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The Cost Effectiveness of Respite A Literature Review

**Prepared for Health Canada
Home and Continuing Care Policy Unit
Health Care Policy Directorate**

By

Janice M. Keefe, PhD

&

Marlie Manning MEd, MA

**Mount Saint Vincent University
Halifax, Nova Scotia**

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Please direct inquiries to:

Janice M. Keefe, PhD
Canada Research Chair in Aging & Caregiving Policy
Associate Professor
Department of Family Studies and Gerontology
Mount Saint Vincent University
166 Bedford Highway
Halifax, Nova Scotia
B3M 2J6

Tel. 902-457-6780
Fax. 902-457-6226
Email. Janice.Keefe@ MSVU.ca

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Preface

“To every complex question there is a simple answer ... and it is wrong.”

H. L. Menken

The original purpose of this project was to investigate studies, both national and international, that would provide knowledge to the question of whether the provision of respite services is cost effective to governments. As will be explained, it was soon determined that there were findings from very few studies that would satisfy the objective, and so the review question was narrowed to whether the use of respite services by family caregivers delays or prevents facility-based placements of care recipients.

This paper summarizes a scan of the relevant literature. It begins with an orientation to respite services and explanation of why it is important to caregivers. Then it addresses the reasons why there is scant evidence of the services' economic effectiveness, and a synopsis of what is known about whether they prevent or delay placement in facilities. A discussion follows, and recommendations for research directions are offered.

Introduction

Respite is defined as “a break, time out or relief for the caregiver” (Lysne, 2002, p. 1). Advocates for caregivers and care recipients emphasize that respite is not a service but rather *outcome* for caregivers, reinforcing that it is a personal, subjective experience. Respite services are understood in this paper to be those that intend to provide that experience or outcome. They may be adult day care, in-home respite care, overnight or longer-term respite stays in facilities, or a mixture of services. Whether respite services reduce amounts of facility-based care is only one aspect of understanding their cost effectiveness to governments, and cost effectiveness is only one aspect of understanding the totality of respite's effectiveness for caregivers, care recipients, care providers and their agencies, and society-at-large.

The importance of this knowledge is rooted in the devolution of health care services, away from hospitals, mental health centres, nursing homes and other facilities, and into communities and onto families. A consequence of the shift has been the exponential growth of in-home care, in numbers of people who receive care in the home, complexity and diversity of their care needs, and often, the length of time their care is required. There are now more children whose lives depend upon in-home technology, more seniors in homes who are assisted in tasks of daily living, and more people who choose to die in their homes.

Family members or others who have personal relations with the care recipients assume most of the responsibilities for in-home care. Indeed, caregivers in Canada have been described as “the invisible back-up that allows our health care system to keep functioning as it continues to shift away from institutionalized care” (Brodhead, 2004, p. 1). Most caregivers are women, 77 percent according to a 2002 Decima study completed for Health Canada to provide a current profile of family members who provided care to someone in their home or family member's home in the previous month (Decima, 2002). They are usually wives or daughters of the care recipients. Of the former, many are aging. Seventy percent are over 45 years, 25

percent are at least 65 years, and of the latter, many have responsibilities and stresses extraneous to caring for someone who is ill or has a disability, such as being a single parent, or having limited income, or being at greater risk of losing paid employment. The study also found that about half the care recipients were 65 years of age or older and 17 percent, at least 85 years.

Persons at least 65 years old accounted for almost 13 percent of the national population in 2000, but by 2050, they are expected to represent 25 percent (Statistics Canada, March, 2001). A significant proportion will have functional needs for assistance. Guidance might be taken from two national surveys of 1986 and 1996. Both indicated that about forty percent of those at least 65 years were functionally disabled, and about half of them required some assistance to manage the tasks of daily living (as reported in Keefe, Carrière & Légaré, 2004).

Over the decades, caregivers have played an increasingly significant role in health care delivery, and it is safe to expect that the demands *for* and *on* them will continue to increase if only because of demographic projections. According to findings using data gathered from national demographic surveys, the proportion of disabled persons at least 65 years old could grow at an annual growth rate of between 1.9 to 2.5 percent (Keefe, Carriere, & Legare, 2004). As well, projections based on the Canadian Study of Health and Aging (CSHA) suggest there will be close to 800,000 seniors with a diagnosis of Alzheimer's disease by 2031, and there will be more people living longer with disabilities (McDowell, Hill, Lindsay, & Kristjansson, 2002).

In 2002, more than two million Canadians aged 45 years and older provided care and support, duties that include personal care tasks such as bathing and toileting, household chores such as grocery shopping and cleaning, supervision, and emotional support (Statistics Canada, 2002). A small proportion of them administer or assist with medical treatments, from managing medicines to monitoring life sustaining technologies, and providing palliative care medications. There are gender differences in the types of tasks provided and in the health consequences of their caregiving responsibilities (Statistics Canada, 2002). Women are more likely than men to provide personal care – tasks previously identified by Keating et al., (1999) as more demanding. These physical demands raise concerns about caregiver burnout and long term health consequences. They are not gender neutral; the proportion of women whose health has been affected by their caregiving duties is twice that of men.

The need for caregivers to have an occasional break from these responsibilities was identified in 2002, not only by the Decima study but as well by Cycle 16 of the General Social Survey (Decima, 2002; Statistics Canada, 2002). The findings conform to studies completed in other countries like the United States and the United Kingdom (ARCH, 2003; Arksey, O'Malley, Baldwin, Harris, & Mason, 2002).

Countries including Australia, Germany, Norway, Sweden, the United States and United Kingdom, have increased monies to and attention towards more universal provision of respite services for caregivers (Keefe, 2004). Canada as yet does not have a universal framework to support or compensate caregivers, although all provinces and territories provide respite services in their publicly-funded home care programs. There are variations among and within the jurisdictions, as well as between urban and rural communities in descriptors such as availability of services, costs to consumers, and range of services offered (Health Canada, 2003). Jurisdictions may not always have services for people with mental illnesses and some other health conditions, and all provide extended respite services for circumstances of palliative care (ibid.).

Commonsense dictates that respite services provide a substantial contribution to sustaining the health care system because their utilization results in a reduction of caregiver burden and stress. However, the

results of a 1999 literature review suggest that the evidence of impact on caregivers is not known (McNally, Ben-Schlomo, & Newman, 1999). After a review of 29 studies, the findings were that there was little evidence to demonstrate an enduring or consistent beneficial impact on caregiver wellbeing. As well, there remains scant evidence about respite services' economic value.

Barriers to knowledge of the cost effectiveness of respite

The task of conducting a literature review on the cost effectiveness of respite presents a myriad of challenges, which might best be understood by breaking the task into its components of (a) a literature review, (b) cost effectiveness, and (c) respite, and identifying the challenges within each.

Any literature review that is not contained by guidelines or constructs for assessing the quality or relevance of studies is vulnerable to criticism for not necessarily reflecting current evidence and for bias (Woolf, 1992). To protect against that, *systematic* literature reviews are used in health care research, which produce

evidence from scientific studies [that is] located, evaluated and synthesized using a strict scientific design which must itself be reported in the review. The aim is to ensure a review which is comprehensive, unbiased and may be used with confidence for decision-making about research and delivery of healthcare (p. 947).^[1]

Any systematic literature review requires significant resources, both human and time. Usually two investigators review each article independently for relevance and quality, and judgements are mediated by others who represent perspectives from a range of professional and disciplinary fields. A systematic review of respite requires an extra amount of time because search terms are poorly indexed and abstracts are sometimes unsatisfactory (Arksey et al., 2004a).

