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The Lived Experiences of Sandwich Generation Women and Their Health Behaviours

by

Allison Steiner

Wilfrid Laurier University, 2015

# THESIS

Submitted to the Department of Kinesiology and Physical Education

in partial fulfillment of the requirements for

Master of Science

Wilfrid Laurier University

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#### Abstract

Sandwich generation caregivers simultaneously provide care to their aging parents/in-laws and at least one child under 18 years living in the home (Sinha, 2013). In 2012, 2.23 million Canadians were considered sandwiched caregivers. This group is expected to grow as individuals are delaying marriage, resulting in delayed childrearing (Robinson, Barbee, Martin, Singer, Yegidis, 2003). Further, the government has been advocating for caregiving to move from formal to informal caregiving. Although this would help the government immensely, this creates challenges for middle-aged adults occupying multiple roles. The purpose of this study was to explore the lived experiences of sandwich generation women and the influence caregiving had on their health behaviours. This study used phenomenology as its theoretical orientation. Oneon-one semi-structured interviews were the main form of data collection for nine sandwich generation women. The following themes emerged: (1) The role of the caregiver; (2) Caregiving: It is a balancing act; (3) Stormy seas: It is not always sunshine and rainbows; and (4) Silver linings amidst the turmoil. By reflecting on their past and current experiences, the sandwich generation women described the perceived challenges and benefits associated with their complex caregiving roles. Further, the mothers' health (e.g. physical activity, nutrition, sleep and mental health) was compromised due to time constraints placed on their lives as a result of caregiving. This study provides sandwich generation caregivers with insights into the challenges and/or silver linings they may experience while caregiving. Additionally, this research provides important implications for government legislation and healthcare providers.

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I am sincerely grateful for my participants. They willingly gave up time from their busy schedules to help me with my thesis. Through their insights I hope to provide support to other sandwich generation caregivers.

I have been fortunate enough to work with many older adults. As well I have personally witnessed caregiving by my own family members. By working with this population, I was able to better understand the challenges experienced by both aging adults and caregivers, which lead me to be passionate about this area of research.

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# **Review of the Literature**

#### **1. Introduction to Caregiving**

In Canada, the government has been advocating for the care of older adults to move away from formal caregiving to informal caregiving, due to the current condition of the healthcare system. The government's rationale for this shift is that there is a shortage of healthcare workers, withering government funds and an aging population (Keefe, 2011). Formal care refers to "a range of home care and community support services provided to older persons (as well as to other groups such as children with complex continuing care needs) by a mix of providers, some who are contracted by the Community Care Access Centres (CCACs) including personal support workers, nurses, occupational therapists..." (Williams et al., 2010, p. 6), which is provided at a monetary cost (Talley & Crews, 2007). Informal caregiving refers to unpaid help that is provided by families, friends and social networks. Informal care may range from emotional to instrumental supports, such as navigating individuals to formal services (Williams et al., 2010). Ideally the government and health care providers would like to keep individuals in the community for as long as possible, in order to reduce the financial strain on the health care system and to decrease institutionalization (Talley & Crews, 2007). The concept of "dehospitalization" allows more individuals with compromised health to be provided with medical diagnostics and treatments as outpatients, which further allows individuals to live in their homes as opposed to being treated on an inpatient basis (Raveis, Karus, & Siegal, 1998). However "dehospitalization" increases the demand of caregiving on family members.

This chapter covers past literature in regards to caregiving, specifically the sandwich generation. The purpose of the current study was to explore the lived experiences of women in the sandwich generation and the influence multigenerational caregiving had on their health behaviours.

#### **1.1 Defining Caregiving**

Caregivers have been defined as individuals over the age of 15 years, providing care or help in the past 12 months to someone with a long-term health condition, a physical or mental disability and/or someone with problems related to aging (Sinha, 2013). Additionally, caregiving may be described as any extraordinary care provided to a spouse or family member that is beyond usual or normal (Schulz & Quittner, 1998). For example, dressing and bathing a spouse with Alzheimer's is "unusual" and represents an individual providing care. Caregiving can also be extended to parents responsible for the care of a child with a disease or disability, which would involve the parent taking on responsibilities that typical parents do not have (Quittner, Opipari, Regoli, Jacobson, & Eigen, 1992). The responsibilities that parents or spouses perform are done without compensation, although the nature of the caregiving tasks are similar to paid professionals. Caregivers complete these tasks themselves, as they often feel there are no alternatives to caring for their family members (Schultz & Quittner, 1998).

Results from the General Social Survey (GSS) on Caregiving and Care Receiving estimated that 13 million Canadians aged 15 and older provided care to a family member at some point in their lives. In the year 2012, 3.65 million Canadian's had provided this type of care. The types of care provided included driving individuals to appointments, preparing meals, assisting with bathing and dressing and/or helping with medical needs/treatments (Sinha, 2013). In Canada, it has been estimated that informal care accounts for 25 billion dollars in unpaid labour each year (Hollander, Liu, & Chappell, 2009). Between 2000 and 2030, the number of individuals aged 65 and older are expected to double, with those over the age of 85 being the fastest growing portion (Federal Interagency Forum on Aging-Related Statistics, 2010).

Therefore, an aging population may require higher levels of care in the future from family members (Coughlin, 2010) and the Canadian Healthcare System (Keefe, 2011).

#### 1.2 Gender Roles in Caregiving: Women's Work?

Throughout history females have assumed the majority of caregiving roles and have provided care to aging family members and children (Ford, Good, Barrett, Harrell, & Haley, 1997). Historically, males have been socialized to be family breadwinners and raised to invest large amounts of time in their careers, which have ultimately placed limitations on their caregiving responsibilities (Moen, Robison, & Fields, 1994). Conversely, women were more likely to move in and out of employment, hence less frequently working in full time positions. This made it easier for women to spend time on both caregiving and other responsibilities. Additionally, women have earned lower incomes than men and therefore economically it made more sense for women to sacrifice potential wages to allow men to provide a steady income. Women in general were seen as the nurturers of society and responsible for "home and kinship" (Moen et al., 1994). It had also been noted that women were more likely to become caregivers when compared to men (Kramer & Kipnis, 1995) and provide more assistance (Ford et al., 1997). In 2012 the GSS revealed that 54% of caregiving was provided by women (Sinha, 2013). Additionally, women were more likely than men to spend over 20 hours/week on caregiving tasks (17% versus 11%). Women also provided greater assistance with activities of daily living (ADL) and instrumental activities of daily living (IADL), such as assisting with personal care (e.g. dressing, bathing, food preparation) and household tasks (e.g. cleaning, shopping, laundry) (Sinha, 2013). In comparison, other research has shown that men were more likely to provide assistance in tasks such as handiwork and transportation (Young & Kahana, 1989), decision-

making, personal assistance (Horowitz, 1985) and overall case management (Kramer & Kapnis, 1995).

Miller and Cafasso (1992) explained that gender roles illustrated the tendency for women to take on more nurturing roles (e.g. personal care), while men had a higher propensity to take on more instrumental tasks (e.g. financial matters). The result of these predetermined gender roles was highly influenced by society, culture and religious traditions (Read & Wuest, 2007). Further, gender roles instilled feelings of responsibility and moral duty in females to assume caregiving roles, in order to avoid feelings of guilt (Read & Wuest, 2007). Harris (2002) contended that this responsibility had been expected from women, whereas males may have felt more alone or abandoned when given the caregiving role (Harris, 2002). Females sense of selflessness, which had been proposed as a cultural ideal, further assumed that adult daughters would make more sacrifices or accommodations in their own lives to help their families and aging parents (Gonyea, Paris, & Saxe Zerdin, 2008).

With the evolving work dynamics that have changed since the mid 1900s, more women have entered the labour force (Robinson, Barbee, Martin, Singer, & Yegidis, 2003). In Canada, 49% of females over the age of 45 years are employed (Statistics Canada, 2014). Historically, female caregivers had additional responsibilities that further required complex time allocations (Palo Stoller, 1983), such as maintaining relationships, marriage and caring for children. Women who had multiple roles did not displace or reduce their responsibilities. However as a result, females extended their work week in order to fulfill all of their responsibilities (Moore & Hofferth, 1979). The increased number of women working outside of the home, created an increased strain on many female caregivers (Dautzenberg et al., 2000).

#### **1.3 Effects of Caregiving**

**1.3.1 Costs and benefits of caregiving.** There are both costs and benefits associated with caregiving. Costs may be monetary or refer to the non-economic challenges experienced by caregivers, which may result from an individual's quality of life declining in the areas of social, physical and emotional well-being (Fast, Williamson, & Keating, 1999). For example, caregiving may compromise social well-being by decreasing the ability to participate in social events, maintaining the integrity of relationships and establishing new relationships (Fast et al., 1999). Raschick and Ingersoll-Dayton (2004) examined different caregiving relationships with respect to costs and rewards towards caregivers. Please refer to Appendix A for details on relevant studies. Results illustrated that spousal caregivers experienced more costs compared to adult children who received more rewards, such as overall life satisfaction (Raschick & Ingersoll-Dayton, 2004). Lastly, caregiving may also compromise caregivers' employment, as it is becoming more prevalent that informal caregivers are simultaneously in the workplace (Fast et al., 1999).

Although caring for older adults requires many responsibilities that take up time, caregiving has had beneficial effects for some caregivers (see for example, Hinrichsen, Hernandez, & Pollack, 1992; Fletcher, 2011). Hinrichsen et al. (1992) found that caring for older adults could help improve familial relationships and create a sense of gratification related to being helpful. Scharlach (1994) found that there were rewarding aspects to caregiving such as a sense of fulfillment based on repaying parents for past care, enjoyment from spending time together and appreciation for past help.

**1.3.2 Caregiver burden and stress.** Caregiver burden has been continually defined as the stressors individuals may experience while providing care, such as physical, psychological, emotional, social and financial stressors (George & Gwyther, 1986). Caregiver burden may be further divided into objective burden (physical or instrumental care, e.g. number of hours) and subjective burden (emotional or psychological toll, e.g. anxiety and stress) (Montgomery, Stull, & Borgatta, 1985). Razani et al. (2007) investigated the correlation between ADL function of family members with mild dementia and reported level of burden and psychological distress reported by their caregivers. Results showed that when caregivers reported higher levels of burden and psychological distress, they over reported perceived functional impairments in individuals with dementia (Razani et al., 2007).

As care receivers' experience increased illness and disability, the caregiving situation is perceived as stressful by both the caregiver and care recipient (Schulz & Sherwood, 2008). Stressors such as the care receivers' physical disabilities, behaviours, cognitive impairment, and amount of care required can lead to an increased burden to the caregiver (Schulz & Sherwood, 2008). Duxbury, Higgins, and Smart (2011) found that caring for an older adult within the home created the highest levels of financial, physical and emotional strain when compared to individuals caregiving from outside of the home. Further, issues related to caregiver burden may be influenced by resources available to the caregiver, socioeconomic status, social support and health status prior to the onset of the caregiving role (Schulz & Sherwood, 2008).

**1.3.3 Coping mechanisms.** Caregivers use different coping mechanisms to help manage the stressors that are associated with caregiving. Lazarus (1993) defined coping as:

Ongoing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the

person . . . the term coping is used whether the process is adaptive or nonadaptive, successful or unsuccessful, consolidated or fluid and unstable. (p. 237)

Caregiving literature has shown that coping strategies used by caregivers differs depending on gender (Navaie-Waliser, Spriggs, & Feldman, 2002), the illness/disease of care receiver (Sun, Kosberg, Kaufman, & Leeper, 2010) and familial relationship of the caregiver/care receiver (Fletcher, Schneider, & Harry, 2010). For example, Almberg, Grafström, and Winblad (1997) qualitatively explored strain and coping when caring for individuals with dementia. Female caregivers were more likely to use emotion-focused coping strategies (e.g. wishful thinking, stoicism, worrying, etc.) and had experienced burnout when compared to men. In the same study, participants at risk for burnout, most often used emotion-focused coping. Those who were not at risk for burnout used more problem-focused coping, such as seeking information and social support (Almberg et al., 1997).

**1.3.4 Health behaviours.** Health behaviours refer to self-care behaviours performed by caregivers to support their own well-being, while health-promoting self-care are the steps taken to improve one's health, maintain optimal functioning and increase overall well-being. These actions taken towards mental and physical health may pertain to the response to illness, but mainly the actions taken to promote health in the absence of illness and disease. For example, self-care behaviours could include eating a healthy diet, partaking in physical activity and ensuring optimal hours of sleep each night (Acton, 2000). Health behaviours in caregivers may change due to the stress associated with caregiving (Son et al., 2007). Limited research has focused on the health of caregivers, with regards to health behaviours (Acton, 2000), as well as physical and psychological health (Pinquart & Sörenson, 2003). Acton (2000) compared the self-care actions of caregivers and non-caregivers of individuals with cognitive impairment. Results

showed that caregivers exhibited less health-promoting behaviours and had more barriers to health promotion when compared to non-caregivers. It was also found that caregivers were at an increased risk for lack of sleep and had decreased levels of physical activity. Additionally, caregivers who practiced more health-promoting behaviours experienced less stress that may have positively influenced well-being (Acton, 2000). Ourada and Walker (2014) reported that differences in health outcomes for caregivers were dependent on the relationship to the care recipient, as the health effects of spousal caregivers were generally worse than non-spousal caregivers.

#### 2. Introduction to the Sandwich Generation

In 2012, the GSS reported that 2.23 million Canadians were considered to be sandwich generation caregivers (Sinha, 2013). Multiple definitions exist in the literature to explain this phenomenon, which presents a challenge when attempting to compare research. Some researchers broadly defined the sandwich generation as individuals caring for older adults and children at the same time (Durity, 1991; Hammer & Neal, 2008). Other literature extends the criteria of the sandwich generation to having at least one child under the age of 18 living in the home (Sinha, 2013; Tebes & Irish, 2000), the definition which will be used for the purpose of this study. Further, the term multigenerational caregiving will refer to individuals concurrently caring for older and younger generations and will be used interchangeably with the term sandwich generation caregiver.

Miller (1981) was the first to coin the term sandwich generation, which originally referred to women in their early 40's caring for their young children, while caring for their aging parents between the ages of 60 and 70 years old. Now individuals in the sandwich generation tend to be between the ages of 45 and 65 years of age (Sinha, 2013). Demographics of the

sandwich generation have changed, as life expectancies have increased (Chisholm, 1999). More three and four generation families have been maintained due to increased longevity (Grundy & Henretta, 2006). Additionally, it has been reported that individuals are delaying marriage, resulting in delayed childrearing (Robinson, Barbee, Martin, Singer, Yegidis, 2003), with more women having their first child over the age of 40 years (Downs, 2003). In addition, more adult children are returning home after university or moving back home after divorce, which has further extended their dependency on their parents (Chisholm, 1999). Sandwich generation individuals are likely to continue to support their adult children while transitioning and adjusting to adulthood (Ward & Spitz, 1998). Multigenerational caregivers may also be providing more years of care to their dependent children than their parents provided to them, as care is lasting into the mid-twenties (Pierret, 2006). One reason for this may be that the job market relies on students having university undergraduate and/or graduate level degrees. This may contribute to a higher dependency, which changes family dynamics by placing more responsibilities on the sandwich generation (Chisholm, 1999).

#### 2.1 Characteristics of the Sandwich Generation

Aging of the baby boomers, increased life expectancy and decreased fertility have contributed to more seniors needing higher levels of care and fewer adults able to provide this care (Sinha, 2013; Williams, 2004). In addition to providing care to dependent children and aging parents, sandwich generation caregivers also face employment demands. Scharlack (1994) found that when caregivers combined work, family and personal goals, they had minimal time and energy to complete the above tasks successfully. As such, multiple role responsibilities have created the potential for strain on sandwich generation caregivers who have competing demands from the workplace and caregiving (Pierret, 2006). Most research examining sandwich

generation caregivers reported sandwich generation caregivers to be middle-aged (Hammer & Neal, 2008; Vladeck, 2005), female (Sinha, 2013), married (Rubin & White-Means, 2009) and increasingly employed (Pines, Neal, & Hammer, 2011).

In contrast to the above studies, Pierret (2006) found that sandwich generation women were more likely to be out of the labour force and have higher incomes when compared to other women their age. Further, sandwich generation women provided personal and household care to their aging parents and were likely to offer financial support to their dependent children. Interestingly, sandwich generation women provided 6 times the financial assistance (e.g. university expenses, personal care, household chores/errands, etc.) to their children, when compared to their parents or in-laws (Pierret, 2006).

#### 2.2 Women in the Sandwich Generation

As mentioned in previous sections, women typically occupy the majority of caregiving roles (Moen et al., 1994; Sinha, 2013); however, less is known about female sandwich generation caregivers specifically. Research has suggested that once women occupy multiple caregiving roles, they experience more absences from work, health related problems and stress when combining family and work responsibilities (Neal, Chapman, Ingersoll-Dayton, & Emlen, 1993). Nichols and Junk (1997) found that women in the sandwich generation were more likely to assist with housekeeping, shopping, meal preparation and hygiene, as compared to sandwich generation male caregivers. Interestingly, there were no differences among male and female sandwich generation caregivers, in response to current and future financial assistance provided to care recipients, which differs in comparison to other caregiving literature. It has been suggested that the "feminization of the workplace" (p. 84) may contribute to these results, as there are currently more women in the labour force who were once primary caregivers. However, these

results may also be explained by the large number of males in the study in comparison to females (Nichols & Junk, 1997). Although the literature has examined female sandwich generation caregivers (see for example, Pierret, 2006; Raphael & Schlesinger, 1994; Stephens, Franks, & Townsend, 1994), it is still unclear if their roles and responsibilities differ from those of other family caregivers.

#### 2.3 The Sandwich Generation: Myth or Reality?

In opposition to other literature presented, Loomis and Booth (1995) have suggested that membership in the sandwich generation is a rare situation and therefore a myth. The well-being of sandwich generation caregivers was examined. In this study the following measures of wellbeing were assessed: marital quality, psychological distress, financial strain, satisfaction with leisure time, and perceived unfairness of household division of labour. After considering their responsibilities, hours of care and gender, the results indicated that multigenerational caregiving had little to no effect on well-being, except for perceived unfair division of household labour, when compared to the general population. Loomis and Booth (1995) proposed that couples with strong marriages were more likely to take on multigenerational caregiving roles and were thus able to cope well with the added stressors associated with caregiving. The authors also explained that couples providing assistance knew their care recipients intimately, which helped predict their level of need, expectations, and demands prior to assuming the caregiving role. Additionally, individuals initiating a multigenerational caregiving role may value family and perceive the caregiving role as a sense of fulfillment. For these reasons, Loomis and Booth (1995) suggested that most middle-aged adults were capable of fulfilling multigenerational caregiving roles without changes in their well-being. Similarly, Ward and Spitze (1998) found

that being in the sandwich generation was not indicative of poor marital quality and relationships with children and parents.

