

# Adjusting to Mealtime Change within the Context of Dementia

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## RÉSUMÉ

On sait peu de ce qui concerne la façon dont les personnes atteintes de démence et leurs partenaires en soins réagissent aux changements qui se produisent au moment des repas tout au long du passage à travers la démence. En interrogeant 27 personnes atteintes de démence, ainsi que leurs 28 partenaires en soins, nous avons exploré la signification et l'expérience de changements qu'impliquent les repas. Les participants se sont adaptés aux changements de repas en *s'adaptant à une vie en évolution*, comme résultat d'un processus dynamique de *prise de conscience* du changement, en *attachant un sens* au changement, et *réagissant* aux changements. Les événements séminaux, aggravés par une perception des changements, ont déclenché la sensibilisation de changements au moment des repas. On a attaché une certaine signification aux changements à l'heure des repas observés à travers des émotions éprouvées et des stratégies diverses que l'on a développées pour soutenir les valeurs associées aux repas. La réponse au changement est une question de stades, allant d'y résister, à d'être dans un circuit d'attente, à la transformation et à l'adaptation. Comprendre comment les individus et les familles s'adaptent aux changements au moment des repas, et les stratégies qu'ils qui en résultent pour en venir à bout, fournit des aperçus cruciaux pour soutenir les familles tout au long du voyage à travers la démence.

## ABSTRACT

Little is known about how persons with dementia and their care partners respond to mealtime changes that occur throughout the dementia journey. By interviewing 27 persons living with dementia and their 28 care partners, we explored the meaning and experience of change surrounding mealtimes. Participants adjusted to mealtime change by *adapting to an evolving life*, as a result of a dynamic process of *becoming aware* of change, *attaching meaning* to change, and *responding* to change. Seminal events compounded by a sense of things being different triggered awareness of mealtime changes. Meaning was attached to mealtime changes, observed through emotions experienced and diverse strategies developed to support mealtime values. Responding to change ranged from resisting, to being in a holding pattern, to transforming and adapting. Understanding how individuals and families adjust to mealtime changes, and the strategies they develop, provides critical insights for supporting families throughout the dementia journey.

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## Introduction

Meals eaten with others provide a sense of belonging, comfort, and familiarity (Valentine, 1999) and can be a time to de-stress and receive support. For persons living with dementia, mealtimes have been identified as important occasions for building caring relationships in long-term care (Amella, 2002; Kayser-Jones, 1997) and, for families living in the community, connecting with each other and honouring each other's identities (Genoe et al., 2010; Keller et al., 2010). Yet, persons living with dementia and their family care partners journey through a great deal of change (Dempsey & Baago, 1998; Gillies & Johnston, 2004; Truscott, 2003), including changes concerning various aspects of mealtime.

Persons living with dementia experience a range of cognitive and functional changes, which can affect meal planning, preparation, and food consumption (Andersson & Sidenvall, 2001; Rivière et al., 2002). These changes affect not only the nutritional status of the person with dementia but can also result in stress for both the person with dementia and the care partner (Andrieu et al., 2001; Guyonnet et al., 1998; Kellaher, 2000; Keller, Edward, & Cook, 2006). Care partners take on increasing responsibility as their loved ones' abilities become altered (Braun et al., 2009; Tarlow et al., 2004). Consequently, changes experienced at mealtimes, such as difficulties feeding oneself or using utensils, can be extremely stressful for family partners in care (Keller et al., 2006; Rivière et al., 2002).

These changes pose unique challenges, yet research has demonstrated that persons living with dementia and their family members find ways to navigate change in general (Clare, 2002; Harman & Clare, 2006; Harris & Durkin, 2002; MAREP, 2006, 2007a, 2007b, 2008, 2009; Truscott, 2003) and meal changes in particular (Keller et al., 2006; Rivière et al., 2002). The way male spouses, who are caring for their wives with dementia, adapt to mealtime role changes has been elucidated (Atta-Konadu, Keller, & Daly, 2011). What seems to be missing, however, is a more general understanding of the *process* of adapting to mealtime change regardless of the caring relationship or the cooking status or gender of the person with dementia. Mealtimes appear to be an important normal activity for families because they can offer pleasure and a sense of identity, support, and belonging (Genoe et al., 2010; Keller et al., 2010). It is, then, important to understand how persons with memory loss and their care partners identify mealtime changes, make decisions about changes, and adjust to those changes so that support can be provided to these families living in the community.

The purpose of this article is to provide insight into the process of adapting to mealtime changes that persons

living with dementia and their care partners experience. Mealtimes provide an important space to nurture attachment between persons with dementia and their family members. When this space is threatened as the disease progresses, ambiguous loss and detachment experienced by the person with dementia is highly likely (Boss, 1999; Dupuis, 2002). Through understanding the challenges to be faced and the way in which families adjust to these changes, health care service providers have the information necessary to provide the best possible support to families throughout the dementia journey.

## Background

This article reports on a key theme from our three-year longitudinal Eating Together Study. The purpose of the study was to uncover the meaning and experience of mealtimes for families living with dementia, and it resulted in the development of the Life Nourishment Theory (LNT). The LNT explains how "mealtimes are the way we are" and how mealtimes reflect the rest of life being experienced. The theory consists of three concepts focusing on the mealtime experience: (a) *being connected*, (b) *honouring identity*, and (c) *adapting to an evolving life*. Indeed, mealtimes are generally observed as a space for families to build and maintain connections to one another (see Keller et al., 2010), and they afford family members opportunities to honour each other's identities (see Genoe et al., 2010). This article focuses on the third theme of the LNT theory – adapting to an evolving life – and describes the process of adjustment to mealtime change that people living with dementia and their family care partners navigate over time.

## Literature Review

Mealtimes, because they typically involve sitting down and taking part in a "proper meal" (Charles & Kerr, 1988), are well-known to provide a vehicle for socialization and support of the family unit (Ochs & Shohet, 2006; Valentine, 1999). Mealtimes provide an opportunity to come together, share activities of the day, and de-stress (Fiese & Marjinsky, 1999). However, this is not the case in all families: tensions, poor communication, and power struggles are also seen at mealtimes, which can make the family meal a stressful event (Burgoyne & Clarke, 1983). Researchers have found that infrequent family meals are linked to low self-esteem and emotional problems whereas shared meals promote personal resilience (Larson, Branscomb, & Wiley, 2006).

With advancing age, eating alone can occur for many reasons, including loss of a spouse and having eating difficulties that result in isolation, such as dysphasia.

Lack of eating companions, which can happen in families living with dementia, has been described as leading to a sense of apathy and loss of meaning for older adults (Ekberg, Hamdy, Woisard, Wuttge-Hannig, & Ortega, 2002; Sidenvall, Nydahl, & Fjellström, 2000). Alternatively, apathy and social withdrawal, which occur in the early stages of dementia (Derouesne et al., 2002), could influence the types of connections and activities that occur at mealtimes and, accordingly, could influence the benefits of eating with others. In addition, care partners do complain of changes in social interaction and capacity for conversation that affects the mealtime experience (Keller et al., 2010). What is required is an understanding of how families adapt to mealtime changes that challenge the ability to connect and socially engage.

Family roles and identity are often based on gendered activities and relationships, including food-related mealtime tasks (Valentine, 1999). Furthermore, the types of food chosen and the way they are consumed symbolize or say something about who we are as individuals, families, and cultures (Beardsworth & Keil, 1997; Seymour, 1983). When roles, food preferences, and routines are challenged, friction and stress can result. Older women without dementia who lose the food provider role often experience guilt and poor self-esteem (Gustaffson, Andersson, Andersson, Fjellström, & Sidenvall, 2003). The gendered nature of meal provision continues into advanced age (Sidenvall et al., 2000).

Memory loss impacts daily functioning (Bassett & Graham, 2007; Snyder, 2001), including driving (Gillies, 2000), planning, anticipating, and participating in daily activities (Bassett & Graham, 2007). Persons experiencing dementia may forget important events and daily information, such as how to take a familiar route home (Mitchell, Jonas-Simpson, & Dupuis, 2006), or make and follow a shopping list or recipe. Persons with dementia are known to have changes in food preference, as well as changes in routines of how food is accessed, prepared, and consumed (Keller et al., 2006). Whereas women with dementia can resist giving up food-related roles (Calasanti & Bowen, 2006), male spousal care partners can struggle with new food-related roles (Russell, 2007). Furthermore, mealtimes and their many activities can support identity through having and negotiating meaningful roles, protecting dignity and supporting autonomy, as well as reaffirming the sense of self (Genoe et al., 2010). What must be elucidated is the process by which families adapt to mealtime changes that challenge their roles, routines, and preferences.

Prior research has identified strategies used to overcome mealtime changes in community-dwelling persons

with dementia (Keller et al., 2006). For example, if the eating etiquette of a person with dementia is challenged, the person's dignity and independence can be promoted by modeling eating or by changing the types of food consumed (e.g., hamburger vs. steak) or how they are provided (e.g., soup in a cup). Furthermore, Atta-Konadu et al. (2011) found that male spousal care partners and their wives with dementia enter into a "sliding into food roles" process in an attempt to maintain normalcy that involves moving back and forth through steps and strategies. Male partners initially start as helpers to their wives, but a role reversal gradually takes place which sees the husband lead the cooking process and the female partner with dementia provide a primarily supportive role (Atta-Konadu et al., 2011). Further work is needed to understand this process regardless of the caring relationship, gender, and cooking roles of the person with dementia.