The term *cost effective analysis* is complex. A definition is provided in the most recent literature review on respite services (ibid.):

Cost-effectiveness analysis can be seen as an umbrella term to include all studies in which two or more appropriate interventions are compared in terms of both their associated costs and consequences (effects) (Drummond et al., 1997). Such analysis examines the extent to which the balance between input (the costs of resources used) and outputs (effects/benefits/outcomes/consequences) of interventions represent value for money. It seeks answers to such questions as: Is the intervention worth implementing compared with other interventions that could be implemented with the same resources AND/OR Are we satisfied that the resources used to provide the intervention should be spent on intervention x as compared to intervention y? (p. 20)

Cost-effectiveness analysis always requires a numerator, the unit of effect or extent of benefit, and a denominator, or the cost of achieving that benefit. In determining the cost effectiveness of respite care, there are complications to defining and determining both. Cost effectiveness analyses are specialized, best left to the expertise of a health economist, and most often retrieved from databases specific to economic literature. Previous literature reviews on subject matter related to this project concluded that there are substantial barriers to acquiring this knowledge.

The term *respite* is complex as well. Respite is understood to be the relief from - or the reduction of,

prevention of, or maintenance of the homeostasis of - the stress and burden from activities of caregiving. And like stress and burden, respite is an internally felt, uniquely personal experience for each caregiver. There is no exactness to its measurement, and it is unrealistic to expect total relief from stress and burden, but rather only aspects of it. It is achieved by one or many interventions, only some of which are formal services, and of them, respite services. In fact, the effectiveness of respite services is highest when services are offered in tandem with other community support programs (Zarit, 2001). This raises questions about whether the personal experience of relief from caregiver stress was created by service use, or by a combination of support services, or some other set of factors.

There are several types of respite services, each which offer particular relief to caregiver burden. In-home respite services, for instance, allow care recipients to remain in their residence and their caregivers to move outside for short periods. It may be appropriate for end-of-life care and for caregivers of children with complex needs or the frail elderly. Families of adults with chronic mental illness may benefit from the care recipient's short term stay outside the home. If this type of respite service is not preferred by the caregivers, or does not meet their personal needs and circumstances, or the match of worker with recipient or quality of care is not judged by the user to be satisfactory, relief is compromised (Worchester & Hedrick, 1997). Optimum service impact is dependent upon multiple influences of circumstance and situation. If used in amounts too little, or too late in the life span of the caregiving experience, caregiver burden and stress are not reduced as much as when services are used before burden and stress are substantially felt, with regularity and in sufficient amounts (Zarit, Stephens, Townsend, & Greene, 1998).

Respite in general is a messy business to research. It is complex, complicated by its personal and social context. As referenced earlier, some findings of respite services seem to contradict what is reasonable to expect. Not only do studies lack evidence of their effectiveness for caregivers or their economic effectiveness to taxpayers, but respite services tend to be underutilized despite their high demand. Following a 2003 survey of Canadian policy makers who have an interest in respite services, the Caledon Institute suggested reasons for underutilization may include lack of consumer knowledge of their availability, anxieties about exploiting the system, or fears that this is a step towards giving up (Torjman, 2003). Other sources suggest that this is common to some cultures (Feinburg & Whitlatch, 1998; Soderberg, 2003; The Lewin Group, 2001). These complexities present risks to the quality of research findings. The conclusion of all reviews, listed in Appendix A, is that there is a lack of systematic evaluation of respite's generic effectiveness, and even more so, of its cost effectiveness.

After completing three reviews concerning support services for caregivers, investigators from the Social Policy Unit of the University of York issued a report, *Support services for carers: methodological issues in evaluating the literature*, offering "guidance for individuals in evaluating the evidence base for support services for carers" (Arksey, Jackson, Mason, Wallace, & Weatherly, 2004b, p. 1). Problems of management and methodologies were identified, with recommendations including the need for a multiple stage process with articulated aims, objectives and methods, clear definition of good data and good evidence of effectiveness and cost effectiveness, and a typology of criteria to appraise that quality. Further, at least some evidence must attend to whether longer term benefits are realized, and research methods should include an appropriate combination of quantitative and qualitative methods.

The review question: what it is, and what it is not

As expected, an initial electronic search to gauge the extent and quality of the evidence on the topic of cost effectiveness to governments of respite services had the same results as the unanimous conclusions drawn from the literature reviews: there is no evidence to support the cost effectiveness to governments of respite services. Researchers and experts in the field from several countries confirmed that this was to be expected (see Appendix B). On the basis of the paucity of good evidence on respite's cost effectiveness, the review question was narrowed to:

What is known about whether the use of respite services by family caregivers delays or prevents facility-based placements of care recipients?

This review then presents a summary of findings from studies that address the association between the provision of respite services and the timing of placements in facilities. In most cases, the term *facilities* refers to long term care such as nursing homes, but it also encompasses hospitals, psychiatric residential settings and hospices.

It does not account for the costs of respite services. It does not include costs incurred by the government for medical care that may be the result of caregiver burden or stress, whether those costs are from visits to physicians, admissions to acute care facilities, visits to emergency departments, drugs paid by the public purse, or crisis admission to a facility because of caregiver breakdown. It does not account for taxes unpaid by caregivers who discontinued employment, reduced hours of work, or engaged in other means that limited potential income from employment, nor does it include a younger person's limited education as a result of caregiving duties. It does not include the consequences of the vulnerability of children with disabilities to increased abuse in multiple forms, the higher prevalence of domestic assaults on adults with disabilities, or elder abuse (ARCH, 2003). It does not include those costs of respite incurred by their users, and as such are cost effective to the public purse. It does not address whether or not the availability of respite services increases the vulnerability of exploiting caregivers by extending the caregiver lifespan beyond the limits of a caregiver's capacity.

Further, this review does not account for variations in costs of care, policy differences, or cultural specificities from country to country. It is not constrained by defined criteria of a systematic literature review, but it borrows from the findings of several systematic literature reviews and peer reviewed journals. In instances where the studies are identified to have not met criteria for a systematic review, they are noted.

Definitions and methodology

The caregivers included in the literature review were those family members or others who, because of their relationships with the care recipients, tend to the needs of the care recipients at home. Caregivers may live with or in a separate residence from the care recipients, and as well may share their responsibilities with formal service providers.

The University of York researchers report that many caregivers and care recipients in the UK prefer to use the term "short

The care recipients included are those with dementia or other cognitive impairments, adults with mental illnesses, people with other chronic care conditions including the frail

elderly, children with complex needs and palliative care clients. This terms *respite* and *respite services* are used, and sometimes the term *respite* is used as an abbreviation for the services.

The methodology included an electronic search of databases, as well as several websites of organizations and institutions that have affiliation with caregiving and/or respite care. Researchers and consultants in the field were approached for guidance and consultation. This methodology is described in greater detail in Appendix B, Methodology.

