found that, in family caregivers of older adults, the presence of depressive symptoms was low (score of 10.89 on the CES-D with a range of 0-41). This finding is only 5 points below the threshold identified above as the cut-off for clinical depression indicating that caregivers may still experience depressive symptoms but not at the clinical threshold level. In an Italian sample of 70 caregivers and controls, Provinciali and colleagues did not find any significant difference in depression scores between non-spousal caregivers of older adults (35.77) and controls (33.89) (Provinciali et al., 2004). Researchers in the Italian study used a measure other than the CES-D and did not provide detail on how to interpret the means in terms of level of depression.

Anxiety is the second most commonly reported diagnosis for caregivers. All studies of anxiety found a higher prevalence of anxiety among caregivers. Caregivers in a Belgian sample reported higher rates of anxiety (85.9%) (Schoenmakers et al, 2004) than those in China (46%) (Ho et al., 2009).Similarly, non-spousal caregivers in Italy reported higher anxiety than comparable controls (Provinciali et al., 2004).

Stress. Stress related to the caring role is commonly measured when assessing caregiver outcomes. A total of 21 included articles addressed stress and associated responses in caregivers. Stress can be defined as an emotionally disruptive response resulting from problems that threaten available resources, such as psychological resources (Schwarz & Dunphy, 2003). Emotionally disruptive responses include feelings and emotions that caregivers report such anger, distress, low self-esteem, and guilt.

Findings in this sub-category consistently report that caregivers experience stress to some degree. Canadian caregivers providing a minimum of 4 hours of care at least 3 days per week reported their caregiving stress was associated with how unpredictable, uncontrollable and overloaded they found their lives (Chappell & Dujela, 2008). Findings indicated that 49.3% of all caregivers reported some to a great deal of stress (Rubin & White-Means, 2009) and 89% of caregivers of older adults with dementia and diabetes reported feeling stressed due to care and other demands (Feil et al., 2011). Caregivers in multiple studies using different measures all reported a moderate level of stress (Ingersoll-Dayton & Raschick, 2004; Provinciali et al., 2004; Schwarz & Dunphy.2003, ranging in scores from 6.62 on a scale of 4-16 to 16.22 out of 33. Wife caregivers reported a mean of 8.07 and husband caregivers a mean of 6.62 for caregiving stress, on a scale of 4 to 16 with a higher score indicating higher stress (Ingersoll-Dayton & Raschick, 2004). Non-spousal caregivers of disabled elderly in Italy reported moderate stress (27.18) using the Relative Stress Scale (Provinciali et al., 2004) which includes emotional stress and negative feelings (Ulstein, Wyller, & Engedal, 2007). In a study examining the perceived stress in 75 family caregivers of older adults with heart failure, Schwarz and Dunphy (2003) found that on average, caregivers had a moderate level of stress (16.22 out of a possible 33 on the Perceived Stress Scale).

The sub-category of caregiver stress encompasses the feelings and emotions that caregivers report associated with their caring roles that are emotionally disruptive, including anger, distress, low self-esteem and guilt. Anger was a commonly experienced emotion in caregivers (Feil et al., 2011, Jarvis et al., 2006). The AgeD in HOme Care (ADHOC) study was conducted in multiple countries across Europe and measured distress among primary family caregivers (Soldato et al., 2008). This study found prevalence of negative emotions ranging from 1% of caregivers in Sweden to 17.7% in Italy, with an average of 7.5% of caregivers across all 11 countries reporting feeling distressed (Soldato et al., 2008). Guilt was reported in caregivers in interviews (Innes, Abela, & Scerri, 2011); while 67% of Australian caregivers to frail older adults reported a negative effect on their self-esteem (Aggar et al., 2011).

Results from research using qualitative methods provided some examples of these negative emotions and feelings. Caregivers reported experiencing stress due to feeling powerless, guilty and insecure (Efraimsson et al., 2001), experiencing disappointment, resentment, and frustration with how caregiving had affected their lives (Innes et al., 2011), and caregivers reported feeling overwhelmed due to the care demands (Feil et al., 2011; Raschick & Ingersoll-Dayton, 2004). In terms of other negative emotions, 21% of caregivers in Spain reported feeling trapped and experiencing excessive mental burden (del-Pino-Casado, Frias-Osuna, & Palomino-Moral, 2011);

Role strain. Caregivers who provide care along with many other roles, experience role strain. Role strain is strain or tension felt by caregivers as a result of their caregiver responsibilities when they feel they do not have enough time to adequately fulfill their multiple role obligations (Seoud et al., 2007; Wang, Lotus Shuy, Chen, & Yang, 2011). This includes role overload which relates to the internal encounter of being overwhelmed by care-related jobs and responsibilities and addresses the feelings that the tasks are too much to bear (Aneshensel et al., 1995; Chumbler et al., 2003). Evidence on role strain or role overload was presented in eleven articles.

In an interview study in Lebanon, role strain was reported by caregivers who helped older adults with personal care (mean of 5.75 out of a possible range of 0-24) (Seoud et al., 2007). In a cross-sectional study of caregivers to older adults with cognitive impairment, family caregivers scored 7.9 for role overload on a scale of 4-16 with a higher score indicating higher strain (Chumbler et al., 2003). The majority of studies in this sub-category involved care recipients with dementia or cognitive impairment. Adult child family caregivers of older people with dementia reported experiencing low to moderate role strain as a result of their care and work demands (Wang et al., 2011). One study in particular found that 70% of caregivers reported emotional strain associated with their caregiving role (Fisher et al., 2011).

Evidence suggests that, across care recipient characteristics and different study designs, consequences to a caregiver’s mental health include depression and anxiety, feelings of stress and role strain. While there are a handful of studies that provide a different perspective on the proportion of depression in caregivers, the remainder of the research findings report that anxiety, stress, and role strain are consequences to a caregivers' mental/emotional health.

Social well-being consequences. Consequences in this domain were reported in 35 of the 49 articles and included consequences such as reduced socializing with family, friends and others, decreased levels of social activities, disrupted daily routines, risk of social isolation, and affected social support due to the demands of caregiving (Haley, 2003). The first sub-category in this domain includes the quality and quantity of relationships the caregiver has with family, friends, and the care recipient. The second sub-category includes disruptions to activities in the caregiver's social life. Lastly, caregivers report reduced social support.

Compromised relationships. This sub-category in the domain of social well-being includes reduced contact with caregivers' relationship members, reduced quality of those relationships and a changed relationship specifically between the caregiver and care recipient. Consequences to caregivers' relationships were obtained from sixteen included articles.

A US study found that 33.7% of all caregivers had less time with family (Rubin & White-Means, 2009). Family caregivers of people with dementia in Malta reported that caregiving dislocated them from important aspects of community life and from previous pursuits resulting in diminished social circles (Innes et al., 2011). Caregivers of adults over 75 years in Scotland reported not being able to see their friends as often as they would like (Jarvis et al., 2006).

Studies across numerous countries have found that caregivers report a lower quality of their relationships. Twelve to sixteen percent of caregivers reported difficulties and strain on family relationships due to caregiving (Bien et al., 2007;.Jarvis et al., 2006) while 55% were dissatisfied with verbal communication with their family members. (Miura et al., 2005). In a qualitative study of Swedish family members providing home care to elderly relatives, caregivers discussed a negative change in their family relationships (Efraimsson et al., 2001).

A lower quality of relationship with the care recipient is a consequence for many family/friend caregivers (Rozario & DeRienzis, 2008). Despite a range in the number of caregivers reporting compromised relationships (from 12% to 50%) there is ample evidence that caregivers' relationships are compromised and affect their overall social well-being (Bookwala & Schulz, 2000; Yamamoto-Mitani et al., 2004. Compromised relationships with the care recipient were evident in 22% of caregivers who reported they did not have a good relationship with the care recipient (del-Pino-Casado et al., 2011) and 34% who found it difficult to maintain that relationships (Egbert et al., 2008). Only 13% of family caregivers of people with dementia in Belgium reported low relationship quality with the care recipient (Schoenmakers et al., 2009) however this study provides no detail on caregiver characteristics which makes it hard to interpret this finding.

Disrupted social activities. Caregivers also experience consequences in social activities such as a limited social life and activities, having no time for themselves and delaying or cancelling vacations. Sixteen articles contained information on disrupted social activities in caregivers. Individuals who provide care to an elderly care recipient reported experiencing restrictions carrying out their social activities (Bookwala & Schulz, 2000; Rozario et al. 2008).). Another US study of caregivers found that 34.5% reported a limited social life (Rubin & White-Means, 2009).

Caregivers of frail older adults in Australia reported that their daily schedule and activities were disrupted due to care responsibilities (Aggar et al., 2011). Relatives of Swedish elderly aged 80 years or older, reported experiencing restrictions to their social life as a result of their caregiving role (Herlitz & Dahlberg, 1999). In a comparative study of Chinese non-caregivers and caregivers for elderly persons, caregivers reported lower participation in social activities than non-caregivers (Ho et al., 2009).

A common consequence experienced by caregivers of older adults was not having enough time to do things for themselves, such as visit with friends

(Chumbler et al., 2003; Ingersoll-Dayton & Raschick, 2004; Jarvis et al., 2006; Raschick & Ingersoll-Dayton, 2004; Rubin & White-Means, 2009).

Interrupted holidays or missed vacations are a commonly-reported aspect of disrupted social activities for family/friend caregivers. Caregivers report not being able to take a break or holiday due to care (Jarvis et al., 2006) and almost half (49%) of caregivers reported giving up a vacation due to care duties while (Rubin & White-Means, 2009). Qualitative studies provide examples such as one son caring for his mother said he had not had a vacation in three years since his mother got hurt (Vroman & Morency, 2011).

Reduced social support. A reduction in social support is the third sub-category of consequence in the domain of social well-being and was present in 18 articles included in this study. Aspects of social support affected by caregiving include the quality and adequacy of the social support as well as a lack of support resulting in isolation.

Evidence indicated that individuals who provided care often experienced a lack of social support from friends and family (Aggar et al., 2011; Lai & Thomson, 2011; Rhee & Lee, 2011; Rozario et al., 2008; Wallsten, 2000). Caregivers reported poor quality of support (Innes et al., 2011) and a lack of support from family and friends (Feil et al., 2011; Wang et al., 2011). For example, 64% of family caregivers of older impaired persons in Lebanon indicated they had insufficient informal social support from family members and friends (Seoud et al., 2007).

On the other hand, two Asian studies reported that caregivers had adequate support. Caregivers for older adults recovering from a hip fracture in Taiwan reported that they had a moderate availability of perceived social support (Shyu et al., 2012). If these care recipients were recently hospitalized due to their hip fracture, caregivers may have had better access to formal social support services. One study of caregivers in Japan reported that 90% used some type of formal care service from day care services to home-visits for rehabilitation or bathing (Hirakawa, Kuzuya, Enoki, Hasegawa, & Iguch, 2008). This sample was recruited from those eligible for public long-term care insurance in Japan and who were provided various home care services so it is not surprising that they report high levels of formal support. Almost seventy percent (69%) of caregivers in Taiwan indicated that they had family support (Lo, 2009); however there was no mention of the quality or type of support available.

There are a few studies where caregivers reported moderate levels of social support, however the range indicates that there are still those in the sample who do experience reduced social support. A sample of 243 Canadian caregivers reported on average a moderate level of perceived social support with a mean of 26.57 (range of 8-32) on Pearlin's Perceived Social Support scale which has a maximum score of 40 (higher score indicates more perceived support) (Chappell & Reid, 2002). Family caregivers of older adults with heart failure in the USA reported a mean of 24.31 out of a possible score of 36 on the Inventory of Socially Supportive Behaviours Scale (Schwarz & Dunphy, 2003). There was a range of scores from 9 – 36 indicating that although the mean represented moderate to high social support there were caregivers in this sample reporting low social support.

Yamamoto-Mitani et al. (2004) found that Japanese family caregivers of older adults reported experiencing isolation in their care roles. Forty-two percent of family caregivers of older adults at home indicated that they experienced isolation, at a higher level than the norm (Townsend et al., 2010). Caregivers experienced isolation when they felt their family members did not understand how hard caregiving was, when they did not help in caregiving and when caregivers and family members had more conflicts because of caregiving.

In the domain of social well-being there is variability in the levels of social support reported, but caregivers consistently reported compromised relationships with family members and friends as well as with the care recipient and disrupted social activities including lack of time for themselves and vacations.

Evidence indicates that, overall, caregivers experience negative consequences to their physical health, mental/emotional health and social well-being as well as in a variety of sub-categories. Studies consistently report that family/friend caregivers experience high levels of fatigue and report physical pain. Overall poor mental and emotional health including stress and role strain, are commonly reported in individuals who provide care to a family member or friend regardless of their country of residence or personal characteristics. In the domain of social well-being findings indicate that caregivers suffer compromised relationships and disrupted social activities. The literature in this area includes many study designs, sample characteristics and outcomes measures which influences findings in some domains and categories making it difficult to compare results across studies. Despite these differences, it is evident that caregivers experience consequences to their health and social well-being.

Risk Factors for Consequences

The third objective of this systematic review was to examine the risk factors for health and social consequences of care. Risk factors are characteristics that increase the chances of experiencing negative outcomes. Being "at risk" can indicate those more likely to experience a lower quality of life (Chappell & Dujela, 2008). Risk factors in this field of study refer to characteristics of caregivers, care recipients, caregiving demands, and caregiving situations that are associated with an increased likelihood of negative effects on caregivers' social, health, and economic well-being (Lero, Keating, Fast, Joseph, & Cook, 2007).