#### 2.4 The Effects of Caregiving for the Sandwich Generation

**2.4.1 Costs and benefits of caregiving: The sandwich generation.** Little research has focused on the cost to sandwich generation caregivers. Igarashi et al. (2013) completed a qualitative study examining the non-financial costs experienced by sandwich generation caregivers. Participants indicated that care provided to aging parents was often distressing, unpredictable and unanticipated. The sandwich generation caregivers were not prepared to care for their parents and struggled with their changing health status. Additionally the care tasks conflicted with opportunities available to them such as career, travel and personal growth. Similarly, Voydanoff and Donelly (1999) found that the number of hours spent caring for parents was positively correlated with psychological distress in sandwich generation women.

Hammer and Neal (2008) found that married sandwich generation caregivers experienced higher levels of depression with 22 to 36% scoring above the depression cutoff score, which is higher than the general population. Additionally, sandwich generation caregivers experienced higher levels of work-family conflict and greater absenteeism from work (Hammer & Neal, 2008). Similarly, Robinson et al. (2003) reported that sandwich generation caregiving influenced missed obligations and increased chronic stress, which led to decreased productivity in the workplace.

Stephens, Franks, and Townsend (1994) found that women in multiple roles (e.g., caregiver, mother, wife) who accumulated stress in all of these roles had decreased levels of well-being, compared to women who only experienced stress in the caregiving role. Similarly, Remennick (1999) found that sandwich generation women, who immigrated from Russia to

Israel, had diminished well-being due to the stresses associated with multiple roles. Further, Rubin and White-Means (2009) reported that sandwich generation caregivers may have lower quality of life and "more than they can handle" (p. 261), due to the accumulation of multiple roles.

Other studies further explained the costs experienced by sandwich generation caregivers. Pines, Neal, and Hammer (2011) conducted focus groups with dual-earner sandwich generation caregivers and found that stress was influenced by the changes in their parents health. As well, this study found that there was a positive correlation between job burnout and stress associated with parent care (Pines et al., 2011). Green (2012) completed a qualitative study that examined families caring for children with disabilities and aging parents. Results indicated that the onset of aging needs in parents, resulted in a loss of support that had previously been provided, for the care of the child with special needs. This support had been fundamental for caregivers' coping and ability to maintain well-being (Green, 2012).

Most sandwich generation caregiving research has focused on the negative aspects associated with membership in the sandwich generation, although limited evidence exists citing the benefits of caregiving. For example, Christenson, Stephens, and Townsend (1998) found that caregivers occupying multiple roles felt feelings of mastery (Christenson, Stephens, & Townsend, 1998). Mastery is defined as the belief that an individual is able to influence life events and is competent in managing them. In this study, they found that managing multiple roles (e.g., wife, caregiver, mother) contributed to positive psychological well-being. Additionally, high levels of mastery influenced life satisfaction (Christenson et al., 1998). Marks (1977) explained that having multiple roles may not have a negative effect on psychological health, but could potentially lead to positive outcomes, such as increased psychological well-being and greater

physical health. Further Stephens and Townsend (1997) found that mastery derived in the labour force helped buffer the stress of parental caregiving. Occupying a caregiving role may be beneficial to women who previously performed very few roles, creating a sense of meaning and belonging in life (Dautzenberg et al., 1995). Multiple roles including caregiving has also been described as providing a sense of ego gratification, status enhancement and status security (Sieber, 1974).

Stephens, Franks, and Townsend (1994) examined the positive effects of women in multiple roles: caregiving daughter, mother and wife. They found that caregiving daughters and daughters-in-law felt rewarded by their multiple roles. Accumulations of rewards in two of the three roles (e.g. daughter, mother, wife) resulted in significantly elevated levels of well-being in comparison to women who felt all of their roles were stressful (Stephens et al., 1994). Pines, Neal, and Hammer (2011) found that couples in the sandwich generation reported significantly lower levels of job burnout, when compared to the general employed population. Results from focus groups indicated that strong marriages helped sandwich generation caregivers decrease job and couple burnout, even though they had multiple stressors (e.g. work, marriage, parenting, caring for aging parents). This further illustrates that multiple roles may benefit other areas of sandwich generation caregivers' lives.

A few qualitative studies have supported these findings, further demonstrating the possible benefits of being a sandwich generation caregiver. Ingersoll-Dayton, Neal, and Hammer (2001) found that sandwich generation caregivers experienced benefits in multiple roles. For example, care provided may be seen as reciprocal, as older adults offered other forms of help (e.g. financial, emotional support, childcare, household tasks) in return to their adult daughter or son. Ingersoll-Dayton et al. (2001) contend that any potential benefits of caregiving are

dependent on the past or current familial relationship with the care recipient. Pope (2013) examined the influence caregiving had on adult daughters' perspectives about their own future in later life. Results revealed that the caregiving experience may provide benefits such as gaining awareness of aging successfully (Pope, 2013). Additionally, Igarashi, Hooker, Coehlo, and Manoogian (2013) found that sandwich generation individuals learned from their experience caring for their own parents. Specifically participants planned for the future and changed their health behaviours. This was done in order to avoid burdening their own children with caregiving tasks (Igarashi et al., 2013).

2.4.2 Coping mechanisms: The sandwich generation. Little research has been conducted in the area of coping mechanisms and the sandwich generation. Neal and Hammer (2009) examined dual-earner sandwich generation couples and their use of specific coping mechanisms, such as increasing emotional resources (e.g. seeking moral support, comfort and humour in situations), resources that decrease social involvement, and coping mechanisms that involve prioritization. Results indicated that sandwich generation caregivers that used emotional resources for coping reported higher levels of well-being and decreased depression. Furthermore, coping mechanisms that involved decreased social involvement had a negative impact on wellbeing, while prioritizing strategies (e.g. setting aside time for valued/important activities) showed positive effects on well-being in the future (Neal & Hammer, 2009). Although having a dependent older adult living in the home is not a requirement of sandwich generation caregiving, an additional study explored multigenerational households and coping strategies elicited (Pruchno, Burant, & Peters, 1997). Multigenerational households included parents, their dependent children, and an aging parent, all living within the same home. Results differed from Neal and Hammer (2009), as associations were found between women who used more emotion

focused coping mechanisms and negative well-being (Pruchno et al., 1997). Additionally, the use of more acceptance strategies benefited husbands, wives and children, which resulted in less depression in the wives and children.

Igarashi et al. (2013) qualitatively explored the experiences of midlife sandwich generation adults by conducting focus groups. Throughout the caregiving experience, the sandwich generation caregivers faced disappointment due to the unexpected needs of both generations. The sandwich generation caregivers used creative ways to help cope with their situation by reframing the setbacks influenced by caregiving. For example individuals gained pleasure by vicariously experiencing their children's achievements or held off making plans to avoid disappointment when cancellations were required, because of obligations for their care recipients (Igarashi et al., 2013). Remennick (1999) completed a qualitative study that examined female sandwich generation immigrants. Many of the women struggled adapting to their new country and had many stressors associated with providing care to their aging parents. Positive coping mechanisms included the use of some paid assistance and social support through their cultural networks. Yet, the women reported using cigarette smoking as an effective coping mechanism over the long-term and rather a cost to overall health.

**2.4.3 Health behaviours of the sandwich generation**. There are very few studies that investigated health and/or health behaviours of adult children caring for their aging parents, let alone individuals who are members of the sandwich generation. Marks, Lambert, Jun and Song (2008) contended that family relationships may affect the health status of the caregiver, and thus represents an issue that should be examined more thoroughly. Additionally, it is possible that some sandwich generation members are able to maintain their health behaviours. Chassin, Macy,

Seo, Presson, and Sherman (2010) suggested a selection effect takes place when there are multiple possibilities for individuals to take on caregiving roles. For example, individuals who are in greater health and participate in more self-care practices may be more inclined to take on multigenerational caregiving. Further caregivers may be motivated to maintain their own health behaviours due to the possible decline in the health of their care recipients (Chassin et al., 2010). This is supported by Igarashi et al. (2013) as sandwich generation caregivers in this study indicated that they wanted to optimize their health, in order to decrease the caregiving burden for their children in the future. It is also feasible that caregivers may receive benefits from being a caregiver, which may lead to better health behaviours (Chassin et al., 2010).

Only one study known has thoroughly examined the health effects and health behaviours of sandwich generation caregivers. Chassin et al. (2010) compared the health behaviours of individuals among four groups: (1) sandwich generation caregivers, (2) caregivers of older adults or (3) children and (4) non-caregivers. Five health behaviours were examined: checking ingredient labels on food items for health value, choosing foods to eat based on health value, using a seatbelt, exercising regularly and tobacco use. The investigators predicted that individuals in the sandwich generation would have compromised health behaviours when compared to the other groups, which would potentially result in reduced available time for their own health needs, as they placed the health of others before their own. Results revealed that sandwich generation caregivers were significantly less likely to check food labels or make food choices based on nutritional value, compared to all other groups. In addition, sandwich generation caregivers and individuals caring only for parents were less likely to use their seatbelt and smoked more cigarettes. Lastly, sandwich generation caregivers and individuals caring only for children were less likely to exercise. Chassin et al. (2010) contended that these results may

not be solely the result of lack of time, but rather that sandwich generation caregivers placed the health of others before their own.

Hoffman, Lee, and Mendez-Luck (2012) examined the health behaviours of baby boom caregivers, in comparison to baby boom non-caregivers. Results indicated that baby boom caregivers were more likely to engage in negative health behaviours such as smoking and increased intake of fast food and soda, which is correlated with obesity. Baby boom caregivers' health behaviours were not associated with sedentary behaviour, but results suggested that there may be a global risk for morbidity due to the accumulation of poor health behaviours over time (Hoffman et al., 2012). Therefore this may suggest that sandwich generation individuals are at a greater risk for decreased health behaviours, as shown by Chassin et al. (2010).

Throughout this paper the factors that facilitate or hinder sandwich generation caregivers have been discussed. Research pertaining to sandwich generation caregiving is limited and conflicting due to methodological issues with these studies (e.g. composition of sample). Additionally, the majority of the caregiving literature focuses on spousal caregiving, rather than sandwich generation caregivers. Further, the health behaviours of sandwich generation caregivers has been understudied, as there is only one study known to date that explicitly examined this topic (Chassin et al., 2010). As such, the current study continued to explore sandwich generation caregivers and their health.

#### **3.** Purpose and Research Questions

The purpose of this study was to examine the lived experiences of sandwich generation women and the influence multigenerational caregiving had on their health behaviours. Mothers' were studied due to their high prominence in caregiving roles. The following research questions were examined: (1) What is the effect of caregiving on mothers? (2) Do sandwich generation

women's health behaviours change once they enter a multigenerational caregiving role? And (3) How do sandwich generation women define caregiving?

# Methodology

#### **1. Participant Recruitment**

For the purpose of my study, it was important to recruit participants "who [had] directly experienced the phenomenon of interest" (Patton, 2002, p. 104). I recruited nine sandwich generation women from the Waterloo Region and Greater Toronto Area. I used posters/flyers to recruit potential participants in both regions listed (see Appendix B). Further, I utilized snowball sampling, which consisted of asking people if they knew of other sandwich generation women whom I might be able to interview (Patton, 2002). Once interested participants were contacted, I ensured that all sandwich generation women fit the predetermined criterion, known as criterion sampling (Patton, 2002).

The criteria for my study was the following: (1) The sandwich generation women had to be mothers; (2) The sandwich generation women must have been caring for at least one child who was under 18 years living in the home; (3) Children of the sandwich generation women must have been neurotypical or perceived as high functioning by the mothers. The children could have a mild physical or developmental disability; (4) Sandwich generation women were excluded if any of their children had a condition that was beyond mild or if they had any continuing complex care needs (e.g. cancer, cerebral palsy, cystic fibrosis), as perceived by the mothers; (5) The sandwich generation women must have been providing care to at least one parent/in-law; (6) The parents/in-laws of the sandwich generation women had to live within the same city or region; and (7) The parents/in-laws requiring care could not live in the sandwich generation women's home.

#### 2. Research Tools & Procedure

#### **2.1 The Qualitative Methods**

Qualitative research methods were employed for my study. Patton (2002) described qualitative data as a way "to take...readers, into the time and place of the observation so that we know what it was like to have been there. They capture and communicate someone else's experience of the world in his or her own words." (p. 47). Patton (2002) further stated that qualitative research has the ability to tell a story of one's experience. I believed qualitative inquiry presented the best avenue to describe the experiences of sandwich generation women and the influence caregiving had on their health behaviours.

I utilized the theoretical orientation of phenomenology to guide my study. Phenomenology "seeks to grasp and elucidate the meaning, structure, and essence of the lived experience of a phenomenon for a person or group of people" (Patton, 2002, p. 482). Further, Creswell (1998) defines phenomenology as "the meaning of the lived experience for several individuals about a concept or phenomenon (p. 51)." I examined the lived experiences of sandwich generation women and the influence multigenerational caregiving had on their health behaviours. Patton (2002) thoroughly described phenomenology as:

How human beings make sense of experience and transform experience into consciousness, both individually and as shared meaning. This requires methodologically, carefully, and thoroughly capturing and describing how people experience some phenomenon –how they perceive it, describe it, feel about it, judge it, remember it, make sense of it and talk about it with others (p.104).

Semi-structured interviews were the main method used in my study for data collection. Through the use of interviews, I was able to gain information on the aspects of sandwich generation women's lives that were not readily observable (Patton, 2002). For example, I "[could not] observe feelings, thoughts and intentions, ... behaviours that took place at some previous point in time [and]...how people have organized the world and the meaning they attach..." (Patton, 2002, p. 341). By using interview questions, I had the opportunity to gather the mothers' insights, further assisting in the understanding of the phenomenon of the sandwich generation. I also used background questionnaires, field notes, member checks and triangulation to complement the richness of the interviews.

**2.1.1 Ethics.** All forms of data collection and procedures employed for my study were approved by the Wilfrid Laurier University Research Ethics Board. Before participating in this study, all sandwich generation women read and signed an informed consent statement (see Appendix C). The mothers were provided the opportunity to ask any questions, prior, during and after the interview and were allowed to stop the interview at anytime.

**2.1.2 Background questionnaire.** Once the informed consent statement was signed, a background questionnaire was completed (see Appendix D). The background questionnaire consisted of: (1) Demographic information pertaining to the sandwich generation women (e.g., date of birth, employment, education and marital status); (2) Perceived health of the sandwich generation women (e.g., overall health, known health conditions, physical activity, drinking and smoking); (3) Information concerning the sandwich generation women's children (e.g., number of children, date of birth and gender of children, number of children living in/out of the home, support provided to children); and (4) Information concerning parents/in-laws (e.g. number of parents/in-laws, year of birth/death of parents/in-laws, conditions/diseases/chronic health problems, number of parents/in-laws living in the home). By reviewing the information collected prior to the interview, I was able to use this information to provide some context for each interview and to guide the line of questioning throughout the interview.

**2.1.3 Interviews.** I conducted semi-structured, one-on-one interviews with nine sandwich generation women. Each interview was arranged at a time and location convenient to the mother and conducted in person. The amount of details provided in the mothers' responses influenced the length of the interviews. As such, on average the interviews were 53 minutes and ranged from 13 to 90 minutes in length. I digitally recorded and transcribed each interview verbatim, once the interview was completed.

In order to collect information pertaining to the lived experiences of sandwich generation women and their health behaviours, I asked 16 open-ended interview questions (see Appendix E). The purpose of the first part of the interview guide was to gather information concerning the sandwich generation women's personal/family life, and to understand how they defined caregiving. The next part of the interview addressed the care they provided to their children and parents/in-laws, the care the partner provided, their feelings about their caregiving role and the perceived effect of sandwich generation caregiving on their children. The following questions pertained to the sandwich generation women's health. I asked each mother to discuss their current and past health, physical activity levels, nutrition and any obstacles they felt may have prevented themself from taking care of their own health. The final portion of the interview guide addressed how the sandwich generation women dealt with their multigenerational caregiving role overall, how they felt their life had been influenced, how they perceived their future role as a caregiver and again how they defined their caregiving role. I used probes to elaborate the mothers' responses when I felt more information was required. One mother required two interviews. The first interview was 49 minutes in length and the second interview was 13 minutes long. The second interview was conducted as it was thought to be easier than a member

check, as this was my first participant. I believed that more probing questions were required after reviewing the mother's transcript.

Following each interview, I concurrently transcribed each interview verbatim and analyzed the data. After completing all of the interviews, a total of 310 pages (single spaced with a blank space between each statement) were transcribed verbatim. This process was undertaken in order to determine when I perceived data saturation to have been reached. Saturation was felt to be achieved when "information [had] been exhausted, when new sources led to redundancy" (Patton, 2002, p. 466), and further interviews would not add to the quality of the data. Saturation was felt to be reached after interviewing nine participants.

**2.1.4 Field notes.** I used field notes to complement data collection and to further provide richness to the information gained from the interviews. Prior, during and immediately following each one-on-one interview, I took field notes. Field notes included the date, location, individuals in the room, interactions, the physical setting and activities that occurred during the interview. I wrote down any details that I thought were necessary to describe as suggested by Patton (2002). These field notes enhanced the data by creating a context for each of the interviews, such as non-verbal communication and key phrases. I used field notes to complement the transcripts by noting any initial thoughts and interpretations for further data analysis (Patton, 2002). Further, when analyzing my data, I used the collected field notes as a contextual reference when determining themes and subthemes.

**2.1.5 Member checks**. Once I transcribed the interviews verbatim, member checks were conducted to allow the mothers to add, clarify, or omit any data from their transcripts. The sandwich generation women received their transcripts through their preferred method of email. This allowed the mothers the opportunity to "correct, amend or extend..." (Lincoln & Guba,

1985, p. 236) responses in their transcripts. This process gave the sandwich generation women the chance to confirm the information they were comfortable divulging and gave them control over any potentially sensitive data they may have provided (Holloway, 2005). I also asked questions that I felt required further clarification from the sandwich generation women. A total of eight of the mothers returned their member checks without changes and provided answers to the questions that I had requested clarification. The member checks also helped contribute to trustworthiness of the data, as it indicated to the participants that I was handling their interview responses in a thoughtful manner and asked for their feedback (Patton, 2002).