Although we know little about the process of adjusting to mealtime changes, the literature provides some insight into how persons with dementia experience and manage other changes that may help inform our understanding of mealtime changes. For example, we know that persons living with dementia draw on practical resources in response to change. Techniques include (a) following a routine (Clare, 2002; MAREP, 2008); (b) relying on care partners for reminders (Clare, 2002; Genoe, 2009; Gillies, 2000; Preston, Marshall, & Bucks, 2007; Van Dijkhuizen, Clare, & Pearce, 2006); (c) using external memory aids such as diaries, calendars, lists, and notes (Clare, 2002; Gillies, 2000; MAREP, 2008; Phinney, Chaudhury, & O'Connor, 2007; Preston et al., 2007); and (d) reframing the situation in more positive ways (Clare, 2002). Although these strategies can occasionally fail, they can be important in the mealtime context, and they are valued because they help maintain or improve self-confidence (Clare, 2002).

Maintaining normalcy is meaningful for persons living with dementia and helps them to respond to changes (Beattie, Daker-White, & Gilliard, 2004; Genoe, 2009; Menne, Kinney, & Morhardt, 2002; Phinney, 1998). For example, Phinney et al. (2007) have indicated that persons living with dementia do not want to relinquish household tasks, and "emphasized how much it mattered to them to be able to continue in these kinds of activities, even if it meant they had to use different strategies than before" (p. 387). Having a positive attitude also helps persons living with dementia cope with change (Genoe & Dupuis, in press; Harris & Durkin, 2002). Couples living with dementia have reported making the best of things to maintain their quality of life by engaging in simple pleasures, looking on the bright side, and living in the moment (Hellström, Nolan, & Lundh, 2007).

Managing life with dementia is indeed complex (Genoe, 2009; Pearce, Clare, & Pistrang, 2002; Steeman, Godderis, Grypdonck, de Bal, & De Casterlè, 2007; Vikström, Josephsson, Stigstodder-Neely, & Nygård, 2008). Keady and Gilliard (1999) have suggested that learning to respond to the changes necessitated by dementia is an active process characterized by trying to make sense of symptoms, followed by the use of coping behaviours to accept the changes. Care partners play a critical role in how changes are experienced directly by persons with dementia and how those changes are supported (Keady & Gilliard, 1999). The care partner's role grows over time as he or she provides more assistance in daily activities, as has been well documented (Chung, Ellis-Hill, & Coleman, 2008; Furlong & Wuest, 2008; Hellström et al., 2007; Vikström et al., 2008). Learning to adapt to these changes, including mealtime changes, is essential to the quality of life of both persons with dementia and their care partners.

Despite the lack of research on the process of adjusting to mealtime changes for family care partners, research on adjusting to changes in general in chronic illness situations has provided important insights to our study. For example, women whose husbands had memory loss have described going through a process in which they recognized that something was no longer right with their spouse (Brown & Alligood, 2004). In this cyclical process, the wives minimized problems they needed to adjust to, drew on internal resources, and acknowledged the need and searched for external help (Brown & Alligood). Similarly, Silva-Smith (2007) explored the process of preparing for the caring role among care partners of older adults who had experienced a stroke. These care partners experienced "restructuring life" as they planned for changes in daily activities. Care partners were required to change their work, chores, and leisure routines, and underwent a linear process from passively waiting (for information) to actively rearranging their living environments (e.g., moving furniture, or making room for hospital equipment). Restructuring allowed them to engage in a stabilization process whereby they created routines that helped them adjust to the changes of caring for their loved one.

Although caregiving research often focuses on the "burden" of caring and the process that care partners undergo to adjust to their new roles, recent research has revealed how care partners experience personal growth as a result of the role, gaining knowledge and resiliency, as well as experiencing improved relationships with the care recipient and other family members (e.g., Netto, Goh, & Yap, 2009). Mealtimes may be important occasions when care partners can experience continued connections with their loved ones or, conversely, may be occasions when these connections

are threatened, reducing the likelihood of positive experiences and rewards in care roles. Our research study aimed to shed light on both possibilities.

The current yet limited literature on mealtime changes in dementia, and the expanding literature on the processes that persons with dementia and care partners go through in adapting to changes associated with the dementia journey, has guided us to consider the process of how dyads – that is, the pair formed by a person with dementia and a care giver – adjust to change rather than simply exploring specific mealtime strategies commonly used to cope with changes (Keller et al., 2006). Furthermore, the literature tells us that both persons with dementia and their care partners are creative and active in managing memory loss. Unfortunately, the interdependent nature of the caring relationship is often overlooked. Braun et al. (2009), for example, noted a paucity of research focusing on the relationship between care partners and persons with dementia.

Although a few studies have explored the experiences of both members of the caring relationship (e.g., Genoe et al., 2010; Graham & Bassett, 2006; Hellström, Nolan, & Lundh, 2005; Phinney, 2006; Vikström, Josephsson, Stigstodder-Neely, & Nygård, 2008), researchers have often focused solely on the care partner, neglecting the relational interaction that occurs within the caring relationship (Graham & Bassett, 2006; O'Connor et al., 2007). In our study, we addressed the shared experience of adjusting to change, particularly since the journeys of dementia experienced by the care partner and person living with dementia are intertwined. Our research contributes new knowledge to the literature on dementia and coping by addressing the closely related journeys and perspectives of both members of the caring relationship, and how they work together to adjust to mealtime changes.

## Theoretical Framework

This study was guided by the Family Adjustment and Adaptation Response (FAAR) model (Patterson, 1988). The FAAR model suggests that a cyclical adjustment-crisis-adaptation process maintains balanced family functioning when family members who face a chronic illness adapt by using resources and coping behaviours to address the situation (Patterson, 1988). The model includes *adjustment* and *adaptation*, which are linked by *crisis situations*. In adjustment, family members meet the challenges they face with their existing resources, and cope well. If a crisis arises, the demands may overwhelm the families' resources and ability to cope. The family then redefines the situation and attempts to adapt to the new circumstances. A crisis may allow families to reframe their situations, and

grow as individuals or as a family, building better coping capacities. The FAAR model recognizes that families go through constant adjustment when living with chronic illness and highlights the importance to individual and family adjustment of personal meanings of change situations.

## Method

O'Connor et al. (2007) have called for longitudinal data to explore how the dementia experience changes over time. We adopted a longitudinal approach to explore the meaning of mealtimes and, for this article specifically, the process of adapting to mealtime changes as the dementia journey progresses. A longitudinal study was needed for us to fully comprehend this process within dyads; meaningful change could be identified in one interview and followed up within subsequent interviews to check on the adaptation process.

We elected to use constructivist grounded theory as our methodology because it focuses on the creation of frameworks or theories through inductive data analysis; moreover, it is a valid methodology for researching social processes and recognizes the co-constructed nature of reality (Charmaz, 2006; Daly, 2007). Constructivist grounded theorists emphasize the existence of multiple perspectives of reality and on developing theory through a process of constant comparisons between and across emerging codes, concepts, and new data collected (Gasson, 2004). As Gasson noted, "[Grounded] theory is based upon patterns found in empirical data" that reflect the *lived* experiences of individuals and groups (p. 80).

In keeping with grounded theory, we recruited participants of the Eating Together Study with the help of Alzheimer Society chapters in Southwestern Ontario using selective and theoretical sampling techniques (Charmaz, 2006). To be eligible, both members of the dyad were required to be willing to participate in the study and able to speak English. Persons with dementia had to be aged 55 or older and in the early to mid-stages of dementia. Their primary family care partners had to be living in the same household or community.

As patterns and themes began to emerge from participant interviews, we used theoretical sampling to identify additional dyads that might help elucidate those themes and explore them in new contexts. Five trained interviewers conducted dyadic interviews, followed by individual interviews approximately two to four weeks later. Approximately one and two years later, the dyads were interviewed again, following the same process.

In the first year of the study (2005-2006), we interviewed 26 dyads and one triad, including 27 persons living

with dementia and 28 partners in care. This sample included 11 male (41%) and 16 female (59%) persons living with dementia ranging in age from 56 to 88 years. Care partners ranged between 30 and 88 years of age. Twelve (43%) were male and 16 (57%) were female. There were 19 spousal relationships and eight adult-child relationships, including three daughters, three sons, one niece, and one daughter-in-law. Diagnoses were based on self-report at the first interview (diagnoses included 1 frontal-temporal lobe dementia, 1 vascular dementia, and 25 Alzheimer's disease).

We used Reisberg's (1988) Functional Assessment Staging (FAST) Scale to determine stage of dementia, which ranged from stage 2 to stage 6D, although the majority were in the early stages (FAST stage 3 or 4) of dementia. This scale identifies stages on the basis of self or care partner's reporting on functioning for daily activities. The FAST scale has seven stages, the last two having multiple incremental levels (e.g., stage 2: subjective work difficulties) to late dementia (e.g., stage 6D: urinary incontinence; 7F: spends all day sleeping, lack of awareness). This scale was chosen as it can be readily completed during a qualitative interview setting in which mealtime activities are discussed, and it would give the researchers a sense of the functional-cognitive changes happening to the participant with dementia. The most important element in this interpretive investigation was how persons with dementia and their family care partners described their experiences and attached meaning to those experiences (Charmaz, 2006; Daly, 2007).