Organization of the review

The findings are presented according to the type of disability of the care recipient because most studies and reviews are approached in that manner. It is done knowing that the categories are artificial, and the boundaries blurry. As illustration, care recipients described as the frail elderly sometimes have dementia-related care needs; diseases of mental health and some children's complex care health needs are chronic illnesses.

Also, the findings are presented with three caveats. The first is that this scan is only a preliminary exploration, and so was approached from an aerial viewpoint. That is, it does not attend to detail. The second is that the scan places more emphasis on caregivers of people with dementia than those of other cohorts, not only because more than half the care recipients in Canada are at least 65 years and many of them suffer from that set of diseases, but because that is the balance of studies on respite services. This is not to suggest prioritization. Rather, it underscores how the knowledge of caregivers must be extended to include those who are caring for care recipients of all ages and with multiple practical and medical needs.

The third caveat is that a lack of good evidence that respite services delay or prevent facility-based care is not a conclusion that respite services are not of benefit to caregivers or of cost benefit to the taxpayer. Rather, it lends direction for future investigations.

Respite services for caregivers of people with Alzheimer's disease and other dementias

From a longitudinal study spanning from 1991-2001 that surveyed more than 10,000 caregivers who resided in 36 urban centres across Canada, the Canadian Study of Health and Aging determined that about 50 percent of persons with dementia live at home and, of them, 97 percent have caregivers (McDowell, Hill, Lindsay, & Kristjansson, 2002). Seventy percent of the caregivers are women, about half of whom are daughters (29 percent) or wives (24 percent) (*ibid*). About 30 percent are in the work force. Half of the caregivers are at least 60 years old, and 36 percent are over the age of 70 years (*ibid*).

Caregivers who are wives are less likely to have back up but more likely to be caring for persons at a later stage of the disease (Alzheimer Society, 2004). Although care recipients with severe functional disability receive more services than those with mild to moderate disability, their caregivers use fewer services than caregivers of people without dementia (irrespective of degree of disability). The study found an association between these caregivers with chronic health problems and depression, the latter almost twice as common in this group of caregivers than other caregivers (*ibid*).

One Canadian investigation (Hebert, Dubois, Wolfson, Chambers, & Cohen, 2001) determined that

of the significant variables associated with institutional placements of people with dementia (N=32), caregiver burden and caregiver depression were two. The other variables were type of dementia, severity of disability, behavioral disturbances, caregiver age and caregiver not a spouse or child. An American investigation that examined data of almost 4000 people with dementia over a three-year period concluded that the burden, self-rated state of health, use of community-based services, and changes in functional abilities of caregivers were associated with expedited placement in long term care facilities (Gaugler, Kane, Kane, Clay, & Newcomer, 2003).

Significantly, the Canadian Study of Health and Aging determined that only 3.4 percent of caregivers use respite services (McDowell et al., 2002). It is this group, particularly those who care for persons with Alzheimer's disease (AD) who are the subjects of more evaluative studies of respite than others. As referenced earlier, the most recent systematic review of these studies was recently completed in 2004 by the University of York in the UK by Arksey and colleagues., and the summary of their findings is:

- For in-home respite services, most caregivers in most studies accessed multiple community resources, so whether the effects of respite influenced the delay or prevention of facility-based placement is unclear (Levin, Moriarty & Gorbach. 1994 in Arksey et al., 2004).
- For in-home respite services, there was no evidence in relation to the cost effectiveness.
- For adult day care services (ADC), there is little evidence of delayed or reduced institutional placements. In one study (1994), patients who used ADC services were as likely to have entered long term care facilities after twelve months as those who did not (Levin & colleagues, 1989, in Arksey et al., 2004). But another study concluded that ADC services may have been beneficial in keeping Alzheimer's patients at home (Wimo et al., 1993, in Arksey et al., 2004). After one year of services, the number of facility-placed people with AD using adult day services was smaller (24 percent, n=55) than the control group (44 percent, n=44).
- For institutional services that provide opportunities for caregivers to leave the home for an evening, overnight, or up to two weeks, there was little evidence that services reduced the demand for long term placements. The experiences of institutional stays may facilitate long term care placements, as reported by Watkins and Redfern (1997), and Larkin and Hopcroft (1993) in Arksey et al., 2004. The shorter term stay in an institution was an enabling experience to those who had decided to place family members, and more caregivers were interested in longer term placements as residential stays grew to a close. Melzer (1990) suggested that the evidence from his evaluation of a respite unit with both day places and overnight beds indicated that take up of institutional/overnight care did not avoid admission to long-term institutional care but it is not obvious which of Melzer's comments apply to day care (as cited in Arksey et al., 2004).
- For respite programs, which allow caregivers to choose from multiple forms of respite, there is nothing to demonstrate cost effectiveness (Arksey et al., 2004a).

The studies of multi-dimensional caregiver support packages, described as a set of support services that include respite services, education, training in practical matters, a support group, and individual counselling, are equivocal. Of five studies concerning a range of support services, one found no significant

difference in placement timing between caregivers who used the services and those who did not (Chu, Edwards, Levin & Thomson, 2000, in Arksey et al., 2004), and two found there was a trend towards delayed institutionalization (Lawton, Brody, & Saperstein, 1991. & Mohide et al., 1990, both cited in Arksey et al., 2004).

First, in a sub-group analysis of caregivers who were offered an array of services in the early stages of AD, there was a much higher likelihood that patients with mild to moderate impairment in the control group were placed in long term institutional care (Mohide et al., 1990). Patients whose caregivers had support services remained in the community on average 52 days longer than patients in the control group (ibid). Although the study sample was small (N=37), this finding seems to support the benefits of ADS in the early stages of the caregiving life span (ibid).

In the second, Lawton, Brody and Saperstein (1991) followed a control group who had access to several support services, and determined that they maintained their loved ones in the community for an average of 22 days longer in the community (as cited in Arksey et al., 2004). The investigators conclude from their review: “in summary, it appears that day care and the multi-dimensional support care packages might provide greater benefits to carers and care recipients but associated costs might be lower or higher” (Arksey et al., 2004a, p. 112).

One study peaks interest because it demonstrates the complexity of assessing economic benefit or impact on the timing of facility-based care. Findings from one study identified that those dementia sufferers who had in-home respite **or** day care (n=85) were more likely to have remained in the community than those who were using these services in conjunction with relief care (i.e. short stays away from home).

From his (unsystematic) examination of studies concerning the effectiveness of respite programs, that is, their benefits to care recipients, caregivers, cost savings and reducing or delaying institutionalization, Zarit (2001) made findings that correspond to the later review by Arksey and colleagues. He reviewed studies of in-home, adult day services, overnight and multi-component programs, and concluded with six points:

- Respite services demonstrate benefits to caregivers when they are of satisfactory quality and used in sufficient amounts.
- Many caregivers do not use these services, or do not use them in enough amounts, or for too short a time period.
- Case management does not appear to increase appropriate use of the services.
- There is a lack of evidence that respite services have an impact on the timing of placements out of the home.
- There has been little attention granted to evaluation of the cost effectiveness of respite services.
- There is little known about the impact of respite care on the care recipients.
- Both reviews (Arksey et al, 2004a; Zarit, 2001) make reference to a set of Canadian studies of economic evaluation of support services. In a study by Mohide et al. (1990), the control group received caregiver-focused support services of health care, education about dementia and caregiving, assistance with problem solving, a self-help family caregiver support group, and

regularly scheduled in-home respite, and physician visits were tracked. Over a six month period, the number of visits did not differ significantly, but the control group kept their loved ones at home for about seven weeks longer than those who had regular nursing visits only. This study was followed by a study by Drummond et al., (1991), that conducted an economic evaluation of support packages using a Caregiver Quality of Life Instrument and QALY (quality adjusted life year, a numeric measure that captures changes in morbidity and mortality). There were no statistically significant differences between the control and study groups, but the support packages were determined to be of higher cost than for standard community nursing care. The study sample was small, and the authors suggested more investigation was merited.