**2.1.6 Triangulation.** Triangulation used multiple sources of data in order to strengthen the study (Patton, 2002). In my study, two types of triangulation were employed: data triangulation and investigator triangulation. Data triangulation involves collecting multiple sources of data from each study participant. In my study, background questionnaires, one-on-one semi structured interviews, field notes and member checks were employed. Investigator triangulation involves the use of multiple investigators reviewing and discussing the transcripts for interpretations and analysis (Patton, 2002). I reviewed the data, in addition to a number of faculty members and graduate students involved in a qualitative research group. In this group we discussed the themes and subthemes of my study. The use of triangulation enhanced the credibility of the study.

#### 2.2 Credibility

It was critical to use rigorous methods to establish credibility and trustworthiness when collecting data for qualitative research. The goal in my study was to produce "high-quality data that [was] systematically analyzed with attention to issues of credibility" (Patton, 2002, p. 552). In order to enhance credibility, I conducted a thorough literature review in the areas of

caregiving, sandwich generation caregiving and health. This ensured that I was knowledgeable about the area of study. In addition, I completed courses in qualitative research and ethics. Further, I received individualized supervision by faculty members who were experienced in using qualitative methodology. Additionally, I participated in a qualitative research group, which provided mentorship by faculty and other graduate students. Lastly, I used époche in order to refrain from judgment when interpreting the mothers' experiences (Moustakas, 1994). I used a journal at all stages of the research process to track progress and to reflect on any preconceived biases that may have interfered with my objectivity as a researcher. This allowed me to assess data at face value and further contributed to credibility.

I ensured that each sandwich generation women met the predetermined inclusion criteria, in order to produce information rich cases. This lent itself to the idea of "quality not quantity", in terms of the data collected, versus the number of respondents interviewed. Data was collected until I believed saturation had been reached. By using the methods described, all data was collected and analysis was performed in a rigorous manner that enhanced the credibility and trustworthiness of the results.

In addition, to enhance trustworthiness and credibility, each mother completed an informed consent statement and was requested to review their interview transcript in the form of a member check. This allowed the sandwich generation women to have a level of autonomy with their results. Further, I conveyed to each mother that the information they shared in relation to their experiences was valuable (Patton, 2002). This helped establish rapport with the sandwich generation women and further added to trustworthiness of my study.

#### 2.3 Data Treatment

**2.3.1 Qualitative analysis: Phenomenology.** I used the theoretical orientation of phenomenological analysis to interpret my findings. For my study, I used many steps to conduct an in-depth analysis of the data collected from the background questionnaires, interview transcripts, field notes and member checks. This included reading and re-reading interview transcripts multiple times, marking and highlighting reoccurring phrases and key statements, which lead to the emergence of themes and the interpretation of the lived experiences of sandwich generation women.

More specifically, I used Moustakas's (1994) steps as a guide for my data analysis. The first step was époche, as I refrained from judgment when reviewing my data. This required that I set aside any preexisting personal biases or opinions about the lived experiences of sandwich generation women. I achieved this by journaling throughout the research process. Before, during and after any step in the study, I wrote down thoughts that could be considered preconceived biases that I had towards the mothers or data. Throughout this process, I was able to refer to this journal in order to maintain neutrality. In addition, during the interview process, to the best of my ability, I responded to the sandwich generation women in a neutral manner and with nonverbal communication to let the mothers know that I was listening. The second step was phenomenological reduction. This involved regarding each case as its own identity, to see the mothers' data in its simplest form. As I highlighted, read and re-read the mothers' transcripts, I was able to identify key phrases and appropriate meaning of the quotations. Through the use of my journal, I began to write down any early interpretations that I felt would assist me in describing the phenomenon of interest. The third step, *horizontalization* and *delimitation* was used to view the data as a whole, providing equal weight to all cases. In this step I introduced the

use of NVivo qualitative data analysis software; QSR International Pty Ltd. Version 10, 2014. I used NVivo to organize my data into meaningful clusters and to remove any irrelevant/reoccurring data. By sorting my data, I was able to derive themes, which were further categorized into subthemes. The next step used was *textural portrayal*, which created an illustration of the phenomenon, while the essence of the experience remained absent. I used visual representations to view the experience of sandwich generation women as a whole. The final step of analysis was *structural descriptions*. This involved elucidating further meaning and creating a deep description of the phenomenon of interest for each participant. This process consisted of continually re-reading the transcripts and making notes about the emerging themes and subthemes. Once all of the steps were completed and the final two steps, *textural portrayal* and *structural descriptions* were merged, the essence of the lived experience of sandwich generation women was established by creation of themes and subthemes.

# Results

My study was comprised of nine sandwich generation women. The mothers' ages ranged from 46 to 52 years at the time of the interviews. All but two of the sandwich generation women were married and the remaining were separated from their spouses. The mothers had attained high school, college, undergraduate and masters/doctoral degrees. As well, some of the sandwich generation women indicated that their health was affected by their caregiving roles. Two of the mothers had diagnosed health conditions (multiple sclerosis and hypothyroidism). The majority of the sandwich generation women revealed that in the past they were more active and ate more nutritious meals. Currently, most mothers did not get enough sleep each night and did not regularly participate in physical activity. The sandwich generation women had 1 to 5 children between 6 and 25 years. All of the mothers provided support to their children. Only one mother had a child with a health condition (Autism Spectrum Disorder), but the mother perceived the condition as mild. Additionally, the sandwich generation women had previously provided care to 1 to 6 care recipients, and currently provided care to 0 to 4 care recipients. The mother that was not currently a caregiver had provided care in the last two years. The care recipients' ages ranged from 40 to 85 years. Some of the sandwich generation women's care recipients had passed away prior to the start of the study. The sandwich generation women provided care to their mothers, fathers, mother in-laws, father in-laws, aunt/uncles and sister. The care recipients had a variety of health conditions and illnesses. For more detailed information about the sandwich generation women, their children and care recipients, please see Appendix F.

# Themes

Analysis of the data revealed four major themes describing the lived experiences of sandwich generation women and their perceived health. The themes included: (1) The role of the caregiver; (2) Caregiving: It is a balancing act; (3) Stormy seas: It is not always sunshine and rainbows; and (4) Silver linings amidst the turmoil. The themes and subthemes are summarized in Table 1. All of the themes will be discussed in turn.

Theme	Subthemes	
1. The role of the caregiver	a) Physical care	
	b) "Sounding board": The emotional aspects of	
	caregiving	
	c) Never enough time in the day	
	d) Am <i>I</i> a caregiver to my children?	
	e) Role transitions and variations in caregiving	
2. Caregiving: It is a balancing act	a) Juggling: Keeping all the balls in the air	
	b) Tug-of-war	
	c) Shifting the equation	
3. Stormy seas: It is not always sunshine and	a) Decreased time with immediate family	
rainbows	b) My social life is closed	
	c) Resentment and frustrations	
	d) Health of the caregiver: What about my	
	needs?	
	e) When the going gets tough	
4. Silver linings amidst the turmoil	a) I am thankful for what I have	
	b) Finding joy in the journey	
	c) It is a learning experience	
	d) Growth in children	

**Table 1:** Themes and subthemes of the lived experiences of sandwich generation women

It is important to note that throughout the sandwich generation women's interviews, caregiving to the care recipients was mostly discussed, as opposed to the care provided to their children. The care required by the children appeared to be significantly less challenging. Additionally, it appeared that the care provided to the older adults was perceived as more demanding and necessitated more of the caregivers' time. Conversely, the care for the children appeared to be expected and therefore was perceived as more manageable. The mothers discussed how their children's care differed from the care recipients' care and the decreased time spent with their children as a result of caregiving. Also, the children were discussed in terms of their inclusion in the juggling act and tug-of-war, although the care recipients typically caused the strain. All other subthemes were largely directed towards the sandwich generation women's care recipients. As a result the mothers experienced the greatest challenges when helping their care recipients and trying to balance other areas of life such as work, being a mother and their spouses.

#### 1. The role of the caregiver

The sandwich generation women were asked to reflect on their overall responsibilities as sandwich generation caregivers. The mothers thoroughly discussed all aspects of their caregiving roles. The sandwich generation women's insights lead to the development of five subthemes: (a) Physical care; (b) "Sounding board": The emotional aspects of caregiving; (c) Never enough time in the day; (d) Am *I* a caregiver to my children?; and (e) Role transitions and variations in caregiving.

#### **1.1 Physical care**

All of the mothers reported that their caregiving roles involved providing physical care to their care recipients. Many of the sandwich generation women discussed that they assisted with

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physical tasks in their care recipient's day-to-day lives, such as assistance with instrumental activities of daily living (IADLs) (for example housework, transportation, shopping for

groceries).

Well sure, there's a lot of physical tasks, like for example, my mother in-law, has nobody to depend on now, um to, it was my father in-law's job to take her, grocery shopping, to take her out for any type of entertainment. To take her to doctors appointments, to take her anywhere. And now she is homebound unless, we take her.  $\sim$  Naomi

But, uhh, stuff like, um you know, taking care of her health needs, and her financial needs and whenever she's sick, we do cooking for her, stuff like that. I guess, [whatever] her needs are.... But, we uh, we together, um coordinate whatever her needs are, in terms of appointments or anything else that she needs. Shopping, grocery shopping. ~ Elyse

At times when some of the mothers' care recipients were less able, they assisted them with

activities of daily living (ADLs), in addition to IADLs.

Um, so, we would take [my mother in-law] to appointments. We started taking her to appointments, because she was unable to, she, quick, very quickly she was unable to, to drive.... Um, then at home, um, her gait, was very unstable. So we would help her with walking to, like ev-, whether it was walking to the washroom or even helping her in the washroom.  $\sim$  **Robin** 

... when she was not taking, for example medications, or if she was not eating. I would go over and help feed her.... She would not take food from my father. Um, he would not do the toileting, so I would do the toileting. If we went out on outings, you know that was my responsibility to take care of her and take her to um, the washroom and get her diaper changed, get her cleaned up. So, um, sort of practical functions. Dressing, helping dress her, but not on a daily basis. ~ Diane

Unlike the other sandwich generation women, Melanie started to care for her mother when she

was very young. Melanie's father had died at a young age and her mother was involved in a

serious car accident when she was in her fifties, which resulted in health complications. As her

mother became older her care demands increased.

But, I am, um as far as the rest of the caregiving, my mother, has never driven, even ever, ever. So, the caregiving for me has been, my whole life really, since I turned 16 I was responsible for taking her grocery shopping, when I got my license. When I, to her

hairdresser appointments, to any appointments.... So, um, my job with her entails, um, everything from, um, providing for all of her, all of her gro-, like groceries and things.... Taking her to all of her appointments. Dental appointments, doctor appointments. ~ *Melanie* 

Kate recalled that her in-laws required help when moving from a house to an assisted living

facility.

Right, and then there's some things that they are not capable of doing at all, where we just have to make sure that we step in.... We didn't expect 86 year old and 87 year old people, to actually tangibly and physically move their stuff.... So that became our responsibility. ~ Kate

While the requirements of physical care varied across the sandwich generation women, it was

clear that assisting with ADLs and IADLs was a significant role in their caregiving

responsibilities. The extent of the care provided was largely in response to the care

recipients' decreased capabilities, due to age or health related issues.

# **1.2 "Sounding board": The emotional aspects of caregiving**

All of the sandwich generation women revealed that their caregiving roles involved a level of emotional care. Throughout the interviews multiple mothers referred to emotional caregiving as functioning as a "sounding board" for their care recipients.

It was a very stressful death, and so it was a lot of emotional caring.... So for her now, she is someone that, she will call, I'm her second voice. So if she makes a financial decision or she is thinking about something or something's not working in the house. It's me whom she calls, to say "what do you think about this?" or "do you want to that?".... And she can do the day-to-day of her life no problem at all. But it's just the sounding board, that aspect of it. ~ Kate

So he understands, but it's um, a role of continually, trying to convince, and, and um [pause] tell him of the reality of the situation is. And, he is riddled with anxiety, because he doesn't want to, her to have this kind of, death.... You have to act as a sounding board, and, you're, you're like a sponge because, you have to allow them to express what's going on. ~ Diane

Additionally, the mothers mentioned that their caregiving roles involved providing emotional

care in the realm of supporting their care recipients through their age-related changes.

If it is, uh listening when they have, something that they [pause] need to talk about. I would say particularly, my mothers a widow, and she doesn't necessarily have someone in her life that's there to listen... I was there to listen. I was there to, to guide, I was there to direct. I was there to say "you're okay...things will get better", and, and it has. ~ Meredith

Um, I think it's more being there for support and being, being supportive of that individual and understanding like as they, their, um, for age-related um, age-related issues, understanding and being patient with umm, with frustration of, of the frustration of them not being able to do things that they used to.  $\sim$  **Robin** 

Lyla felt that being present emotionally helped her mother survive medical emergencies.

You know what, there were times when, I had turned up at the hospital and honestly, she probably would have died, three or four times over if I hadn't have been there. ~ Lyla

Although some of my mothers' parents or in-laws were not suffering from any major health

conditions, they still required emotional care due to the changes their spouses were

experiencing medically.

And it's a lot on [James]'s mom, so there's a lot of stress that's going on... Because she's grieving, her husband's not the same man, that he was three months ago before the stroke. She's trying to figure this all out. And yet she won't leave his side, to actually still do what she needs to do. So we worry about her mental health as well.... And her physical health as well.... And so she'll keep saying, "just please call me, please call me." ~ Kate

Um, I was [my father's] [pause] emotional council, I guess.... And, a support system to him. To try and help [pause] him through what he was dealing with.... And um, and now I see my role as [pause] supporting more him than my mom, because she is in a nursing home, currently. So, it's um, progressed with helping my dad cope with his grief, and the loss of her. ~ Diane

Overall, the sandwich generation women described their caregiving roles, as being emotionally involved in their care recipients' lives, whether they acted as a sounding board, provided moral support or functioned as a secondary caregiver to their parents. In addition, the mothers

conveyed the importance and magnitude of providing emotional support and the positive effects it had on their care recipients' well-being.

# 1.3 Never enough time in the day

All of the sandwich generation women discussed how lack of time affected their caregiving roles. Many described that they needed to be available or on-call for their care recipients, rather than providing a specific amount of hours of care each week.

*I guess caregiving is, the, uh, is looking after someone being available to [pause] be called upon to help out wherever necessary.* ~ Meredith

You have to be on-call, available you know to, help her out with whatever issues she's having.... But it's, you just have to be available, right? ... Like you know we all just try to be available and, make sure everybody's okay, and you know, things are smooth for everyone. ~ Naomi

*Um* [*pause*] at first it would be, as a caregiver, to be present as my parent's age. And available to them, to assist them with their needs. ~ **Diane** 

As well, many of the mothers revealed that being in a sandwich generation caregiving role

took up a large amount of time, whether it was spent with the care recipient or not.

...if you look at hands on hours, that's one thing.... But then you have to look at, the amount of mental space that it is taking. So it, it, eh, it is a really interesting thing, it's not exactly, hours, I would always say it is the amount of, um [pause] just concern and preoccupation, would be the word that I describe it.... It's not even involving them.... So it, just takes an inordinate amount of time, is what I would say. ~ Kate

... I pay her bills monthly.... So there's a certain amount of time that maybe, I'm not spending with her, as a personal caregiver. But, I'm at home, spending an hour doing her financing, going online to pay her bills.... Dealing with government remittance forms.... So, so it's not always on a weekly basis, where I'm actually physically with her. But, you can be sure that within a week, there's at least two hours a week that I spend um, uh cont-, like uh supervising and organizing her life.... To make it easier for her. So absolutely, there's, there's time involved. ~ Melanie

... as my mother got older and she suffered very badly from diabetes. So it got very, it got worse cause she had to go on dialysis. So it was very time consuming, because she was in

and out of hospitals.... So that was, I was in charge of that. And uh, it was just very, very time consuming, yeah. ~ Lyla

Further, some of the sandwich generation women revealed the quality of the time spent with

their care recipients was more important than the quantity of hours given.

... time doesn't define the quality of what you are doing. Um, you could be sitting there doing nothing actually with somebody. Um, and just being there for them is uh and it's just your presence is, is important. But I don't define, um I don't say "okay well now I did 30 hours with my parents" therefore I've you know, I fulfilled my, my requirement and that's a good quality amount of time, because that good, good quality amount of time could be just a couple of hours as well. ~ **Robin** 

... But I mean, it's uh, it's their necessities that need to be met. So, whether it is going to be 4 hours of your time, or two days a week, or four days a week. I think that's, that's the better, is what kind of care you're providing them, that, it shouldn't have a time constraint. I don't think it does. ~ Joanne

Sometimes it's just not, um, doing things. It's just sitting and being with the person. Um, you know I spend sometimes a whole hour on the phone with her. Just listening to stories and over and over. So I guess, you know, dealing with her physical needs as well as the emotional ones, I believe that's part of it. ~ Elyse

All of the mothers described the considerable time commitment, both physically and

mentally dedicated to their caregiving roles. Time was discussed in terms of being available,

the quality versus quantity of time, and the time spent with or without the care recipient.

# 1.4 Am I a caregiver to my children?

The majority of the sandwich generation women described the differences between

caregiving and parenting. Some of the mothers' perceived that the amount of emotional care

provided differentiated caregiving from parenting.

I think caregiving, when you add [pause] caregiver, you're adding a sense of [pause] more, more of an emotional sense, than, than a parent.... Um [pause] it's kind of the difference of between a teacher and an educator. A teacher is, giving information and an educator is, there's more invested in it I guess. ~ Meredith

Um, parenting is more of a guiding, um, uh, uh a guidance, and still caring.... Whereas caregiving is just providing that comfort and support, and, and and life things they need to survive.... You're not providing any of the guidance.... That said, I think what the major differences. You're parents, you're still going to feed and clothe your kids, but you're still going to guide them to be more independent... To survive without you. Whereas caregiving, you're just sort of [pause] you're just making sure they're comfortable, they're fed, and they're and they're and their hygiene is looked after. ~ Joanne

Umm [pause] it's a different, I find that um, with children, it's less physical and more emotional. So, you know when you were young, and the kids you drive them to gymnastics and driving them to all their programs.... And that was more physically taxing.... Whereas the issues that, um, watching them come home because they have three essays due the same week. It's more emotional.... Um, so I think you know physically, there's less physical involvement with my children. Emotionally it's a different type of, of emotional involvement. ~ Melanie

In addition, some of the mothers believed that being a caregiver to their children entailed

providing assistance with the tasks they could not complete on their own.