By year 3 of our study, 18 dyads remained; two persons with dementia and two care partners had died, and others moved out of the area or into long-term care and were not located. Of the dyads providing data in year 3, 13 were still in the community and four persons with dementia had moved into a long-term care home (nursing or retirement). One couple had moved into a retirement living facility.

Data collection and analysis occurred concurrently so that emerging themes could inform further data collection. Over three years, five interviewers were involved in collecting data from the 26 dyads and 1 triad (mother with dementia, son, and daughter-in law). Upon completion of interviews, researchers wrote a post-interview reflection on key concepts and ideas identified in the interviews. Interviews were transcribed verbatim; and the interviewer listened to or read them during the time span between the dyadic and individual interviews, which typically occurred one month apart. To identify a substantive theory of the role of mealtimes within the dementia context, we used initial coding, focused coding, theoretical coding, and constant comparison as we will explain. Each interviewer created

a key-theme document, which identified key concepts and exemplary quotes from each dyad family. The interviewers shared these documents with the research team to help with identifying and defining emerging themes.

In initial coding, each interviewer analyzed data using line-by-line coding and constant comparison, staying close to the data while remaining open to theoretical possibilities. Following initial coding, we engaged individually and as a group in focused coding to synthesize, explain, and categorize larger segments of data. Concept maps were developed for each family in year 1 to help identify emerging themes and concepts that were consistent or that differed across families. Finally, in theoretical coding, we developed the relationships between categories and aimed to move the analytic story in a theoretical direction (Charmaz, 2006); this typically involved a smaller subset of the research team to bring together the theoretical linkages and present them to the rest of the team for discussion and confirmation. Memo-writing occurred throughout data analysis to fill out categories and make comparisons among data, codes, and categories.

During the first two years of data collection, the team met every two to three months for half-day meetings to share key-theme documents and concept maps that had been made for each dyad. In doing so, we could compare data by individuals and dyads. We could also, as a group, identify common and variable themes and patterns, which allowed for comparisons between individual and shared experiences and meanings. These regular team meetings helped to guide theoretical sampling decisions and further data collection. Decisions were made jointly about categories emerging in the data and how the team might “fill out” the themes. This was done through recruitment of new participants who represented different family relationships. For example, while we had several spousal relationships at the beginning of our data collection, we had fewer adult-child relationships. As data collection went on, we purposely sought out adult-child dyads to further develop our emerging themes. Additionally, we added questions and probes to the interview guide for subsequent interviews to specifically uncover process and connections among concepts emerging from the data. As the theme *adapting to changes* evolved, we targeted interview questions around how change was identified and recognized to be meaningful and how and when adaptation occurred.

These team meetings led to the identification of the three core concepts – *being connected*, *honouring identity*, and *adapting to an evolving life* – and their interrelationships which make up the Life Nourishment Theory. We continued data collection until reaching theoretical

saturation, when no more new properties or theoretical insights were revealed (Charmaz, 2006). After the first year of data collection, we presented our preliminary findings to 10 families in a group forum; they offered insights into their experiences, contributing additional examples of the themes, and all agreed that their experiences and voices were accurately and broadly reflected in our interpretations.

## Findings

As mentioned, the overarching concept of the Life Nourishment Theory is that “mealtimes are the way we are”; accordingly, we believe that the experiences and meaning of mealtime changes exemplify how families experience dementia changes more generally. In essence, mealtimes reflect the life that is lived, and by examining mealtime changes, we have a window into the rest of life. Selected quotes from the study participants exemplify the process of *adapting to an evolving life* through mealtime changes. In fact, our findings demonstrate the interconnections between changes and adaptations in daily life in general, and changes and adaptations related to mealtimes more specifically; they are so intertwined that in some cases it is difficult to tease out mealtime changes on their own. For example, if a dyad had challenges with lethargy and in dealing with this change due to dementia, this specific challenge was noted as also affecting mealtimes. In the quotes that follow, “PWD” indicates that the quote was spoken by a person with dementia; “CP” indicates that the quote was by a care partner of the person with dementia; and “Dyad” indicates that the quote came from a dyad interview (as opposed to an individual interview with either the person with dementia or the care partner).

*Rosemary (PWD):* My capabilities haven’t changed but how much I can do has changed. So the volume of what I’m able to do is less now. ‘Specially, um ... I’m a little groggy today [laughs], um, evening stuff. I’m finding evenings, I’m pretty tired in the evenings now, and in fact sometimes I think I –

*Evan (CP):* –fall asleep at the dinner table.

*Rosemary:* Yeah [laughs]. Evan got – a couple of times he said, um, “Mom, I think you better take your meds”, and “Mom, maybe you better go and lay down now”. (Dyad 5, year 2)

In the above exchange, Rosemary’s lack of energy affected all aspects of her life, including mealtime. Thus, we believe our findings on adapting to an evolving life have important implications beyond mealtime changes.

*Adapting to an evolving life* is a fluid and dynamic process described by our participants as they adjusted

to mealtime changes. Ideally, as changes occurred, persons living with dementia and their care partners became aware of the changes, attached meaning to them, and responded to them (see Table 1). While some dyads adjusted to change with relative ease, for others, the adjustment was more difficult and depended on the type of change required and its significance to their lives. Adapting to an evolving life involves several sub-processes: (a) triggering awareness, (b) attaching meaning to change, and (c) responding to change.

**Triggering Awareness**

Triggering awareness, the first sub-process of the *adapting to an evolving life* process, refers to how participants realized that changes in the dementia journey had occurred or were occurring. Change could sometimes be difficult to recognize, but awareness was triggered either through (a) inklings of change or by (b) experiencing a seminal event.

*Inklings of change* occurred when a series of small incidents gradually led to the recognition that a new level had been reached in the dementia journey. For example, Kathy (PWD) noticed that while she could still cook from memory and had no challenges with using appliances or food safety, she was finding it harder and harder to follow a recipe:

I will be honest. The one thing I'm noticing – I used to love to bake, um, cookies, didn't I? And, um, but I don't seem to do that as much now. I'm not as comfortable following [a recipe], because the cooking I do for [CP] Jeff's dinner is just from memory. I just know how to put it together. But to follow a recipe: I'm *not* fond of doing that. (individual interview, year 2)

Thus, this gradual change was slowly being noted, and Kathy was withdrawing from specific cooking activities that challenged her capacity. More often than not, the small, gradual changes were noticed first by care partners. In year 2 of our study Roberta (PWD) said: "I don't know my gradual changes, do I?" Her husband

and care partner, Eric, responded: "Well, often not". (Dyad)

Another care partner in a different interview told us about some of the small changes he noticed in his spouse. He noted how these changes may go unnoticed by those who were not always around the person living with memory loss:

It's hard to pick out any one thing. It's just a general overall deterioration. There's not really any one simple thing that you could say, "OK, that was it". But just little things. Like she used to be always able to go to the store and if she wanted something she would remember from the time she left home until she got there. [chuckling] But the other day we went, I guess it was Sunday, we went out and I stopped at [the grocery store]. I left her at [the store] and went and did what I had to do. Come back to pick her up. But before she went into [the grocery store], she had said to me, "Now what was I supposed to get?" There's a *lot* of that kind of thing going on but you don't ... say friends [come] in to talk to her: they don't notice that this is happening. But I'm there right with her so I notice it more ... she asks questions that she knew the answers to 20 minutes ago. (Martin, CP, individual interview, year 2)

In addition to inklings of change, awareness that change was occurring could be the result of *experiencing a seminal event*. This was usually a dramatic or crisis situation that led to immediate changes in how mealtimes were conducted. Rosemary (PWD) told us about having fires in her kitchen, which signified to her and her family that it was time for her to stop using the stove on her own, and for her son and care partner to take over this form of cooking:

So it would be in around that time, around 2000, that Evan [CP] pretty much took over. Because at that time I had also experienced the fires. And it wasn't that I was burning things, but because I had an actual fire, and I didn't know exactly what I did to cause that fire ... (Rosemary, PWD, individual interview, year 1)

**Table 1: Sub-processes and categories of *adapting to an evolving life***

Sub-processes	Categories	Properties
Triggering awareness	Inklings of change Experiencing a seminal event	
Attaching meaning	Continuing participation threatened Challenging emotional connections and threats to relationships Retaining peace of mind Meeting basic needs	
Responding to the change	Transforming and living with change  Maintaining a holding pattern Resisting change	Learning about the change Doing things differently Mobilizing resources

One couple shared a story about experiencing a seminal event in which the person with dementia came back from the grocery store without the appropriate food for dinner, which signaled to his care partner that something was really wrong. This event eventually led to a diagnosis of dementia.

*Art (PWD):* Well this is an odd, a rather extreme example. About three years ago you asked me to go out and get something nice for dinner.

*Faye (CP):* Yes.

*Art:* I came back with a jar of relish.

*Faye:* I could not believe.

*Art:* I must have thought, "Oh I got the relish". But I didn't get anything to go *with* the relish, like hot dogs. I brought back a jar of relish for dinner, yeah.