Results of the narrative synthesis identified 4 main categories of characteristics of risk factors: caregiver characteristics, care receiver characteristics, characteristics of the caregiver-care receiver dyad, and the context and nature of the care situation. These categories were determined after examining the evidence on all the potential characteristics that was associated with caregivers' health and social consequences. Figure 4 provides a hierarchical illustration of characteristics found to be important across these 4 categories and the types of characteristics within each category. Caregiver characteristics include gender, age, overall health, financial adequacy (meaning the level to which a caregiver feels their financial resources meet their needs), employment status, and culture (which include language, immigrant status, and cultural context). Characteristics of the care receiver include the nature of the receiver's disability or illness, age and gender.

Dyad characteristics include the geographic proximity of the caregiver to the care receiver, the relationship between the caregiver and the care receiver (kin or non-kin relationship) and the quality of the relationship between the caregiver and care receiver. The fourth category of risk factors relates to the context and nature of the care situation: the amount and duration of care provided, the type of care provided, support available and competing demands that the caregiver experiences (for example caregiving to multiple care recipients or the presence of a child living at home).

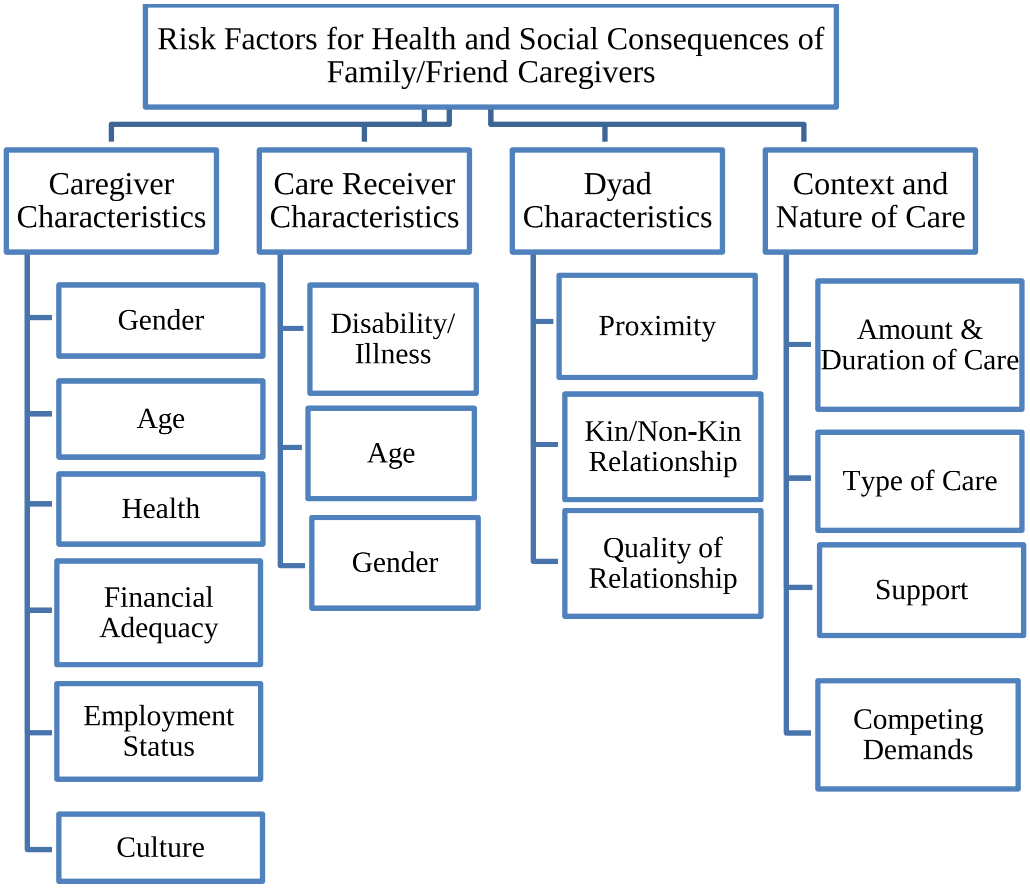

Figure 4. Risk factors for health and social consequences to family and friend caregivers.

Risk factors are reviewed for overall impact on health and social wellbeing. Where data are available, risk factors also are identified for each of the domains of consequences (physical health, mental/emotional health and social well-being). Table 1 identifies the risk factors affecting health and social consequences incurred by family/friend caregivers over all the consequences as well as across the three main domains. The number within each cell indicates the number of references containing evidence on the relationship between the risk factor and the domain of consequence, a zero indicates there was no evidence for that relationship within this sample of literature.

Table 1

Risk Factors by Domains of Consequences. Number of articles cited for each relationship.

↓ Risk Factors	Domain of Consequence →	Overall	Physical Health	Mental/ Emotional Health	Social Well-Being
Caregiver Characteristics	Gender	5	3	8	5
	Age	4	2	4	0
	Health	6	n/a	5	1
	Financial Adequacy	5	2	0	0
	Employment Status	3	1	5	2
	Culture	3	2	4	0
Care Recipient Characteristics	Disability/Illness	17	2	16	4
	Age	2	1	1	0
	Gender	1	1	1	0
Dyad Characteristics	Proximity	2	1	2	3
	Kin/Non-Kin Relationship	7	2	9	2
	Quality of Relationship	3	0	6	0
Context & Nature of Care	Amount & Duration of Care	5	3	9	1
	Type of Care	1	3	2	1
	Support	5	2	5	1
	Competing Demands	0	3	4	1

Risk factors for overall health and social consequences. Risk factors are important across all the domains of consequences. When a specific type of consequence is not specified, examining risk factors irrespective of a particular domain of consequence is useful. It provides an overall picture of caregivers who are at greatest risk of suffering consequences to their health and social well-being. Table 1 shows that, in some cases there is no evidence in the literature for risk factors within that domain (indicated by "0" in the cell). While there may be no evidence in this sample of literature, this does not indicate that there is no relationship between the consequence and the risk factor.

Caregiver characteristics and overall consequences. Caregiver characteristics include gender, age, health, financial adequacy, employment status and cultural characteristics.

Gender. Across overall consequences, female caregivers reported experiencing more consequences to their health and well-being than male caregivers (Imaiso et al., 2012). Female caregivers scored significantly higher on an overall measure of consequence than male caregivers in France (Buyck et al., 2011), Canada (Lai & Thomson, 2011), and South Korea (Lee et al., 2007). Survey data from the NLTCS found that female caregivers experienced significantly greater consequences than caregiving men using a global measure of caregiving costs (Raschick & Ingersoll-Dayton, 2004).

Age. There are differences in the findings regarding how age of the caregiver affects their caregiving experience. Greater consequences were reported among younger caregivers in Canada (Lai, 2007) and France (Buyck et al., 2011), and in caregivers in their forties in South Korea (Lee et al., 2007). In the Canadian study of Chinese Canadian caregivers over the age of 18, half (54.7%) were between the ages of 35 and 54 years (Lai, 2007). The study in France consisted mostly of employed men (75%), with no details on age of the caregivers (Buyck et al, 2011). Lee et al. (2007) reported that, among caregivers aged 20 to 89 years old, caregivers in their forties suffered the greatest consequences while those in their twenties experienced the lowest burden. Younger caregivers and those in their forties (which are at the young end of the range of 20-89) are more likely to be employed and have a family so are balancing multiple responsibilities and caring for an older adult may be an unexpected situation for which they are ill prepared. However this does not provide any explanation for why Lee et al. (2007) found that caregivers in their twenties reported the least burden. Also caregivers aged 65 to 74 reported more overall consequences than caregivers under 65 or over 75 in sample of Japanese caregivers to elderly (Kuzuya et al., 2006). Further research and analysis is warranted to sort out the source of these inconsistencies.

Health. There are consistent findings that poor personal health is associated with a caregiver's experience of negative consequences. Several studies found a link between self-rated health and a caregivers' life satisfaction indicating a decreased quality of life with poor health (Chappell & Dujela, 2008; Llacer et al., 2002; Lo, 2009). Similarly when using the SF-36 measure of overall health, caregiver health and well-being was inversely associated with all physical, mental and social health domains (Ho et al., 2009; Miura et al., 2005). Caregivers in a Japanese study that used the NLS-FE, reported greater overall consequence when they had poor physical health as assessed by a nurse (Kuzuya et al., 2006).

*Financial adequacy***.** The next risk factor for caregivers for overall health and social well-being is poor financial adequacy. Self-rated financial adequacy was measured by asking caregivers to rate how well their current financial status satisfied their needs (Lai, 2007). In several articles Canadian researcher Lai and his colleagues found that caregivers with low perceived financial adequacy reported greater overall consequences to their health and social well-being (Lai, 2007; Lai, Luck, & Andruske, 2007; Lai & Thomson, 2011). Studies across the world reported the same finding from South Korea (Lee et al., 2007) to Spain (Llacer et al., 2002).

Employment status. Findings on relationship between employment status of the caregiver and overall consequences are varied. Caregiving studies in France and Canada found that, for overall caregiver health and social well-being, current employment was associated with worse consequences (Buyck et al., 2011; Lai et al., 2007). Lee et al. (2007) found that, for South Koreans providing care to disabled older family members, being employed was associated with better overall health and well-being. Care recipients in South Korea were recruited from community centres and adult care programs indicating that caregivers were sharing care responsibilities with community services which may help them balance care and employment demands. In comparison, samples in the former two studies were random.

Culture. Characteristics that represent culture as a risk factor include immigrant status and religiosity and show mixed results. Researchers found that religion was a buffer against consequences, such that caregivers with higher religiosity experienced fewer consequences (Llacer et al., 2002; Vroman & Morency, 2011). Research in Canada looking at Chinese immigrants found that being an immigrant (vs. a non-immigrant) and practicing religion (vs. not having a religion) significantly predicted higher burden (Lai, 2007). Lai (2007) notes that religious affiliation is often associated with higher levels of well-being and he proposes several explanations for why this study found the opposite. Caregivers who are negatively affected by caregiving may use religion as a way to cope with high levels of consequence or religious caregivers may feel more guilt leading to more negative consequences.

Care recipient characteristics and overall consequences. Care receiver characteristics include disability or illness such as cognitive impairment or dementia, functional limitations and problematic or difficult behaviours. Other characteristics are the age and gender of the care recipient.

Disability/illness. There are numerous studies which report that care to recipients with a higher level of disability, with dementia, those displaying problematic behaviours and with overall worse health, results in greater consequences to the caregiver. Numerous studies provide evidence that care to recipients with a higher level of need or disability resulted in greater overall consequences to the caregiver (Imaiso et al., 2012; Jarvis et al., 2006; Lai, 2007; Lai et al., 2007; Lai & Thomson, 2011; Lee et al, 2007; Llacer et al., 2002). Schoenmakers et al. (2004) reported that caregivers of recipients with high care needs were 1.7 times more likely to experience high caregiving burden than caregivers of care recipients with low care needs. Caregiving to care recipients with greater loss of autonomy with respect to personal care was associated with lower well-being in caregivers (Seoud et al., 2007).

Dementia is often associated with a higher level of need and problematic behaviours that result in caregivers experiencing greater consequences to their health and well-being. The presence of dementia or cognitive impairment in care recipients was risk factor for caregivers (Buyck et al., 2011; Kuzuya et al., 2006; Lee et al., 2007; Miura et al., 2005; Schoenmakers et al., 2009; Schoenmakers et al., 2004).

Similarly, research from several countries found that caregivers experienced greater overall consequences when the care recipient displayed problematic behaviours (Buyck et al., 2011; Chappell & Dujela, 2008; Chappell & Reid, 2002; Kuzuya et al., 2006; Llacer et al., 2002; Schoenmakers et al., 2009; Schoenmakers et al., 2004). A care recipient's overall health and number of chronic conditions are additional characteristics that affect the magnitude of caregiver's consequences (Lai, 2007; Lai et al., 2007; Lai & Thomson, 2011; Schoenmakers et al., 2009). Greater overall burden is also experienced by caregivers when a care recipient has a mental illness (Chappell & Dujela, 2008).

One study of Japanese caregivers of cognitively impaired older persons presented different findings. Hirakawa et al. (2008) found that consequences to caregivers` overall health and well-being did not differ by presence of dementia or level of severity of dementia in the care recipient. The researchers attribute these findings to the explanation that many care recipients with cognitive impairment may reside in several recently-opened small, home-style facilities covered by long term care insurance. Another possible explanation is that many of the caregivers to recipients with dementia use formal care services which may lessen the consequences of caregiving.

Age. Findings on age of the care recipient as a risk factor are presented in two studies with differing results. Lai (2007) reported greater overall consequence to the caregiver when care was provided to an older care recipient. In contrast, Lee et al (2007) found that overall caregiver consequences were greater when care receivers were at the younger end in the range of 65 to over 80 years (45% of the care recipients were over 80 years). The authors of the latter study attribute this effect to the potential that caregivers to younger care recipients may feel obligated and pressured by cultural norms to provide care (Lee et al., 2007) as may be the case for women in South Korea who are caring for a parent-in-law. Also, caregivers who care for a younger care recipient may feel more negative consequences as they anticipate caring for longer periods of time.

Gender. One study in Japan found that caregivers experienced greater overall consequences when the care recipient was male (Kuzuya et al., 2006).

Dyad characteristics and overall consequences. Dyad characteristics are features of the relationship between the caregiver and the care receiver such as their geographic proximity, including co-residence, the type of relationship such as being a family member/kin or non-kin, and the quality of the dyadic relationship.

Proximity. Two studies reported the same findings that co-residence of the caregiver with the care recipient negatively affects overall consequences. More than 90% of primary caregivers in a study in South Korea lived with their care recipient and these caregivers experienced greater consequences to their psychological health, physical health, family and social life than those who did not (Lee et al., 2007). Female caregivers sharing a house with the person they care for were more likely to find caring negatively influenced their overall quality of life (Jarvis et al., 2006). Unfortunately additional information was not available to determine whether there were confounding variables such as co-residence due to higher care needs of the care recipient which also contributes to greater consequence as noted above.