... uh parenting is more of a guidance role.... With caregiving, it's more [pause] it's more um, I think [pause] a process of caring and helping a person who is unable to help themselves. And although children are, at times, unable to help themselves, that's where there could be a little bit of um, overlap between the two..... You are there to provide them support uh, whether it's uh, mental support or physical support [pause] to assist them to be able to live day-by-day to the best that they can, dependent on their conditions. ~ **Robin** 

Joanne who had a son with high functioning Autism Spectrum Disorder explained the

differences between parenting and caregiving through the following quote.

But [Jonathan] obviously, um more so, because of his uh, his challenges in life. Um I have, I have to make sure that he, is, eating, um appropriately, and um that he goes to school, that he gets dressed, that he's doing things that he should be doing. Um, not things that he would do on his own, without being told. So yeah, um, it's providing that support to him in that sense. Um, yeah I'm still caregiving. Picking him up from school.... Taking him to school. All my children. ~ Joanne She felt that she needed to assist her children with tasks they could not complete on their own.

All of the mothers believed that there were differences between caregiving and parenting for children, although overlap existed between the two roles. Some mothers discussed that caregiving for a child consisted of higher levels of emotional care than parenting. While other sandwich generation women felt that caregiving involved assisting their children with tasks they could not complete on their own.

## 1.5 Role transitions and variations in caregiving

All of the sandwich generation women discussed the highs and lows of their caregiving roles. This emerged either through the transitions within their caregiving roles or the differences between caregiving roles. The majority of the sandwich generation women had experienced changes or transitions in their caregiving roles. Several mothers' roles changed when their parents or in-laws health changed quickly or without warning.

She's 85, she broke her hip, she realized she couldn't stay in her house because, the house was, was multilevel.... Um, she was completely dependent on other people for everything.... And, she aged.... In 6 months, she aged 5 years.... I think I was a daughter till then. ~ Meredith

It was pretty much overnight. When she found out that she, when um, she started forgetting, we had to start making lists up for her, up, up how to live, how to boil water, what pills to take. And we used to leave, we would leave notes. But then we realized, that, she wasn't able to cope with that and then ended up having to have full time care. Um, right, like almost immediately actually. It, was, happened, within, within [pause] I would say 48 hours. We saw that decline, that immediate decline. ~ **Robin** 

Other sandwich generation women experienced transitions in their caregiving roles when

their parents or in-laws health started to decline further.

But I would say in the last [pause] maybe 3 years, it's gotten progressively worse.... In terms of they're ability to come and go, and to be independent. And so, we've taken on a greater role, in terms of helping them, with their day-to-day lives. ~ Naomi

Umm, my husband and I made a move, from our former neighbourhood to live across the street, from them. When we felt that they were [pause] in greater need to, um, to have us, you know, across the street. So, um, and then, after my mother's, um, disease was diagnosed, it became a, a completely different role.... So the caregiving role just kept on evolving as my mother's disease progressed. To the stage where, um, prior to him arranging for a live-in caregiver, um, I would go over and help with toileting, and uh, try to help feed. ~ Diane

So, my role became increasingly, um, heavier. So I was young, I was 21 when my father passed away.... My responsibilities really changed because.... Her being a widow, um and never managing anything.... So she um, she at that point, we had to get very involved, because she really did not ever deal with accountants, and lawyers because my dad used to take care of all of that.... So uh, really, essentially became more of a caregiver at the age of 21 when my dad passed away. And then as the years progressed I became more and more as she became, um, less mobile. ~ Melanie

Kate's caregiving role was unexpectedly initiated and then expanded on two occasions.

Initially she became a caregiver to her mother when her father passed away unexpectedly.

Then years later, her caregiving demands increased when she needed to take care of her in-

laws.

So it was very immediate, we lived with [my mother] for the first two months or three months that we could... to make sure we were right there. And then, we moved to actually be closer to the house... we moved to be closer, because we were there so much. ~ Kate

So in the span of two short months, we moved, [my in-laws] from being very independent ... to being living in assistance.... And he's still, is still struggling. I'm not sure if we've got the right end point for him yet. But definitely it's the pull now of [James]'s parents, because it's just so immediate, they're so far [away from our home], there's so many things to be done to transfer somebody's life.... And to shut down somebody's life financially, transportation, you name it. Everything had to be shifted. ~ Kate

Meredith's caregiving role had transitioned from higher levels of care with more time constraints, to lower levels of care with less time constraints, due to her mother's recovery from her broken hip and being newly retired. Um [pause] I think my role as caregiver, has shifted [pause] this fall, because I am now at home. And I have more time. And I look back and I'm not sure how I was coping, when I was working full time.... Trying to do all those caregiving jobs. ~ Meredith

In addition, most of the sandwich generation women conveyed that their caregiving situations were variable and required different levels of care. Kate compared the differences between her

own care recipients, recognizing their varied needs.

Uh, it's so multifaceted, and it depends on who the individual is, as well. Right, so to me what caregiving is, is finding out what that person's looking for. So some people for example, my mom right now, is looking for very tangible support, she needs help with her computer, she needs help with the pool. Our caregiving for her, is very much giving our resources to help her with what she needs. Um, [James]'s parents on the other hand, are going through a different transition, and they require a whole different type of care, which is I, very acute right now, very immediate.... So yeah, it's very diverse, it's very dynamic, and again it, it morphs in terms of whether it's chronic caregiving.... Whereas some people are in a very acute form, where you have to really step it up and give much more caregiving at that time. ~ Kate

Other mothers felt that the intensity of their caregiving roles varied depending on the help

required by the care recipients.

Umm [long pause] I mean there are different levels of caregiving obviously.... Um, um, I have [pause] I mean the most severe is you know, is being there for your parent, being there for whoever is caregiving, at, at all times. ~ Joanne

*Umm caregiving [pause] I guess could go from one extreme to another, uh one to like a very low level of care, of care to a very high level of, of having someone dependent on you.* ~ **Robin** 

As well, Lyla was a caregiver at two separate times in her life: once for her mother, and later

on for her father in-law. On the first occasion she revealed that her children were younger

and her mother required higher levels of care, which made the care experience more

challenging.

But my care for [my father in-law] wasn't as intense as my mother.... For me to take my mother in-law when she could and stuff.... Yeah it wasn't as intense. With my mother it

was different, cause my kids were younger. And more needy and uh and there was more care to be done with her.  $\sim$  Lyla

Melanie revealed that caregiving varied, as different care tasks were involved between caregiving roles.

So many, I mean, there's many different roles of caregiving.... Umm, well it's so, I mean caregiving is such a broad, a broad word. ~ Melanie

The majority of the mothers described the ways their roles had morphed throughout their caregiving experiences. The sandwich generation women specifically noted the health needs (e.g. immediate needs vs needs becoming more advanced) of their parents and in-laws, and the number of individuals that required care as factors that affected role transition. In addition, the mothers described that different caregiving roles involved varying levels of care. The sandwich generation women revealed that their caregiving roles were sometimes chronic or acute and involved different tasks and hours of care. This further emphasized that although the caregivers' roles continued to increase, their caregiving roles still varied from one another.

#### 2. Caregiving: It is a balancing act

All of the sandwich generation women revealed that their multigenerational caregiving roles were like balancing acts. Between all of their responsibilities as mothers, caregivers, work and other duties, they were often pulled in many directions. In addition the mothers revealed that they expected this balancing act to change in the future. The three subthemes, a) Juggling: Keeping all the balls in the air; b) Tug-of-war; and c) Shifting the equation will be discussed in turn.

#### 2.1 Juggling: Keeping all the balls in the air

The majority of the mothers felt that their sandwich generation caregiving roles consisted of a lot of juggling between their caregiving tasks and care recipients. The sandwich generation

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women had to plan effectively to ensure that all their tasks were completed successfully. Kate

described that specific events were challenging when a lot of juggling was involved.

We walk into the apartment and [James]'s mom just needs so much emotional support and things to do. And then [Jerry] himself, is just very removed because he's had this stroke, so he's not communicating well, he's not moving well and there's just this whole pile of energy in this whole, this little, one bedroom new apartment. So it just doesn't work that well. So even [James] said, "I don't think I'll bring the kids up here as much, any, anymore, I'll just keep them in the car, I don't know." ~ Kate

Other mothers conveyed that they often had to juggle between their varying responsibilities

over a specified period of time.

But when you're stretched that thinly, umm you know, you are juggling, home, career, marriage, kids, you know grandparents etc.... It's pretty difficult to do, anything well.... So you settle for doing the best that you can at the time. ~ Meredith

So I have to juggle.... Like okay I need to make sure she's at her appointment, she's okay. But I still need to cook and be home, to get my, you know I'm having a dinner party. And then the following day when she has her MRI, I have parent teacher interviews all morning at [my daughters school]. But I have to have her at 3 o'clock, at [the hospital].... I look at my days and I'm like, "okay all mornings dedicated to my children. All afternoon is dedicated to my mother.... So it's hard. It's a tough juggle. ~ Melanie

So with carpool, and you know I had to juggle with carpool and dinners. And if my mother, cause my mother was very unstable for about 2 years. You know, I had to juggle taking her to appointments and dialysis, she did you know, she did three times a week for like 6 hours a day.... So I had to organize wheel-trans. Sometimes she couldn't get that, because she was too sick. So it was all, balancing. ~ Lyla

The mothers used careful planning and organization to make their juggling less challenging.

Um, there are times, uh where there are conflicts, yes. Uh and eh, and I'm not able to be there, those, slim occasions where I can't, be with my parents, because I have a, an event that might be very overwhelming of my time. Uh, and if I actually want to get some sleep, then, uh, I actually, um I will give my parents advanced notice or I'll cook in advance, and um, make it, um make sure there's food or make sure they're covered somehow, um for that week.... And I just sort of you know, will call my parents as I need to, to make sure everything is fine. But I may not see them. ~ Joanne

... because um my mother in-law's needs, became more um, she, she needed us more as her health uh, declined. So I would try to really make sure that I was there for my youngest daughter. Uhh to be able to, be there after school for her. To take, be there in the morning for her.... So we tried to keep to things as normal as possible for her. So that, there, the disruption wasn't there for her. And that was, with a lot of scheduling, with some help from friends as well, to help us out with, carpooling and to get her to dance. And [pause] and getting that support from, from like outside the family. ~ **Robin** 

The sandwich generation women described the juggling between their caregiving roles and other responsibilities. Various organizational strategies and outside sources/support were used to help juggle caregiving. It was important to note that although the mothers had to deal with a lot of responsibilities at once, they perceived themselves to be successful at completing these tasks.

# 2.2 Tug-of-war

The majority of the mothers perceived that their caregiving roles were like a tug-of-war, as they felt they were being pulled in multiple directions by their care recipients and other obligations. At times the sandwich generation women felt overwhelmed by all of their responsibilities. Some of the mothers described their busy schedules and the challenges they faced when trying to incorporate all of their responsibilities.

The kids are at three different schools, three different interests and a husband. Cook, clean, well don't clean the house, but cook, umm and work as well. To contribute to the house. Then you have to also, you know care for your parents.... It's an overload, it's an overload some days. ~ Joanne

... and even today, for example, I'm looking at my day, and I've got my ... responsibilities, plus I'm doing a lot of, uh, uh talking out in the community, and just when I think it's done at quarter to 7, it's meet the teacher night so I will be going to meet the teacher at 7 o'clock at night... so you don't get to come back, you now have to look at their schedule and incorporate that somehow too.... So, that's the way you have to get through it, but you can't not shift something and you have to decide, where are you going to take it from, cause we all have the same amount of time in the day. ~ Kate

Other sandwich generation women had felt a tug-of-war between the time spent with their

care recipients and immediate family.

It was very difficult, because you know I think guilt was the main thing for me. Cause when you're with your parent, you're guilty that you are not home with your kids.... And when you're with your kids, you [are] guilty that you are not with the parent. So guilt was a big thing for me.  $\sim$  Lyla

... it's like a check and balance thing, you just have to always, you know [pause] kind of know that you're doing what's right, but not at the expense of [pause] you know your own family and kids, right. They always have to be the priority. But, you also always want to do what's right. You know, so, you have to sort of balance that. ~ Naomi

But sometimes I think the exposure [of Alzheimer's Disease] is too great [for my daughter]. I can't visit [my mother] as a result as often. I would have to hire a babysitter.... And then, go up there and if it's, and she wants to see me on the weekend, because I work full-time during the week. So, it's been very challenging. ~ Diane

As well, some of the sandwich generation women had experienced tug-of-wars with their

mothers while dealing with their health conditions.

Um, and that's, that's the biggest issue that we have, is, we don't want her to be in pain. So a lot of our arguing [pause] that goes on between us. Is for me at the age of 83, I feel, why should she be in any pain at all. Up the morphine, I'm taking care of your financials. We take you shopping. We can do as much as we can, why should you have to suffer? But she feels, "no. I don't want to take more stuff for my pain. I don't like the way I feel.".... So it's a battle, there's, it's a very hard, um there is no, there is no line that makes it right. ~ Melanie

Right now we realize it's a lot of mental illness... that's brought on a lot of vomiting, she vomits a lot. Everyday... Everyday. And we realize that there's nothing wrong with her, because we, done all the tests.... You know she's 82 years old.... So, we just you know, we just let her do what makes her feel good at this point.... We're not challenging her anymore. We did a lot. Because we couldn't, you know "you're not listening." But now it's like, okay that makes her feel good, let it be. ~ Elyse

Most of the sandwich generation women described experiencing a tug-of-war in their caregiving roles. The mothers revealed that lack of time was a factor. Specifically they had difficulty dividing their time between their family members and care recipients' health

issues. It is important to recognize that the tug-of-war posed a greater challenge than the previously described juggling act. The tug-of-war situations imposed greater time demands on the mothers, which left them with less time available for other commitments.

## 2.3 Shifting the equation

The majority of the mothers felt that their roles and responsibilities for their children and care recipients would change in the future. The mothers expressed that the balancing act would evolve to one that allowed for more dedicated time to their spouses and their care recipients, as their children gained more independence and eventually would no longer live at home.

... I mean my daughter will be away so she'll be far more independent to a certain degree.... And so it's a, it's a very different type of ... involvement. As they get older. Yeah less, less involvement with my kids, probably more with my mother over the years. ~ Melanie

*Um, as my children become more independent, well they are fairly independent, but as, they, grow older and they become more independent, of course I won't have that as much, for me to be, uh, to be helping them out so much.*  $\sim$  **Robin** 

Kate and Naomi looked forward to the days when spending more time with their spouses would

be possible.

... again, and we are having like a big discussion about ... if the time comes back to him, how he'll want to use that time? .... And taking more control in personal reflection about, when this time comes back to us, what will we do with it? .... And I don't think either one of us will give it away so easily again. ~ **Kate** 

But, I, I, hope it will free up some time to spend more quality time with my husband, to travel a little more.... To do you know things that, you, you really can't do until then.... Until you don't have all those responsibilities. ~ Naomi

However, all of the mothers were cognizant of the fact that their roles were dependent on the

future, as they would have to renegotiate their time commitments.

I think it will get worse .... I think, because I'll, right now I'm dealing currently, with mostly one parent. And, and my sister. I think, as soon as my father starts to go downhill,

it'll, it'll get more [pause] it'll get more, problematic.... It'll be more time consuming to the point, where, I, I dunno, I'll be devoting more hours during the week.... So, it'll be a lot more constraints on me. The older he gets and the older [my sister] gets, especially. ~ Joanne

She's 84, her pain is increasing. She's going to become less and and less mobile.... Um, and it will become, it will become even harder.... That whole thing. So it will absolutely, it's going to get harder unfortunately till she passes away. ~ Melanie

I think it's probably going to increase. It's gonna have to increase, because as my mother gets sicker, and more immobile, and more, it's gonna.... It's going to be hard but we'll, we will take the challenge whatever it is. ~ Elyse

Consequently, as the sandwich generation women's demands change, they believe they would be able to include themselves within the balancing act. Further, as the mothers' children become more independent, more time could be spent with their spouses. However, the sandwich generation women may have to continue balancing the increasing demands of their care recipients. Therefore the equation may transform to one that focuses on their personal relationships and more on their parents and in-laws, rather than the needs of their children.

### 3. Stormy seas: It is not always sunshine and rainbows

All of the sandwich generation women had experienced negative costs associated with their multigenerational caregiving roles. The costs were non-financial in nature and created challenges in the lives of the mothers. The following five subthemes emerged: a) Decreased time with immediate family; b) My social life is closed; c) Resentment and frustrations; d) Health of the caregiver: What about my needs? and e) When the going gets tough.

#### **3.1 Decreased time with immediate family**

Most of the sandwich generation women conveyed that they spent less time with their families because they were caring for their parents or in-laws. Additionally some of the mothers

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specifically expressed they were not able to spend quality time with their spouses due to their

caregiving demands

It was hard. Because I would be, uh, I had to leave my husband really to take care of my family.... Because my mother needed me, whether she was in the hospital or we visit at night.... Um, for, that period of time. The focus was get your job done, and then [pause] go to your mom. ~ Meredith

But [my care recipients are] overbearing, right. And so, because they really don't have a whole lot of other things to think about, at this point in their life.... So that can become a little bit stressful. You know, on a, on a couple. Because really you don't even, have a lot of your own time.... You know, as a married couple, with all these responsibilities. ~ Naomi

The sandwich generation women also commented specifically about the decreased amounts

of time with their children, due to their caregiving roles. Diane's daughter was a toddler

when her mother was diagnosed with Alzheimer's Disease.

... my, my daughter didn't have my full attention during that time.... She won't [remember]. It's more, It's more lost time that I'm aware of.  $\sim$  Diane

Other mothers felt they had lost time with their children during periods when their caregiving

responsibilities were more demanding.

*Especially, when my mother was um [was] hospitalized... for a month.... So I was pretty much an absentee mom.... And between my sister and I, we were there, all the time. We were literally there till we put her into bed at night.* ~ Melanie

So, so they got, they got first hand, like a lot of times, "Mom, you're not home." .... You know, if I was with my father. Um, "where's dinner?" "I'm sorry" you know "I have to be with" you know. So yeah, in a sense, in that sense it did effect them a little bit. ~ Elyse

Lyla's children were not aware of her absence, because they were very young, when her

mother required a lot of her time. Lyla tried to compensate for these times so her lack of

presence was not felt.

They never actually said, "why are you gone so much?".... And I always.... Arranged stuff.... I always arranged play dates for them, so they didn't miss me so much.... I always

had a nanny, here .... So and she was young my nanny, so she was always involved with them. So, I don't think they really lacked anything.  $\sim$  Lyla

Due to the increased time required by their care recipients, the mothers revealed that they spent less time with their spouses and children. This was often in times of medical emergencies or when their care recipients required higher levels of care.