Finally, and although it was not addressed in either review, a book by Guttman (1991) addresses the impact of day care respite on family caregivers of patients with AD. Using a model of respite provision to some female primary caregivers (N=63) and comparing the effects to a similar group who received no day care services (N=55), the findings included a decreased interest in facility-based care, fewer hospital admissions, and shorter lengths of stay in hospital after six months of ADC. The findings of course contradict other studies, and may be attributed to the small sample size. But a study from Japan (Hirono, Tsukamoto, Inoue, Moriwaki, & Mori, 2002) that tracked 150 people with AD for one year determined that caregiver burden was a significant predictor of death or institutionalization of the care recipient. The use of day care and home care services during the course were significant protective factors (ibid).

Respite services for caregivers of people with chronic diseases, including the frail elderly

Chronic disease is a broad category, generally understood as illness that last longer than three months and is marked by frequent recurrence. It is a major health burden in Canada and other industrialized countries - the cause of disability, loss of productivity, and deterioration in quality of life. According to the National Population Health Survey of 1999, more than half of all Canadians reported having a chronic condition, and as the population ages, the numbers will of course increase. Cardiovascular diseases, cancers, diabetes, and chronic respiratory diseases are the world's most common global chronic diseases, as reported by the World Health Organization (2005). In Canada, cardiovascular disease ranks first in economic burden (Centre for Chronic Disease Control and Prevention, 2005). Arthritis/rheumatism, a group of more than 100 conditions, ranks second (ibid).

According to the Participation and Activity Limitation Survey (PALS), a national survey of persons with disabilities sponsored by the Government of Canada, 41 percent of Canadians over 65 years are disabled, 10 percent between 15 and 64 years, and 3 percent of children up to the age of 14 (Statistics Canada, 2001). This review indicated that of caregivers for people with chronic disease, it is caregivers of seniors who are the focus of most studies, no doubt because the cohort is responsible for more caregiving hours than any other. That inhibits illumination of challenges for caregivers of people with other disabilities.

A paper by Gordon and Perrone (2004) notes there are few studies of younger-aged married couples in which one spouse is disabled. Three studies identify fatigue, worry and feelings of not being acknowledged as aspects of the burden for caregivers of younger people with chronic disease (Aronson, Cleghorn, & Goldenberg, 1996; Cheung & Hocking, 2004; Schneider, 2004). One study underscored how

respite is not used by many of these caregivers, nor is it used enough to have positive effects. This was reported in another study (Wilkinson et al, 1997) of almost 300 subjects less than 75 years of age who had each suffered a stroke in 1989-90. Of the 104 interviewed, caregivers of only five had used respite services, even though one third of the patients were considered severely disabled and another third moderately disabled. The researchers noted that the provision of health and social services was likely to be inadequate for this population (ibid).

Other than those studies referenced earlier for people with dementia-related disabilities, there were few investigations on the relationship between respite with the timing of placements in facilities for caregivers of people with chronic disease. Two studies are noted on the website of the American National Respite Coalition (<http://www.archrespite.org/NRC-Lifespan.htm>). A finding from a 1992 study reported that the provision of respite care for the elderly with chronic disabilities resulted in fewer hospital admissions for acute medical care than for two control groups who received no respite care (Chang, Karuza, Katz, & Klingensmith, 1997). An earlier study found that 64 percent of caregivers of the elderly who received 4 hours of weekly respite reported improved physical health, 78 percent reported improved emotional health, and 40 percent said they were less likely to institutionalize the care recipient because of respite (Theis, Moss, & Pearson, 1994). [2]

Respite services for caregivers of people with mental illness

Although mental illnesses are a set of chronic diseases, it is considered here under a separate heading, primarily because it is considered in most research studies in this fashion. The category is also segregated because the question of whether respite services delays or prevents facility-based care includes not only placements in long term care, but for shorter term hospitalizations.

Indeed, the category of mental illnesses has long been segregated from the medical disease sector, and for those who suffer with it, from mainstream society. Within that context, the closures of psychiatric in-patient facilities in most of Canada in the 1960's and '70's caused extraordinary burden to caregivers and families of those who were discharged to the community. There was not only a scarcity of adequate community support services for both groups, but also a reluctance to use them because of the social stigma and discrimination attached to the disease. Societal attitudes may have changed somewhat, but the emotional impact of caring for a family member with mental illness has not. An investigation on the effect of chronic illness on the psychological health of family members determined that brain-related conditions, including mental illness, impose the most significant risk to the psychological well being of family members (Holmes & Deb, 2003). Among the recommendations to policy makers is that consideration of respite and other support services be given priority to families with brain-related disorders.

The broad range of mental illnesses includes depressive, mood, and anxiety disorders, substance abuse, and psychotic diseases, and can be transient, episodic, long lasting and sometimes progressive. Onset usually occurs in adolescence and young adulthood, but depression among the elderly is common. From findings of the Canadian Community Health Survey of 2002, Statistics Canada (2003) reports that major depression is as common as other leading chronic diseases and the third highest source of direct health care costs in the country. A Health Canada report (2002) states that 20 percent of Canadians will have a mental

illness in their lifetime. Most caregivers for people with mental illness are family members and the Canadian Psychiatric Association (2004) states that about one-third of them work outside the home.

In May 2004, Decima Research Inc. released a report sponsored by Health Canada, titled *Informal/Family Caregivers in Canada. Caring for Someone with a Mental Illness*. The objectives were to determine the number and present a profile of caregivers, establish the extent of care provided, identify service gaps, and define the impact on families.^[3] Of relevance to this review, the survey concluded:

- About 70 percent of the caregivers are women. More than half (64 percent) are between 18 and 54 years. About 60 percent are employed, and about 20 percent care for another person who is ill or disabled.
- Almost half have provided on-going care for at least five years, particularly for those caregivers of a child, parent, or spouse. More than 70 percent report they became caregivers because they had no choice.
- About half of them think there is a lack of home care and community supports. Caregivers most often end caregiving experiences because of the care recipients' placements in institutions. About two thirds think they are competent to provide care.
- Less than half have received the services of community supports. Three quarters of caregivers report they either frequently (27 percent) or occasionally (47 percent) need a break from their caregiving responsibilities, and about half of that group do not get it as often as they think is required. One-quarter say they rarely (16 percent), or never (10 percent) require a break. Those with higher needs for respite are less likely to be satisfied with the amount of relief they have.