Kin/non-kin relationship. Kin caregivers consistently report greater consequences to their health and well-being compared to non-kin caregivers. Although most studies find that being a spouse is an important risk factor, other kin relationships such as adult children and daughters-in-law also suffer consequences. Being a spouse significantly predicted greater caregiver consequences in several studies (Buyck et al., 2011; Kuzuya et al., 2006; Lee et al., 2007; Llacer et al., 2002; Raschick & Ingersoll-Dayton, 2004). Researchers in

Spain (Llacer et al., 2002) and in the USA (Raschick & Ingersoll-Dayton, 2004) found overall that spouses had lower levels of well-being than adult children carers. Lee et al. (2007) also reported that spouses had the highest consequences, however daughters-in-law reported consequences almost as high as spouses. Other research found higher consequences in caregivers who were not adult children, implying that spouses were included in those who reported greater consequences (Imaiso et al., 2012). Only one study reported that spousal caregivers in a Polish sample reported lower negative impact of caregiving (Bien et al., 2007) and the authors hypothesize that spousal caregivers may have found caregiving meaningful and satisfying.

Quality of relationship. Caregivers who report a lower quality of relationship with the care recipient also experience greater consequences to their health and well-being. The quality of the dyadic relationship affected the magnitude and prevalence of consequence resulting in worse outcomes when the quality of the relationship was poor (Schoenmakers et al., 2009). A low level of satisfaction with the relationship with the care recipient was associated with a lower overall quality of life for the caregiver (Miura et al., 2005). Caregivers who also felt they did not receive companionship from the care recipient reported greater overall consequences (Raschick & Ingersoll-Dayton, 2004).

Context and nature of care characteristics and overall consequences. The context and the nature of care factors at the level of the caregiving situation include the amount and duration of care, the type of care provided, the presence of support from others or shared care, and whether the caregiver has competing demands. These factors are at the micro level of the individual caregiver, the care receiver, or the caregiving situation.

Amount and duration of care. Providing more hours of care is a risk factor for experiencing greater consequences. More caregiving hours compared to fewer hours on a continuous scale was associated with higher caregiver burden and lower well-being in Canadian as well as in South Korean caregivers (Chappell & Reid, 2002; Lai, 2007; Lee et al., 2007). Being the primary caregiver or providing more types of care tasks implies providing more care hours and was associated with greater overall negative outcomes (Buyck et al., 2011; Lai, 2007; Lai & Thomson, 2011).

Type of care. The type of care provided is associated with the consequences experienced by caregivers in one study. Caregivers who provided care at night, often involving personal care, reported greater overall caregiving consequence (Imaiso et al., 2012).

Support. Consistently, caregivers who have limited or low social support indicated worse consequences. Canadian studies found that caregivers with low social support reported lower well-being and overall greater consequences (Chappell & Dujela, 2008; Chappell & Reid, 2002; Lai & Thomson, 2011). Similarly in South Korea, caregivers with less informal support reported worse overall health and well-being (Lee et al., 2007); while in Spain, caregivers with low support also reported lower well-being (Llacer et al., 2002).

There were no studies addressing competing demands with respect to overall health and well-being consequences. This risk factor is addressed within each of the domains.

There are some clear trends in the influence of risk factors on caregivers' overall health and social well-being. Factors that identify caregivers at higher risk of experiencing overall consequences with respect to caregiver characteristics include being female, being in poor health, and not having enough financial resources. There were no consistent findings on risks related to age of caregiver, employment status or religiosity

Numerous studies report clear and consistent findings that caregivers are at greater risk of experiencing consequences when caring for recipients with higher care need, and greater problem behaviours. Only one study out 12 reported that the severity of dementia did not increase consequences to caregivers. Findings on age of the care recipient and caregiver as risk factors were equivocal.

Dyad characteristics of co-residence and kin relationship increase the risk of consequences to caregivers. Most findings report that spouses are at greatest risk but there is evidence that adult children are also at risk.

Lastly, in the category of context and nature of care characteristics, providing more hours of care and having limited support are risk factors for caregivers. There was only one study on the type of care as a risk factor and none for the influence of competing demands so it is not possible to determine their influence on consequences.

Risk factors for physical health consequences. There were fewer findings on the risk factors to a caregiver's physical health than there was for overall health and social consequences, perhaps because physical health is often encompassed in measures of overall health and well-being. Presented below is evidence from research studies on factors that influence a caregiver's physical health in sub-categories, including their fatigue and energy, physical pain, and functional limitations. Variations in the magnitude of consequences to a caregiver's physical health can be explained predominantly by caregiver gender, care recipient's level of illness or disability and factors associated with the context and nature of care including amount of care, availability of support and presence of competing demands. There was varied evidence on the influence of caregiver employment status and no findings for quality of relationship as a risk factor for physical health consequences in caregivers. In this domain, health of the caregivers is not included as a risk factor since the domain is consequences to a caregivers' physical health.

Caregiver characteristics and physical health.

Gender. In this domain, studies consistently report that female caregivers experienced worse physical health than male caregivers (Chumbler et al., 2003; Ho et al., 2009; Suwal, 2010). These physical consequences included high blood pressure, heart and circulation problems, bodily pain, and insomnia among others (Chumbler et al., 2003; Ho et al., 2009).

Age. Two studies reported that older caregivers suffered greater physical health consequences. In a sample of caregivers 45 years of age and over, older caregivers reported that assisting someone over the age of 65 caused their physical health to be affected (Suwal, 2010). Yamamoto-Mitani et al. (2004) reported that a caregivers’ age was negatively related to their physical health, so greater age was associated with poorer physical health.

Financial adequacy. Caregivers who report inadequate financial resources also report poorer physical health. Researchers in Belize noted that a caregiver’s poor health was exacerbated if they lived below the poverty line as there were minimal services or programs available to support caregivers (Vroman & Morency, 2011). Caregivers in Australia associated financial strain with low perceived health status (Aggar et al., 2011).

Employment status. Within the domain of physical health consequences, findings on employment status of the caregiver as a risk factor are limited to one study. Caregivers in the USA who were employed reported poorer physical health than those not employed (Rubin & White-Means, 2009).

Culture. Cultural factors such as immigrant status, language and ethnicity are risk factors for poor physical health. In a Canadian study, Suwal (2010) found that immigrant family caregivers were almost three times more likely to say their health was affected as a result of caregiving than non-immigrants. This same study also reported that family caregivers who spoke a language other than the national languages (French or English) had greater physical health consequences (Suwal, 2010). In other research, African American spousal caregivers compared to Caucasian caregivers, reported greater interference from health problems (7.81 vs. 6.71) and more difficulty performing activities of daily living (ADLs) (11.28 vs. 9.61) (Wallsten, 2000).

Care recipient characteristics and physical health.

Disability/illness. Minimal findings addressed specifically the impact of care recipient disability or illness on a caregiver’s physical health. Findings from an American spousal caregiver (CHES) study found that caregivers of those with greater ADL or IADL difficulties experienced greater health risks (Beach et al., 2000). Poor physical health was experienced by caregivers caring for someone with severe dementia (Vroman & Morency, 2010).

Age. Evidence on how age of the care recipient might be related to the caregivers’ physical health was only available from one study. Caring for younger care recipients was found to be related to poorer physical health of family caregivers in Japan (Yamamoto-Mitani et al., 2004). This Japanese study recruited caregivers from community nursing organizations and the age range of the care recipients was 65 to 104 years. Caregivers providing care to care recipients at the younger end of this range may be more likely to be spouses and have health complications themselves' while those caregiving to older recipients are adult children or younger generation family and friends. This suggests interactions among the risk factors and confounding variables.

Gender. Physical health was compromised when caregivers were providing care to male care recipients (Yamamoto-Mitani et al., 2004). Findings on the risk factors of age and gender are not reported in other studies within this domain which indicates an area for further exploration.

Dyad characteristics and physical health.

Proximity. Co-residence was associated with poorer caregiver physical health in one study from the UK which found that caregivers' sleep was negatively affected by co-residing with the care recipient (Jarvis et al., 2006).

Kin/non-kin relationship. Spouses and wives in particular experience greater physical health consequences. Spouse caregivers in a US study were more likely to report high blood pressure than children, and spouses were more likely to report heart and circulation problems than both children and more distant relatives (Chumbler et al., 2003). In a Japanese sample of family caregivers, wife caregivers has the lowest reported physical quality of life (score of 11.11 on a possible range of 4-20 with higher score indicating better quality of life) compared to husbands (12.37) while daughters-in-law has the highest physical quality of life score (12.46) (Yamamoto-Mitani et al., 2004).

Context and nature of care characteristics and physical health.

Amount and duration of care. Across findings from different countries and different methodologies, caregivers who provided more hours of care and for longer periods of time experienced greater physical health consequences. Caregivers in Israel with a high intensity of care (more than 16 weekly hours of care) reported greater physical functioning difficulties than non-caregivers

(Soskolne et al., 2007). Aggar et al. (2011) found that a threshold of 20 hours of care per week resulted in more health problems in a sample of Australian caregivers. Caregivers who provided care for 2 years or more experienced greater physical difficulties (Soskolne et al., 2007), while in a longitudinal study, caregivers general physical health declined over a period of 12 months (Shyu et al., 2012).

Type of care. Greater caregiver involvement, such as providing personal care, had a negative impact on carer's physical health (Beach et al., 2000; Suwal, 2010) compared to helping with outdoor tasks, which are associated with better physical health in caregivers (Llacer et al., 2002). These findings coincide with findings on amount of care, as providing personal care requires more time on a regular basis than outdoor tasks which are often seasonal.

Support. Frequency and satisfaction of contact with formal and informal support affected the physical health of family caregivers. Caregivers who were dissatisfied with amount of contact with their relatives were more likely than those satisfied with the amount of contact to experience negative health outcomes (Suwal, 2010). In a sample of Japanese family caregivers, those with poorer physical health were more likely to use social services (Yamamoto-Mitani et al., 2004), which may indicate that those who are suffering more tend to seek out and use formal social services while those with support from family and friends suffer fewer consequences.

Competing demands. Caregivers with competing demands, such as caregiving to children under the age of 18 living at home or stressful life events, report poorer physical health. Caregivers who had a stressful life in general (Suwal, 2010) and who experienced more stressful life events Beach et al. (2000) reported poorer physical health. Finally sandwiched caregivers with a child at home and those caring for an older adult, reported more negative physical health effects (Rubin & White-Means, 2009).

Risk factors for mental/emotional health consequences. There is the most evidence on the risk factors to a caregiver's mental/emotional health compared to physical health and social well-being domains. Consequences to caregivers' mental/emotional health include depression/anxiety, stress and role strain. Variations in the magnitude of consequences to a caregiver's mental/emotional health can be explained predominantly by caregiver gender, a care recipient's level of illness or disability and quality of the relationship between the caregiver and care receiver. There were no studies that addressed financial adequacy as a risk factor for mental/emotional health consequences and only one for care recipient age and gender as a risk factor.

Caregiver characteristics and mental/emotional health.

Gender. Seven out of eight studies in this domain that addressed gender differences found that female caregivers experienced worse consequences than males in many of the mental/emotional health sub-categories. These articles found that women experienced greater depressive symptoms or presence of depression than male caregivers (Bookwala & Schulz, 2000; Schoenmakers et al., 2009; Schoenmakers et al., 2004). A variety of mental/emotional health consequences are experienced more negatively by women than men, including role strain (Chumbler et al., 2003; Ho et al., 2009), emotional burden or emotional exhaustion (Rhee & Lee, 2001; Sugihara et al., 2004) and general psychological health (Ho et al., 2009; Jarvis et al., 2006). Contrary to all previous evidence on gender of caregiver, male adult children caregivers in Taiwan reported greater role strain than female adult children (Wang et al., 2011). Almost 50% of the Taiwanese sample was sons, the mean age was 48.6 years and 85.7% were married. The authors of this study acknowledge that the characteristics of their sample are not the norm for caregivers and therefore findings should be interpreted with caution.

Age. The relationship between caregiver age and mental/health consequences is not clear. Part of the difficulty in making a statement is the small number of studies from the same country. Chumbler et al. (2003) found that being younger was associated with higher role overload in caregivers aged 18 to 86. Similarly, Townsend et al. (2010) linked younger age to higher psychological strain (in caregivers aged 19 to 92 years). Other researchers noted contradictory findings in which older caregivers reported diminished psychological health (Egbert et al., 2008). These studies were all conducted in the USA but the differences may be attributable to the variety of measures of mental /emotional health from role overload to psychological strain to psychological well-being.

Health. Caregivers with decreased physical health indicate poorer mental/ emotional health as well. Caregivers who reported poor physical health also experienced higher role overload (Chumbler et al., 2003), diminished psychological well-being Egbert et al. (2008), more depressive symptoms and higher stress (Rozario et al., 2008; Rozario & DeRienzis, 2008) as well as greater emotional consequences overall (Rhee & Lee, 2001).

Employment status. The relationship between a caregiver's employment status and mental/emotional health consequences is not clear based on findings of this review. Caregivers experienced greater role strain and stress when they balanced employment and care demands according to several studies (Herlitz & Dahlberg, 1999; Rubin & White-Means, 2009; Wang et al., 2011). Employment was also a risk factor for African American caregivers and Japanese family caregivers, however the relationship between being employed and consequences is different. In African American female caregivers, being unemployed was associated with higher depression and stress (Rozario & DeRienzis, 2008). Being unemployed may also add a level of stress due to financial strain for caregivers. Unemployment was as a risk factor for poor mental/emotional well-being in a sample of Japanese family caregivers of older adults which reported that unemployed caregivers reported better physical quality health than unemployed caregivers (Yamamoto-Mitani et al., 2004).The Japanese caregivers may have had more caregiving supports as they were recruited from client lists of community nursing organizations. This caregiving support would help balance the demands of caregiving and employment thus reducing any negative influence on psychological health. It may also be the case for some employed caregivers that perhaps employment provides a diversion for caregivers from their care responsibilities.