# 3.2 My social life is closed

Most of the sandwich generation women conveyed that their caregiving roles influenced their social lives. The mothers described how the time consuming task of providing care to their parents or in-laws resulted in less time being spent with their friends or the children's friends.

There are social implications. We haven't been able to make plans with many people.... Because we don't really know what's going to happen with [my husband's] family. Um [pause] the kids in terms, of sometimes we'll say, "you know what, we've got enough energy for two of you, we just really don't want to include any friends over right now, were just, we don't have it." ~ Kate

You know I, I've, my social life has become very closed. So, I just, we have to stay close to my dad. I see it as it kind of a positive. But, that's one thing that's kind have been very shut down. Social life.  $\sim$  Diane

... you have to be on-call, so you just can't have your day to yourself.... Anymore.... Or a day that I feel like doing something for myself. I want to go out for lunch with a friend.... I want, I want to go to a mall. I want to have just like a carefree day. ~ Naomi

As well, the mothers noted that their social lives were affected by their demanding caregiving

roles which often left them too tired to socialize. Melanie experienced occasions where she

would cancel plans with her friends, due to long frustrating days with her mother.

... I had her down at her neurologist for several hours. That night I had plans with, four girlfriends to go for dinner. And, um, after being at the neurologist and then the whole way home in the car, listening to her complain about her caregiver, complain about um, something that my other niece had done.... By the time I brought her home, it was 5:30.... Traffic was terrible. It took us an hour to get home from [the city] to get her back [home]. And as soon as I got home, um, I called my girlfriend. My head was pounding

and I called my girlfriends and I said, "sorry I cannot, meet you tonight. I'm just so drained" that I was not in the mood.... To even go out and see people. I stayed home. ~ Melanie

Similar to Melanie, Lyla often felt too exhausted to socialize with her friends. Her caregiving

role also influenced her demeanour when with her friends.

Sometimes I was just too tired to even go out. Plus my demeanour was low at times and didn't feel much like socializing when my mother was going through a tough time.  $\sim$  Lyla

Meredith found that when she was employed in addition to her caregiving responsibilities,

she had decreased time to be social. She reflected on her social life with respect to her prior

obligations.

I would say that for a short period of time (January - September of this year), my social life was definitely impacted. Between caring for my family, and my mother and holding down a full-time job along with coaching, I had little time for socializing. Now that I am retired, I have been able to devote more time to rekindling friendships and saying yes to invitations. ~ Meredith

The sandwich generation women felt that their social lives were affected by their caregiving roles. The mothers conveyed that their care recipients' needs took precedence over their time with friends. Additionally the time spent with their care recipients often caused them to cancel or alter their scheduled plans. Therefore, as a result the mothers' social lives were often closed or non-existent due to their caregiving roles.

## 3.3 Resentment and frustrations

All of the mothers described resentment and frustration within their caregiving roles. These feelings resulted from the demands placed on their time or their views on gender roles in caregiving. Some of the sandwich generation women felt that time constraints were placed on the their lives, which caused feelings of frustration.

Some days I feel sorry for myself, sometimes I think, "when did I become this... cliché?" .... And, so, sometimes I get very frustrated because you see other people doing some real freedom [pause] laden things that look just so interesting and [James] and I don't have that opportunity right now.... It's just the days where you can't find, the perspective and there are some days like that where you just, so frustrated with how hard everything is. ~ Kate

As well, some of the mothers noted that they were overwhelmed by their caregiving roles.

... sometimes you know I have my days, where I resent, you know.... Of dealing with everything.... I feel like, I'm you know, we're filling a role, but it's also, I feel sometimes a little stifling.... Their different personalities, their stronger personalities.... I have to have them in my home.... They all mean well, but they all have an opinion.... And so you know, sometimes it can be a little bit frustrating. And hard to deal with. ~ Naomi

But there are days where I think oh my gosh, I just can't do this anymore. So I do have my moments.... Where I, I, I really feel like I'm being pulled at both ends. ~ Melanie

There are times where I get really frustrated.... That I, you know, I get frustrated and get mad [at my mother].... Umm, well I'm you know, I'm going through my own things, so yeah I have a, there are days where I you know, I just, you know I left, I just want to give up and say, "I can't take care of mom anymore.".... It's, it's frustrating and um that's when my sister will say, "you know what, I'll take over, don't worry, I'll take over." It's been hard to juggle both. ~ Elyse

Lyla experienced many challenges while caring for her mother. When given medical

instructions, her mother would do the opposite, which caused Lyla to become frustrated.

And like the thing with my mother, the more you told her not to have something, the more she ate it. So bananas are very bad if you have kidney problems, because they are very high in potassium.... She never ate bananas, so as soon as she was told she couldn't. She would eat bananas and end up in the hospital.... So that was frustrating too.... Because she would be very uh [pause] very like, wouldn't listen to anything.... So she would put herself back in the hospital, due to her diet. So that frustrated me too. ~ Lyla

Melanie had been providing care to her mother for many years and felt that she was not able to receive any support from her mother in the realm of childcare. This led her to feel some resentment towards her mother and her caregiving role, as she did not receive any reciprocal care. ... my mother, never drove and um, was always you know lived with all this unfortunately, unfortunate health issues. She was never a grandmother to my children or helped me.... I feel sort of um, you know ripped off in a way, I guess I would say that I would say, is that I saw how all my mother friends', mothers would take the babies to the little groups or do things or help pick them up after school if they couldn't.... So I never had the support of, the way I think a mother should be.... She was not able to be there, she was always in pain. So she could not come and babysit my children. She could not lift my children up when they were babies.... So um, I, I've never had that type of help because, I was always worried about my mother. ~ Melanie

Diane experienced many frustrations as she felt that she received a lack of information from health care providers on how to physically care for her mother. She was forced to teach herself through trial and error, or after hurting herself while attempting to transfer her mother.

On the other hand, I had no education. When I was toileting, you know, no one told me things, like um, make sure you have uh, sterol latex gloves or, or what kind of, diapers are easy to get up.... I did not have that inclination... provided to me, and, so [pause] there's a kind of, a lack of information I think, that's given to caregivers, where like just practical stuff.... That would make it easier.... Why isn't there a package of information on how to set up your life so you can get, the minimum done across everything in a period like that? .... Safety. There's nothing, when I think about it, there was nothing like that. ~ Diane

Some of sandwich generation women expressed that caregiving was still widely considered a woman's job, and not a role frequently taken on by men. This was demonstrated by the gender stereotypes that existed in their families, namely the natural nurturing traits more often found in women.

They, it's definitely more of a women thing though, I think. Like I think if, even if my mother in-law were ill, she lives [out of town], um she's got two sons. They would never care give for her. Like it would be my responsibility.... I know that, that, I'd have to move her here and take care of her here, because she has nobody. There'd be no one to take care of her.... Like I said, it's very um, I think caregiving roles are definitely more of a women oriented thing than a man oriented thing overall. ~ Melanie

Um, I guess because I am female. [pause] I hate to say that, but that's the truth.... Um yeah, sorta expected it in all honesty. Uh, I mean because I have 3 brothers and I know I am the only girl. And really it's a, it was a, I grew up in a very male dominant, um, family. Umm yeah, it was expec- yeah I would say it was definitely expected. ~ Robin

But my mother moved here from [the U.K.] and uh, you know I have an older brother, but you know sometimes guys aren't as involved as the girls are. So I felt compelled, to be, you know take care of her, because she took care of me my whole life.... I mean I hope, I have three boys, what chance do I have at anyone changing my depends.... That's why I'm very nice to my nieces. ~ Lyla

Although Kate's husband was also highly involved in their caregiving situation, she felt that

he had not coped as well, because women were used to making sacrifices in their lives.

... women are much better at it than men. So for example the sacrifices that I've made for my mom, came much more easy here, then the sacrifices that [James] is making for his parents.... Whereas I keep saying to him, women are so much used, more familiar with making these sacrifices when they are pregnant.... When they have young children, we are much more willing to step aside and feel it's part of our responsibility to nurture. ~ Kate

Frustration and resentment were experienced by all of the mothers. This frustration and resentment was either due to time constraints placed on the sandwich generation women, feeling overwhelmed by their caregiving roles or frustrations with the lack of information provided to them concerning caregiving. In addition, almost half of the mothers conveyed that women were expected to take on caregiving roles. They described that females were considered better nurturers and were used to making sacrifices in their lives to care for others versus men. Therefore, the mothers experienced frustrations and resentments in their roles, because of their care recipients' and the expectations placed on them to be caregivers by virtue of the fact that they were women.

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#### 3.4 Health of the caregiver: What about my needs?

In the interviews, all of mothers revealed that their health was affected in some manner as a result of their caregiving roles, as opposed to the background questionnaires information presented in Table B (see Appendix F). The sandwich generation women attributed their compromised health due to the decreased amount of time they had, as most of their time was dedicated to their care recipients and/or children. For example, most of the sandwich generation women felt their sleep was influenced by their caregiving roles. Further, the mothers with chronic conditions commented that they often felt exhausted, making it difficult to complete their caregiving tasks.

... I have a low thyroid which happened after preg-, I was pregnant with my son. So that's been an issue, because when you have low thyroid, that often that is very low energy, um you sort of, you sort of feel foggy.... So sometimes I will go months and months of being soo drained and soo exhausted.... So when I'm not feeling well, and I know that day I have to spend half the day with my mother, and then half the day running to do something with my children or you know going to buy stuff for projects.... You know, um, it definitely exhausts me. ~ Melanie

... I think that's where [my husband and I's] sleeping patterns are really bad right now.... Ands that's, and so we're feeling 24 hours right now. There is no control of your schedule.... You don't sleep when you feel like sleeping, you don't eat when you feel like eating. You are, managed by someone else's schedule. ~ Kate

Some of the mothers revealed that they put the health of their children before their own

#### health.

I'm for sure more tired. I have not had, I've al-, you know I wanted to maintain, some, um, consistent [pause] level of physical activity on a weekly basis.... And I haven't been able to because of all the varied responsibilities. Um, so I've sorta, okay you gotta take something out of the equation to fit everything into a day.... And it's always the stuff that relates to me that I take out. ~ Naomi

I'm more concerned with my children's health than I am, or my parent's health than I am than with myself. Um I don't run to the doctor if I've got [pause] a cold or something like that.... I'm not rushing to go see anybody.... Um, I mean, I do, there's some maintenance,

but uh yeah, I haven't, I'm not running to do all the tests and things like that. So, for myself and I should. ~ Joanne

As well, many of the sandwich generation women had felt they experienced decreased levels of physical activity, because of their demanding caregiving roles, either with their current or previous caregiving roles.

... I have no time to do exercise and I'm supposed to be.... So, um, that's something that I have, I have to mind the time for. Because it's not staying physically in shape, it's actually rehabilitation, for my, what my disease [multiple sclerosis] has done to me. So, I have to, I have to do that. I have to find a space to do that. And currently, I don't have the time.  $\sim$  **Diane** 

Unfortunately I find I'm always making excuses not to exercise. Which I think, also plays a big role on my overall health, because I don't exercise. Um, so I think that's, I keep trying to incorporate that but I find as I do week by week, believe it or not. Between my family and my mother, I find I don't have the time between all her appointments.... I'm not um, you know between my mom, the kids, being at home. I find my day is filled.... So physical activity hasn't really come into it. ~ Melanie

Several of the mothers believed that their nutrition was compromised as well, as they would

often skip meals or choose food choices that were convenient, rather than healthy.

But, I sure do feel a little run down over that. Cause [pause] sleep is the first to go, and then I wasn't eating properly. Because if I had spare time, rather than eat, I would go visit my mother.... And um, watch her eat maybe.... And I don't, I don't. I tend to forget to eat.... Um, I would skip meals.... And then realize, "okay, I need." ~ Meredith

I definitely did not eat properly. I would miss, uh, miss meals and, and then I would get home late at night. I wouldn't feel like eating. So yeah, definitely felt like nutrition wasn't my priority. ~ Lyla

... I think because I wasn't at home as much, I don't think I, we sort of, um, went out a lot to eat actually. Um, so we were eating in restaurants more. So I guess it is sorta hard to control what's going into [food] aside from making healthier choices. ~ Robin

The majority of the sandwich generation women felt that caregiving also affected their

mental health and their stress levels.

... I found that I was very, deflated and almost um, I wouldn't say depressed but just really aware of where we're going and there wasn't going to be an end to this [caregiving], anytime soon. So I had a really hard time finding joy, cause I was really worried about, how this, eminent change was going to happen.... So I found myself very weepy. And I was, I'm not a weepy person. But it was almost feeling like this, despair in terms of, "how do we get this to go?" ~ Kate

Not health as in, I mean mental state maybe.... Um, but more anxious definitely, because you know some days she can be good and the next day I'd be rushing her to hospital. I mean one day we went over there, one morning. I always call my mother in the morning, and one morning I called her. Very early and she wasn't answering, and I was scared to go there. ~ Lyla

*I definitely feel a lot more stressed. Umm so-, something [no one], anyone asks for it, you know, to see their parents go through that. Um, definitely a lot more stressful.* ~ **Joanne** 

In addition most of the mothers described the obstacles that prevented them from taking care

of their health.

Obstacles would be the schedule of our kids and the schedule of our parents. And also just the energy level that we have.... It's not there right now.... We are both deflated, and I have to, and I keep having to remind [my husband] of that. ~ Kate

It's just the time. And, and then maybe it's my choice of what to do, when I do have the time.... And so, it's, time or, motivation to do whatever. Uh we have a stationary bike in the basement. I said in my retirement, I was going to cycle everyday for at least 20 minutes long. Haven't gotten on that one yet. But I will. And I think it's just, right now, the dust is settling. ~ Meredith

Is just, being on-call all the time.... You know I find that you know, I find that like stressful you know, and so um, you know I have to make split second decisions. "Okay so she needs her groceries, I guess I can wait on exercising. I'll get it in tonight, or I'll get it in later." And then later comes and I'm, either too tired, and I just don't feel motivated.... Or something else came up. ~ Naomi

Health was believed to be compromised to some extent in all of the sandwich generation

women. Time and lack of motivation were the main obstacles in taking care of their own

health. Sleep, physical activity, nutrition, mental health and stress were the primary areas of

health perceived to be influenced by caregiving. As well, the mothers noted that they put the health of their care recipients and children before their own health.

# 3.5 When the going gets tough

In response to the difficulties associated with caregiving, all of the mothers used a variety of coping mechanism to help them through challenging or stressful times. For example, the sandwich generation women turned to their friends for support, as one of the means in which to cope with their caregiving responsibilities.

Um, I have some good friends that are there as sounding boards.... Talking to a third party. I have a couple of girlfriends who are good listeners, and I would do that for them too. And, uh, one lives pretty close, so I could just hop in the car and go visit and so. ~ Meredith

So, no I, I actually my, my girlfriends have been a huge support for me. So, they've checked in with me.... And, they'll do things, like they'll come and, pick me up with my daughter and we'll go out and we'll just like hang out. They'll just provide great support that way. ~ Diane

And, and so yeah, I have the support of some of my friends, that are going through similar situations.... So, I'm, in, I'm not alone in this, that's how I feel. So when I'm frustrated, I can you know talk about it, and we can. And then I feel okay about it after. ~ Elyse

A few of the mothers revealed that they turned to their spouses or family members to help

them cope with their caregiving roles.

We are very good at saying, "what could I do to make your day better?" And we say that to each other each time, "is there a time where we can meet or do anything?" And it is, it's just careful planning, being aware of it and so, I feel like I am little bit better mentally right now [than my husband] and physically in terms of my health. ~ Kate

Um [pause] well listen, you know with, with respect to my mother, you know, I do talk to my sisters.... We do share, you know the responsibility of figuring her out, and making sure we're on the right track with keeping her healthy and well. Um, with my mother inlaw, we do a, [Jay] has a brother and a sister in-law here too. So we, you know, we try to get them involved as much as we can, even though, we seem to be the ones that take [the] lions share of the responsibility. ~ Naomi

As well, some of the mothers found escapes to deal with their sandwich generation

caregiving roles, such as not calling their care recipients, blocking out their role or traveling.

I do [pause] um it's a very stressful, time with my mother, uh specifically. And my sister as well. So, I try to, give myself some breathing time, alone time, where I just shut myself off from work, kids, uh and my family.... Just for my own sanity. So, uh and that could just be you know reading a book, in my room. Um, and that's about it, I mean, that's pretty much what I do.... Uh, whether I am in the car, like I could just shut things from my brain, because you have to. ~ Joanne

But, like I said, the only way I shut off is sometimes I don't call [my mother]. And I'll find if I don't speak to her for a day, I can sorta regroup myself. But I know when I do call the next day. I get an earful.... Like there are some days, at the end of the day, I go "oh my god, how did I make it through this day?" Um, so I think you know, other than that and my other crutch is having a glass a wine. So that's my other crutch. I will come home at the end of my day, and when I prepare dinner or with dinner I have my glass of wine. So that's sort of my, okay I can, sort of release it a bit. ~ Melanie

I went away a couple of times. I mean that for me, traveling is a big stress reliever. That's what I do.... I've always handled everything in my life that way. Like I'll just rejuvenate somewhere else you know.... If I can do it.  $\sim$  Lyla

The sandwich generation women also used physical activity as a way to relieve stress related

to their caregiving roles.

If it's really high stress, than I would go and workout somewhere. I like that. I like pushing my body to, exhaustion.... So, um, if, if it's up to me and I'm the only one, I would go and do something physical. ~ Meredith

... whether you are caregiving or not, I always feel that exercise alleviates that stress. It always, it gives you that time for yourself, um [pause], you know, to take a breather, uh and actually [pause] exert yourself a little bit and makes you feel good. ~ Robin

Although the sandwich generation women did not necessarily all use the same strategies,

they all used a number of methods to help them cope with their sandwich generation

caregiving roles. The mothers used their friends and family as support systems, found escapes from their roles and used physical activity to deal with their caregiving roles.

## 4. Silver linings amidst the turmoil

Although all of the mothers reflected on the negative effects of their caregiving roles, all the sandwich generation women were able to identify the silver linings associated with their caregiving roles. The sandwich generation women's insights led to the development of four subthemes: (a) I am thankful for what I have; (b) Finding joy in the journey; (c) It is a learning experience; and (d) Growth in children. Each will be discussed in turn.