Similar to their literature review on the effectiveness of respite for those who care for people with dementia, researchers from the University of York completed a systematic review of literature on the broader subject of support services for caregivers of people with mental health problems (Arksey, O'Malley, Baldwin, Harris, & Mason, 2002). The support services included respite, home care, education, support and counselling services, social activities, telephone and computer services, and improvements or modifications to physical environments. Again, most services were for caregivers of people with Alzheimer's disease or other dementia (70 per cent), and the balance was divided evenly between caregivers of people with schizophrenia (15 per cent) and other serious mental illness (15 per cent) (ibid). Of a total of 204 studies considered, thirteen had "an economic element" (p.29). A summary of the general findings:

- A variety of support services to caregivers result in some relief to caregiver burden and stress, whether the work is directly with families using interventions that include visits by family support workers, counselling or therapy, or by training and education, or respite care.
- Some studies reported tentative evidence that the use of respite services increased the rate of facility care of the care recipient, however, the findings require further investigation.
- In most studies addressing the economics of respite or other support services, methodological challenges were not successfully overcome. Examples of the identified challenges are instruments that could not detect statistically significant differences and a lack of longitudinal studies to examine effectiveness and cost-effectiveness in the short and longer term.

Of the total number of studies, 36 concerned respite care (ibid). The respite services considered were adult day care (both social and medical models), in-home respite (including programs of trained attendants making home visits, trained volunteers doing the same, and home visits specifically offering a physical or psychological component), institutional respite (stays for care recipients for periods extending up to several weeks in hospitals or other health facilities) and mixed respite. Two had an economic evaluative component.

One study concerned adult day care services. In a sample size of 179 patients with acute psychiatric illness who were randomly assigned to either day hospital care or “24/7” inpatient care, no significant difference resulted on tests for either caregiver burden or mental health of the patients (Creed, Mbaya, & Lancashire, 1997, as cited in Arskey et al., 2002). Because adult day care was less costly, it was concluded to be cost-saving. Another study assessed the economic implications of mixed respite services, in this instance, provision of day and residential respite care tailored to the needs of each care recipient (Donaldson & Gregson, 1989, as cited in Arskey et al., 2002). The sample was 35 elderly “mentally infirm patients”, of whom 25 had caregivers. On average, patients in the intervention group were placed in facilities almost six months later than control patients (ibid). There were no studies that addressed the cost benefit of in-home respite or of institutional respite services.

A more recent and non-systematic review of literature was conducted in Australia (Jeon, Brodaty & Chesterson, 2005). From examination of more than 700 articles that were written between 1967 and 2002, the investigators came to conclusions similar to the other reviews: there was a need for greater quality, quantity, variety, and flexibility in respite provision for all populations, the need for more research, and resolution of contradictory outcomes, methodological difficulties, and the absence of evaluative research on effectiveness.

Of studies considered for this project that were not included in the literature reviews, three are noted – and in keeping with the above findings, the outcomes are also contradictory. The first is a 1988 study (Geiser, Hoche, & King, 1988) of 14 psychiatric patients living in the community who were invited to schedule respite admissions of two- to seven-day periods every six to eight weeks. The planned institutional respite care stabilized patients and reduced their subsequent hospital stays. A decade later, another study addressed whether the consequences of scheduled intermittent hospitalization had impact on hospital utilization, community adjustment, and self-esteem of persons with mental illnesses (Dilondardo et al., 1988). Of the 57 patients, about half were prescheduled for four hospital admissions, each lasting nine to eleven days annually for two years. They showed self-improvement in several areas at one year, but no statistically significant differences in hospital utilization, financial management, substance abuse, or psychological well-being. Of significance, there was scant mention in either study of the impact on caregivers or family members other than their impressions of patient improvement.

A New Zealand respite care service program for clients of mental illness conducted an evaluation to determine, among other things, whether their residential services “[kept] people out of hospital” (Gawith, Sargent, & Kirk, p.9). Again, reference was made to “few systematic surveys, research-based studies, or reports specifically on planned or emergency care providing residential respite for adults with mental health problems” (p. 36), and the absence of an answer to the question of cost effectiveness of the service. Of the people who were tracked, more than 300 used the services and eight were turned away because of a lack of

beds. The data “did not show conclusively that respite stays decrease in-patient stays overall because other factors influence outcomes. However, the data are consistent with the proposition that if respite care was not available, then hospital admission rates would increase” (p.40).

Respite services for caregivers of children with complex needs

The term, children with complex needs has no universal or agreed upon definition, however it is generally understood that the term encompasses three groups of persons under the age of 19 years: those with conditions that have lasted or are anticipated to last at least twelve months, that result in limitations to function, activities or social roles, and that require ongoing therapeutic intervention (see, for instance <http://healthlinks.washington.edu/nwcpwp/wph/needs.html>). There are increasingly more children with chronic care needs because survival rates are increasing, and more who are cared for in the community. In the report, *Disability in Canada: A 2001 Profile*, it was approximated that 1.6 percent of the preschool population is diagnosed as having a disability, and of them, 68 percent have developmental disabilities, almost 9 percent are as yet undiagnosed, and 62 percent are considered to be chronic illnesses (Human Resources Development of Canada, 2003). Of children between five and 14 years, 4 percent have disabilities, and of them, about 50 percent are considered to be moderate to severe. A submission to the Commission on the Future of Health Care in Canada by the Children and Youth Homecare Network (CYHN) considers the research for in-home living for this cohort to be limited (CYHN, 2002). The findings for this project align with that view.

As the numbers of children with complex needs increases, so too does the burden and stress on families. The burden of care includes significant financial demands to families. In Canada, over one quarter of children with disabilities live in low income households, whether the disabilities are mild, moderate, or severe (HRDC, 2003). In the UK, the costs of raising a disabled child ate up to three times the costs of parents of non-disabled children (Glendinning et al., 1999).

Included among the types of respite for parents of children with complex needs are in-home services, residential, hospital, and hospice stays, camps and “link” families, that is, families willing to commit to welcoming the child into their home over a long term course. The search results for this group were similar to the others. There is a general call for more support for their caregivers and families and, of all services, respite care is one of the most frequently identified (Kirk, 1998; Knoll & Bedford, 1989).

There are few studies that link respite with the timing of placements out of the home. But there is evidence to support the economic benefit of the services to governments, and by more ways than out-of-home placements. For instance, one article refers to projects demonstrating the value of respite care to adoptive families of children with complex needs (National Adoption Clearing House, 2002). Without the assurance of services, children may remain wards of the state, and so at the expense of the government. Another article concerns a study of respite use for families with developmentally disabled children (Cowen

& Reed, 2002). Through logical regression, it was determined that life stress, social supports, and service levels were significantly related to child maltreatment, and that appropriate levels of respite are a strategy to reduce caregiver burnout. These findings appear to be supported by a 1989 national survey of families of children with disabilities, in which 35 percent of the respite users indicated they would have considered out-of-home-placement for their family member without the availability of the services (Knoll & Bedford, 1989). As well, the American National Respite Network (National Respite Coalition, 2002) makes reference to the connection between respite services and reduction of involvement with child protection authorities, child neglect and abuse, and foster home placements - all of which are of cost to the taxpayer^[4].