Culture. There is a large amount of variation in this group of findings and additional work on culture as a risk factor is warranted to explore these relationships. In a comparative study among Japanese and Korean caregivers, researchers found that Korean caregivers experienced greater overall consequences to their mental/emotional health than Japanese caregivers (Rhee & Lee, 2001), which the authors attribute to the possibility that the Japanese care recipients were utilizing national long-term care services thus reducing the demand on caregivers. A study in the USA found that white, non-Hispanic caregivers had greater role overload than other ethnicities (Chumbler et al., 2003).

Among spousal caregivers in Spain, religiosity was negatively associated with depression indicating that caregivers with low religiosity experienced greater depressive symptoms (Llacer et al., 2002). Religiosity may help spouses give meaning to their caring experience, however religion may not act as a buffer for consequences in the same way for adult children. For example, Christian caregivers in a Lebanon study comprised half of adult children (48% adult children, and only 22.6% spouses) reported higher levels of emotional consequences and stress than did their non-Christian counterparts (Seoud et al., 2007).

Care recipient characteristics and mental/emotional health.

Disability/illness. Unequivocally, care recipients who have greater functional limitations present more negative consequences to their caregiver's mental/ emotional health. For example, caring for someone who was incontinent or needed help with ADLs and IADLs was associated with high levels of depression and role strain (Fisher et al., 2011; Herlitz & Dahlberg, 1999; Izawa et al., 2010; Schoenmakers et al., 2009; Seoud et al., 2007). Caregiver stress was present when care recipients had mental health challenges (Rhee & Lee; Rubin & White-Means, 2009). Stress was significantly more common among caregivers of depressed care recipients compared to those of non-depressed care recipients (18.8% vs. 5.9%) (Soldato et al., 2008) and when caring for someone with dementia or cognitive impairment (Chumbler et al., 2003; Fisher et al., 2011; Izawa et al., 2010; Seoud et al., 2007; Wang et al., 2011). Specifically, caregivers of elderly with dementia reported nearly five times more feelings of anxiety than caregivers of non-demented elderly (Schoenmakers et al., 2004). Dementia or cognitive impairment often comes with disruptive or difficult behaviours in care recipients, which exacerbates consequences to a caregivers' mental and emotional health (Bookwala & Schulz, 2000; Fisher et al., 2011; Herlitz & Dahlberg, 1999; Izawa et al., 2010; Llacer et al., 2002; Seoud et al., 2007). A care recipient's type of illness can also affect a caregiver's mental health. Caregivers to cancer patients and those with heart disease reported less psychological stress than caregivers to those with dementia, lung disease, diabetes or stroke (Townsend et al., 2010). This is somewhat consistent with findings above that caregiving to those with dementia results in greater consequences than caregiving to those with other diagnoses. However the authors of this study attribute the lower consequences in cancer caregivers to the distinct disease trajectory of cancer making it easier for individuals to cope (Townsend et al., 2010).

Age and gender. In their study of Japanese caregivers, Yamamoto-Mitani et al. (2004) found that caregiving to younger male family care recipients was associated with poorer mental/emotional quality of life. As previously noted findings from this study should be interpreted with caution as the design was non-experimental and involved non-random sampling. Further research needs to be done to validate these findings or offer additional evidence.

Dyad characteristics and mental/emotional health.

*Proximity***.** Consistent with other domains, caregivers who co-reside with their care recipient suffer greater mental/emotional consequences (Soldato et al., 2008; Soskolne et al., 2007). Daughter caregivers who were co-residing with their parent had significantly higher depression and lower positive affect compared to those not living with their parent (Soskolne et al., 2007). Due to the cross-section design of these studies it is not possible to say whether co-residing in the care situation caused greater mental/emotional consequences in the caregiver, or if, for example, daughters were living with their parents due to their poor emotional health. However it may be the case that caregivers who co-reside experience greater consequences if they feel that they cannot escape from their role.

Kin/non-kin relationship. It was predominantly spouses who were found to report the greatest consequences to their mental health and well-being (Rhee & Lee, 2001). Depressive status in caregivers was associated with being the spouse of the care recipient (Izawa et al, 2010; Llacer et al., 2002). Wives were at greatest risk of experiencing mental/emotional consequences such as depression (Bookwala & Schulz, 2000), stress (Ingersoll-Dayton & Raschick, 2004), and low psychological quality of life (Yamamoto-Mitani et al., 2004). In an Israeli study, wife caregivers were significantly more depressed than daughters (23.22 vs. 17.95) (Soskolne et al., 2007). Caregivers who were wives and daughters-in-law experienced more depressive symptoms than other kin caregivers in a representative sample of Tokyo family caregivers (Sugihara et al., 2004). When considering other consequences to mental health, such as role strain, some additional findings indicated that adult children experienced greater role strain than other types of caregivers (Chumbler et al., 2003; Seoud et al., 2007). Adult children caregivers are middle-aged and often still employed which may relate to their greater experience of role strain.

Quality of relationship. There is considerable evidence that poor quality of the relationship between the caregiver and care receiver is an important risk factor in this domain. Greater role strain in caregivers was associated with the presence of less mutuality in the caregiver-care receiver relationship (Wang et al., 2011). Stress was reduced when caregivers felt they received companionship and help from their care recipient (Ingersoll-Dayton & Raschick, 2004). A good quality of the dyadic relationship was also associated with less depression in caregivers (Rozario & DeRienzis, 2008; Schoenmakers et al., 2009). Beach et al. (2000) found that spousal caregivers who reported a higher quality of their marital relationship also reported lower anxiety.

Only one study indicated that a closer relationship was associated with greater mental health consequences. Townsend et al. (2010) found that caregivers who found it painful to see changes in the care recipient (which may indicate a closer relationship) reported higher psychological strain.

Context and nature of care characteristics and mental/emotional health.

Amount and duration of care. Negative mental and emotional health consequences are common when the caregiving situation involves a greater intensity of care (often measured in number of care hours). Caregivers with a higher intensity of care reported higher depression and lower positive affect compared to non-caregivers and those with fewer hours of care (Soskolne et al., 2007). Increased depression was associated with a higher intensity of care and greater level of assistance (Beach et al., 2000; Bookwala & Schulz, 2000; Schoenmakers et al., 2009). Ho et al. (2009) found that extended hours of providing care was associated with a 33% increased risk for depression in caregivers. Adult children caregivers in Taiwan experienced more role strain when they spent more time caregiving per day (Wang et al., 2011). In addition to amount of care, an extended duration of care had a negative impact on the mental/emotional health of caregivers (Rhee & Lee, 2001; Shyu et al., 2012).

Type of care. Certain types of care are associated with greater mental/emotional health consequences. Greater negative mental health in caregivers was experienced when they were required to provide higher emotional support to the care recipient (Egbert et al., 2008). Care tasks that involve less direct care are associated with fewer consequences to mental health. Caregivers who provided less direct care, such as helping with outdoor tasks experienced less depression than other caregivers (Llacer et al., 2002).

Support. Consistently, caregivers that have inadequate social support and assistance with caregiving are at greater risk for mental/emotional health consequences. Higher psychological strain and emotional burden was reported in caregivers who lacked caregiving help from others and who had low perceived social support (Rhee & Lee, 2001; Townsend et al., 2010). Having a secondary caregiver reduced stress experienced by caregivers (Rubin & White-Means, 2009). Caregivers who had more interpersonal conflicts and received less emotional support from family and friends reported higher role strain (Seoud et al., 2007). Another mental/emotional health consequence, depression, was reported by female caregivers when they had no one to help with care and had low social support (Rozario et al., 2008).

Competing demands. Evidence from four studies indicated that when a caregiver had competing care demands their mental and emotional health was at greater risk. Most often the source of competing demands was the presence of a child living at home. Caregivers, who had other household members needing care such as children under 18 living at home, reported poor emotional health and higher stress (Rhee & Lee, 2001; Rubin & White-Means, 2009). Adult child family caregivers to older people with dementia reported greater role strain when they had more children under the age of 18 years (Wang et al., 2010). Caregivers with more stressful life events reported more anxiety (Beach et al., 2000).

Risk factors for social well-being consequences. There is less evidence of the risk factors to a caregiver's social well-being compared to the mental health domain. Variations in the magnitude of consequences to a caregiver's social well-being can be explained predominantly by caregiver gender and employment status as well as by co-residence and a care recipient's level of illness or disability. Areas of social well-being that are affected include compromised relationships, disrupted social activities, and reduced social support. There were no studies that examined the relationship between consequences to social well-being and the risk factors of age, financial adequacy or culture of the caregiver, age or gender of the care recipient or quality of the dyadic relationship. There was minimal evidence about the ways in which characteristics of the context and nature of care affected a caregiver's social well-being making it hard to interpret the findings and draw conclusions.

Caregiver characteristics and social well-being.

Gender. Caregivers who are female consistently report greater consequences to their social well-being in all sub-categories of consequences. Female caregivers reported not being able to see friends as often as they would have liked (Innes et al., 2011; Jarvis et al., 2006). Compared to caregiving husbands, caregiving wives reported more restrictions in their personal and social activities as a result of their caregiving role (Bookwala & Schulz, 2000). Female caregivers also reported poorer relationship satisfaction with the care recipient than male caregivers (del-Pino-Casado et al., 2011; Herlitz & Dahlberg, 1999).

Health. Consistent with the other domains, researchers found that a caregiver's disrupted daily schedule was significantly associated with poor self-perceived health problems (Aggar et al., 2011).

Employment status. In this domain, employment status was a risk factor for caregivers experiencing social well-being consequences. Employment increased the likelihood of caregivers reporting that they had no time for themselves (Rubin & White-Means, 2009). Employment was correlated with a carer's social activity restrictions indicating that caregivers who were employed experienced restrictions to their social activities (Herlitz & Dahlberg, 1999).

Care recipient characteristics and social well-being.

Disability/illness. When a care recipient required more help with personal care caregivers felt that care responsibilities encroached on their social lives (Herlitz & Dahlberg, 1999; Rubin & White-Means, 2009). Bookwala and Schulz (2000) also found that more frequent disruptive behaviours in care receivers were associated with more activity restrictions and less relationship closeness in spouses in the CHES study. A care recipient's type of illness can also affect reports of negative social well-being. Caregivers to cancer patients reported less negative social outcomes than caregivers to those with heart disease, dementia, lung disease, diabetes or stroke (Townsend et al., 2010). Cancer caregivers may receive more support from family, friends and support services as cancer receives more exposure than many other diagnoses.

Dyad characteristics and social well-being.

Proximity. Research in two studies consistently indicates that caregivers who co-reside with their care recipient experience consequences to their social well-being. Co-resident caregivers reported higher disrupted daily schedules and activities, (Aggar et al., 2011). Herlitz and Dahlberg (1999) found that co-resident caregivers to care receivers over 80 years of age in Sweden reported a restricted social life and an impaired relationship with the care recipient. In a similar

European study of caregivers to adults over 75 years of age, co-residence restricted caregivers' social life, outside activities, ability to see friends as often as liked and restricted their ability to take holidays (Jarvis et al., 2006).

Kin/non-kin relationship. Family caregivers were more likely to suffer consequences to their social well-being than non-kin. Australian adult children of frail older adults reported a significantly lower level of perceived family support (Aggar et al., 2011). Female spouses in a small European sample reported not being able to maintain social lives and personal relationships due to their care responsibilities (Innes et al., 2011).

Context and nature of care characteristics and social well-being.

Amount and duration of care. Caregivers of frail elderly who provided more than 20 hours of care per week indicated experiencing higher disrupted daily schedules (Aggar et al., 2011). This finding is not surprising given that more hours spent caring means there is less time for the caregiver to participate in other activities.

Type of care. Caregivers in Sweden who provided more personal care to recipients, reported restrictions to their social life (Herlitz & Dahlberg, 1999). Personal care tasks also require more time than other types of care which negatively affects social well-being as noted above.

Support. Caregivers who did not receive support from others reported greater social well-being consequences such as feeling isolated (Townsend et al., 2010).

Competing demands. Sandwiched caregivers who provided care to an older adult and care to a child at home, experienced greater consequences to their social well-being and reported no time for themselves (Rubin & White-Means, 2009).

Across all the domains of consequences there are some clear trends in the literature of those caregivers that are at greatest risk of experiencing consequences. Individual characteristics of the caregiver that are associated with increased risk of experiencing consequences include: being female, having poor health and having inadequate financial resources. There are also consistent findings for risk factors in care recipient characteristics. Caregivers who provide care to the following care recipients experience worse consequences: care recipients with greater functional limitations; those with dementia or cognitive impairments; and care recipients who have difficult or problematic behaviours. Spousal caregivers who co-reside with their care recipient are at greater risk than non-spousal and non-co-residing caregivers, of experiencing health and social consequences, particularly wives and those who report a poorer quality of relationship with the care recipient. Lastly, characteristics of the context and nature of the care situation appear to be especially important. Caregivers who provide more hours of care, over a longer period of time, and with less support, report a greater magnitude of negative consequences to their health and social well-being.

In summary, although there are these clear trends regarding risk factors, there are some areas lacking in consistent information or any findings at all. As indicated in Table 1, there are certain cases where there is no evidence in the literature of the effect that some risk factors have for the domains of consequences. Within the domain of social well-being there are six specific characteristics lacking information on how they may affect the magnitude of consequence. Further, some risk factors may only have one or two studies with findings addressing the relationship between the risk factor and the domain of consequence. These are areas where future research could be done to provide additional evidence and contribute to the knowledge on high risk caregivers.

Discussion

Across the literature on health and social consequences for caregivers, three main domains were identified: physical health, mental/emotional health and social well-being. Within each of the domains there are sub-categories that delineate areas of consequence experienced by caregivers. Reviews have been done on single consequences (i.e. stress) or particular care situations (i.e. dementia, stroke) (Campbell, 2009; Greenwood et al., 2008). This is the first review of all health and social consequences of caregiving to older adults in the community across care recipient diagnoses. The taxonomy of the health and social consequences of caregiving for family and friend caregivers to older adults guides researchers to include the full spectrum of possible consequences. Creating an awareness and inclusion of all domains of consequence can impact the conceptualization of how caregivers experience care to older adults. This research adds to the knowledge about caregiving risk factors and overall well-being.