*Faye:* You said, "Oh look". And he was so excited about it. He walked in the door and he said, "Look what I got, the perfect thing for our dinner tonight"... I was absolutely stunned and so that was ... the start of the confusion and the impairment that we found out [about] quickly after that. (Dyad, year 2)

## Attaching Meaning

Once awareness of a change had been triggered, families attached meaning to the change in terms of how it threatened or challenged valued ways of being and relating. When a change was meaningful or interpreted as significant, participants experienced a host of feelings that indicated something of value was at risk in their lives. Such feelings included hurt, anger, fear, worry, loss, failing, frustration, aggravation, a sense of stress, and restriction. Participants rarely, explicitly in their conversation, made a direct connection between their feelings and threats to valued ways of being, but this link became evident through their chosen course of action to resolve the conflict they felt. In other words, their response to change was aimed at upholding the ideal being challenged, thereby helping to alleviate associated emotions. The process of attaching meaning to mealtime changes encompassed feelings related to the change and recognizing what was truly important that was being affected by the change. We identified four categories of attaching meaning. These categories describe how meaning was attached to experienced changes. They include: a) continuing participation threatened, b) challenging emotional connections and threats to relationships, c) retaining peace of mind, and d) meeting basic needs.

*Continuing participation threatened* occurred for both persons with dementia and their care partners as meal preparation and other mealtime tasks or activities

became more difficult. When continuing participation in such tasks or activities was important to the individual or couple, and yet was perceived to be threatened by the change, various emotions surfaced. In some cases, frustration arose when participants with dementia had difficulty with tasks that had been easy in the past:

Well it's just that she would get confused, uh, couldn't find something or a recipe that she knew how to do. She would have forgotten a part of it or something and then she would get quite frustrated that she couldn't do it. (Harry, CP, individual interview, year 2)

Not being able to participate as desired also led to feelings of inferiority:

What can annoy [my wife] is my – I would call it lethargy. It's not depression, it's like this morning: [I said] "Is there anything I can help you with?" Like I knew there was but I needed direction. I didn't want to sit there and do nothing. And sometimes it makes me feel inferior. (Art, PWD, individual interview, year 2)

Meaning was attached to mealtime changes through the feelings experienced and recognition that continuing participation in mealtime preparation was valuable to the person with dementia. By attaching meaning and by understanding the implication of the change, families could move forward with strategies to maintain a suitable or desired level of participation.

The second category of attaching meaning, *challenging emotional connections and threats to relationships*, was evident in dyads who valued their relationships; therefore, the feelings they expressed at changes in their relationship that occurred as a result of dementia were strong. For example, in the case of Debra (CP) and her mother Alice (PWD), verbal communication and recognition of their mother-daughter relationship was viewed as meaningful. From year 1, Debra was concerned about her mother's not being able to recognize who Debra was as Alice's dementia progressed. Debra used conversation at mealtimes as a way to keep this connection:

[My goal is] To keep her talking. I find that she doesn't talk as much as she used to. And ... like me knowing what's going to happen really sometimes sets me back. So I try, like I say, to keep it [the talking] going as long as I possibly can, at mealtimes. (Debra, CP, individual interview, year 3)

Over the three years of our interviews, Alice, Debra's mother, gradually became less vocal. Yet, the dining table, a source of family cohesion and symbol of conversation to Alice, provided the stimulus needed to help maintain the communication needed to sustain this mother-daughter relationship.



The manner in which families emotionally reacted to changes could further affect their relationship. For many, how they communicated and interacted as a couple was affected by progressive memory loss. Mealtimes were a common time and natural occasion for relationship building and for making connections through emotional support and conversation. When a dyad's relationship was challenged by changes in relating to one another, it was especially difficult to deal with emotionally.

Some days he says some pretty hurtful things ... But I don't dwell on that stuff 'cause I know it's not real you know, that when he's like that, that's not [my husband], that's Alzheimer's yapping. [chuckling] So I just have to remember that and not get upset. (Miriam, CP, individual interview, year 2)

Maintaining a positive relationship was the ideal that dyads strove for. Various strategies were used to respond to various changes: dyads tried to not take things personally and interpreted the "problem" as part of the disease progression and not because of hurtful intent. It was more important to keep the relationship positive rather than criticize or get angry. For example:

Well, sometimes you don't know what to do, because it's a different ... well something, a different behaviour [at meals] comes up. Now you have to cope with it, and you have to not lose your cool. You know you can get angry, and that's not good for him. It's not good for me either. So I have to learn not to be angry. (Donna, CP, individual interview, year 2)

This comment was made when the person with dementia was starting to have challenges with etiquette at mealtimes, by eating directly from the serving bowl. Although the behaviour itself did not impact this particular couple's relationship per se, Donna had had experiences in the past of getting angry with Mark (PWD) over changes in his behaviour. She learned that this greatly hurt him and set their relationship back. As the strength of the emotional connection between Donna and her husband was threatened, strategies were needed – such as Donna's learning not to be angry but to stay calm – to preserve emotional connections and protect the relationship.

In addition to continuing participation in meaningful activities and maintaining a positive relationship, *retaining peace of mind* was also valued by participants with dementia and their care partners. With continual changes that could affect perception and judgement, peace of mind with cooking activities was a common issue. As we have noted, in addition to the emotions that the study participants expressed, participants made significant adaptations, demonstrating that for

these individuals the adaptations were meaningful changes. For example, Rosemary (PWD) and her family created rules around use of the stove, which provided peace of mind for both her and her family who lived in the same household with young children:

But I DO NOT, ever, ever, ever use the stove when ah, Evan [CP] isn't home. Because I've had two fires, so I know that's not a good thing. So I don't use the stove when somebody's not around. So, um, if I'm here alone, then I'll rely on the microwave. (Rosemary, PWD, individual interview, year 1)

In almost every interview over the three years of data collection, Rosemary retold this story thereby demonstrating the meaningfulness not only of cooking and preparing food for her family, but also of the threat to her peace of mind that resulted from the fires. As well, this story also revealed the work that was needed to restore peace of mind, which was achieved by the rules she and her family placed on her cooking behaviour.

In the following series of quotes, we can see further how meaning was attached to the changing ability to cook meals and how desiring peace of mind led to adaptations by Harry and Bonnie, a husband and wife dyad, in which Bonnie had dementia and had the role of cooking. In the first year of interviews, she commented:

I like to try new things. I think it's an experiment, and you're learning. I think you feel as though you're accomplishing something different, you know? And I try to cook the foods that he likes. So therefore [when] we do what a *man* likes, you're free! (Bonnie, PWD, individual interview, year 1)

This quote demonstrates how her continued participation in cooking was meaningful to her role as wife. Between years 1 and 2 of interviews, Bonnie started to lose the capacity to plan and carry out simple mealtime activities. To adapt to this mealtime change and retain peace of mind, her husband Harry (CP) initially, in year 2, said he "made it a point of sitting here at the table and watching her and so on, and if she asked where something was I was able to tell her". However, as his wife progressed during the year, this situation became more challenging, so he tried a frozen meal service to ease the cooking burden but found that she was resistant to the use of these foods:

Bonnie never wanted to eat them [frozen Meals on Wheels]. And I thought they were very good. And I kind of put it down to the fact that she was disappointed that she wasn't doing it [the cooking], that this is something that I've *had* to get to bring in, you know. (Harry, CP, individual interview, year 2)

Harry tried this strategy because it provided him peace of mind to know they were consuming good-quality,

safe meals. Sometimes changes required other shifts in the ways meals were handled or, more significantly, to consideration of placing Bonnie in a care facility. In any case, the risk of harm ultimately became too great and “retaining peace of mind” became an important way of attaching meaning in order to adjust to the changes. In Harry and Bonnie’s case, Bonnie’s resistance to eating frozen pre-prepared meals concerned Harry. He worried about food safety and his capacity to take over the cooking role, but also that Bonnie was not eating well. This, in conjunction with other changes associated with Bonnie’s dementia, ultimately led to a nursing home admission:

I do feel that there’s been a big weight lifted off my shoulders, I have to say that. And I know that she’s – I’m satisfied ... that she’s getting much better care now than I could have given her. It’s best for her. (Harry, CP, individual interview, year 2)

This evolving change in the role of cooking and the meaning attached to that role, as well as to how peace of mind was managed, demonstrates that what is considered meaningful can be different for each person.

Finally, attaching meaning to changes at mealtimes was also evidenced in the concern for *meeting basic needs* that a mealtime fulfilled – specifically, good-quality, healthy food, and eating together.

In an interview, Connie (CP) recognized the need to maintain good meals because her aunt, Isobel (PWD), had diabetes, and Connie felt concerned when difficulties with cooking increased. Isobel lived alone and could manage adequately, although sometimes she lacked motivation for cooking and would skip meals, putting her at risk with her diabetes:

She can still care for herself, it’s just the meals are the challenge, and with her having the underlying diabetes that makes it a little more of a concern than just the fact that [meals] can sometimes be sporadic. (Connie, CP, individual interview, year 2)

Participants attached meaning to the declining ability to cook all meals from scratch, but attached even greater significance to the more basic need of eating for good health.