Of the studies reviewed, most concerned the families of children with developmental disabilities. At Oklahoma University, researchers followed a control group of children who were placed for 30 days in a short term inpatient facility and an experimental group who were offered three to seven days of respite (Mullins, Aniol, Boyd, Pagem, & Chaney, 2002). At the time of discharge and six months following, the parents of *both* groups experienced a decrease in psychological distress, indicating that respite care appears to result in stress reduction over time at costs lower than placements from family homes. The university as well is examining the relationship of respite and the reduction of incidents of child abuse (Aniol et al., in press).

Other studies concerned children who are “technology dependent”, that is, who “have dependence on a technological device to sustain life or optimize health and have the need for substantial and complex nursing care for substantial parts of the day or night” (Kirk, 1998, p. 101). A unique consequence to caregivers and families is not only the need to perform advanced technological procedures, sometimes on a constant basis, but the loss of privacy, transformation of the home because of the technology, and the challenges of finding appropriate respite providers. Again, the University of York in the UK provided a literature review although its broader concern was how families coped with the challenges of parenting technology-dependent children (Kirk, 1998) The review contributed to a final report that provided numbers and a profile of this population, and recognized the lag between the increased numbers and extent of disabilities and community support services (Glendinning, Kirk, Guiffrida, & Lawton, 1999).

A Massachusetts social services program designed to provide cost-effective family-centered respite care for children with complex medical needs found that for families participating for more than one year, the number of hospitalizations decreased by 75 percent, physician visits decreased by 64 percent, and antibiotics use decreased by 71 percent (Mausner, 1995). In that same year, a New York study determined that the use of respite services was associated with a statistically significant reduction in somatic complaints by primary caregivers, and a trend in the data suggested an association between respite use and a decrease in the number of hospitalization days required by children (Sherman, 1995).

The Canadian Association for Community Care (CACC) conducted a three-part study on respite care for families of children with special needs, beginning in 1995. The first published report, *Home Based Care for Medically and Psychologically Fragile Children; Analysis and Literature Review*, summarized a literature review, survey of members and telephone interviews with key informants (CACC, 1995). The results were integrated into a final report that called for a complex system of respite to meet a variety of needs from families “heavily burdened with time constraints and financial challenges” (CACC, 2002). The

final draft argued that

Parents and professionals found that respite services are an absolutely essential aspect of home care for many children with special needs and their families. In particular, respite is a quality-of-life issue in families where children have medically fragile, complex, technology-dependent conditions – necessary for the physical, emotional, and social health of all family members and the family as a whole. A coordinated, comprehensive program of services for children with special needs – in which respite is an integral part – contributes to the health of the community. It does so, by assuring that families who have children with special needs at home are contributing members of their communities, and are able to prepare citizens of the future who are as capable as they can be (ibid., p. iv).

There was no mention of the consequences to the public of not having adequate respite services, or to costs of its provision.

Respite services for palliative care

End-of-life or palliative care is the provision of health care and social services when the response to curative treatment is not helpful and life expectancy is short. Research findings confirm that the preferred setting by care recipients and their families is at home, and although there are substantial numbers of descriptive studies, there is a paucity of evaluative work on the effectiveness and cost effectiveness of home-based palliation (Kirby, 2002; Romanow, 2002; Twycross, 1997)

Respite services are usually home care and inpatient, the latter in palliative care wards of hospitals or hospices, sometimes for day care and at other times, for short term admissions often for symptom control. Specific to this project, there is as well a paucity of research on respite care for this caregiver group, few empirical studies on assessing the effects of specialist palliative respite care interventions on caregiver well being, and almost no reference to the possible economic benefits of respite (Ingleton, Payne, Nolan, & Carey, 2003).

“Caring for a dying family member is a ... singular experience, set in a world apart from everyday life. ... Caregivers differentiated between cognitive breaks and physical (getting away from) breaks of respite. To achieve a cognitive break and yet remain within the caregiving environment was viewed as important, whereas the physical separation from it was significant only if it contributed in some meaningful way to the caregiving. ... The meaning of respite is rooted in the desire to bring a measure of quality and normalcy to the life of the dying person. Respite means staying engaged in living life with the dying family member. (from the abstract of *The experience of respite during home-based family caregiving for persons with advanced cancer*. Strang, Koop & Peden, 2002)

About 220,000 Canadians die annually, and it is estimated that between 50% and 70% of terminally ill patients prefer to die at home in comfort of familiar surroundings (Grande, Todd, Barclay, & Farquhar, 1999). A 1997 Angus Reid poll indicated that 90 percent of Canadians wish to remain in their own homes, yet only 6 percent of caregivers feel they could adequately care for their loved ones without hospice palliative care support. In all provinces and territories, access to respite hours is restricted only to availability. There is no cost to caregivers, and no limit to amounts but certainly disparities of access exist. As described in Health Canada’s scan of respite programs in the country, the First Nations and Inuit

Health Branch of Health Canada (FNIHB) does not yet have the mandate to provide palliative care, and

instead, defines it as a supportive service (Health Canada, 2003).

Three literature reviews on the subject of respite services in palliative care were examined for this project. Two are systematic reviews, both completed in 2003 and in the UK. One is focused on respite in palliative care (Ingleton et al. 2003), the other on the impact of respite on caregivers of people at the end-of-life stage of cancer (Harding & Higgins, 2003). The third concerns paediatric respite (Horsburgh, Trenholme, & Huckle, 2002). The reviews underscore the unique features of the palliative process. Caregivers often feel socially isolated, financially overwhelmed, personally stressed, and experience intra-familial tension as do other caregivers, but as well, may be more influenced by spiritual and cultural values, and have greater needs for psychological support and information. They may be more reluctant to leave those who are dying; “time away” is counter to values of self-reliance and independence, and to being with loved ones. They must be skilled to provide necessary treatments and feel confident about their abilities to do so.

Certainly the quality of in-home end-of-life care depends in large part upon adequate care and support of the caregiver and the family, and a large component of that is their complete faith in the competencies of the respite care providers, not only to be vigilant but medically skilled, and emotionally attuned to the patients (Darbyshire, Haller, & Fleming, 1997; Simons, 1998).

None of the three reviews describe studies associating respite services with the timing of hospitalization. One Canadian study that was not addressed in any review concerned the evaluation of a night respite service offered to caregivers of 53 patients in eleven months (Kristjanson et al, 2004). The findings suggest that at least some patients would have been transferred to an inpatient setting for end-of-life care, but were able to die at home with this support (ibid). The article makes reference to a previous study providing “compelling evidence” that in-home palliative care is more cost effective than hospital-based palliative care (Chochinov & Kristjanson, 1998, in Kristjanson, 2004). There was evidence to suggest that patients who would have otherwise been admitted to inpatient care were instead able to die at home. From the literature review on the effectiveness of interventions with caregivers of patients who were receiving palliative care for people with cancer, three evaluative studies concerning respite were noted. One determined that users of a community palliative care service offering home care, day care, and respite, valued the totality of the services, but the services were not segregated for separate evaluation (Ingleton, 1999). Another determined an association between hospice home services utilization and stable quality of life of caregivers for over four weeks, although the services were not described (McMillan, 1996). A third study evaluated the respite services of a sitting service, and determined that 42 percent of their referrals were for respite care, and 70 percent of the users considered the service “very important to them” (Johnson, Cockburn, and Pegler, 1988). No cost benefit was inferred.