The majority of articles provided findings on consequences to mental and emotional health while there was the least amount of evidence on consequences to a caregiver's social well-being. There were several areas of consequences and characteristics of findings that were consistent across all the included literature. For example, female caregivers and those in poor health were at greater disadvantage than males and those if better health, across the domains of consequence. Co-residence is an important risk factor across health and social well-being, but is confounded by other characteristics such as relationship status, specifically for spouses.

In other findings there was evidence that provided different or contrasting perspectives. Differences with respect to age of the caregiver and their employment status were evident within almost all of the domains while gender was consistent. Given what previous research has found with regard to gender differences in caregiving it is not surprising that female caregivers consistently report worse health and social consequences than men. What is unexpected is that there is no clear direction for employment status of caregivers as a risk factor.

Interpretations of these differences and possible explanations were provided to help make sense of this large body of literature. In some instances the sampling method of the studies could have been the source of the difference or else the studies were conducted in separate countries with varying levels of support and differing health care systems or with samples with different characteristics. For example the research done in Japan often recruited samples from those who received long term care insurance services and may not represent all care situations.

Within each of the domains there are some important observations that add to our understanding of the caregiving experience and present areas for further research. For example, findings with respect to caregivers' self-perceived health varied. Some research evidence presented a range of caregivers who reported poor health, from 10% (Rhee & Lee, 2001) up to 65.6% of caregivers (Fisher et al., 2011). In other studies, up to 69% of caregivers said their health was very good or excellent (Egbert et al., 2008). When caregivers were asked about physical health symptoms or problems, they consistently reported greater consequences than non-caregivers. Perhaps using another measure of health or multiple measures to correlate self-reported health with number of illnesses for example, would be more reliable for determining consequences to caregiver's physical health. In this body of literature there was minimal research on how risk factors influenced a caregiver's physical health so it was hard to determine factors that may have explained some of the inconsistencies in self-reported health status.

Within mental/emotional health consequences, rates of depression ranged from 12.5% (Izawa et al., 2010) to 40% (Fisher et al., 2011) in caregivers which indicates that, although a majority of caregivers do not report depression, it can still be a significant consequence for many family members and friends providing care. Caregivers unequivocally suffered from stress; one study in particular found that 65% of sandwiched caregivers' experienced stress (Rubin & White-Means, 2009).

With respect to social well-being, 12% (Bien et al., 2007) to 50% (Miura et al., 2005) of caregivers in the included studies reported that their relationships were compromised, including 13% (Schoenmakers et al., 2009) to 34% (Egbert et al., 2008) of relationships with care recipients. Even higher proportions were noted with respect to caregivers reporting disrupted social activities (34% to 56%) (Rubin & White-Means, 2009). This presents an interesting hypothesis that supporting positive and healthy relationships and involvement in social activities could be valuable ways of mediating consequences experienced by caregivers. Overall, greater understanding is needed of consequences in the social well-being domain and how risk factors affect the magnitude and prevalence of these consequences.

Risk factors as presented in Figure 4 provide a set of hypotheses that warrant further exploration. More evidence is needed to determine with confidence the role of these risk factors within each domain of consequence.

There are a number of limitations to this study. First there was no second reviewer for each step of the process from identification, screening, inclusion to data extraction. The search strategy was developed with a research librarian in order to ensure an appropriate strategy and use of terms . A second reviewer did periodically review a portion of the studies to confirm agreement with the inclusion and exclusion criteria of the primary reviewer and no discrepancies were noted. Second there was no quality assessment conducted on the articles. Although quality assessment is a component of systematic reviews it is often not performed in scoping reviews. This body of included literature is broad, multiple methods are used and findings which make it difficult to conduct quality assessments that are comparable. Lastly, only studies published in English were included which may exclude some valuable findings in other languages; however international literature was still captured. Despite these limitations, the findings provide valuable and reliable evidence.

Future research in this area would benefit from additional longitudinal studies, those addressing policy contexts, and the inclusion of social support variables and would benefit from incorporating literature on caregiving interventions. This body of literature comprises predominantly cross-sectional research thus limiting the ability to assess causality between caregiving and specific consequences with any confidence. It is clear that caregivers suffer greater consequences than non-caregivers, however longitudinal studies that compare individuals prior to and after care provision would provide valuable information. There may be pre-disposing reasons that increase an individual’s likelihood of providing care and thus of experiencing consequences. For example spouses may be more likely to take on caregiving for their partner than adult children.

Studies in this sample rarely addressed the policy context within or across countries of study. For future research it would be interesting to explore how the implementation of specific policies or health care services influenced the experience of caregiving. There were also limited comparisons across multiple countries with their differing policy contexts. One study that compared Japan and South Korea did note that some effects may have been due to the long term care insurance in Japan while caregivers in South Korea are responsible for supporting the care receiver financially (Rhee & Lee, 2001). A study of caregivers in 11 European countries did not provide any comparisons or interpretations between countries which could have provided a wealth of information (Soldato et al., 2008). This review included a substantial number of studies from Asia, however there was minimal comparison between Asia and North America within studies. Differences between these countries with differing health care systems and populations could be explored with respect to cultural norms such as filial piety and differing policies for health care and long term care provision. Even within North America there are different health care environments which would affect the caregiving situation. Such as between Canada, with universal health care, and the United States which does not offer the same services.

The results of this scoping review have solidified that caregivers do suffer consequences to their social well-being and research should include this as a domain of consequence in addition to physical and mental health. Research would benefit from collecting information on a caregiver’s social support network as caregivers with greater social support experience less consequence. However studies rarely take into account a caregiver’s social resources when studying the caregiving experience.

Further reviews or research on the health and social consequences of family and friend caregiving could benefit from incorporating literature on interventions. Much work has been done to develop and test interventions to address the caregiving consequences experienced by caregivers. With this new taxonomy on the domains of consequences, existing interventions could be assessed for effectiveness in reducing or preventing specific consequences. Also, new interventions could be developed that take into account all domains and sub-categories of cost as well as identifying those caregivers at greater risk of experiencing consequences.

This review included only care to adults over the age of 65. However this body of knowledge and the taxonomy could be expanded to include care provided to adult care recipients of all ages as well those care settings outside the community. Broadening the applicability and scope of the taxonomy would enhance its value to the many stakeholders interested in the consequences of family and friend caregivers.

The taxonomy on the health and social consequences of care developed through this systematic review is useful to many different stakeholders as noted in the introduction. It also contributes a holistic review of this body of knowledge and is useful for generating further hypothesis, and planning services. The conceptual framework provides a means of organizing all possible consequences of care for researchers and ensuring that all areas of consequences are included.

Policy makers may use this information to guide policy development or provide recommendations. Public awareness is important so that caregivers and health care professionals are aware of the risk factors. Fisher et al. (2011) confirm that supporting caregivers is essential to reducing their overall consequences, sustaining their ability to care and prevent or postpone institutionalization of care recipients.

When assessing a care recipient as a client or patient, professionals need to consider the caregiver as well. Identification of caregivers at high risk is valuable information for service providers and health care professionals working with older adults and their caregivers. Caregivers are a complex group with varying levels of risk and findings highlight the need to offer support to caregivers financially and socially in addition to physical and emotional health.

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Appendix A

Definitions

Concept	Definition	Source
Activity of Daily Living (ADL)	Tasks such as feeding, bathing, grooming, dressing, using the toilet, walking across a room, and transferring such as getting out of bed. Often used to determine level of disability.	Fisher et al., 2011; Kuzuya et al., 2006; p.30
Anxiety	Experience of symptoms such as easily startled, restless, particularly irritable, tremble or shaky, feeling dizzy or light headed, having trouble swallowing or sweating a lot,	Beach et al., 2000; p.34
Care	Care is distinguished from support by defining it as a set of tasks and services provided by a family member/friend because of the recipient's long term health need or disability.	Cranswick et al., 1999
Care Recipient	Care recipient identifies an individual who receives care from a family member or friend due to a long term health problem or disability.	Fast et al., 1999
Caregiver	An individual providing care or assistance to a family member, friend or neighbour who has a physical or mental disability, is chronically ill, frail, or is at the end of life.	Duxbury et al., 2009; Health Canada, 2002; p.1, 15
Compromised Relationships	The sub-category in the domain of social well-being which includes reduced amount of social networks and relationships for caregivers, reduced quality of those relationships and a changed relationship specifically between the caregiver and care recipient.	p. 37
Depression	Presence of symptoms such as loss of appetite, trouble falling asleep, tired all the time, stay away from people, feel worthless, trouble concentrating, or thinking a lot about death.	Beach et al., 2000; p.33
Disrupted Social Activities	Consequences in social activities such as a limited social life and activities, having no time for themselves and delaying or cancelling vacations.	p.38
Family/Friend Caregiver	Refers to an individual who provides care on an ongoing basis to a family member or friend and is based on a personal, often long term relationship.	Lero et al., 2007; p.1

Fatigue/Lack of Energy	Sub-category including feeling tired and exhausted, experiencing a lack of/or disrupted sleep, and low energy levels.	p.29
Financial Adequacy	How well a caregiver's current financial status satisfied their needs.	Lai, 2007; p.43
Functional Limitations	Refers to a caregivers’ ability or inability to perform activities of daily living and/or instrumental activities of daily living.	Fisher et al., 2011; p.30
Instrumental Activity of Daily Living (IADL)	Tasks such as grocery shopping, housework, meal preparation, taking medications, making telephone calls, and managing finances. Often used to determine level of disability.	Fisher et al., 2011; Kuzuya et al., 2006; p.30
Knowledge Synthesis	The integration of evidence from diverse knowledge sources to help inform knowledge users and decision makers.	Grimshaw, 2008; p.9
Literature Review	A common type of review which seeks to identify what has been accomplished previously, allowing for consolidation, for building on previous work, for summation, for avoiding duplication and for identifying omissions or gaps.	Grant & Booth, 2009; p.9
Mental/ Emotional Health	Domain of consequences that includes depression/anxiety, stress, and strain.	p.32
Meta-analysis	Technique that combines statistically the results of quantitative studies to provide a more precise effect of the results.	Grant & Booth, 2009; p.9
Pain	Magnitude of physical discomfort that caregivers experience and including indicators such as back pain and headaches.	p.30
Physical Health	Domain of consequence including feelings of fatigue and lack of energy; pain and physical strain; and finally, functional limitations due to caregiving activities.	p.26
Psychological Stress	Defined as an emotionally, disruptive response resulting from problems that threaten available resources, such as psychological resources. Emotionally disruptive responses include feelings and emotions that caregivers report such as anger, low self-esteem, feeling overwhelmed and frustrated.	Schwarz & Dunphy, 2003; p.34
Reduced Social Support	Aspects of social support affected by caregiving include the quality and adequacy of the support as well as a lack of support resulting in isolation.	p.39

Risk Factor	Characteristics of caregivers, care recipients, caregiving demands, and caregiving situations that are associated with an increased likelihood of negative effects on caregivers' social, health, and economic well-being. Being at risk can indicate those at risk of experiencing lower quality of life.	Chappell & Dujela, 2008; Lero et al., 2007; p.42
Role Overload	Relates to the internal encounter of being overwhelmed by care-related jobs and responsibilities, and addresses the feelings that the tasks are too much to bear.	Aneshensel et al., 1995; Chumbler et al., 2003; p.36
Role Strain	Strain or tension felt by caregivers as a result of their caregiver responsibilities when they feel they do not have enough time to adequately fulfill their multiple role obligations.	Seoud et al., 2007; Wang et al., 2011; p.36
Sandwiched Caregiver	Those caring for a parent or parent in law or grandparent who also had at least one child, any age, living at home.	Rubin & White-Means, 2009; p.29
Scoping Review	Aims to determine the main concepts underpinning a research area, as well as the main sources and types of evidence available. Conducted to examine the extent, range and nature of research in a particular field and produce a profile of the existing literature.	Arksey & O'Malley, 2005; Brien et al., 2010; CRD, 2008; p.10
Social Well-being Costs	Included consequences such as reduced socializing with family, friends and others, decreased levels of social activities, disrupted daily routines, risk of social isolation, and affected social support due to the demands of caregiving.	Haley, 2003; p.37
Systematic Review	Seeks to systematically search for, appraise and synthesize research evidence, adhering to pre-determined guidelines.	Grant & Booth, 2009; p.9
Taxonomy	Classification arranged in a hierarchical structure and, in this case, is used to conceptualize the categories of costs of care.	Keating et al., 2012; p.10

Appendix B

Table B1

Search Strategy 1 for Small Databases

1	Family caregiv*
2	Informal caregiv*
3	1 or 2
4	Consequence*
5	Outcome*
6	Cost*
7	burden
8	4 or 5 or 6 or 7
9	3 and 8
10	Limit 9 to yr=”1999-Current”
11	Limit 10 by publication type (if possible): journals, peer reviewed journals, periodicals

Table B2

Search Strategy 2 for Large Databases

1	Family caregiv* OR Informal caregiv*
2	Cost* OR Consequence* OR outcome* OR Burden
3	Health OR Well-being OR Stress
4	Physical OR Physiological
5	Psychological OR Emotional OR Mental
6	Social OR Psychosocial
7	2 AND 3 AND 4
8	2 AND 3 AND 5
9	2 AND 3 AND 6
10	7 OR 8 OR 9
11	1 AND 10
12	Limit 11 to yr=”1999-Current”
13	Limit 12 by publication type (if possible): journals, peer reviewed journals, periodicals

Appendix C

Data Extraction Table

Reference (Author, year, title)	Study Details											Domains of Consequence				Additional Details					
	Country	Study Objectives	Caregiver Details	Care Recipient Details	Sample/Participant Characteristics	Theoretical Framework	Study Methods/Procedures	Source of Data	Measures/Instruments	Validity/Reliability	Analysis	Physical Health	Mental/Emotional Health	Social Well-being	Other	Gender Differences	Magnitude /Risk Factors	Future Research	Strengths and Limitations	Recommendations	Comments

Appendix D

Characteristics of Included Studies

Reference (Author, year, country)	**Sample Characteristics**	**Caregiver Details**	**Care Recipient Details**	**Study Design/ Methods**	**Source of Data**	**Domain of Consequence**	**Risk Factor Characteristic**
Aggar et al. (2011). Australia.	N=93 Mean age 65.9 years (37-94). 59% female. 41% spouses, 42%, 42% daughters, 17% sons. 41% employed, 54% retired, 5% not working.	Nominated family member/ friend who provided unpaid care and support to frail older person	Aged 70 years and over living in the community. Frail elderly: 3 or more of the following: unintentional weight loss, fatigue, decreased grip strength, slow gait speed and low physical activity.	Self-completed descriptive postal questionnaire.	Caregivers were nominated by elders enrolled in randomized trial investigating frailty.	Physical (Fatigue/Lack of Energy, Functional limitations). Mental/ Emotional (Stress). Social (Activities, Support).	Caregiver (Health, Financial Adequacy), Dyad (Proximity, Relationship), Context & Nature (Amount & Duration).
Beach et al. (2000). USA	N= 394 caregivers.	Individual whose spouse has difficulty with at least one ADL/IADL due to physical or health problems or problems with confusion.	Disabled co-resident spouse. Most common diagnoses are stroke, arthritis, heart disease and memory problems.	Structured interviews by trained interviewers in caregiver's home.	Caregiver Health Effects Study is part of larger Cardiovascular Health Study (based on population sample of 5201 individuals over age 65)	Physical Health. Mental/ Emotional (Depression/ Anxiety).	Care Receiver (Disability/ Illness), Dyad (Quality), Context & Nature (Amount & Duration, Type, Competing Demands).