The longitudinal nature of this study provided the opportunity to identify how meaning was attached to evolving changes at mealtimes. The following excerpts describe a mother and daughter who lived separately but ate three or four meals together each week during year 1. By year 2, Emma (PWD) had transitioned into a retirement home. Over time, it could be seen in this dyad that changes in mealtimes were still meaningful as they resulted in emotional responses and various strategies to support what the dyad valued. However, these excerpts also demonstrate how the “basic needs” met by the mealtime also changed over time:

Well, it’s a great chance for me to check in with Mom, and see how she’s doing and spend some time with her. And I need to eat anyway, and sharing a meal is always nice. It is nice, I mean there’s definitely, when you’re eating with another person, there’s something really nice about sitting at a table, and having all of the items, eating them all at the same time, all on the same plate. And I think, nutritionally I probably eat better with Mom, than I do when I eat on my own. (Melissa, CP, individual interview, year 1)

And

I’ve been limited to just the stovetop at the moment. They’re a little worried about what I’ll do if I have the oven on, you know, if I’ll make a mistake or something. ... I do miss cooking. Yeah. Every now and then I think I want to make a pie. “No,” [I think], “I better not, [laughs] no.” But I will someday. You know I will make a pie ‘cause I know I can do it, and I’m sure it will be OK. I won’t tell anybody I’m going to do it [laughs] if you don’t! (Emma, PWD, individual interview, year 1)

And

I think it’s important to recognize and grieve the losses associated with the way things used to be. And then also to look at the ways in which the change [moving into retirement home] will make things better. So ... look for the good in that new normal. So if mom and I can’t be quite so spontaneous [with eating out] or if we can’t be quite so hands-on in preparing food ... at least the eating together is more focused on the *eating together* and not so much around the logistics. (Melissa, CP, individual interview, year 3)

We can see that in year 1, Melissa felt that the eating of good food and “checking in” were basic needs that could be met by preparing food and eating with her mother a few times a week. For Emma, being able to bake provided her with a sense of independence that she valued. Emma used to bake pies and give them to people in her younger years when they needed a bit of “nurturing”. To her, the basic need met by mealtimes was showing this nurturance to others. By year 3, this dyad had redefined what was “most basic” about mealtimes together now: the being with each other and enjoying each other’s company.

Some mealtime changes were not meaningful. For some dyads or individuals, each change in mealtime routines was not overly significant and little meaning was attached, while for others, because the change affected a strongly held value, significant meanings and thus feelings were attached. For example, Ann (PWD) was fine with no longer preparing food when she and her husband moved into a retirement home. Food

preparation was becoming too challenging and threatened their peace of mind. Relinquishing this role brought relief:

*Interviewer 3:* Do you miss handling food in any way?

*Ann (PWD):* No not really, no. Because I was to the point, I was having so many problems, you know. And it was *frustrating*. Like it was a *frustrating* thing where I don't have that now. I'm here [at the retirement home] and I don't have any of that. I don't have to worry. I don't have to say, "Well, what are we going to eat today? We should go get some, or whatever, or what should be have?" I don't have to worry about that. It's all there. (Individual interview, year 2)

Kathy and Emma, on the other hand, strongly identified with food preparation as their "role" in the family and expressed their concerns about the loss of the role:

*Interviewer 3:* Could you imagine what you'll feel like if you couldn't do it [cook for spouse]?

*Kathy (PWD):* It would be a great disappointment. Because it gives me a lot of pleasure, like I enjoy throwing things in and having a taste: "Mm. That tastes good." That's a pleasure to me. (individual interview, year 3).

And in another exchange:

*Melissa (CP):* I'm kind of thinking it would be nice to have Christmas at my place. And then bring my mom over. And you could then cook with me. [laughing]

*Emma (PWD):* Oh that would be fine. *I'd love* to do that. *I really miss cooking* (Dyad, year 2).

What became clear in our data was that the meaning of a mealtime change, such as a woman's losing the cooking role, varied depending on how closely aligned the change was with other values, and as with Kathy and Emma, their identity. When a change was not particularly meaningful, or became less meaningful over time, the emotional response was minimal and adaptation occurred more readily. Those changes that posed a threat or harm to the dyad were interpreted differently and resulted in deep emotional responses. In these situations, adjustment to the change was often more challenging.

## Responding to the Change

Participants described a range of responses to mealtime changes. Some responses were more positive than others. Positive response to change involved transforming; some participants experienced a "holding pattern" rather than undergoing active change, and others, at least initially, resisted the change.

## Transforming to and Living with Change

Transforming occurred when participants were able to come to terms with the mealtime changes and adjusted their lives to accommodate them. They did so by learning about the change and doing things differently. Along the way, they mobilized their resources to help them ease into the change. Participants *learned about the change* through research and experience. One person with dementia noted that living with memory loss was a learning process for everyone involved. For example, Rosemary (PWD) talked about how she and her son had to learn how to work in the kitchen together: "As I say, it was a learning process in the beginning. Everything is a learning process". (Rosemary, PWD, individual interview, year 1)

Participants used the Internet, support groups, and other resources to learn about what was happening to them and find ideas to manage changes. A care partner talked about the various ways he did research in order to learn how to best support his wife:

So I mean, at least going to caregivers [support group], you have a pretty good idea, you know, what you're up against. And sometimes there'll be things on the Internet, articles that will come up, this sort of thing. There's one that comes about every week, and I don't get time to read it all. (Harry, CP, individual interview, year 1)

It was through such support groups and networks, for example, that Harry learned about a private meal delivery program, whose services he tried in order to support mealtimes in their home.

Learning also occurred through experience, often through trial and error as participants tried possible solutions and figured out what worked and what did not. Connie (CP) spoke about trying different options for ensuring that her aunt had healthy meals, such as using a slow cooker, and using a meal preparation service (which provided cut-up ingredients that customers assembled and took home for meals that could be put in the freezer):

And you try it and if it doesn't work then – eh, go on to the next thing, Okay, what else can we try, you know. Like everything, life is just trial and error. Try this; if it doesn't work, well, how do we revamp it and how do we re-introduce this one. (Connie, CP, individual interview, year 2)

This process could be very difficult and slow: "I always find something new. It's like learning to write with your left hand. So we're learning to write. [But] It's not just that, it's how to approach it". (Martha, CP, dyad, year 2)

Once participants learned about a given change, they began *doing things differently* to address challenges.

Doing things in different ways helped to avoid frustration: “I guess I don’t really like it, but you learn new ways of adapting. It’s like – you know, are you going to sit frustrated about it, or are you going to come up with new ways [to adapt]?” (Martha, CP, individual interview, year 1)

In the case of Martha, and her husband, Peter, with dementia, they had to continually adjust their cooking habits. Peter was used to preparing his own breakfast and lunch and was making some errors in the kitchen; moreover, they both were experiencing changes in physical health that necessitated changes in their diet.

In a different example, Isobel (PWD) talked in year 3 about having alternatives in place in case something did not go as planned: “I’m kinda getting used to the surprises now that when I go to prepare something, maybe the thoughts aren’t there to do it ... I just, oh well, okay then we’ll go to plan B”. Having alternative options, such as a frozen dinner she could heat up in the microwave, allowed her to manage the change and avoid frustration. Isobel’s care partner addressed the compromise that was required in order for Isobel to be able to transform:

...they get stuck ...and they don’t think that “I’m still me, and I’m still capable and I can still do this, I just have to find a different method of doing it”. If it’s somebody who loves to cook, well okay, maybe you’re not going to be preparing the whole grand meal you used to but you can still help out in the kitchen, you can peel the potatoes, you can mash the potatoes, you can, you know, beat down the bread. There’s ways of still participating – just look for them. It doesn’t have to be the all or nothing ball of wax. It has to be a compromise. (Connie, CP, Dyad, year 2)

Participants did things differently in a variety of ways, including (a) eliminating or reducing stressful tasks and events; (b) taking one’s time, or pacing, to match skill level; (c) doing things together with a care partner; (d) simplifying tasks; (e) compensating for losses by engaging in explicit activities devised to overcome a change (e.g. creating a list of items NOT to buy at the grocery store to avoid over-purchasing) and (f) changing goals to match abilities.

Participants also transformed themselves as a response to change by *mobilizing their resources*. They drew on both their personal coping mechanisms and the support of others to maximize their abilities to adapt. One participant talked about the importance of having the right attitude and being willing to change in order to be able to live with memory loss:

Gordon (PWD): You’ve gotta have it here in your own mind to do it or not do something, fight it or whatever. Any other help doesn’t, whether it’s

there or not, doesn’t mean anything to the person. Well, basically it [positive attitude] has to be in the mind. Yeah. I would say I can’t see anything else influencing it.

Interviewer 4: And also I think it’s your attitude of accepting what’s going on but it’s still making the best of it which is what you do and then using the humor to work along with that.

Gordon: Yeah. (Gordon, PWD, individual interview, year 2)

Some participants drew upon humour and their spirituality to better cope with mealtime changes, while others focused on the positive aspects of their lives instead of the challenges. Participants reframed their perspectives by reorganizing priorities and spending less time worrying about things that once seemed very important. In doing so, they were able to change their expectations about daily life. For example, when we asked a study participant if she was planning to make her usual pies for an upcoming family event:

Donna (CP): Oh yes, yes. We do that for Christmas. I take some out to [daughter’s house]. I don’t know if I’ll make them though. I may get up to [bakery].

Mark (PWD): You’re the best maker upper.