Discussion

The purpose of this project was to find answers to the question of the cost effectiveness of respite care but, for reasons explained in the text, the final review question was constrained to whether respite services reduced or prevented facility-based care. The evidence to both is equivocal, in part because the knowledge has been sought infrequently by researchers, and when it has, substantial research challenges often have been unresolved.

Equivocal evidence does not reduce the value of the project. Rather it provides an opportunity to understand complexities of the question, suggest directions for further research, and articulate issues that emerged in the process of the investigation. The following discussion refers more to the broader question of cost benefit of respite services; the question of respite's impact on the use of facility-based care excludes more input and output costs.

With respect to issues that emerged, several are conspicuous. The first few are the consequences of considering caregivers for people of all ages and with a broad spectrum of disabilities. It underscores and reinforces (a) that caregivers are a large component of the human resource sector of Canada's health care system, (b) caregiver and care recipient needs are diverse and require a multiplicity of services to meet them, and (c) caregiver wellbeing is a critical objective to the goal of a sustainable health care system. So too is the determination of how to accomplish that most effectively and efficiently.

Other issues refer to evidence that respite services provide optimum impact to caregivers when used as one of many available supports. The segregation of respite's impact from that of other services is difficult, if not impossible. But as significantly, it is so interdependent with those services that the sole utility of segregating it (and other services) would be to apportion costs of individual support services to various payers. To use a simile for clarity, it may be like measuring the cost effectiveness of an anaesthetist in a surgical procedure. Irrespective of the result of a cost effective analysis, the specialist is a required component to the surgical team, and necessary if the team is to be successful. Conversely, the effectiveness of the anaesthetist's optimum impact is dependent upon the rest of the team.

Related to that is evidence that respite services provide optimum impact to caregivers under certain conditions - availability at times convenient for and by type preferred by caregivers, service usage beginning early in the caregiving life span and continuing frequently, regularly, and in sufficient amounts over its life course. The totality of those conditions is unlikely to ever be met in Canada, and many of them, unlikely to be met in most regions. But to attempt to determine the cost benefit of respite services when they are currently offered in substantially suboptimal conditions, as frequently reported by many Canadian caregivers, is akin to determining the cost effectiveness of a medical procedure, when it has been poorly executed on patients who receive inadequate post-operative care. Economic benefit might better be determined when service provision is closer to meeting those conditions.

Economic benefit of respite services is more regionally specific and temporally dependent than was explicated at the beginning of the project. This is because the uniqueness of national economies, health and

social policies impedes portability of findings across national and inter-provincial boundaries, and from one period of time to another. Several variables – for example, provider wages, criteria for service eligibility, amounts, transportation assistance, and consumer costs for nursing care – change as provincial and intra-provincial policies evolve. Predictably, policies will maintain an active pace of evolution as primary health care reforms continue. The implication of this is that an accurate determination of cost effectiveness has to be done locally and often. This is a conundrum of an issue of social complexity.

Other issues that have impact on a cost effective investigation relate to respite's inherently personal and social context. Some examples are the challenges of asking appropriate questions to caregivers and being attuned to the meanings of their responses, the exploration of the dichotomy of high demand for respite service but low service usage, the use sometimes of adult day service for facilitating residential care placements, and the anticipated development over time in caregiver "identity" to one of a consumer entitled to make informed decisions and choices about support services.

The aggregate of challenges may qualify the question of respite's cost effectiveness as a *wicked problem*, a term coined some decades ago by a German academic, Horst Rittel (1973). A wicked problem is one of social complexity, a symptom of another problem, and the precursor to other problems as answers emerge. It has more than one answer - none of which are exactly right, only good or better, bad or worse - and it requires innovation and creativity (Retrieved on February 11, 2005 from <http://cs.wvc.edu/~aabyan/FAS/book/node40.html> and <http://www.cognexus.org/id42.htm>).

Recommendations for Research

Based on the results of a preliminary scan, the following recommendations are suggested. to strengthen the evidence concerning the cost benefit to government of respite services.

Recommendation one is to consider whether the cost effectiveness to governments of respite services might better be determined when analyzed as one of many caregiver support services. There may be less complexity and more application to a research question that determines the economic benefit of a complete menu of support services that best supports caregivers' wellbeing and the wellbeing of their families.

Recommendation two is to collaborate, not only to collectively benefit from findings, avoid unnecessary replication and expand the limits of creativity, but to increase opportunities for research designs that include control and comparator groups. Collaboration could be among researchers in different nations and across the provinces and territories, and among experts in the fields of health and social policy, respite and caregiving and health economics.

Summary and Conclusion

This literature scan somewhat resulted in a compendium of literature reviews on the subject of respite care for various groups of caregivers, and highlights the equivocal evidence of (a) the cost effectiveness to governments of respite services, and (b) whether respite services delays or prevents facility-based care. The project was to address the "when", "where" and "if" the use of respite care is a cost effective means to delay placement in a long term care facility or acute care hospital. A summary of the findings are as follows:

- For caregivers of people with dementia, the effects of respite are not usually segregated from

the effects of other support services. More studies have been completed on adult day care, and of them, the results of more than one study are contradictory. For respite services that are in-home, institutional stays or of multiple types, there is no substantive evidence of cost effectiveness or delay in facility-based placements. There is contradictory evidence when a menu of support services is provided.

- As well for caregivers of people with dementia, there is evidence that respite services are most effective to caregivers when they are of high quality, used early in the caregiving life span and then regularly, frequently and in sufficient amounts. Most caregivers do not use the services, or underuse them, or for too short a time. This does not change with the involvement of case management.
- The finding of underutilization of services applies to caregivers of people with chronic disease. There was a paucity of research for this group of caregivers other than seniors with functional disabilities and no conclusive evidence of effectiveness or cost effectiveness.
- For caregivers and families of people with mental illnesses, the studies were limited in number and contradictory in results. There does appear to be a trend in the evidence that respite services reduce hospital admissions for episodic attacks.
- For children with complex needs, there are few studies that link facility placements with respite services, but there are indications of economic benefit to governments in other ways. The adoptions of children with special needs are more easily facilitated with the assurance of respite services, and children with developmental disabilities are more vulnerable to mistreatment or placements out of the home without use of respite services.
- For caregivers who are providing palliative care, there is limited evaluative research on the effectiveness of interventions for them, and almost no reference on the cost-effectiveness of allocating support services to them.

The wicked problem of determining the cost effectiveness of respite is of course complicated in this country because supports to caregivers are beyond the parameters of Canada's insured health services, and the provinces and territories are domains of responsibility for health care. Economic analyses of respite would therefore be specific to those jurisdictions. If precise evidence is required, the analyses will be specific to regional health authorities and relevant for only as long as input costs are stable.

One benefit of this review is that it reinforces the complexity of the question of the economic benefit of respite care. Some questions are more easily answered than others, and the determination of the cost effectiveness of this service is not one of them. It may be that an expectation for reliable evidence of satisfactory quality to the specific question of the cost-effectiveness of respite care requires adjustment.