Reference	**Sample Characteristics**	**Caregiver Details**	**Care Recipient Details**	**Study Design/ Methods**	**Source of Data**	**Domain of Consequence**	**Risk Factor Characteristic**
Bien et al. (2007). Poland.	N=254. Majority were female and married. Rural: 40% male, 57% employed full time, 77% adult children. Urban: 24% male, 27% employed full time, 76% adult children.	Primary caregiver identified by the care recipient.	Community dwelling older adult (75 years or older) functionally impaired, need help with ADLs. N=238.	Personal interviews using COPE index instrument.	Urban sample from the city of Bialystok, rural sample from neighbouring rural community of Sokolka.	Physical Health. Mental/ Emotional (Stress). Social (Relationships).	Dyad (Relationship).
Bookwala & Schulz. (2000). USA.	N=283. 51% female, mean age 72.5 years, 90% white. Male caregivers 77.2 years. Female caregivers 75.8 years.	Provided assistance to spouses with at least one IADL or ADL	Spouse who had difficulty with at least one ADL or IADL due to physical or health problems or problems with confusion.	Structured interviews in caregiver's home.	First wave of CHES, multisite project that examines health effects of family caregiving. Ancillary study of CHS which provides descriptive data on health status and risk factors for onset and course of heart disease and stroke in large population based sample 65+.	Mental/ Emotional (Depression/ Anxiety). Social (Relationships, Activities).	Caregiver (Gender), Care Receiver (Disability/ Illness), Dyad (Relationship), Context & Nature (Amount & Duration).

Reference	**Sample Characteristics**	**Caregiver Details**	**Care Recipient Details**	**Study Design/ Methods**	**Source of Data**	**Domain of Consequence**	**Risk Factor Characteristic**
Buyck et al. (2011). France.	Total sample: N=10,687. Age 54-70 years.75% men. 85.3% married. 87.6% retired. Caregivers: N=2901 regular caregivers (27.1% of total sample).	If one or more person over 65 in social sphere who needed assistance in their daily lives and if provided regular assistance to this person.	Mostly family relatives, living in their own home with a physical dependency.	Individual self-questionnaire by mail.	Employee records of Electricite de France-Gaz de France and 2008 Gazel Cohort Study.	Mental/ Emotional (Depression/ Anxiety).	Caregiver (Age, Employment), Care Receiver (Disability/ Illness), Dyad (Relationship), Context & Nature (Amount & Duration).
Chappell & Dujela. (2008). Canada.	N= 92. 68.5% females, 83.3% married. Average age 60.7 years.	Caregivers to persons age 65 and older who were living in the community. Caregivers with heavy burden= providing minimum of 4 hours of direct care for at least 3 days per week.	Average age 80.1 years. 50% spouses.	Face to face interviews using structured questionnaires and were re-interviewed after 1 year.	Purposive sampling selecting caregivers with heavy burden.	Mental/ Emotional (Stress). Social (Relationships, Support).	Caregiver (Health), Care Receiver (Disability/ Illness), Context & Nature (Amount & Duration, Support).
Chappell & Reid. (2002). Canada.	N= 243. mean age 51.12yrs (range 21-85); 69.1% female, 56% employed.		Mean age 80.35 (range 65-99); 67.9% female; 37% married, 28.4% co-reside. 45% have cognitive problem.	Face to face structured interviews.	Participants recruited from random sample of residential telephone numbers in Victoria, BC.	Mental/ Emotional (Stress). Social (Support).	Care Receiver (Disability/ Illness), Context & Nature (Amount & Duration, Support).

Reference	Sample Characteristics	Caregiver Details	Care Recipient Details	Study Design/ Methods	Source of Data	Domain of Consequence	Risk Factor Characteristic
Chumbler et al. (2003). USA.	N=305. 69% women. 47% adult children, 24% spouses, 29% more distance relatives. Mean age 54.9yrs (range 18-86).	Defined as having the family member either living with or personally checking on the impaired senior.	English speaking, 70yrs+, residing in community. Mean age 78.4yrs (range 70-95). Disability index 3 out of 1-14. Memory impairment 4.5 (out of 0-30)	Telephone survey designed to collect data on older adults with mild to moderate cognitive impairment from a random sample of community dwelling seniors.	Arkansas Older Adult with Cognitive Impairment and Family CG Project. Screening older adults for cognitive impairment over the telephone.	Physical (Fatigue/Lack of Energy). Mental/ Emotional (Role Strain). Social (Activities).	Caregiver (Gender, Age, Health, Culture), Care Receiver (Disability/ Illness), Dyad (Relationship).
del-Pino-Casado et al. (2011). Spain.	Total analyzed sample N=1272. Average age 54 years (range 16-90). 86.2% primary cg, 83.2% women. 60.3% offspring. Pilot study n=204.	Informal caregivers with no more than one care receiver.	64.2% met one or more ADL dependency criteria,	National cross-sectional survey.	Probability sample representative of Spanish households.	Mental/ Emotional (Stress). Social (Relationships).	n/a
Efraimsson et al. (2001). Sweden.	N=5. Age ranged from 45-90 years.	One sister, two husbands, one wife, one son	N=7, aged 75-85. Suffering from diabetes, heart and vascular disorders, Alzheimer's disease, renal failure and stroke.	Unstructured qualitative interviews.	Recruited from local district nurses from families registered for home care. Municipality of Sweden, majority lived in rural areas.	Physical (Fatigue/Lack of Energy). Mental/ Emotional (Stress). Social (Relationships).	n/a

Reference	Sample Characteristics	Caregiver Details	Care Recipient Details	Study Design/ Methods	Source of Data	Domain of Consequence	Risk Factor Characteristic
Egbert et al. (2008). USA.	N=77. 85% white, 61% female, 70% 55years or older.	The person 18+ who provided, arranged or oversaw most of the care to someone 65years old or older who could not look after him or her-self . 52% caring for parents or in-laws.	Individual 65+ who could not look after him- or herself because of illness, disability or frailty in old age.	Phone interviews	Ohio adults recruited via telephone solicitations. Randomly generated list of phone numbers of households most likely to contain members 65+.	Physical Health. Social (Relationships).	Caregiver (Age, Health), Context & Nature (Type of Care).
Feil et al. (2011). USA.	N=21. Mostly female, spouse of care recipient, average 60yrs old and 15yrs education. 11 African American, 5 Asian, 2 Hispanic/Latino, 2 Caucasian and one other.	Family members of patient (veterans) who were actively involved in caring for care recipient with diabetes for at least one year.	N=21. At least 60yrs with diabetes for at least one year. Age range 65 years to over 90. 19 had diabetes for 5 or more years.	Qualitative study using focus groups to obtain in-depth information about caregiving barriers and facilitators to provide diabetes care for their family members with dementia.	Recruited from geriatric and adult primary care clinic at large veteran's administration healthcare facility.	Physical Health. Mental/ Emotional (Stress). Social (Activities, Support).	n/a

Reference	**Sample Characteristics**	**Caregiver Details**	**Care Recipient Details**	**Study Design/ Methods**	**Source of Data**	**Domain of Consequence**	**Risk Factor Characteristic**
Fisher et al. (2011). USA.	N=169. 73.7% female, 53.3% adult children 26% spouse. 62.5% co-reside.	Primary family caregiver (person most responsible for providing care to the care recipient).	Aged 70+. Care recipient with dementia had: higher levels of dementia severity, higher levels of cognitive impairment, difficulty with more daily functions. Compare caregiving to care recipient with dementia and cognitive impairment not dementia (CIND).	Cross-sectional questionnaire. Involves in-home assessment of respondent cognitive impairment.	Aging, Demographics and Memory Study (ADAMS). Nationally representative community-based study of dementia in US that includes dementia and CIND. Drawn from larger Health and Retirement Study, ongoing nationally representative cohort study of people born before 1954.	Physical (Pain). Mental/ Emotional (Depression/ Anxiety, Role Strain).	Care Receiver (Disability/ Illness).

Reference	**Sample Characteristics**	**Caregiver Details**	**Care Recipient Details**	**Study Design/ Methods**	**Source of Data**	**Domain of Consequence**	**Risk Factor Characteristic**
Herlitz & Dahlberg. (1999). Sweden.	N=152. 42% daughters, 20% sons, 15% spouses, n=57 cohabitating (40% spouses, 38% adult child).	Age range 40-87 years with only 2 younger than 40.	80+. Elderly people were asked if they were receiving informal home help regularly (daily) and if a particular friend or relative helped out in this way.	Quantitative interviews in their own home.	Random sample of people aged 80 years and up from national register of total Swedish population identified all persons living in their own homes.	Mental/ Emotional (Role Strain). Social (Relationships, Activities).	Caregiver (Gender, Age, Employment), Care Receiver (Disability/ Illness), Dyad (Proximity), Context & Nature (Type).
Hirakawa et al. (2008). Japan.	N=1559 pairs of caregivers and care receivers. Average age 64 years.	Caregivers to care receivers with no dementia caregivers: 69% women, 46% spouse, 48.5% child. Mild dementia caregivers: 78.6% women, 58% children, 39% spouse. Severe dementia cg: 75.86% women, 60.5% children, 35% spouse.	Community dwelling elderly persons (65+). Mostly women, married or bereaved and around 80 years of age.	Standardized interviews with care recipients or surrogates and caregivers in their homes.	Nagoya Longitudinal Study of Frail Elderly (NLS-FE). Older people recruited from those eligible for long term care insurance, living in Nagoya city and who received home care services.	Social (Support).	Care Recipient (Disability/Illness).

Reference	**Sample Characteristics**	**Caregiver Details**	**Care Recipient Details**	**Study Design/ Methods**	**Source of Data**	**Domain of Consequence**	**Risk Factor Characteristic**
Ho et al. (2009). China.	N=246. 2/3 of caregivers were women, half were 50 years of age or older, 50% were employed outside the home, 74% married and 2/3 had secondary level of education.	Defined as a member who spent at least 4 hours /week providing unpaid assistance to an elderly care receiver in the same household or another household.	Family member, relative or friend aged 65+ requiring assistance in at least one ADL or IADL	Questionnaire administer over the phone. Cross-sectional community based study of caregivers and non-caregivers conducted.	Participants in Hong Kong recruited through random digit dialing and questionnaire administered over the phone to obtain information regarding age and sex of household members aged 35+.	Physical (Fatigue/Lack of Energy, Pain, Functional Limitations). Mental/ Emotional (Depression/ Anxiety). Social (Activities).	Caregiver (Gender, Health), Context & Nature (Amount & Duration).
Imaiso et al. (2012). Japan.	N=196, 106 rural, 90 urban. Mean age all 65.6yrs, 76.5% female, 64.8% not child, 75% no job.	Primary family caregiver who uses home-visit nursing services and lives in rural or urban areas with an elderly recipient. Caregiver in rural community more likely to not be children.	Elderly who necessitates care above level 3 (involving caregiving either for 70 minutes or longer than 70 but not more than 90 minutes).	Mail survey. Latitudinal study is quantitative and designed to examine correlations.	Professional home care facilities selected using Welfare and Service network system; facilities sent questionnaires to family caregivers.	Physical Health. Mental/ Emotional (Depression/ Anxiety).	Caregiver (Gender), Care Receiver (Disability/ Illness), Dyad (Relationship), Context & Nature (Type).