## 4.1 I am thankful for what I have

All of the mothers expressed a sense of gratitude in their caregiving roles. The sandwich generation women described aspects of their lives that they were thankful for in light of their challenging multigenerational caregiving roles. Some of the sandwich generation women were grateful that their husbands were supportive of their caregiving roles.

And [Jeffrey] was great, because he, did the meals, he did the kids homework, etc. And I was lucky that I had a partner who was able to do that.... Um, but, in periods of crisis [long pause] you [pause] if you have somebody to look after one end or the other, you count on them to do that. ~ Meredith

Um, sometimes with the driving, umm uh, giving me relief in other areas so I that, I can spend time with my parents, when I need to.... Um, so if I can't pick up the children, then he'll go pick up the children if I have, if that's what it is. So it's kinda relief in other ways.... As opposed to um, uh, helping out my parents per se, but allowing me to be able to go to my parents when I need to. ~ Joanne

As well, other sandwich generation women were appreciative of their employment or

financial circumstances, which enabled them to provide care.

...so I stopped working in August, because I just could not manage, doing everything, and still looking after kids and doing all of that stuff. So I took that commitment off of my plate .... That would have been the only way that I could do it and I thought about, "what

would someone do if this happened and they had, they had to be at their office, 9 to 5? This would be really tough to manage this.".... So I'm very, very grateful for that. ~ Kate

...I'm fortunate enough that [pause] certain financial um, costs like caregiving are supported and paid for. If they hadn't been, that would have been my only option. To take an unpaid leave, to, to take care of her. And I thought, how, how do families cope with this burden? How would someone in my situation, with a health condition, and a child, who is a chief breadwinner, be able to undertake something as large as caregiving? .... So in some ways I feel fortunate. ~ Diane

I always remind myself, you know like, it's okay. Look at other people that have to, you know, get up and go to work, and do all this, and you know so, really I should consider myself lucky. That thank god that my husband was in a position to say, "you know what, we can do without your income, I'd rather you focus on the house, the kids, and whatever..." .... So, really that, that in itself is a big blessing. And I'm, I'm so grateful for that. ~ Naomi

Some of the mothers were appreciative that their caregiving roles resulted in them becoming

closer with their siblings or in-laws.

I think it brought us all together actually umm. We're a very close family anyway. It's my, my husband and his uh, my husband's family, his brother, he has a brother and a sister. Um they are very close to begin with. But we, I really, myself personally, just from an outside, an outside looking in, I felt that they became a lot closer, um and really underbegan to understand each other a lot more.  $\sim$  **Robin** 

The, the, the year that we spent, my sister, the year of the mourning... my father. Every Sunday we would go to the cemetery.... Then we would stand around, have a coffee, talk. You know, winter, summer, and it was a time for us, us to bond, because we don't see each other all the time.... So it was, it was great.  $\sim$  Elyse

All of the sandwich generation women conveyed feelings of gratitude within their caregiving

roles. The mothers were fortunate for their supportive husbands, work or financial situations

and the closeness developed with their family members, as a result of their caregiving roles.

# 4.2 Finding joy in the journey

The majority of the mothers were able to find joy in their sandwich generation caregiving roles. Some of the sandwich generation women were able to find pleasure in feeling needed by their care recipients.

And that's what I'm trying to keep in my mind as we go through this stage with [James]'s parents right now, is to walk through it with grace. And, make a difference in [James]'s mom's day. Make a difference in [James]'s dad's day and remember just to be compassionate. And caring.... Everyone needs to be needed, and I'm glad I could provide that role for him. ~ Kate

I felt apart from the guilt that I had, that I did as much as I could and uh you know I was very, um I was very happy. I didn't feel any, you know when my mother passed away, I was there and um [pause] and I felt like I was very, I did a lot, as much as I could.... And um [pause] you know I guess, I, I get enjoyment out of helping people. ~ Lyla

As well, some of the mothers conveyed they found joy in caring for their parents, since their

parents cared for them growing up.

You have a responsibility to the older generation and to the younger generation, you know. Um, just the way they took care of us. It's now our turn to take care of them.... Um, but the, the gratification of knowing, doing something, that you're doing what's right. ~ Naomi

Definitely fulfilling, there is no question, umm, for my children especially. Umm, and it's I guess you have role reversal where, my parents took care of me as a, took care of me and now I am helping take care of them.  $\sim$  **Robin** 

It's rewarding, it's rewarding.... So yeah, I'm proud of what we did for [my father]. I, I am.... Not in a sense that we've needed to, we've, we were forced to. We did it and we are all really happy that we did.... I think you know parents have done a lot in our lives, we owe them that to take care of them, you know. ~ Elyse

Melanie found joy in her caregiving role as her mother provided comedy in her life.

And, so I try to use [my mother] as, almost like, sometimes you know comedy in my life.... And I'll take, I'll take what actually makes me anxious and crazy and sort of spin it to clients and make it funny. Because, that's all I can do. I can't cry about it, so I'll try to laugh about it. ~ Melanie In addition, Diane had been able to find moments of joy when her mother was lucid,

moments that were possible because of the times she spent providing care to her mother.

And sat with my mom, and strangely, she was very, very responsive to me. And during that process, even post, post-op, um, she had lucid moments with me. And my father, that, we hadn't had for 6 years.... So I saw, I saw my original mother, during that time...  $\sim$  **Diane** 

Even amidst the turmoil of different caregiving situations, all except one of the mothers were able to find joy in their caregiving roles. The sandwich generation women gained pleasure in feeling needed, reciprocating the care that their parents had provided to them as children, and sharing humour and quality moments with their care recipients.

## 4.3 It is a learning experience

Almost all of the sandwich generation women learned lessons through their caregiving roles. The lessons that the mothers learned helped them within their roles. Some of the mothers learned to say no to certain demands and to negotiate their time spent with their care recipients.

But you know what? It's kinda been a good thing too, because you never say no in your life. And now, I've learned that saying no is okay and.... I've actually enjoyed having a little bit more freedom and flexibility. So again, it's a learning experience through adversity, where you're forced to slow down and not do so much and then I decided that I quite like it. I might not go running back to it anytime soon. ~ Kate

I'm trying to sorta think about me more now.... And say, "okay this has to change. So I'm going to have to rethink everything else.".... And just kinda set up more of a schedule, with my mother, my mother in-law, and the aunt and uncle, to know that on these days I'm available and on these days I'm not.... Than just sorta being available to them on call, "oh okay, maybe I can do today, maybe I can't." ~ Naomi

And um, the thing I have learned, as opposed to my sister, who also care gives for her as well. Um, my sister would sorta just jump, like if my mother said, "oh I need, I'm out of uh, um, Lysol spray or something, you know I need some. Can you get some for me?" My sister, used to jump that, like that day she'll go and buy the Lysol. I, when my mother calls me and says, "I'm going to need whatever." I'll say, "okay I am free on Thursday." If she'll tell me on Monday.... I'll say, "okay mom you'll have to wait till Thursday.".... I don't jump at every whim now, whereas I used to. Because I felt she was taking advantage of it. ~ Melanie

As well, some of the mothers stated that their caregiving roles made them more aware of

their care recipients' age-related and health-related issues. This prompted them to take a

more active role in their care.

I guess the more positive thing is it's made me more aware of my sister, my parent's situation. Um, you know, you can be oblivious to it sometimes, initially. And now you're, I'm definitely more aware it. ~ Joanne

We've learned that.... You know, so losing my father, we realized we needed to spend a lot of time with her.... And just be patient. Patience is the hardest part of it all.... The hardest. As a caregiver. ~ Elyse

In addition, Diane revealed that having to be a caregiver and having a chronic illness taught

her to deal more effectively with spontaneity and unpredictable moments.

I don't, I don't let things hold me back. Unfortunately the disease holds you back.... Despite myself, holds me back, which just completely kinda shuts down the ability, you don't expect it. So I've learnt to deal with surprises. And work through them, which has been, very challenging. ~ Diane

Meredith revealed that being a caregiver for her children and care recipients made her better

in her job as a teacher.

Well, I would say that [pause] caregiving as in caregiving to children. My own kids. Made me a better teacher. Um, now my kids are just becoming, they're just becoming teenagers. So I worked, I've been in high, a high school teacher my whole career.... But I could see the development and then I was using them as, as um, examples. I might talk about them at school. So I think, my role as a mom, as a caregiver, made me a better teacher. ~ Meredith

Through their caregiving experiences, all of the sandwich generation women learned life

skills such as negotiating their care recipients' demands, dealing with unpredictable

moments, becoming better at their jobs and more aware of their parents' needs.

## 4.4 Growth in children

Almost all of the mothers revealed that their children had grown as a result of their caregiving roles. Some of the sandwich generation women's children had shown a willingness to help with care tasks.

And both [Michael] and [Mark], are wonderful. They will help both grandparents. They will do anything that they can. And they are willing to help us, and we can say to them, I, I can say um, "Guys, your dad's pretty tense right now, I can tell that he is. So let's just sorta stay out of his way, let's just be kind, let's not bring, lets manage our own issues, so that we don't bring them to him." And both boys will go "Absolutely, you're right." ~ Kate

Um, thankfully, my older children, the two older ones are much more, independent. They can help out as well in some ways.... Um, especially with my younger son [Jonathan]. Um, and um, it, it they're okay with it. They understand, I think they understand the situation.... Um it's because, it's not something that one person could do at all times in the house, by themselves. Yeah so the children are familiar with, you know caregiving for [Jonathan] as well.... So they're, they're to watch out for him and they have that responsibility as well. ~ Joanne

As well, Meredith's children built an understanding of the role of a caregiver.

Um [pause] I don't know that they, they noticed that I was pretty busy. And [pause] maybe they didn't make quite so many demands on my time. Uh recognizing that this was probably temporary, and Nana needed me more than they did at that particular time .... I think it took them, they had to look beyond what was, normal for them. To see that life wasn't normal right now, because their grandmother needed me. And, uh, their grandmother needed a lot of care, and that this was a tough time. ~ Meredith

Additionally the mothers' children learned about the needs of older adults.

... they see, how we take care of the elderly members of the family.... And um, that's kept them very close to them too. So they relate to that generation as well. Which is sometimes very hard to do.... For the younger generation to relate to the older generation. So it's taught, taught them how to be more compassionate, more sensitive. Um, and more giving to people.... And I see it, I see it even from my youngest.... He does it really, like just, just because he wants to.... You know he'll help him come down the stairs. As soon as he needs to go up, he's right there, right behind him, helping him.... Without asking, always. ~ Naomi ... they help out a lot. Um my mother comes over, tries to come every weekend. My, my son especially, he knows exactly how to deal with her, how to get her out of the car.... How to hold her, where to hold her. Um he, he just has a routine with her. He knows her and knows you know how to take care of her.... They actually go and visit her spontaneously. ~ Elyse

Although some of the mothers did not mention growth in their children, they hoped that in

the future their children would build an understanding of what it means to be a caregiver.

I hope that they are learning to be compassionate, because to me that's the most important thing.... But I'm hoping to teach by example. So I hope that they see how, what I do for my mother.... That even though they may not be involved in the caregiving with my mother to certain, to a degree.... So I hope that, they're internalizing it. ~ Melanie

I hope that they, they see that, they see that and they understand it because, um unfortunately [long pause] society these days um, are um, in society these days, um people are very selfish, and it's more about a "me" generation. I don't find that with my own children, um, so much I mean, yeah.... But, I hope that they, they see what we have done as parents, that will influence them in a positive way. ~ **Robin** 

Yeah so I hope I influence [my sons]. I hope they, you know learn to respect the elders and, and uh, you know, you never know. ~ Lyla

The sandwich generation women's children were able to grow by witnessing their mothers' caregiving roles. This was conveyed through the children's willingness to help, being understanding of the caregiving role and learning how to care for the older generation. As well, other mothers conveyed that they hoped their children would develop and understand caregiving in the future.

#### Summary

All of my themes and subthemes illustrated the lived experiences of sandwich generation women and the influence caregiving had on their health. Additionally, all of my mothers were able to discuss the different responsibilities and roles of caregivers. The sandwich generation women were able to convey the varying balancing acts within their caregiving roles. Lastly, the mothers were able to describe the perceived silver linings and challenges within their multigenerational caregiving roles.

# Discussion

The purpose of this study was to explore the lived experiences of sandwich generation women and the influence multigenerational caregiving had on their health behaviours. Nine sandwich generation women participated in semi-structured one-on-one interviews. Some of the mothers retrospectively described their caregiving roles, while others were currently in caregiving roles. All nine mothers had similar experiences, which revealed four major themes.

The sandwich generation women discussed the role of being sandwich generation caregivers in great detail. To my knowledge, no qualitative studies have specifically provided an in-depth analysis of the tasks involved in sandwich generation caregiving. The mothers discussed the physical aspects of caregiving. Physical caregiving involved driving care recipients to appointments, purchasing groceries, cooking, cleaning, managing finances and moving houses. As well, some of the women assisted with feeding, bathing, toileting and dressing their care recipients. The types of physical care required was a good indicator of the amount of assistance and time needed by the care recipients overall. These tasks were similar to Sinha (2013), but was only specific to caregivers and not multigenerational caregivers. It appeared that the care tasks for sandwich generation women were similar to those providing care for their parents or in-laws. Further, previous literature has noted that caregiving tasks differed between genders with men typically providing transportation, making decisions and managing the care recipients' finances, while women typically provided more nurturing roles (Young & Kahana, 1989; Horowitz, 1985; Miller & Cafasso, 1992); however my female participants revealed that they completed all of the listed tasks, while their husbands completed more childcare tasks when the care recipients demanded more of the women's time. This suggests that husbands may have assisted in the phenomenon of sandwich generation caregiving by having a greater involvement with their

children, as women who functioned as the caregiver to the aging parents or in-laws. This may support why the sandwich generation women discussed their care recipients to a greater degree than their children in the interviews. More research is warranted to explore husbands' roles in sandwich generation caregiving. These findings provide a better indication of the tasks sandwich generation women complete regarding the amount of and types of physical care required by their care recipients. More research in this area is required.

The mothers provided emotional support to their care recipients and children. Although other studies had noted that caregivers provided emotional support to older adults (Chesley & Poppie, 2009; Williams et al., 2010), no studies to my knowledge have thoroughly discussed this aspect of caring for parents or in-laws. Emotional caregiving has been cited in other patient populations, for example caregivers to HIV positive partners comforted and empathized with their care recipients, as well as were emotionally present (Wruble & Folkman, 1997), which were similar to the mothers in my study. Interestingly, the sandwich generation women described that they were 'secondary caregivers' to their parents or in-laws who were not directly experiencing any illnesses. Secondary caregivers are usually individuals providing caregiving tasks, but to a lesser extent than primary caregivers (Ryba & Owen, 2012). The mothers felt that they played a huge emotional role, as their care recipients without health conditions needed a significant amount of support. This support was required to help their parents/in-laws cope with the losses experienced by their spouses. This finding shows that emotional caregiving is extended to more healthy care recipients, rather than care recipients with higher caregiving needs. By illustrating the aspects of emotional caregiving, it appeared that this support was just as important as the physical care.

Emotional and physical caregiving took up an inordinate amount of the sandwich generation women's time. The mothers discussed the time constraints placed on them due to their caregiving roles. Some of the sandwich generation women perceived that they consistently had to be available or on-call for their care recipients. Although the mothers did not report the amount of hours spent caregiving per week, previous literature found that employed caregivers spend about 31 hours a week completing care tasks (Duxbury et al., 2009), which further shows the time commitment involved. The mothers revealed that a lot of tasks were completed without their care recipient present (e.g. administrative and financially related tasks). Therefore caregiving continues after the sandwich generation women physically leave their care recipients. On the contrary, Rubin and White-Means (2009) found that sandwich generation caregivers spent less time caring for their parents or in-laws, when compared to other family caregivers. In my study, time was also a major limitation when the mothers attempted to complete all of their roles (mother, work, spouse, caregiver). They either successfully juggled their responsibilities and at other times experienced a tug-of-war between their obligations, resulting in sacrifices in other areas of life (e.g. decreased time with family or friends). Similar findings were found by Dhar (2012), who revealed that participants felt their roles "clashed" with one another, which made it difficult to complete their caregiving tasks and other priorities. It appeared that the sandwich generation women's time in my study was largely controlled by their care recipients demands.

The multigenerational caregiving roles involved role transitions, which usually occurred as caregiving roles expanded (e.g. increased needs or number of care recipients). Role transition resulted in changed relationships with the care recipients. For example, one sandwich generation woman's mother's health demands caused her relationship to transition from being a daughter to

a caregiver. These results were similar to Donorfio and Kellett (2006), who found that caregiver daughters felt that their relationships changed from mother-daughter to caregiver-care recipient, when their mothers' required more care. This shows that caregivers have to negotiate their relationships with their care recipients, as health status changes. All of the role transitions described indicated the complexities of caregiving roles. In this case, the majority of the sandwich generation women's roles became more challenging and ended up placing more demands on their life. These results are novel, as previous literature solely focused on the transition of caregivers in the form of role acceptance (Donorfio & Kellett, 2006), rather than the expansion and growing challenges experienced by caregivers. Interestingly, the opposite role transition was experienced in one mother, as she retired after working full-time and was a caregiver to her mother. Her retirement allowed her to transition into a place where she could complete all of her responsibilities without any considerable challenges. This may be an area that employed sandwich generation women could look forward to, although retirement may not be feasible for the foreseeable future for many sandwich generation caregivers.

The sandwich generation women also discussed that every caregiving role is variable to one another, in terms of responsibilities. The mothers felt that 'caregiving' is a broad word that is multifaceted and involves different tasks or time commitments. Although, the sandwich generation women mentioned that they are all caregivers, their responsibilities varied depending on the needs and health conditions of their care recipients. As well, the challenges of being sandwich generation caregivers differs based on the age of their children at the onset of caregiving. Therefore if the mothers' children are younger and require more care, the caregiving responsibilities may be perceived as more demanding. This is important to consider, as children

require more physical care when they are younger, which creates a greater tug-of-war among the caregivers' family and care recipients.