Donna: Oh I know but I’ve changed that too. I buy my pie crust now. (Dyad, year 2)

When study participants were able to draw on personal coping resources to find ways to live with dementia, they were able to transform in response to the change, although sometimes it was a lengthy process. Rosemary, for example, talked about how eliminating stressful things in her life helped her to be happier:

When you live in the moment a lot of the things that used to be important for you aren’t anymore. And when you eliminate all those things that aren’t important anymore, a lot of the stress goes with it. And if you don’t have stress in your life, then you’re happy. I don’t know if it’s ... it took us a while to work through and get to that point, but it’s well worth it. (Rosemary, PWD, Dyad, year 2)

In addition to drawing on personal coping resources, participants mobilized resources by accessing external services, including formal support from community organizations and health service providers, and informal resources, like friends and family. For example, Martha (CP) was recently diagnosed and undergoing treatment for a serious health problem that made it challenging for her to prepare food for and eat with Peter (PWD). A few years earlier, Peter had been assessed to determine his health care needs and be provided information on potential services.

And all of a sudden [I thought], “Veterans!” I remember them saying they would pay for Meals on

Wheels. And we haven't needed Meals on Wheels [but] I'm thinking, all of a sudden, I ought to call them, and it [was] implemented just like this. (Martha, CP, individual interview, year 3)

Although many participants were able to adjust to the changes in their lives, some participants found the process of transforming to be quite challenging and time-consuming. Rosemary (PWD) noted just how difficult it was to find ways of adjusting that worked for both herself and her children:

But it was a lot of work. It took a lot of trial and error to [find] something that was totally comfortable, equally as for them as well as for me. And that, that was really important for me to find that balance where it was something that worked equally well for them as well as for me. (Rosemary, PWD, individual interview, year 1)

Learning about what was going on and subsequently adjusting routines, roles, and other aspects of daily life was demanding, regardless of the resources that participants were able to mobilize. It was a struggle to find a way forward that would work for individuals as well as the family unit.

#### *Maintaining a Holding Pattern*

When participants were unable or not ready to transform, they responded to a change by *maintaining a holding pattern* in which they were waiting in uncertainty and experienced change with minimal to no transformation. For example, in year 1, Bonnie (PWD) was beginning to have challenges with cooking. She was not fully ready to give up this role, but Harry (CP) was unsure of how to support her in a way that protected her dignity and supported her participation.

Bonnie (PWD): I'm not one to try a whole lot of things [talking about changing way of cooking]. I do the things that I know, know what to do, and enjoy doing, and that's it. If anybody else wants to do it a different way, well go to it!

Harry (CP): Yeah, that's one of the little things. We'll do something and then I say, "I told you, I go by what it says on the package". Bonnie will have the package open and say "This is the way I've always done it, this and this and this". And then we'll have a little –

Bonnie: Well, I don't have any complaints. So why change? (Dyad, year 1)

Harry was clearly ready to start taking over more of a decision-making role at meals, but Bonnie was not aware of her potential challenges or ready to transform. Other families talked about living in denial until changes had to be addressed. For these families, focusing on the moment was a coping strategy in itself.

For others, when a change was recognized, they reacted passively rather than proactively by addressing concerns around the change. One couple discussed waiting in uncertainty and avoiding making compromises around challenges they were having over differences in food preferences at mealtimes. They talked about eating out every day of the week, either for breakfast or lunch:

Peter (PWD, year 1): No, we don't mark down on concrete stone that ... this is what you're going to do. We mark it on ice, so it maybe it melts in five minutes [laughs].

Martha (CP): See, it's something too with, you know, to me, with the challenges [differences in food preferences] that we have, I guess the best way of [addressing] it is to say "oh, let's go out for breakfast."

Another person with dementia addressed the difficulty she experienced in being able to make a decision regarding how to change:

And then as I say I think I'm on the cusp of making changes. But I'm sort of betwixt and between with that. A little confused right now with the whole issue. And it's difficult. It's a difficult issue to maintain nutrition, as I'm seeing the journey right now. (Isobel, PWD, individual interview, year 1)

For some participants who encountered changes, a holding pattern progressed to transforming with the change, allowing for some adaptation. For other participants, the relevance of the change was not important enough to warrant significant transformation. In one case, Gordon (PWD) recognized that at some point adaptation for himself would be impossible and he would be in a period of waiting as changes continually occurred:

I would say two people under normal circumstances have a better chance of adapting; they can do things. Well if you've got this here [dementia], what adapting can I do?... If my memory continues to get worse, what am I going to adapt? What? I'd like – give me [a] clue. (Gordon, PWD, individual interview, year 2)

Thus, being in a holding pattern was a form of *responding to the change* that was potentially but not always transitional. Being "betwixt and between" for some study participants involved passive responding with little forward movement.

#### *Resisting Change*

Although some study participants were able to transform themselves and live with the changes they experienced while others initially underwent a holding pattern, others actively resisted change. Care partners could

resist change by hesitating to accommodate changes in behaviour, while persons with dementia resisted change by refusing to adapt or refusing to accept help:

I now invariably cut her meat up for her – which sometimes she resents, like heck. Last night at dinner I started to cut it up for her; she said “I can do that”. And in the end she doesn’t. You know that’s one of those silly things. And this is understandable, it’s one of those changes that go along. And, if I didn’t do that she’d eat all the vegetables probably and leave the meat. [My] cutting the meat gives her the option to eat it. (Duncan, CP, individual interview, year 2)

Often this resistance to adapt to a meaningful change led to anger on the part of the care partner and to feelings of frustration for the person living with dementia. For example, a person living with dementia who was required to eliminate salt initially felt angry about the change in diet:

There’s no taste to it. I’d sooner have salt and go to the bone yard than not have salt and have to suffer and say [to myself], “you can’t have salt, you can’t have salt, you can’t have salt ...”. Get out of my life! People and their stupid ideas. (Peter, PWD, individual interview, year 2)

By year 3, his wife had altered her cooking methods and Peter recognized the excessive salt in restaurant and processed food. Later, Peter used this as an excuse for their diminished eating outside of the home.

Care partners resisted change by either denying the presence of dementia or refusing to believe that change was necessary. They felt angry when their loved one forgot instructions or details and was unable to perform his or her typical mealtime roles. For example, Richard (PWD) talked about feeling badly when his care partner sent him to get a food item and he forgot what she had asked for, blaming himself for forgetting:

Because with my memory loss or, let’s say, like [I’m] forgetful, I keep forgetting things and she says something, I go down there [to the basement for a food item], I have something else on my mind, then I have to ask again. And then she thinks I don’t pay attention. And that hurts me. I wouldn’t say it would hurt in a bad way but I think [to myself] “Yes, why don’t you open your ears” you know, or “Why don’t you listen?” (Richard, PWD, individual interview, year 2)

Isobel also acknowledged that although she often knew that she needed to make changes, she did not necessarily follow through because this would indicate acceptance of the change and the progression of the disease:

Learning to accept them [changes] for me is what, yeah ...I would know them, but I wouldn’t neces-

sarily accept them ... I’d say to you “Yeah, I understand it” and “Yeah, I know it” but behind your back I’d say “Ah phooey to that, I’m not going to do that”... Sometimes I want to be mischievous and sneaky. (Isobel, PWD, individual interview, dyad, year 2)

For some study participants, resisting change could be seen as negative if it blocked the ability of the person with dementia and their care partner to transform and live with the change. For instance, Roberta explored how hard it was to accept the changes in her life which made it difficult to move on: “I don’t know if I can ever accept [losing my license]. I have to accept it. I guess, I have to go on with life. I don’t know. How do I accept that? I don’t know” (Roberta, PWD, dyad, year 2).

Resisting change was not always negative and sometimes was a technique that persons with dementia used to resist the stigma surrounding dementia and threats to identity. As Isobel (PWD) indicated, being mischievous and sneaky were valued aspects of her sense of self and represented her value of being independent. Thus, resisting changes that challenged valued ways of being were a way to maintain a positive sense of self. At various times, depending on the type of change faced, families resisted change, refusing, at least at that point, to accept a change as inevitable.

### The Process of Adapting to an Evolving Life

Although change is a part of life in general, families living with dementia experience changes they could never anticipate. Their lives are truly evolving each day, requiring continual adaptation. This cyclical process is ongoing, however, and changes can mount up quickly before adaptation can take place. For example, Bethany (CP) and Gordon (PWD) typically had a nonchalant attitude towards meal preparation. With Gordon’s diagnosis of diabetes, Bethany recognized the need to be more involved in ensuring healthy meals and helping Gordon with supper preparation. When asked by the interviewer to identify when mealtimes became less social and more functional, Bethany stated:

I don’t know. I’d say... maybe the last 6 months or so. And I think right now with Gordon’s [diabetes] diagnosis, [mealtimes were] like it was another burden. And so, although as I say we have been eating properly for, you know, a good few years, it’s like it’s even more important [now]. And we need more of a routine. And that’s why at this moment it feels like it’s a burden. (Bethany, CP, individual interview, year 3)

Even health problems were not considered as important as mealtimes and were left unaddressed in the

face of dealing with mealtime changes associated with dementia. For these changes, the family lived in a holding pattern or dismissed the issue:

Actually I'm going to the doctor to find out what's going on there [why I'm lethargic and gaining weight]. And then this one doctor said to me, "Well we'll check for sleep apnea". I said, "Lookit, I've got so many things wrong with me, please don't start on that one". [chuckling] I just don't need another thing to check in on me. Because I just went through so many things in the last five years. I just don't want to look at another thing. (Roberta, PWD, individual interview, year 2)

Sometimes care partners consciously decided not to address the change in order to preserve the dignity of the person with dementia. Karen, for instance, was concerned about her husband's excessive polishing of the kitchen sink; he would spend up to half an hour a day cleaning the sink:

So, I haven't really decided how to handle that [cleaning the kitchen sink], whether I should just let that go or if I should draw to his attention that that's really rather compulsive behaviour and maybe he wants to ... kind of take a look at that and realize, "Is this something I'm doing excessively that I don't need to do?" (Karen, CP, individual interview, year 2)

In some cases, this knowledge of continual change meant that decisions (e.g., travel, moving to a retirement home) were postponed as they would result in too much change and it would be too difficult to adapt. As Elizabeth, a woman with dementia, observed:

Well, I would like to stay right where I am. And then if time, as time progresses if I find that I *have* to move there [a retirement home], I would. But reluctantly. I would much sooner stay here. I think Frank feels that as long as he can cope with things [making meals] and we work together [at meals], we *will* stay here because I think moving is very traumatic.