Reference	Sample Characteristics	Caregiver Details	Care Recipient Details	Study Design/ Methods	Source of Data	Domain of Consequence	Risk Factor Characteristic
Ingersoll-Dayton & Raschick. (2004). USA.	N=441. 253 wives, mean age 72.77 years. 188 husbands, mean age 77.89 years.	Primary caregiver of care recipients living in non-institutionalized community settings.	Spouses with one or more limitations in ADLs or IADLs including wide range of functional and cognitive abilities.	Survey.	National Long-Term Care Survey (NLTCS) community survey conducted in 1999. NLTCS longitudinal study beginning in 1982 from sample of Medicare recipients.	Physical (Fatigue). Mental/ Emotional (Stress). Social (Activities).	Dyad (Relationship, Quality).
Innes et al. (2011). Malta, Europe.	N=16. 4 spouse caregivers (2 husbands, 2 wives), 9 children (8 daughters, 1 son) and 3 daughters in law.	Caring for a relative with dementia.	Care had a formal diagnosis of dementia, was attending the memory clinic, continued to live in the community.	Qualitative exploratory study with interviews.	17 family caregivers were interviewed from the memory clinic patient list.	Social (Relationships, Activities, Support).	Caregiver (Gender), Dyad (Relationship).
Izawa et al. (2010). Japan.	N=893 caregivers paired to care recipients. 213 men, 680 women. Age range 31-90, mean age 64.9years. 45.4% spouses.		893 community dwelling disabled elderly (337 men, 556 women); aged 65-104, mean age 80.4. 62.3% women	In client's homes, through standardized interviews with care receivers or surrogates and caregivers.	Nagoya Longitudinal study of frail elderly (NLS-FE). Data from care managing centres records taken by trained nurses.	Mental/ Emotional (Depression/ Anxiety).	Care Receiver (Disability/ Illness), Dyad (Relationship).

Reference	Sample Characteristics	Caregiver Details	Care Recipient Details	Study Design/ Methods	Source of Data	Domain of Consequence	Risk Factor Characteristic
Jarvis et al. (2006). UK.	N=172	Caregivers caring for someone over 75 years of age.	Age 75 years or older.	Questionnaire sent via mail.	Sample drawn from Scottish general practice population. Subsample of carers to people over 75 identified within large general practice in large Scottish town.	Physical (Fatigue). Mental/ Emotional (Stress). Social (Relationships, Activities, Support).	Caregiver (Gender), Care Receiver, (Disability/ Illness), Dyad (Proximity).
Kuzuya et al. (2006). Japan.	N=1478. Carers of fallers: n=451, 24.8% men, mean age 64.1 years, 38.5% are adult children, 38.5% spouses. Carers of Non fallers: n=1027, 27% men, mean age 64 years, 41.3% spouses, 34.5% adult children.	Caregivers of family member.	Receiving long term care insurance and home care services. Fallers (n=567) age 80.4 years vs. non-fallers (n=1307) age 81.0yrs.	Cross-sectional analysis of baseline data collected in client's homes through standardized interviews with care receiver or surrogates and caregiver and data from care managing centres records taken by trained nurses.	NLS-FE (1875 community dwelling frail elderly (men 632, women 1243, age 65 and older) eligible for long term care insurance, in Nagoya City and received home care services from the Nagoya City Health Care Service Foundation of older people.	Mental/ Emotional (Depression/ Anxiety).	Caregiver (Age, Health), Care Receiver (Disability/ Illness), Dyad (Relationship).

Reference	**Sample Characteristics**	**Caregiver Details**	**Care Recipient Details**	**Study Design/ Methods**	**Source of Data**	**Domain of Consequence**	**Risk Factor Characteristic**
Lai. (2007). Canada.	N=339. 94% first generation immigrants. 65.5% female, 54.7% between ages of 35-54 years. 35.4% daughters, 22.4% sons. 67.8% were primary caregiver.	Self-identified as Chinese, over 18 years and providing care to an older Chinese adult 65yrs+ and assist with simple tasks to intensive personal care.	Chinese elderly, living with the caregiver or not. Average age 74.6 years. Average number of illnesses = 3.	Cross-sectional telephone survey with structured questionnaire.	Survey identified random sample of 338 Chinese caregivers of Chinese elderly family members in Calgary, Alberta. Sample obtained through calling Chinese surnames in the phone book.	Physical Health. Mental/ Emotional Health. Social (Relationships).	Caregiver (Age, Financial Adequacy, Culture), Care Receiver (Disability/ Illness, Age), Context & Nature (Amount & Duration).
Lai et al. (2007). Canada.	N=339. Mean length of residency in Canada: 18.39 years, first generation immigrants 92.9%, 67.8% primary caregivers. 117 men, 222 (65.5%) women. 54.7% aged 35-54 years. 35.4% daughters, 22.4% sons.	Chinese caregivers 18 years older provide care to an elderly Chinese care recipient 65+.	Chinese elderly, mean age 75 years	Telephone survey using structured questionnaires.	Survey identified random sample of 339 Chinese caregivers of Chinese elderly family members in Calgary. Sample obtained through calling Chinese surnames in the phone book.	Physical Health. Mental/ Emotional Health. Social (Relationships).	Caregiver (Financial Adequacy, Employment Status), Care Receiver (Disability/ Illness).

Reference	Sample Characteristics	Caregiver Details	Care Recipient Details	Study Design/ Methods	Source of Data	Domain of Consequence	Risk Factor Characteristic
Lai & Thomson. (2011). Canada.	N=340. 73.8% female, 37.9% primary caregiver. 19.7% aged 35-44 years, 32.9% 45-54 years, 25.3% 55-64 years, 13.5% 65-75, 8.5% over 75.	A person 35+ who has provided assistance to an older adult in the past 12 months, with at least 1 care task because of a long-term health condition of the care receiver, who did not receive any financial remuneration for this assistance.	Older adult with long term health condition. Mean number of care receiver illnesses 5.10. Female receiver had significantly more illnesses than men (5.34 vs. 4.45). Mean age was 75 years	Phone survey.	Calgary and surrounding areas, via telephone directories. Two part phone survey. Part one for demographics, part two for family caregivers about roles, responsibilities and experiences	Social (Support).	Caregiver (Gender, Financial Adequacy), Care Receiver (Disability/ Illness), Context & Nature (Amount & Duration, Support).
Lee et al. (2007). South Korea.	N=1000. 78.6% women, 21.4% men. Mean age 52.36 years, range 20-89. 42.4% daughters-in-law, 24% spouses, 16.8% daughters, 11.5% sons, 5.3% others.	Caregivers over age 21 who were primary caregivers for disabled older family members.	Disabled older family members. 30.5% men, 69.5% women. Average age 78.09 years. 49% had dementia, 22.7% stroke, 28.3% other.	Data collection interviews in respondent's homes or other location in person.	Comprehensive Study for the Elderly Welfare Policy in Seoul. Recruited from community: adult care centres, nursing centres, and general recruitment. Two non-probability sampling employed to recruit 1000 participants.	Physical Health.	Caregiver (Age, Financial Adequacy, Employment Status), Care Receiver (Disability/ Illness, Age), Dyad (Proximity, Relationship), Context & Nature (Amount & Duration, Support).

Reference	Sample Characteristics	Caregiver Details	Care Recipient Details	Study Design/ Methods	Source of Data	Domain of Consequence	Risk Factor Characteristic
Llacer et al. (2002). Spain.	N=195. 68 carers of same generation (spouses and 2 sisters), mean age 75.7 years; 126 carers in younger generation (daughters, sons, daughters in law, nieces and granddaughters) mean age 60.7 years.	Primary carers providing assistance in ADL to community dwelling elderly. Care receiver asked to identify the person who helped the most in the following six personal care ADLs.	77% co-reside, 12% rotate between children. Need help with ADLs.	Home interviews.	Primary cg of people over 65 needing help with ADL identified during fieldwork for second wave of longitudinal study "Ageing in Leganes".	Physical Health. Mental/ Emotional (Depression/ Anxiety).	Caregiver (Health, Financial Adequacy, Culture), Care Receiver (Disability/ Illness), Dyad (Relationship), Context & Nature (Type, Support).
Lo. (2009). Taiwan.	N=39 caregivers, 98 non-caregivers. Mean age of caregivers 50.4 years and 50.4 years for non-caregivers.	Female caregivers aged 40-65, providing practical or psychosocial support to older family members (65+) on a daily basis for at least 2 hours/day for over 6 consecutive months.	65+ living in the community	Face to face interviews. Cross-sectional comparative study.	A convenience sample of caregivers and non-caregivers in urban area of Tainan in southern Taiwan. Researchers approached potential participants in small businesses (coffee shops) and public areas (markets).	Physical (Functional Limitations). Mental/ Emotional (Stress). Social (Support).	Caregiver (Health).

Reference	Sample Characteristics	Caregiver Details	Care Recipient Details	Study Design/ Methods	Source of Data	Domain of Consequence	Risk Factor Characteristic
Miura et al. (2005). Japan.	N=85 pairs of caregivers and care receivers. Mean age 64.33 years. 77.65% female. 34% adult children, 29.41% spouses, 23.53% daughter in law, 12.94% other.	Family caregivers.	N= 115 impaired elderly above 65 residing in the community with family who received public welfare service under the national LTC insurance system. 68.24% female, mean age 80.81 years, mean dementia rating 14.54/	Self-administered questionnaire.	Randomly selected family principal caregivers in Nobeoka City, Miyazaki Prefecture, in southern Japan.	Physical (Fatigue/Lack of Energy, Pain, Functional Limitations). Mental/ Emotional (Role Strain). Social (Relationships, Activities).	Caregiver (Health), Care Receiver (Disability/ Illness), Dyad (Quality).
Provinciali et al. (2004). Italy.	N=38. 30/38 females, mean age 53.8 years (range 40-72). 84% married. 18/38 daughters, 10/38 daughters in law. 32% primary caregivers. Compare 38 caregivers to 37 controls.	Non-spousal family caregivers who were between the ages of 45-75 years, were not receiving corticosteroids, or immune-suppressant drugs, no infectious, auto-immunising no neoplastic diseases.	Representative sample of the over 75 year old disabled elderly population living in the area.	In person data collection to administer a set of assessment scales in order to gain information on health, psychological and socioeconomic status.	Random sample of 70 subjects extracted from a list of 559 over 75 recipients of Health Home Care Services provided by the health district.	Physical Health. Mental/ Emotional (Depression/ Anxiety, Stress).	n/a

Reference	**Sample Characteristics**	**Caregiver Details**	**Care Recipient Details**	**Study Design/ Methods**	**Source of Data**	**Domain of Consequence**	**Risk Factor Characteristic**
Raschick & Ingersoll-Dayton. (2004). USA.	N=978. 253 wives, 188 husbands, 402 daughters, 135 sons.	Subsample of community survey consisting of wives, husbands, daughters and sons classified as primary caregivers.	Non-institutionalized elderly with at least 1 ADL or IADL dependency lasting over 90 days.	Cross-sectional study. Interviews.	National Long Term care Survey (NLTCS). Systematically selected people over 65 years.	Physical (Fatigue/Lack of Energy). Mental/ Emotional (Stress). Social (Activities).	Caregiver (Gender), Dyad (Relationship, Quality).
Rhee & Lee. (2001). Korea and Japan.	N=404 Koreans. N=766 Japanese. Korea: average age 57.8 years, 80.2% female, adult children 54.7%. Japan: 64.7 years old, 79.2% female, 66.4% adult children. 10% had other household members for whom they also care.	Primary caregivers to persons aged 65+ who were bedridden or had symptoms of dementia or stroke: who helped with ADLs.	Ability to do ADLs at home but not without help, or need help with ADLs and lie down most day, or lie down all day and need help with 1 ADL. Korea: 56.7% female, 52.7% married, mean age 77.1 years. Japan: 66% female, 86 years mean age, 41.7% married.	Telephone interview survey.	Survey "A Survey on Family CG of Impaired Elderly" in Japan and Korea. Two subsamples: 1-random sample of impaired elderly receiving public community care services and 2-excluding those who received services.	Physical Health. Mental/ Emotional (Stress). Social (Support).	Caregiver (Gender, Health, Culture), Care Receiver (Disability/ Illness), Context & Nature (Amount & Duration, Support, Competing Demands).

Reference	**Sample Characteristics**	**Caregiver Details**	**Care Recipient Details**	**Study Design/ Methods**	**Source of Data**	**Domain of Consequence**	**Risk Factor Characteristic**
Rozario et al. (2008). USA.	N=358. N=100 wife caregivers, n=258 daughter caregivers. Wives significantly older (68.89 vs. 48.74 years).	Females self-identified as African American (AA), 18+, currently providing unpaid ADL, IADL or decision making help to an elder.	Self-identified as AA, Black, Negro, Colored. Gets unpaid help from an AA woman with at least one ADL or IADL or in decision making.	Cross-sectional study. Computerized structured questionnaire to conduct in home interviews.	Data came from larger study of 521 urban and rural Midwestern AA female caregivers of older AA (65+). Names initially from Medicare list.	Physical Health. Mental/ Emotional (Depression/ Anxiety). Social (Activities, Support).	Caregiver (Health), Context & Nature (Support).
Rozario & DeRienzis. (2008). USA.	N=521. Mean age 53.8 years. 45.1% employed, 12.3 years education. 50.9% rural. 20.2% wives. 50% daughters.	African American (AA) women, 18 years+, who currently provided unpaid help to an older person.	African American, 65+ enrolled in Medicare.	Computerized structured questionnaire to conduct in home interviews.	Black Rural and Urban Cg Mental Health and Functioning Study. Using a sample of family caregivers that is systematically drawn from the community.	Physical Health. Mental/ Emotional (Depression/ Anxiety, Stress). Social (Relationships).	Caregiver (Health, Employment), Dyad (Quality).