Throughout the interviews, the mothers contemplated whether or not they were caregivers to their children in comparison to being in a parenting role. The sandwich generation women described the perceived differences between caregiving and parenting. The sandwich mothers felt that caregiving for their children encompassed more emotional care, rather than physical care. Further the sandwich generation women felt that there was more invested in a caregiving role, when compared to parenting. It appeared that not every parent may be a caregiver to their children, but every caregiver is a parent. This helps to describe that the two roles overlap with one another; however, the roles may not be interchangeable. The mothers also discussed that parenting involves more of a guidance role, and that once their children start to become more independent, it transitions from one that is less physical and more emotional in nature. This further emphasized the mothers' perceptions on what it means to be a caregiver to children. It is important to note, the literature describes caregiving as any extraordinary care that is beyond usual or normal (Schulz & Quittner, 1998). Hence, when parents are responsible for the care of children with diseases or disabilities that typical parents do not have, their role is considered caregiving (Quittner, et al., 1992). It appeared that the perceived role of a caregiver to children or older adults, depend on the families dynamic or the families personal circumstances. If parents have not been exposed to taking care of a child or parent with major health concerns, their perception of caregiving may be different. As well, any preconceived ideas or expectations of caregiving may influence if one believes they are caregiver or not. Similarly, Donorfio and Kellett (2006) found that prior to becoming caregivers, participants would not have considered

their caregiving responsibilities to be caregiving, which further shows how perceptions of caregiving change.

Throughout the interview process, the sandwich generation women mainly discussed the responsibilities of caring for their parents or in-laws, as opposed to their children. It appeared that the mothers' care recipients placed more demands on their time and life as compared to their obligations at home. It is possible that the mothers' had a higher inclination of what their care responsibilities would be for their children, as some of the mothers did not expect to be caregivers to their parents and/or in-laws. When a role is unexpected, it may be perceived as more challenging and therefore cause more stress. Further perhaps the unexpectedness of caregiving influences the burden experienced by caregivers. As well, becoming a parent may be perceived as a more natural progression in a couple's relationship, as compared to becoming a caregiver. Although at times the sandwich generation women discussed their care recipients and children as separate entities, they still described their interplay. This interaction was conveyed in terms of the mothers' scheduling and organization of their time, which included juggling between their children, care recipients, spouses and other responsibilities.

The sandwich generation women conveyed feelings of resentment and frustration because their care recipients demanded a considerable amount of their time and their care responsibilities were overwhelming. The lack of time and care tasks required of the sandwich generation women made them feel stifled and sometimes obligated to fulfill their roles. This was similar to Williams et al. (2014) whose participants felt resentment towards their caregiving roles, because they did not choose to be informal caregivers. Further, in Donorfio & Kellett (2006), adult daughter caregivers mentioned that their caregiving roles resulted in feelings of anger and frustration, while Chambers, Ryan, and Connor (2001) and Igarashi et al. (2013) found that caregivers felt

there was a lack of information on caregiving in the realm of physical care. These results show that health care providers need to provide more hands on instruction and support, if family members are expected to be caregivers in order to decrease burden and negative feelings that arise from caregiving.

The mothers revealed that their health was compromised, and in part due to their multigenerational caregiving roles. This was largely the result of the sandwich generation women placing the needs of their children and care recipients ahead of their own health. These results have been cited in other caregiving populations, for example the Autism Spectrum Disorder literature (Fletcher, Markoulakis, & Bryden, 2012). Chassin et al. (2010) believes that sandwich generation caregivers put their health last, although the authors felt that sandwich generation caregivers' health is not influenced by lack of time. On the contrary, the amount of time available, posed a major limitation to the sandwich generation women's health. The responsibilities of caregiving, family and work consumed the majority of the mothers' time, leaving barely enough time to attend to their own health. This is important to recognize, as poor health in sandwich generation caregivers will potentially have ramifications on their ability to complete caregiving tasks and other obligations. If sandwiched caregivers are not healthy, the needs of their children and care recipients will go unmet, which may result in further complications, such as an inability to assist with medical care or ADLs/IADLs. In short, the health of caregivers has the ability to influence not only caregivers, but all of their care recipients (e.g. children and parents/in-laws). The following sections will discuss the sandwich generation women's health behaviours, specifically the mothers' level of physical activity, nutrition, sleep and mental health.

The sandwich generation women discussed that their caregiving roles compromised their physical activity levels. The mothers felt that they were unable to get as much exercise as they intended, as their care recipients' needs always came first. The sandwich generation women also felt that when they did have some spare time, they were often too exhausted to engage in physical activity. These results were similar to Chassin et al. (2010), who found that sandwich generation caregivers were less likely to exercise when compared to non-caregivers and caregivers only caring for their parents.

Most of the sandwich generation women indicated that their nutritional habits were influenced by their caregiving roles. Interestingly, the mothers revealed that they would skip meals, rather than overeat, due to their busy schedules, which often left them with no time to eat. Under eating and not providing enough sustenance could eventually become detrimental to the sandwich generation women's health. Not consuming an optimal amount of calories may result in decreased energy expenditures (Carels et al., 2008), which may make it more difficult to complete caregiving and other responsibilities. It is important for sandwich generation caregivers to ensure that they are looking after themselves, so they can complete their roles successfully and remain healthy.

The sandwich generation women perceived that their sleep and energy levels were influenced by their caregiving roles. Since their care was usually required around the clock, the mothers felt that they were unable to sleep enough hours each night. This further showed that the mothers put everyones' needs before their own health. Similarly, Chambers et al. (2001) found that family caregivers were regularly physically or mentally exhausted from their caregiving roles. It is also important to note that of the mothers in my study who had health issues revealed that their conditions caused them to feel fatigued, which sometimes made it difficult to complete

their care tasks. This subsequent challenge requires more research in the future. Therefore, caregiving was believed to have influenced the mothers' sleep patterns, and often contributed to exhaustion, which compromised their ability to be sandwich generation caregivers.

The sandwich generation women reported that their mental health was affected as a result of their caregiving roles. It appeared that mental health was influenced at times when their caregiving demands were intense and required a lot of their time. These findings were similar to past literature (see, for example, Duxbury, Higgins, & Schroeder, 2009; Hammer & Neal, 2008; McGarrigle, Cronin, & Kenny, 2014; Solberg, Solberg, & Peterson, 2014; Voydanoff & Donelly, 1999;). For example Solberg, Solberg, and Peterson (2014) found that being the primary caregiver of a care recipient with dementia resulted in increased stress, anxiety, feelings of irritability and was associated with negative personal health. This apparent strain further emphasizes the importance of using coping mechanisms to buffer stresses associated with multigenerational caregiving.

Overall it appeared that the mothers' health behaviours were compromised due to the mothers putting their care recipients and children's needs ahead of their own. This posed a challenge to the caregivers and again created this perceived tug-of-war. Sandwich generation women have to constantly negotiate the tasks that are important, which often forces them to neglect obligations that are important to their own well-being (e.g. physical activity, nutrition, social activities, etc.), which could compromise their own health.

Although the mothers' care recipients and children placed a lot of demands on their lives, the sandwich generation women were still able to look past their challenges and recognize moments that were positive in nature. All of the sandwich generation women perceived a sense of gratitude in their caregiving roles, as they were thankful for their personal experiences. The

mothers were appreciative of their husbands, as they were understanding and supportive of their care giving roles. The mothers' spouses were able to help with the children, when their care recipients demanded more of their time. In addition, the mothers felt a sense of gratitude for their finances or work circumstances. The sandwich generation women either had flexible jobs, enough finances to provide some formal care to their care recipients or their husbands' jobs allowed them to not be employed. Flexibility in the workplace made taking time off work possible for the mothers, but this may not be feasible for other caregivers. As well, some of the mothers revealed that they became closer with their siblings, parents or in-laws as a result of their caregiving roles. Similar results were found in Hinrichsen et al. (1992), as caregivers reported improved familial relationship due to their caregiving roles. Although many of the mothers felt fortunate in their caregiving situations, it is important to note that these results may be indicative of the sandwich generation women's socioeconomic status (SES) and personal circumstance, which could arguably be considered to be reflective of middle to high SES.

The mothers also found joy in their multigenerational caregiving roles, despite the difficulties that they experienced. The sandwich generation women genuinely felt that their roles were rewarding and provided a sense of fulfillment in their lives. If sandwich generation women are able to derive joy from their care tasks, even if brief, this may help buffer the stresses associated with their caregiving roles. These results were similar to Stephens et al. (1994) where adult daughter caregivers felt feelings of reward when occupying multiple roles such as mother, caregiver and wife. As well, the sandwich generation women found joy in their caregiving roles, as they felt they were repaying their parents for the care they provided to them. The mothers felt that it was their responsibility to provide care to their parents or in-laws. This reciprocation of care was also seen in the literature (Mitchell, 2014; Dhar, 2012; Scharlach, 1994; Wallhagen &

Yamamoto-Mitani, 2006). For example, results from Dhar (2012) indicated that caregivers experienced emotional bonding with their parents, as they were repaying them for past care, which resulted in feelings of joy. Therefore, the sandwich generation women were able to derive joy from many aspects of their challenging multigenerational caregiving roles.

All of the mothers learned lessons from their sandwich generation caregiving roles. These lessons helped the mothers, as they learned to adapt to situations that involved their care recipients. Further the lessons resulted in certain responsibilities to be easier, therefore allowing some relief in areas that were previously stressful. The sandwich generation women learned to negotiate the time that was dedicated to their care recipients, rather than constantly being on-call and available. As well, they learned to better adapt to unpredictable situations and became more aware of their parents or in-laws health needs. These results were similar to Igarashi et al. (2013), as sandwich generation caregivers learned that the needs of their care recipients were often unanticipated. This increased awareness may allow caregivers to provide care more freely, and could decrease the resentment and feelings of frustration in their roles. Therefore by learning lessons the mothers were able to adapt and make their roles more manageable.

The sandwich generation women recognized that their children had grown as a result of their caregiving roles, a finding that is novel in the sandwich generation caregiving literature. The children were willing to help out with their grandparents, were understanding of their mothers' caregiving roles and learned about the needs of the older generation. Therefore this finding illustrates that the children benefited from their mothers' roles. Further, the children's contributions to their mothers' caregiving roles may also provide a reprieve, which may further benefit the sandwich generation women. Duxbury et al. (2009) suggested that children may reduce the strains associated with eldercare. Recognizing the needs of the older generation may

be a positive for the children, as the sandwich generation women consistently discussed other people's children's lack of compassion for others. These results show the positive influence of being a caregiver, and having older adults present in the lives of children. In addition, some of the mothers expressed that they hoped their children would be prepared for their potential caregiving roles in the future. Igarashi et al. (2013) found similar results with sandwich generation caregivers who hoped that their children would understand how to care for them in the future. If caregivers' children have an understanding of what caregiving entails, they may be better equipped to be caregivers in the future, which could make their future roles less burdensome.

#### Limitations

There were limitations to my study, regardless of the steps taken to ensure rigor, credibility and trustworthiness of the data. For example, the sandwich generation women's socioeconomic status (SES) could have placed limitations on the data collected. The majority of my sandwich generation women were middle to high SES. This may have influenced the content of the interviews, as the majority of the mothers were white, employed, educated and married. The mothers' experiences, challenges or benefits may have resulted from their marital status or income. As well, married and employed sandwich generation caregivers would likely have dual incomes, which would allow for increased financial resources for more formal support and husbands to pick up slack at home. As well, the mothers questioned what they would do if they were single mothers. Another limitation may have been the cultural backgrounds of the mothers who were all white. Cultural differences in the area of caregiving have been noted throughout the literature (Dhar, 2012; Mitchell, 2014; Remennick, 1999; Wallhagen & Yamamoto-Mitani, 2006). Perhaps more variability in the data would have emerged if the mothers were more

culturally diverse. The last limitation was that my interviews involved retrospective reflection, which may affect/distort how the caregiving was actually experienced. It must be noted that my qualitative results were not meant to be generalized, but may not be the best source of support for women that do not fit my participants demographics.

#### Implications

This study provides significant contributions to the caregiving and sandwich generation caregiving literature. The results of my study provide implications for government legislation, sandwich generation caregivers and health care providers. Further this document supports and adds to previous reports on caregiving, which could further signify the importance of government assistance for employed multigenerational caregivers. As the population continues to age and more women become caregivers, there will be a greater demand for more flexibility in the workplace. My study suggests that there could be times of emergency that require caregivers to immediately leave work, time that may come without warning and cause absenteeism in the workplace. Therefore, the government needs to create a framework that would allow employees to have relief when their families require increased help, if they expect individuals to be informal caregivers.

Further, my study has important implications for sandwich generation caregivers. If translated into a more accessible medium, multigenerational caregivers will be able to learn from the experiences of the mothers in my study. They may realize that they are not alone in their roles, which could potentially provide them with relief. Further, this study will help reinforce the importance of the caregivers' personal health, while being in a caregiving role. By studying the lived experiences of sandwich generation women, individuals will be better prepared to be multigenerational caregivers or understand the challenges that occur within the role. If future

caregivers are able to organize their lives more effectively in regards to caregiving, less burden may be experienced. As well, by reading this study, sandwich generation caregivers will learn that being in a caregiving role has potential to be beneficial, could provide a sense of fulfillment in day-to-day life and improve or strengthen relationships between family members.

Lastly, the results from this study have important implications for health care providers. Front-line health care practitioners such as doctors, nurses and social workers may build a greater understanding of the challenges experienced by sandwich generation caregivers once they leave health care facilities. These professionals will be able to provide increased support to caregivers, specifically in the realm of physical care for older adults or how to deal with emergency situations.

#### **Future Research**

To date, the majority of research focuses on family caregivers, rather than sandwich generation caregivers. I believe it is important to continue to study this phenomenon, as the number of individuals caring for both their children and parents is going to increase in the future as life expectancy continues to increase. Future research should qualitatively explore lower SES sandwich generation caregivers, as they may experience greater challenges and inequalities. As well, it would be beneficial to study single or divorced sandwich generation caregivers to determine if their experiences are different from married caregivers. From a methodological standpoint, it would be advantageous to conduct longitudinal studies that would enable more indepth information to be obtained and potentially capture sandwich generation caregiving at different time points (e.g. when a caregiving role is initiated, at demanding times and once caregiving has resolved or settled into a more chronic/manageable routine). This method was used in an unpublished case study by Boyczuk (2014) who studied a sandwich generation

couple. Boyczuk found that caregiving responsibilities were dynamic in nature and fluctuated. This "ebb and flow" contributed to their feelings of being overwhelmed. This would provide a better understanding of sandwich generation caregiving roles. As well, more research needs to be conducted in the area of sandwich generation caregiving and health behaviours. Future studies could involve multigenerational caregivers to use diaries to track their eating habits, physical activity and sleep, which would allow greater understanding of the health of sandwich generation caregivers and implications for their compromised health. In addition, future research is warranted in the area of siblings of primary caregivers. This will provide a better understanding of the individuals who support the primary caregiver and care recipients and perhaps add more knowledge about the division of labour between sibling caregivers.

#### Conclusions

Being a sandwich generation caregiver is unquestionably a challenging and rewarding role. All of the mothers discussed their multigenerational caregiving roles, which enabled them to share their lived experiences of being sandwich generation women. By reflecting on their past and current experiences, the mothers provided in depth examinations of their roles of caring for both their children and aging parents or in-laws. My study also examined the health behaviors of sandwich generation women, which appeared to be compromised in all of the mothers. In addition to discussing their multigenerational roles, the mothers reflected on the silver linings and challenges associated with their caregiving roles. The sandwich generation women also revealed that their roles constantly included various balancing acts that would inevitably change in the future.

My study continues to build on previous literature concerning sandwich generation caregivers. This research provides an in-depth perspective of the role of multigenerational

caregivers and their health. It is expected that other sandwich generation caregivers will be able to better anticipate their caregiving roles and use this study's findings as a resource for support. As well, mothers may be provided with a better understanding of how their caregiving influences health, which may cause them to be more cognizant of their own health when faced with sandwich generation caregiving roles.

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## Appendix A

#### **Relevant studies**

Authors/Year	Year	n	Qualitative or Quantitative
Acton	2000	Caregivers (n=46)	Quantitative
		Non-caregivers (n=50)	
Almberg, Grafström, & Winblad	1997	Caregivers of individuals with dementia (n=46)	Quantitative
Chassin, Macy, Seo, Presson, &	2010	Sandwich generation caregivers (n=1763)	Quantitative
Sherman		Caregivers of older adults (n=691)	
		Children (n=1676)	
		Non-caregivers (n=813)	
Christenson, Stephens, & Townsend	1998	Women in multiple roles (n=296)	Quantitative
Green	2012	Sandwich generation caregivers of children with disabilities (n=8)	Qualitative
Hammer & Neal	2008	Married sandwich generation caregivers (n=309)	Quantitative
Hoffman, Lee, & Mendez-Luck	2012	Caregivers (n=5688)	Quantitative
		Non-caregivers (n=12941)	
Igarashi, Hooker, Coehlo, &	2013	Sandwich generation caregivers (n=29)	Qualitative
Manoogian			
Ingersoll-Dayton, Neal, & Hammer	2001	Sandwich generation caregivers (n=63)	Qualitative
Loomis & Booth	1995	Sandwich generation caregivers (n=71)	Quantitative
Neal & Hammer	2009	Dual earner sandwich generation couples (n=234)	Quantitative
Nichols & Junk	1997	Sandwich generation women (n=50)	Quantitative
		Sandwich generation men (n=168)	
Ourada & Walker	2014	Caregivers (n=293)	Quantitative
Pines, Neal, & Hammer	2011	Dual earner sandwich generation caregivers (n=120)	Quantitative/Qualitative
Pope	2013	Adult daughter caregivers (n=15)	Qualitative
Pruchno, Burant, & Peters	1997	Multigenerational families (n=140)	Quantitative
Raschick & Ingersoll-Dayton	2004	Spousal caregivers (n=441)	Quantitative
		Adult children (n=537)	
Razani et al.	2007	Family members with mild dementia (n=34)	Quantitative
		Caregivers (n=34)	
Remennick	1999	Sandwich generation women (n=30)	Qualitative
Rubin & White-Means	2009	Sandwich generation caregivers (n=77)	Quantitative
Scharlack	1994	Caregivers (n=94)	Quantitative
Stephens, Franks, & Townsend	1994	Women in multiple roles (n=95)	Quantitative
Voydanoff & Donelly	1999	Sandwiched generation women (n=1226)	Quantitative

## YOU ARE INVITED TO PARTICPATE IN RESEARCH REGARDING...

# The lived experiences of sandwich generation women and their health

## Purpose

The purpose of this research study is to examine the lived experiences of sandwich generation women and to explore whether their health is influenced by their caregiving role. Sandwich generation caregivers are individuals caring for both their children and aging parents/in-laws. Sandwich generation women will be asked to reflect on their caregiving role, health, ways they deal with their caregiving role and discuss if their lives have changed as a result of their caregiving responsibilities.

## About the Researcher

The principal researcher is a graduate student at Wilfrid Laurier University, who is conducting this study for her master's thesis. Research advisor, Dr. Paula Fletcher is a Professor in the Department of Kinesiology and Physical Education.