*Interviewer 1:* In what ways, Elizabeth?

*Elizabeth:* Well there's too many changes. I mean here we have a routine, we know what we're doing every day. And it's a comfortable rut. (PWD, individual interview, year 2)

Some families resisted change and lived in a holding pattern. For some, this was a denial of the challenges being faced by the person with dementia. For example, Karen was convinced that Max (PWD) could function on his own at meals while she was away four days, even though in the same interview she talked about leaving him notes to work the microwave and finding he could not always do this correctly. Upon her return,

she found that it did not go well and that the house was a disaster:

*Karen (CP):* I decided, with the timing on it [the microwave] I kind of said I'm not going to make meals for this many days while I'm gone. I will have things available that all he has to do is open the corner [of the frozen food package] and put it in the microwave, you know, for something hot. There's always [a restaurant] salad bar and baked potatoes and so on. And so that was my strategy for that. I just decided at that point that I really wasn't going to get involved with trying to make meals for four days.

*Interviewer 3:* And were those frozen meals used?

*Karen:* Some, yeah.

*Max (PWD):* I don't know.

*Karen:* And I think he went out.

*Max:* I'm pretty sure I did but I don't remember much about that.

*Karen:* So, he didn't suffer any, he wasn't a lot thinner when I'd come home or anything like that. (Dyad, year 3)

Being able to accept a change helped families move from resisting or a holding pattern towards transforming. For example, Peter (PWD) was resistant to changing his diet in year 2. By year 3, Peter had clearly accepted that the need for the change was important for adaptation.

*Interviewer 3:* You sort of got past, being angry about the decision, and accepting it.

*Peter (PWD):* Yeah. Mm. Well for your own good, eh. For your own health. Like myself. For your own health. Change your ways. So instead of being – ornery about it, just say, "Well, yeah I guess – there's logic to it. Truth to it. (Peter, PWD, individual interview, year 2)

As well, Duncan (CP) talked about the many changes the communal environment of a retirement home entailed, including eating with others:

*Duncan (CP):* Well, when we first moved in here you – almost feel so miserable, to – again remembering probably in a, in an obscure way what life was like before and then having to adapt to this. And in the end if you suddenly realize, this is life, you might adapt to it and get it under your belt and then go ahead. That's my attitude, our attitude. So once you've accepted that, fine, make the most of it. (Duncan, CP, individual interview, year 3)

When asked about "accepting" change, families often indicated that acceptance was not the same as adaptation. For these families, "acceptance" implied that they were "okay" with the changes they were living

through. To them this was irrelevant; transformation – often, continual transformation – was required in order for them to adapt because they could not change diagnoses or progression of the dementia disease. However, transformation and adaptation did not equal acceptance. For example, Emma talked about adjusting but not *accepting* the difficult personalities at her dinner table in a retirement home:

*Interviewer 3:* There was a lady last year that was, sort of, abrasive. Is she still there?

*Emma (PWD):* Who was that?

*Melissa (CP):* I think that would be Grace and I think she, she's – I think you'd find her, her attitude, a bit negative.

*Emma:* Yeah, she has a bit of a negative attitude but it doesn't bother me anymore.

*I3:* Okay, so you've gotten used to that.

*Emma:* Yeah, I've gotten used to that ...well, you know, it just came into my own mind now: it's kind of like going to a summer camp in a way. You're suddenly part of a much larger group and you adjust. (Dyad, year 3)

How a change was identified or triggered in the minds of care partners and persons with dementia appeared to influence the attachment of meaning and responding to the change. Seminal events often signaled that participants reached a new level, resulting in greater meaning being attached; they addressed these changes by dealing with the change directly to ensure that what was valued – typically safety and independence as well dignity and self-respect – was retained. Slow changes were more likely to be overlooked, and attachment of meaning as well as response to the change seemed to be less explicit. For example:

Max (PWD) isn't as comfortable having strange people – strangers – in for dinner so we don't do that unless we have a familiar couple and just that sort of thing. It's a little compensating thing, and I think we probably all do that – don't even realize till afterward where we've compensated. (Karen, CP, individual interview, year 3)

In this case, Karen had not realized until the study interview how much smaller their social circle was becoming as a result of Max's language difficulties nor how meaningful this change was for her. In addition to the type of change and its meaningfulness, care partners described having to take the leadership role in helping the person with dementia adapt to the change. For example, Kathy (PWD) was experiencing more challenges with hosting family occasions at her home. Her family strategized how a daughter who lived close by would make the entrée and dessert, while Kathy would make the vegetables. Her husband and care

partner commented on how they took leadership with this strategy to decrease her anxiety over the meal preparations:

I think what ... we are very, as a family, are conscious [of] – and I don't want to use the word *concern* but *conscious* – is that we want Kathy to take the role that is most comforting to her and causes her the least anxiety, the least stress. So if we can do that I think maybe pushing that up [will help]. (Jeff, CP, individual interview, year 3)

Although there may initially be resistance on the part of the care partner, for many care partners the process of adapting became second nature as the disease progressed; as a new mealtime change arose, they figured out what was needed and automatically adapted their activities. For persons with dementia, adapting to change took longer because they needed time to process new information, and the adaptation became quite challenging as dementia progressed. For example, one dyad spoke of adapting to the situation of eating with others and having to develop new communication patterns after they had moved into a retirement residence. Martin (CP) spoke about personally having to adapt to eating with others, and then commented on how this adaptation challenged Ann (PWD):

You don't have a choice. Either you've got to get along or you sit by yourself. You have to talk to people or you sit and talk to the wall. You just bring yourself to the point where you say, "Well, I've just got to do it".... And we have found, or at least I've found, since we've come here, of course this is all new, all new memories. You've got to find a new place to sit at the table ... and she has new memories to make. New things to get in order, and she's having trouble with that. And I've noticed – well, I asked the doctor; I said, "Has she slipped this last month?" And he said, "Well, maybe not. Maybe it's just because she's in a new situation". (Martin, CP, individual interview, year 2)

As the dementia progressed further, some care partners felt that it was easier for the family to adapt, as the person with dementia no longer attached meaning to changes in the same way. For example, Michael (PWD) used to be quite talkative and often dominated a conversation. Eileen (CP) noted that whether at meals alone or in the company of others, he was quiet. He did not complain about this change, but rather just enjoyed the food.

*Interviewer 3:* So Michael isn't talking very much at meals?

*Eileen (CP):* No. But I'm not desperate to make conversation up. I'm ... as I think I told you before I'm a much better listener than a talker. And he doesn't seem to be lacking anything or desperate to make



conversation. So we can sit quietly there, and enjoy the food. (Eileen, CP, dyad, year 3)

Later, in the same interview, came additional reflection:

I can pinpoint this further because if we sit down at the church, at the table for eight, people sitting there and they're a little further away, then I certainly like to talk to the people immediately beside me. And those on my right-hand side. But I do not find much conversation going on between Michael and the other couple. It's, I'll say, that is not important to him. (Eileen, CP, dyad, year 3)

In addition to the meaning of the change itself, some families discussed how learning to adapt led to personal growth. For some care partners, living with the continual change resulted in a form of resilience. Others tried to find the positive aspect of changes. For example, Martha (CP) tried to view a reduced-salt diet for Peter (PWD) in a more positive light:

I believe change is – there's reasons for it and there's a rainbow at the end of things. I really have to believe that. Like, you know, are we gonna get closer? Are we, there's some reason that we're to get closer: perhaps eating at home rather than going out or something? I believe there's something that's – and we will enjoy it again, I just know, because we are those type of people. We do – I [do] – love overcoming obstacles, and I'm sure he will too, and I know we'll get there. I know Peter will be [a] happier camper, [a] happy camper when we adjust to this. (Martha, CP, dyad, year 2)

Beyond trying to see the positive aspects of a situation, this sort of comment, provided in a dyad interview, may also have been an intrinsic part of the adjusting process: by trying to find a silver lining in an otherwise devastating change, this talk could help the couple to work through the change they were currently dealing with. For other families, letting go of change helped them to move forward in positive ways. They realized that changes were peripheral to who they really were and to what made them happy. For example, Michael, who has dementia, stated in response to accepting the loss of his driver's license:

It's [his wife's being able to drive] probably is enough for most of the things that we do. Being in this room in the moment and having a nice lunch, and having done the crossword, and a nice view out of the window are remarkably pleasant and sufficient at this time. (Michael, PWD, individual interview, year 2)

Thus, the process of adapting to an evolving life not only identifies how families figure out that a change is happening, associate meaning to a change, and respond to that change, but the process of responding to the change also provides them an opportunity to grow through this adaptation.