Reference	Sample Characteristics	Caregiver Details	Care Recipient Details	Study Design/ Methods	Source of Data	Domain of Consequence	Risk Factor Characteristic
Rubin & White-Means. (2009). USA.	N=777. 77 sandwiches caregivers, 700 other caregivers. Sandwich caregivers younger (48 vs. 56 years), more likely to be female (81% vs. 57%), more likely to be employed (73% vs., 35%), had higher income and were twice as likely to be married.	Sandwiched caregivers (care to older adult and child at home) including child, child in law, or grandchild of NLTCS respondent, with weekly caregiving hours equal to 1-168.	Care receivers with chronic impairment (lasting 90 days or more). All care receivers have a number of limitations: 3.5 ADLs and 5.5 IADLs	Interviews & individual reports of chronic impairment (lasting or expected to last 90 days or more).	1999 National Long Term Care Survey (NLTCS), a longitudinal study designed to estimate chronic disability status and institutionalization rates of older persons (65+). Includes special caregiving survey.	Physical (Fatigue/Lack of Energy, Pain). Mental/ Emotional (Stress). Social (Relationships, Activities).	Caregiver (Employment Status), Care Recipient (Disability/ Illness), Context & Nature (Support, Competing Demands).
Schoenmakers et al. (2009). Belgium.	N=92. Two groups: care recipients with dementia and a control group.	Primary family caregiver.	N=105. Community dwelling, with regular visits by a nurse for more than 1 month, suspicions of dementia. Group divided into demented and control group. Mean age 81.4 years. 72% female.	Controlled, observational, cross-sectional study. Self-completed questionnaires.	Recruitment in socio-demographically representative Belgian region. Health care professionals asked to identify older persons meeting criteria.	Mental/ Emotional (Depression/ Anxiety). Social (Relationships).	Caregiver (Gender), Care Receiver (Disability/ Illness), Dyad (Quality), Context & Nature (Amount & Duration).

Reference	**Sample Characteristics**	**Caregiver Details**	**Care Recipient Details**	**Study Design/ Methods**	**Source of Data**	**Domain of Consequence**	**Risk Factor Characteristic**
Schoenmakers et al. (2004). Belgium	N=180. Three groups: Study group - demented are receivers, Control group1 - no mental disease (NMD), Control group 2 - mental disease but not dementia (MD).	N=90. family members (spouse, child, brother, sister), neighbours or a good friend. Study groups mean age 84 years, control group men age 81.5 years.	N=180 community dwelling elderly. 3/2 male to female ratio. Mean age study group 84 years, control group NMD 81.3 years.	Descriptive field study. Two sessions of interviews to complete questionnaires.	Recruited by professional caregivers and care providing organizations.	Mental/ Emotional (Depression/ Anxiety).	Caregiver (Gender), Care Receiver (Disability/ Illness).
Schwarz & Dunphy. (2003). USA.	N=75. Males 26.7% (n=20) and females 73.3% (n=55). Average age 63 years. Spouses 51% and adult children 37%. 88% white, 79% at least high school education. 80% financially comfortable.	Family caregivers of adults with heart failure living in the community providing support for ADL.	Older adult with heart failure living in the community. Excludes care receivers in hospice and those cognitive impaired.	Interviews in respondent's homes about perceived stress, depressive symptoms and social support after hospital discharge.	Convenience sample of family caregivers identified by professional health care staff.	Physical (Functional Limitations). Mental/ Emotional (Depression/ Anxiety, Stress). Social (Support).	n/a

Reference	Sample Characteristics	Caregiver Details	Care Recipient Details	Study Design/ Methods	Source of Data	Domain of Consequence	Risk Factor Characteristic
Seoud et al. (2007). Lebanon.	N=319. 84% female. 48% adult children, 22.6% spouses. 55% housewives. Mean age 46 years, 50% between 30-49 years.	Lebanese, 18 years+, Arabic speaking, primary caregiver (person most responsible for providing care) for at least the past 6 months to care recipient, provided help with at least 1 ADL or IADL at least once a week and co-resides.	Relative 65yrs+ requiring assistance to accomplish personal care. Mean age 76 years, 60.8% women, 55.2% widowed, 3/4 no medical insurance coverage. 44% had poor state of health and 41% weak state of health.	Face to face interviews in caregivers homes. Exploratory correlational study.	Non-probabilistic convenience sample drawn according to predetermined quotas of subjects from each region of Lebanon quotas calculated based on demographic weight and SES of region. Interviewers recruited caregivers for study by going door to door.	Mental/ Emotional (Stress, Role Strain). Social (Support).	Caregiver (Culture), Care Receiver (Disability/ Illness), Dyad (Relationship), Context & Nature (Support).
Shyu et al. (2012). Taiwan.	N=135. 57.8% women. Average age 52.8 years. 88.7% married. 32.6% sons, 26.7% daughters-in-law, 20% spouses, 14.1% daughters. After 3 months, n=122, after 6 months n=116, after 12 months n=98.	18+, assuming primary responsibility for providing direct care or supervising the care received by the care recipient.	65 +, previously hospitalized for surgical internal fixation or arthroplasty after hip fracture, live in northern Taiwan, independent in ADL before fracture. 66.7% women, average age 78.3years.	Prospective correlational study. Face to face interviews. Data collected from family caregivers at 1, 3, 6, and 12 months after discharge of older hip-fractured care recipients.	Recruited from medical centre.	Physical (Fatigue/Lack of Energy, Pain, Functional Limitations). Mental/ Emotional (Role Strain). Social (Activities, Support).	Context & Nature (Amount & Duration).

Reference	**Sample Characteristics**	**Caregiver Details**	**Care Recipient Details**	**Study Design/ Methods**	**Source of Data**	**Domain of Consequence**	**Risk Factor Characteristic**
Soldato et al. (2008). Europe.	N=3415.	Primary caregiver defined as the family member, friend or neighbour (but not paid provider) who was most helpful to the participant and who they could most rely upon.	Mean age 82.4 years, 73.3% women.	Cross-sectional study of care receivers across 11 European countries. Data collected from MDS reports.	AdHOC project. Random sample of elderly admitted to home care programs in urban areas of Prague (Czech Republic), Copenhagen (Denmark), Helsinki (Finland), Amiens (FR), Nurnberg & Bayreuth (Germany), Reykjavik (Iceland), Monza (Italy), Rotterdam (NL), Oslo (Norway), Stockholm (SW), Maidstone & Ashford (UK).	Mental/ Emotional (Stress).	Care Receiver (Disability/ Illness), Dyad (Proximity).

Reference	Sample Characteristics	Caregiver Details	Care Recipient Details	Study Design/ Methods	Source of Data	Domain of Consequence	Risk Factor Characteristic
Soskolne et al. (2007). Israel.	N=402 caregivers and non-caregivers. N= 202 matched pairs of wife caregivers (101) and non-caregivers (101), and 200 matched pairs of daughter caregivers (100) and non-caregivers (100). Non-caregivers individually matched to caregivers by relationship to care recipient, age and country/region of birth and daughters by marital status as well.	Hebrew speaking women aged 35+, wives or daughters. Caregivers: women who self-identified as the primary caregiver to elders who needed assistance with 2+ ADL or 3+ IADL functions, or needed to be under constant supervision due to cognitive decline. Non caregivers: wives or daughters of individuals who did NOT need continuous assistance with ADL/IADLs or constant supervision.	Elders need help with ADLs or IADLs. And one group of elderly who do not need help with ADLs/IADLs but may have needed some temporary help because of recent hospitalization.	Cross-sectional comparative study. Phone interviews.	Participants recruited from family members of older patients (65+) discharged from 3 Internal Medicine wards of medical centre in Jerusalem.	Physical (Functional Limitations). Mental/ Emotional (Depression/ Anxiety).	Dyad (Proximity, Relationship), Context & Nature (Amount & Duration).

Reference	**Sample Characteristics**	**Caregiver Details**	**Care Recipient Details**	**Study Design/ Methods**	**Source of Data**	**Domain of Consequence**	**Risk Factor Characteristic**
Sugihara et al. (2004). Japan.	N=807. At baseline: mean age 62.2 years. 29.9% wives, 29.9% daughters, 20.3% daughters-in-law, 12.1% husband, and 7.8% sons. 96.4% co-reside.	Identified as the family member who was primarily responsible for the impaired elders' care, including wives, husbands, daughters, sons or daughters in law.	65+ needed help with ALDs or if they had memory or behaviour problems.	Longitudinal study with 3 interviews over the course of 30 months. Face to face interviews.	Representative sample of caregivers living in a suburban city to the west of Tokyo.	Mental/ Emotional (Depression/ Anxiety, Role Strain).	Caregiver (Gender), Dyad (Relationship).
Suwal. (2010). Canada.	N=3501, 570 immigrant family caregivers (16.3%) and 2931 non-immigrant family caregivers (83.7%). 18.6% of immigrant family caregivers were over 65, only 14.6% of non-immigrant caregivers were over 65 years. Half of caregivers were female.	Provided informal care to adult 65+ with long term health condition.	65+ with long term health condition.	Cross-sectional study. Telephone interview survey.	General Social Survey 2002, Cycle 16. Data collected all over Canada and respondents aged 45+ were interviewed by telephone.	Physical (Fatigue/Lack of Energy). Mental/ Emotional (Stress).	Caregiver (Gender, Age, Culture), Context & Nature (Type, Support, Competing Demands).

Reference	**Sample Characteristics**	**Caregiver Details**	**Care Recipient Details**	**Study Design/ Methods**	**Source of Data**	**Domain of Consequence**	**Risk Factor Characteristic**
Townsend et al. (2010). USA.	N=162. Mean age 61.77yrs (range 19-92yrs); predominantly female and Caucasian; almost half were spouses among the other half 82% were adult children/children-in-law and 18% were other. 86% co-resided full time, and 5% part time.	Providing care to care recipient 65+; over 18yrs; English speaking; included significant others and friends "like family".	Receiving home hospice care through HWR; first hospice admission; average age 79.41yrs; average of 3 major illnesses; just over 20% had 5 or more conditions. 68% cancer, 48% heart disease, 23% dementia, 23% lung disease, 22% diabetes and 15% stroke.	Cross-sectional survey with structured, in-person interviews with family caregivers.	Recruited from hospice home care social workers caseload (employees of Hospice of the Western Reserve) including 8 sites in greater Cleveland Metro area.	Physical Health. Mental/ Emotional (Stress, Role Strain). Social (Support).	Caregiver (Age), Care Receiver (Disability/ Illness), Dyad (Quality), Context & Nature (Support).
Vroman & Morency. (2011). Belize.	N=30 (only 29 data analyzed due to recording quality). 3/4 cg were female. Mean age 52yrs, range 23-82. 18 = adult children, 8=grandchild, 6= spouse, 4=other (niece, neighbour). 29/30 co-resided.	People who provide unpaid, in-home care to an older adult unable to live independently or for him/herself.	n=33. Mean age 84yrs, range 67-102.	Qualitative exploratory study using semi-structured interviews with open ended questions.	Participants identified by HelpAge Belize.	Physical (Fatigue/Lack of Energy, Pain). Mental/ Emotional (Role Strain). Social (Relationships, Activities).	Caregiver (Financial Adequacy, Culture), Care Receiver (Disability/ Illness).

Reference	Sample Characteristics	Caregiver Details	Care Recipient Details	Study Design/ Methods	Source of Data	Domain of Consequence	Risk Factor Characteristic
Wallsten. (2000). USA.	N=234, 118 caregiving couples, 116 controls. Caregivers: 18 Caucasian males, 31 Caucasian females, 19 African American (AA) males and 49 AA females and 1 native American female. Mean age 75.03 years. Mean years married 47.12.	Caregivers were married to EPESE sample member; consider themselves a caregiver to spouse. Comparison group chosen by selecting couples in which one spouse was EPESE sample member with no ADL, IADL or cognitive impairments.	Adult over 70 years of age who either could not do at least 1 ADL or 2 IADLs or was cognitively impaired. Mean age 78.77yrs.	Cross-sectional data from longitudinal study. Interviews conducted at home.	Sample for data from first year of Duke School of Nursing Caregiver/Care Receiver Study drawn from Established Populations for Epidemiological Studies of the Elderly (EPESE), longitudinal study based on stratified sample of 4162 community residents aged 65+ living in five county area of central N. Carolina.	Physical (Functional Limitations). Social (Support).	Caregiver (Culture).

Reference	**Sample Characteristics**	**Caregiver Details**	**Care Recipient Details**	**Study Design/ Methods**	**Source of Data**	**Domain of Consequence**	**Risk Factor Characteristic**
Wang et al. (2011). Taiwan.	N=119. Mean age of 48.6 years, range 29-66. 24.4% daughters, 47.9% sons, 27.7% daughters-in-law. 85.7% married and majority co-resides (69.7%).	Adult child family caregiver had primary responsibility for providing direct care or supervising care received by family member with dementia, aged 18+ and able to read and write in Chinese.	65+, diagnosis of Alzheimer's Disease, vascular dementia or both, clinical dementia rating of $\geq$ 1 and living at home (not institutionalized). Mean age 79.3yrs, range 65-96. Majority female (63%) and widowed (57%).	Cross-sectional, secondary data analysis. Mail questionnaire.	Dyads of older people with dementia and adult-child family caregivers were purposive sampled from larger study on caregiving to people with dementia.	Mental/ Emotional (Depression/ Anxiety, Role Strain). Social (Support).	Caregiver (Gender, Employment Status), Care Receiver (Disability/ Illness), Dyad (Quality), Context & Nature (Amount & Duration, Competing Demands).
Yamamoto -Mitani et al. (2004). Japan.	N=325 caregivers. Average age 60.4 years. 81.9% female, 28.2% wives, 28.2% daughters, 21.4% daughters-in-law. 75% married, 1/4 employed, 10.7% had children less than 15 years. Most co-reside.	Family caregivers providing home based care for elderly relatives 65+.	N=337. Mean age 81.6yrs (range 65-104). 57.6% female. 53.7% cerebrovascular disease. Dependence level: 36.5% bedbound, 38.9% completely bedbound. 29.7% normal dementia level.	Information from nursing records and questionnaires administered by nurses.	Selected from clients of 21 visiting nurse organizations in various areas of Japan-Tokyo metro area.	Physical Health. Mental/ Emotional (Role Strain). Social (Relationships, Support).	Caregiver (Age, Employment Status), Care Receiver (Age, Gender), Dyad (Relationship), Context & Nature (Support).