## **Participants**

Participants must be a mother, providing care to at least one child under 18 years who lives in the home and at least one aging parent or in-law who does not live in the sandwich generation caregivers home.

## Procedure

Each participant will read and sign a consent form and fill out a background questionnaire, which will take approximately 15 to 20 minutes. Once the background questionnaire is completed, the one-on-one interview will be scheduled at a time and location convenient to the participant. The interview will be approximately 60 to 120 minutes in length. All interviews will be audio taped and then transcribed word for word. The participant will be asked to review the transcript (member check) from her interview and return it to the researcher with any added or removed information or clarification of the researcher's questions.

## **Interested in Participating?**

If you feel that you are suitable for this study, please contact Allison Steiner at stei7060@mylaurier.ca or Dr. Paula Fletcher at pfletcher@wlu.ca or (519) 884-0710 ext. 4159.

#### Appendix C

#### WILFRID LAURIER UNIVERSITY INFORMED CONSENT STATEMENT – Interview with Adult Participant Principal Researcher: Allison Steiner Advisor: Dr. Paula Fletcher

You are invited to participate in a research study about the lived experiences of sandwich generation women and their health. The purpose is to discover sandwich generation women's perspectives of their caregiving role and to see how their caregiving role may influence their health.

The principal researcher, Allison Steiner, is an MSc student in Kinesiology at Wilfrid Laurier University and is conducting this research for her thesis. Research advisor, Dr. Paula Fletcher, is a Professor in the Department of Kinesiology and Physical Education.

#### **INFORMATION**

Female sandwich generation caregivers will be recruited to participate in this study. All participants will meet the following criteria: (1) The sandwich generation caregiver has to be a mother. (2) The sandwich generation women must be caring for at least one child who is under 18 years living in the home. (3) Children of the sandwich generation women must be typically developing or the child(ren) could have a mild physical or developmental disability perceived as high functioning by their parents. (4) Sandwich generation women will be excluded if any of their children has a condition that is perceived as beyond mild (e.g. a moderate or severe developmental and/or physical disability) or if they have continuing complex care needs (e.g. cancer, cerebral palsy, cystic fibrosis). (5) The sandwich generation women must be providing care to at least one parent/in-law. (6) The parents/in-laws of the sandwich generation women must live within the same city or region. (7) The parents/in-laws requiring care do not live in the sandwich generation women's home.

First, participants will read and sign a consent form, then complete a background questionnaire, which will take approximately 20 minutes. The one-on-one interview will take place next and will be 60 to 120 minutes in length. All interviews will be audio taped and then typed verbatim by the researcher. The participants will be allowed to add, remove or change information on their interview transcripts after the interview through a member check. This process allows the participants to review their contributions to the study for accuracy and make changes if necessary. The data collected from this research will be locked in the Kinesiology and Physical Education office at Wilfrid Laurier University for future use.

#### RISKS

The participants will be asked to participate in an interview that will take approximately 60 to 120 minutes. There will be time to move around and take a break if the participant wishes to do so. All information will be password protected and pseudonyms will be used to protect each participant's identity. The sandwich generation caregivers may become emotional when discussing their care receiver's conditions and abilities. To reduce this, the researcher will give

Initials

the participant time to respond to each question and allow the participant to end the interview at any time or refrain from answering any questions with which they feel uncomfortable.

#### BENEFITS

This research will explore the effects of caring for both children and parents/in-laws and to see if sandwich generation caregiver's health is influenced by caregiving. The participants will benefit by knowing that they are contributing to the sandwich generation caregiving research. If there are positive as well as negative outcomes of being a sandwich generation caregiver, perhaps individuals initiating a caregiving role will be better prepared to take on their new responsibilities. Policy makers may also apply the results of this study to existing government mandates and perhaps better meet the needs of employed sandwich generation caregivers.

#### CONFIDENTIALITY

All identities, such as names of people and places, will be removed from the transcripts. Each transcript and questionnaire will be coded by a number so that the name of the participants will not be attached to their personal information. The audiotapes and transcripts will only be accessible to the researcher and the researcher's advisor. All raw data and tapes will be locked securely in a filing cabinet in the Kinesiology and Physical Education Department. Any direct quotations will be anonymous and all participants have the right to refuse the use of their direct quotes in public or conferences resulting from this research. Documents, records and audiotapes from this study will be kept with the researchers until the study is completed and raw data and tapes will be stored securely and kept for 5 years. Pseudonyms will be used in final reports of the study. The general location of the research project will be referred to as "Southwestern Ontario". Because this project employs e-based collection techniques, the confidentiality and privacy of the data cannot be guaranteed during web-based transmission.

#### **COMPENSATION**

There is no compensation for participating in this study.

#### CONTACT

If you have questions at any time about the study or the procedures, (or you experience adverse negative effects as a result of participating in this study) you may contact the researcher, Allison Steiner, at stei7060@mylaurier.ca. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in this research have been violated during the course of this project, you may contact Dr. Robert Basso, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 4994 or rbasso@wlu.ca

#### PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study, every attempt will be made to remove your data from the study, and have it destroyed. You have the right to omit any question(s)/procedure(s) you choose.

Initials\_\_\_\_\_

#### FEEDBACK AND PUBLICATION

The results from this research will be presented in a poster presentation and thesis defense presentation. The researcher will also submit the results to a journal to be published. Participants will be given the opportunity to receive an executive summary of the research from the principal researcher when the final results are available in the summer of 2015.

#### CONSENT

I have read and understand the information above. I have received a copy of this form. I agree to participate in this study.

Participant's Signature	Date
Investigator's Signature	Date
I agree to be audiotaped during the face-to-face interview	V.
Participant's Signature	Date
Investigator's Signature	Date
I agree consent to the use of direct quotations in presenta	tions/papers resulting from this study.
Participant's Signature	Date
Investigator's Signature	Date

### Appendix D

The

#### <u>The Experiences of Sandwich Generation Women Caregivers and Their Health:</u> <u>Background Questionnaire</u>

Please fill out the following questions in the space provided or by choosing the most appropriate answer. You may choose not to answer any questions.

1. What is your date of birth (MM/YYYY)?	
2. Are you:	
<ul> <li>Employed full time (please specify occupate</li> <li>Employed part time (please specify occupate</li> <li>Stay at home mom</li> <li>Sick leave</li> <li>Other (please specify):</li></ul>	tion):
3. What is the highest level of education you have	completed? Check one.
<ul> <li>Elementary school</li> <li>High school</li> <li>College</li> </ul>	<ul> <li>Undergraduate degree</li> <li>Masters or Doctoral degree</li> <li>Other:</li></ul>
4. What is your current marital status? Check one.	
<ul> <li>Married or Common-law</li> <li>Separated</li> <li>Divorced</li> </ul>	□ Widowed □ Single
following questions are about your health:	
5. How would you currently describe your health?	Check one.
<ul><li>Excellent</li><li>Good</li></ul>	□ Fair □ Poor
6. Do you currently have any illnesses/conditions/i	mpairments?
<ul><li>No</li><li>Yes (please specify):</li></ul>	

- 7. Do you feel as though your health has been affected as a result of your caregiving role? Check one.
  - □ Yes
  - □ No
- 8. Please check all that apply:

Do you	Currently	In The Past
Regularly engage in physical	□ Yes	□ Yes
activity	□ No	□ No
Smoke cigarettes	□ Yes	□ Yes
	D No	□ No
Drink alcohol on a regular basis	□ Yes	□ Yes
	□ No	□ No
Eat nutritious meals	□ Yes	□ Yes
	□ No	□ No
Sleep enough hours each night	□ Yes	□ Yes
	□ No	□ No

## The following questions are about your children.

9. For each child that you have, please complete the following:

	Date of Birth (MM/YYYY)	Gender	Does this child currently live at home?	Do you support this child in any way?
Child 1		□ Male □ Female	□ Yes □ No	□ Yes □ No
Child 2		□ Male □ Female	□ Yes □ No	□ Yes □ No
Child 3		□ Male □ Female	□ Yes □ No	□ Yes □ No
Child 4		□ Male □ Female	□ Yes □ No	□ Yes □ No
Child 5		□ Male □ Female	□ Yes □ No	□ Yes □ No

## The following section is about your parents and/or in-laws.

10. For any parent/in-law/step-parent that you provide care for currently or provided care for in the past, please complete the	
following information:	

Relation	Fill out where applicable	What is this care recipient's marital	Health conditions, illnesses
(e.g. mother, father)	(MM/YYYY)	status?	and/or impairments
1.	Date of Birth	□ Married	
		□ Separated	
	Date of Death	Divorced	
	Date of Death	□ Widowed	
		□ Other (please specify)	
2.	Date of Birth	□ Married	
		□ Separated	
	Date of Death	Divorced	
	Date of Death	□ Widowed	
		□ Other (please specify)	
3.	Date of Birth	□ Married	
		□ Separated	
	Date of Death	Divorced	
	Date of Death	□ Widowed	
		□ Other (please specify)	
4.	Date of Birth	□ Married	
		□ Separated	
	Date of Death	- Divorced	
	Date of Death	□ Widowed	
		□ Other (please specify)	
5.	Date of Birth	□ Married	
		□ Separated	
	Date of Death	Divorced	
	Date of Death	□ Widowed	
		□ Other (please specify)	

**\*\*** Thank you for taking the time to fill out this questionnaire **\*\*** 

#### Appendix E

#### **Interview Guide**

Thank you for taking the time to discuss your role as a sandwich generation caregiver. The purpose of this study is to look at your role as a sandwich generation caregiver, as well, to see if your caregiving role has any influence on your health. Your responses will be a great help to my Masters thesis.

- 1. Please tell me about yourself.
  - Probes:
    - □ Education
    - □ Worklife/career
    - □ Upbringing
    - □ Lifestyle
- 2. Now let's talk about your family.

Probes:

- □ Partner? (occupation, relationship, health)
- □ Children? (activities outside of school, education, health conditions)
- 3. Can you define caregiving for me?

#### Probes:

- □ Are there any factors that influence your definition: your own experiences? Upbringing/cultural background?
- □ Education/work? Paid/unpaid?
- □ What types of tasks? Hours of care provided?
- Do you consider the care you provide to your children to be caregiving? Adults?
- 4. What type of care do you provide to your children?
  - Probes:
    - □ Do you provide this care everyday?
    - Describe a typical week caring for your child/children
    - Does your spouse help provide care for your children?
- 5. Please tell me about your other care recipient(s).

Probes:

- □ How was your caregiving role initiated?
- □ Health conditions/illnesses/diseases of your care recipients
- □ Type of care you provide
- Do/did any other family members (or other individuals?) provide care?
- □ Typical week when providing care (including parenting role)
- □ Relationship(s) with the care receiver (okay, bad, strained, excellent, improved...)
- □ Specific events that increased or decreased the caregiving demands
- $\Box$  How did you feel when these events/situations came up?
- □ Do any of your care recipients help care for your children? (Or previously?)

- 6. Does your partner complete any caregiving tasks?
- 7. How do you feel about your caregiver role as a whole? Probes:
  - □ Before becoming a sandwich generation caregiver?
  - $\Box$  If no longer caregiving, afterwards?
- 8. Do you feel your child/children's lives have been influenced by your caregiving role? Probes:
  - □ Not enough time for them/lack of individualized attention?
  - $\Box$  Does one role take up more time than the other?
  - $\Box$  Do they help with your caregiving role?
  - □ Become more empathetic?

Let's talk about your health and health behaviours.

- 9. Since becoming a caregiver, do you feel your health has changed? Probes:
  - Describe your health prior to becoming a caregiver
  - □ Improved? Declined? Stayed same?
  - □ Physical activity
  - □ Nutrition/eating habits
  - $\Box$  Personal health
    - □ Do you feel you put the health of others ahead of your own?
  - □ Current meds including OTC meds
  - □ Smoking: current/former?
    - Alcohol practices?
- 10. Do you feel there are obstacles that prevent you from taking care of your health?
- 11. How do you deal with your sandwich generation caregiving role? Probes
  - $\Box$  Do you have any support?
  - □ If any, what type of support do you have?
  - $\square$  Exercise?
  - □ Support groups?
  - □ Social support?
  - $\Box$  Avoidance?
- 12. Do you feel any aspects of your life have been influenced as a result of your caregiving role?

Probes:

- $\square$  Positive?
- □ Negative?

13. What do you think your role as a sandwich generation caregiver will look like in the future?

Probes:

- Do you think your caregiving responsibilities will change?
- □ Do you think your role as a sandwich generation caregiver will continue?
- $\square$  1 year? 5 years? 10 years?
- 14. Is there anything else you would like to add about your role as a sandwich generation caregiver or health as a result of your caregiving role?

I would like to go back to one of the questions I asked at the beginning of the interview.

15. Now that we have discussed caregiving, can you tell me how you would define caregiving or what caregiving entails?

Probes:

□ Has anything changed?

16. Do you have any questions for me?

Thank you for taking the time to discuss your role as a sandwich generation caregiver and health with me. Your responses have been very helpful.

## Appendix F

## Table A: Background information on participants

Sandwich generation	Age	Number of children	Previous number of care recipients	Current # of care recipients	Employment	Highest level of education	Marital status
women							
"Kate"	49	2	3	3	Full-time	Master/Doctoral degree	Married
"Meredith"	52	2	1	1	Other	Undergraduate	Married
"Naomi"	50	5	6	4	Stay-at-home mother	Undergraduate	Married
"Joanne"	46	3	3	3	Full-time	Undergraduate	Married
"Diane"	52	1	2	2	Full-time	Undergraduate	Separated
"Melanie"	46	2	1	1	Part-time	College	Married
"Robin"	52	3	3	2	Part-time	Undergraduate	Married
"Elyse"	52	2	2	1	Part-time	High school	Separated
"Lyla"	49	3	2	0	Stay-at-home mother	College	Married

## Table B: Participants' health

				Physical activity		Smoke cigarettes		Drink alcohol		Eat healthy		Sleep enough hours each night	
Sandwich generation women	Perceived health status	Current health conditions	Health affected by CG	Currently	Past	Currently	Past	Currently	Past	Currently	Past	Currently	Past
"Kate"	Excellent	No	Yes	Yes	Yes	No	No	No	No	Yes	Yes	No	Yes
"Meredith"	Excellent	No	No	No	Yes	No	Yes	No	No	Yes	Yes	Yes	No
"Naomi"	Good	No	No	Yes	No	No	No	No	No	Yes	Yes	No	Yes
"Joanne"	Good	No	No	No	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes
"Diane"	Fair	Yes <sup>1</sup>	Yes	No	Yes	No	No	No	No	Yes	Yes	Yes	Yes
"Melanie"	Good	Yes <sup>2</sup>	Yes	No	No	No	No	Yes	Yes	Yes	Yes	No	No
"Robin"	Excellent	No	No	Yes	No	No	No	Yes	Yes	Yes	Yes	No	Yes
"Elyse"	Good	No	No	No	Yes	No	No	No	No	Yes	Yes	No	No
"Lyla"	Excellent	No	No	No	Yes	No	Yes	No	No	No	Yes	No	No

<sup>1</sup> Multiple Sclerosis <sup>2</sup> Hypothyroidism

Sandwich generation women	Age Cander Live at home Support provided		Health conditions		
66 <b>1</b> / a.4 a.99	12	Male	Yes	Yes	N/A
<b>"Kate</b> " 11		Male	Yes	Yes	N/A
"M ana di41 "	14	Male	Yes	Yes	N/A
"Meredith"	12	Female	Yes	Yes	N/A
	23	Male	No	Yes	N/A
	21	Male	No	Yes	N/A
"Naomi"	20	Female	Yes	Yes	N/A
	17	Female	Yes	Yes	N/A
	10	Male	Yes	Yes	N/A
	16	Male	Yes	Yes	N/A
"Teenne"	14	Female	Yes	Yes	N/A
"Joanne"	11	Male	Yes	Yes	High functioning autism spectrum disorder (ASD)
"Diane"	6	Female	Yes	Yes	N/A
4 <b>5</b> 7 1 • 9	17	Female	Yes	Yes	N/A
"Melanie"	15	Male	Yes	Yes	N/A
	25	Female	No	No	N/A
"Robin"	23	Female	No	Yes	N/A
	18	Female	Yes	Yes	N/A
%T1	20	Female	No	Yes	N/A
"Elyse"	17	Male	Yes	Yes	N/A
	18	Male	No	Yes	N/A
"Lyla"	16	Male	Yes	Yes	N/A
-	10	Male	Yes	Yes	N/A

## Table C: Background information of participants' children

Sandwich generation women	Relation	Age	Marital status	Health conditions
	Mother	74	Widowed	Arthritis, high blood pressure
"Kate"	Mother in-law	83	Married	None
	Father in-law	84	Married	Stroke (cognitive and motor decline)
"Meredith"	Mother	85	Widowed	Broke hip
	Mother	81	Widowed	Decline in hearing
	Mother in-law	81	Widowed	Osteoarthritis, problems with mobility
"Naomi"	Father in-law <sup>*</sup>	84**	Married <sup>***</sup>	Gallbladder cancer
	Father <sup>*</sup>	72**	Married <sup>***</sup>	Prostate cancer
	Aunts and uncles	N/A	Married	Osteoarthritis, age-related issues
	Mother	78	Married	Depression, severe pain
"Joanne"	Father	85	Married	Age-related issues
	Sister	40	Other	Mentally challenged, depression
"Diane"	Mother	84	Married	Alzheimer's Disease
Diane	Father	82	Married	Anxiety due to spouses condition
"Melanie"	Mother	82	Widowed	Rheumatoid arthritis, diabetes, neuropathy, depression, lower vertebrae fracture, high blood pressure, hypothyroid, severe chronic pain
	Mother in-law <sup>*</sup>	79**	Widowed <sup>****</sup>	Cancer, diabetes
"Robin"	Mother	77	Married	None
	Father	81	Married	Diabetes, high blood pressure, memory loss
"Elyse"	Mother	80	Widowed	Stomach/digestive ailments, high blood pressure, decreased mobility due to small tear in spine
	Father <sup>*</sup>	81**	Married***	Rectal cancer, Amyotrophic Lateral Sclerosis (ALS)
"Lyla"	Mother*	$80^{**}$	Widowed <sup>***</sup>	Diabetes
Lyla	Father in-law <sup>*</sup>	80**	Married <sup>***</sup>	Cancer

#### Table D: Background information about each care recipient

\* Care recipient had passed away prior to study \*\* Care recipient's age at death \*\*\* Care recipient's marital status at death \*\*\*\* Average age of care recipients includes ages of care recipients who had previously passed away