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Appendices

Appendix A

Literature Reviews

This project relied upon and benefited greatly from the following literature reviews concerning the associations of respite services and caregivers:

- Arksey, H. et al. (July 2004). *Review of respite services and short-term breaks for carers for people with dementia*. UK: Social Policy Research Unit, University of York. Retrieved January 10, 2004 from <http://www.sdo.lshtm.ac.uk/carers.htm#arksey2>
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- Harding, R. & Higginson, I. (2003). What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine* 2003; 17: 63 /74.
- Horsburgh, M., Trenholme, A., & Huckle, T. (2002). Paediatric respite care: A literature review. *Palliative Medicine*, 16, 99-105.
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Most of the reviews considered were systematic. For them, the table below summarizes the number of studies identified from the database searches, the numbers determined to fall into the parameters of the study, and the numbers included in the review after meeting criteria of quality.

Review Author and Subject	No. of Studies Identified in Initial Search	No. of Studies Relevant to Topic	No. of Studies Considered

Arksey et al., 2004 Effectiveness and cost effectiveness of respite services, dementia	70	42	5	Appendix B Methodology The review proceeded in steps. The first was an electronic request for information addressed to experts
Arksey et al., 2002 Effectiveness of support services, mental health	36	2	2	
Harding & Higgins 2003 Palliative care, cancer Evaluation of interventions		22	22	
Ingleton et al. 2003 Specialist Palliative Services No evaluative studies	260	51	28	
Kirk, 1998 Issues for families of technology-dependent children	Cited. Original not reviewed			
McNally et al. 1999 Respite and caregiver wellbeing No economic evaluations		29	29	
Nocon & Qureshi Review of respite literature Few evaluation studies	Cited. Original not reviewed			

in policy fields of caregiving, home care and community support services. About 30 responses were received, and all had similar conclusions as reflected in the following excerpt of an email from one researcher: "... what I can say is that there is very little literature on cost-effectiveness; it was a real struggle for the health economist in our team!" Using the responses as guideposts, the second step was to conduct a database search on the same topic, and when the results proved to be equivocal, the review question was constrained to whether respite services prevented or delayed facility-based care.

The electronic search used several databases for published articles as well as websites of several universities, governments and organizations. The databases chosen were PAIS, a database of international public and social policy, PubMed, the search engine of the National Library of Medicine, and EBSCO, a multi-disciplinary research database (and from it, the databases of Academic Search Primer, Ageline, American Humanities Index, ERIC, Medline, MLA Directory of Periodicals, MLA International Directory and PsycINFO). Search terms and their results are identified in Appendix B. All searches were conducted in English, but we were advised that the same situation exists in the French literature. Efforts were made to determine if studies recognized that policy, programs and projects affect women and men differently. Our observations were that this was not considered in the findings of the articles, but frequently noted in their text.

This was not a systematic or exhaustive literature review, not only because of resource constraints but eight literature reviews shared a common theme. In addition to the reviews, more than 70 abstracts were scanned on the topic of respite care, and of them, 32 articles were considered. All provided context for the review question but only two were specifically related. As identified in Arksey et al. (2004), search terms

were vague, and on more than one occasion, we found information that was relevant to the topic but hidden in the body of articles of another subject.

Search Words

Search Term 1	Search Term 2	Search Term 3	EBSCO*	PubMed	PAIS
respite			1567	994	
respite care			1567	747	
respite care	economics				0
respite	caregiving		104	83	
respite	caregivers			350	
respite	economic				2
respite	cost effective	caregiving		0	0
respite	effectiveness			28	
children	Respite		149	211	2
children	caregiving	respite	5	9	
children	caregivers	respite		50	
children	Respite	disabilities	73	47	
children	Respite	cost effective	0	2	
children	Respite	economic	3	40	
children	Respite	developmental	15	25	
children	Respite	government	3	12	
children	Respite	at-risk	5	6	
children	Respite	technology	2	9	
children	Respite	emotional disorder	0	1	
children	Respite	emotion	0	5	
children	Respite	chronic care	0	5	
children	Respite	complex needs	0	8	
children	Respite	disability	73	18	
children	disability	respite caregiving		1	
children	complex health needs	respite caregiving		0	
long term	caregiving		102	241	
long term	caregiving	respite	5	7	
long term care	caregiving		102	161	
long term care facilities	Respite	prevention		4	
chronic care	caregiving		0	97	

Search Term 1	Search Term 2	Search Term 3	EBSCO*	PubMed	PAIS
chronic conditions	Respite			10	
chronic disease	Respite		57	51	
chronic disease	caregiving		0	126	
chronic disease	economics		2203	4048	
mental illness	caregiving		0	868	
mental illness	Respite		0	329	
mental health	home care		826	2454	
mental health	Respite		62	76	
mental disorders	caregiving		32	856	
mental disorders	Respite		35	326	
chronic mental illness			613	41 328	
chronic mental illness	caregiving		0	68	
psychiatric	Respite		0	45	
psychiatry	Respite		0	11	
depression	Respite		0	54	
psychiatric	caregiving	respite	0	9	
palliative care	caregiving	respite		1	
palliative	Respite		21	51	
adult children	caregiving		256	84	
adult children	caregiving	respite	0	1	
cognitive impairment	caregiving	respite	0	3	
cognitive impairment	caregiving		94	56	
brain injury	Respite		1	4	
brain injury	caregiving		0	8	
frail elderly	Respite		60	25	
Multiple sclerosis	caregiver	respite		3	
policy	Respite care				2
policy	Respite care	cost-effectiveness			0
Search Term 1	Search Term 2	Search Term 3	EBSCO*	PubMed	PAIS
home care					607
home care	Respite				7
managed care	Respite				0
support services	caregivers			2009	
residential	determinants			3	

placement					
residential care	caregiving	respite		0	
institutional care	Respite			36	
cost of care	Respite		0	171	
cost analysis	caregiving	respite		20	
cost	caregiver burden	respite		26	
delay	caregiving	respite		1	
institutional-ization	caregiving	respite		9	
institutional-ization	caregiver	adult day program		4	
institutional-ization	prevention	respite caregiving		29	

*EBSCO – Academic Search Primer, Ageline, MedLine, MLA PsychInfo

[1] This definition and description, as well as a rationale for why a systematic review is important, how it is done, and where further information can be found, is offered on a website produced by Leeds University, UK: <http://www.comp.leeds.ac.uk/comir/people/eberry/sysrev/sysrev.htm>.

[2] Neither study was found in the databases used in this review. Because both were published more than ten years ago and due to resource and time constraints, the search to locate these studies was abandoned.

[3] The diagnoses that were considered for the survey were mood, anxiety, eating and personality disorders and schizophrenia. Dementias, developmental disabilities and brain injuries were excluded.

[4] The website as well reports findings from two other reports that are relevant but cannot be traced by our electronic search and time constraints prevented a manual search. One was a 1996 evaluation of the Iowa Respite Child Care Project for families parenting a child with developmental disabilities which found that when respite care is used by the families, there is a statistically significant decrease in foster care placement (Cowen, Perle Slavik, 1996). The second is a 1989 US national survey of families of a child with a disability in which 35% of the respite users indicated that without the services they would have considered out-of-home-placement for their family member (Knoll, James, Human Services Research Institute, March, 1989)