Figure 1: Adapting to an evolving life

## Discussion

Adapting to an evolving life is a cyclical process whereby persons living with dementia and their family care partners become aware of, attach meaning to, and respond to the continual changes associated with dementia. Evolving life involved constant negotiation to ensure that the decisions they made best supported everyone involved in the caring relationship. The process of adapting to an evolving life is presented in Figure 1.

Although the Eating Together Study focused on mealtimes, our findings reflect current understandings of dementia by highlighting the creative ways that change occurs and is responded to from the perspectives of both the person living with dementia and his or her care partner. Previous research tended to focus on the experience of either the care partner (e.g., Brown & Alligood, 2004; Brown, Chen, Mitchell, & Province, 2007; Chung, Ellis-Hill, & Coleman, 2008; Furlong & Wuest, 2008; Silva-Smith, 2007) or the experience of the person living with dementia (e.g., Clare, 2002; Harman & Clare, 2006; Harris & Durkin, 2002; Parsons-Suhl, Johnson, McCann, & Solberg, 2008; Sorensen, Waldorff, & Waldemar, 2008). (For exceptions, see Hellström et al., 2007; Vikström et al., 2008). Our findings, however, highlighted the interdependencies and intricacies of both the persons with dementia and their primary family care partners as they experienced and interpreted changes in the context of their shifting lives. Additionally, our study explored the process that people living with dementia and their care partners navigated as they adapted to the life changes brought on by the dementia experience, whereas earlier dementia research has tended to focus on what changes occur, and how people cope with them.

The process of adapting to an evolving life is fluid and dynamic and requires frequent re-negotiation as abilities and roles change, enabling persons living with dementia and their care partners to find possible solutions to changes that satisfy both. Families learn how to adapt and draw on internal and external resources to do so. This finding is consistent with the caregiving literature (Chung et al., 2008; Silva-Smith, 2007); moreover, it has been found to be consistent with groups of older adults who have been diagnosed with a chronic illness, particularly musculoskeletal conditions (Stamm et al., 2008). Brown and Allgood (2004) found that wives caring for husbands with dementia “were continually adjusting, on a day-to-day basis, both reaching within themselves to tap inner resources and reaching out to others for help to manage care for their husbands” (p. 114). Similarly, Chung et al. reported that family care partners

encounter complex and continuous challenges that require constant negotiations between themselves and their relatives. Family carers face their problems and actively develop their own strategies for managing that situation as best they can. However, the circumstances are not stable and are constantly changing, and strategies that have been effective at one time are no longer useful. Carers must constantly assess and reassess the situation and try to be as effective as possible. Carers constantly have dilemmas that they have to resolve. (p. 376)

Our findings extend Keady and Gilliard’s (1999) notion of coping with dementia as an active process. We, too, found that persons living with dementia tried to explain the symptoms, used coping behaviours to accept or at least adjust to changes, and worked with care partners to adapt. However, we explored the process in more detail, demonstrating the interrelated themes of triggering awareness, attaching meaning, and responding to change. Furthermore, we included the perspective of the care partners, who engaged in the process along with their loved ones with dementia – one’s attached meanings influenced the other’s, as well as the manner in which they both responded.

Our work also extends the “sliding into food roles” for male care partners and their wives with dementia (Atta-Konadu et al., 2011). Consistent with this work, the shifting back and forth in food preparation roles among spouses reflects that sometimes families are in a holding pattern, waiting to make change, and that learning is a large part of transformation and adaptation and takes considerable work for both members of the dyad.

Our finding that participants first became aware of the change, either as a result of a seminal event, or noticing small changes slowly over time, is not unlike Brown and Allgood’s (2004) notion of *realizing wrongness*,

which describes the experiences of wives caring for husbands with dementia. The wives occasionally experienced a crisis event, which forced them to recognize that something was wrong; more often, recognition of change was slow, resulting from an accumulation of unusual behaviours. Chung et al. (2008) similarly reported that care partners grew to recognize changes slowly over time, often finding other excuses to explain changes. Critical incidents were also identified as moving along the sliding process for spousal partners (Atta-Konadu et al., 2011).

Similar to our finding of transforming, the literature suggests that a learning process occurs when people are faced with a chronic illness, such as dementia. Indeed, Furlong and Wuest (2008) reported that care partners go through a learning process to accept and respond to their spouse’s changing behaviour, and that this often occurs through experimentation, not unlike the process of trial and error that our study participants experienced. In addition to learning, our findings support current research on accessing resources for support. Husbands whose wives were living with dementia similarly reported seeking formal and informal supports (Brown et al., 2007). Furlong and Wuest (2008) suggested that care partners first draw upon informal supports, then seek out formal supports as dementia progresses.

Research also supports our findings in terms of some of the changes that care partners and their loved ones instigate in order to adjust. For example, Vikström et al. (2008) suggested that caregivers collaborate with their loved ones in everyday activities to avoid frustration. Gustaffson, Andersson, Andersson, Fjellström, & Sidenvall (2003) also reported that older women with chronic illnesses and disabilities similarly simplified and adjusted their mealtime tasks in order to maintain independence and the ability to perform these activities.

Hellström et al. (2007) reported that couples living with dementia find ways to retain their quality of life, such as living in the moment and engaging in simple pleasures, supporting our finding that life with dementia does have positive moments and that identifying what is meaningful about changes can support a more positive transformation. In our study, what was meaningful about mealtime changes resulted in families identifying what was valued and potentially being lost by the change. Families negotiated new ways of doing things to retain these valued aspects – such as conversation and companionship – of mealtimes. Netto et al. (2009) called for a focus on a more holistic approach to care, suggesting that the journey can be one of meaning and enrichment. Noonan, Tennstedt, and Rebelsky (1996) proposed that there were two dynamics or processes involved in carer meaning: *searching* for meaning

(or continually trying to make sense of the care situation and role) and *finding* meaning (or experiencing the care context as meaningful). Our findings suggest that persons with dementia and their primary care partners work together in seeking and finding what is meaningful about mealtime changes. Similarly, Atta-Konadu et al. (2011) identified sub-processes of *reciprocating nurturance* (e.g., providing healthy nutritious meals) and *navigating through sliding roles* as a way to ensure that what was meaningful to the family was retained as food roles shifted to the male care partner.

Our work has several strengths. It contributes the development of a substantive theory using longitudinal data that includes both the voices of persons with dementia as well as their care partners, while exploring an area of life not previously investigated in-depth. This work, however, does have some limitations. Although we started with 26 dyads and one triad, by the end of year 3 our numbers were reduced to 18 dyads. It is possible that these families may have experienced changes that we were unable to capture, and their process of adapting to their evolving life may have differed from that of those who remained in the study.

Furthermore, those who volunteer to participate in a longitudinal study of this nature may differ from other families living with dementia; one interpretation is that study participants were managing their disease in a more positive way. Finally, all of our families were Caucasian, most had adequate or above average incomes and lived in one region of the country. A few were European immigrants, but the majority were raised in Canada. Thus, we lack diversity in ethnicity, religion, and socioeconomic background that likely influenced the families' adjustment process. Change in these different contexts needs to be examined.

## Conclusions and Directions

Our findings suggest that persons living with dementia and their care partners adapt to mealtime changes, as well as to the broader changes in other aspects of their evolving life that the dementia journey represents. Because this study only begins to explore the dynamic process of change inherent in living with dementia within the context of mealtimes, considerably more research is needed to further understand the process that both persons living with dementia and their care partners go through to manage life with dementia in satisfying ways. Furthermore, research is needed to confirm that our findings, evidenced in mealtime changes, reflect the changes and adaptation process that occurs in other aspects of life for families living with dementia.

Our findings consider evolving life over just a three-year period of time, which represents only a portion of the dementia journey. How families continue to adjust

to change over time, and as persons living with dementia transition to long-term care, are areas yet to be explored. Our continued longitudinal work with our families will shed light on this question, we trust, as we will follow these families who are retained in the study for a maximum of six years.

The study's findings can be used by health care service providers to aid in understanding how the changes we viewed at mealtimes are meaningful and important to families living with dementia. With an understanding of the three-part process of (a) recognizing the change, (b) attaching meaning, and (c) transforming to accommodate the change, formal service providers may be better positioned to buffer the transitions that occur, over the course of dementia, at mealtimes and outside of mealtimes. For example, understanding that emotional reactions to a change are a signal that a meaningful, valued dimension of existence is being challenged could result in identifying what is being challenged (e.g., continued participation in mealtime activities), with the added result that other ways to support this dimension might be explored.

In addition, our research provides new knowledge regarding the significance of mealtimes and their role in the assessment of persons living with dementia and their care partners, as mealtimes can be a window into the family relationship and customary activities. Counsellors, educators, and clinicians can monitor the mealtime experiences as an indicator of the capacity of persons living with dementia and their care partners to respond to the life changes they are experiencing. This will help health care professionals to identify additional supports. Moreover, by providing information to families living with dementia on how they may experience change, families may be better prepared to recognize and respond to mealtime and more global life changes by actively seeking out ways to transform in meaningful ways that promote overall wellness.

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