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## **CONSERVING HABITUS Home, Couplehood and Dementia**

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### **ABSTRACT**

Compared to research on home in circumstances of aging, place and care, our knowledge about home in relation to couplehood is limited despite increases in the percentage of married and cohabiting older people in UK. Specifically, our understanding of experience and meaning of home for couples where one partner has dementia remains under-explored. This article presents a scoping review of published empirical literature to examine older couples' experiences of home in dementia. The literature identified and reviewed through searching academic databases and Google Scholar is interdisciplinary and a thematic analysis suggests interactions of couplehood, home and dementia. To discuss these interactions, we use Bourdieu's framework of field, capital, practice and habitus. We observe that habitus may gradually alter and fracture. But, in locating and supporting performance of (adapted) everyday relationship and domestic practices, home has a distinct role in contributing to conserving habitus and in turn continuity of relationship and home. Gradual fracturing of habitus with progression of dementia however also suggests that continuity of relationship and home remain contingent, but this needs further investigation. It is an element of home futures that cannot remain invisible.

KEYWORDS: older couples, dementia, home, habitus, practices, partners

### **INTRODUCTION**

Together, growing demographic salience of couplehood in later life (ONS 2014; 2017); persistent policy focus on promoting 'aging in place' (i.e., at home) confirming place attachment in later life (Sixsmith and Sixsmith 2008); and the fact that two-thirds of older adults with dementia in the UK live in community settings (Prince et al.: 2014),

suggest a need to situate and understand couple relationships in dementia in relation to home. Emerging relational perspectives in dementia (Hellstrom et al.: 2007; Wadham et al.: 2016) notably stress the significance of couplehood to maintaining the wellbeing of both partners (Merric et al.: 2016; Relationships Alliance 2018). Dementia is unique in facing couples with cognitive changes that are prolonged and progressive, generating distinctive caregiving/receiving demands that may extend over several years while living at home.

'Home' as a concept and a key setting where older adults are the unit of analyses occupies a central place in gerontological literature (see Peace, Holland and Kellaher 2006; Rowles and Bernard 2013). Home in relation to couplehood in later life, however, remains under-explored (for exceptions, see Mason 1989). While we identified two reviews on the role of home environment (Soilemezi et al.: 2017a) and experience of home (Forsund et al.: 2018) in relation to dementia, we know little about the role and significance of home for later life couples and, where dementia dominates the life of one member (see Frank 2005).

In our article, home, couplehood, and dementia form the basis of a scoping review that aims to examine and convey a detailed understanding of the role and significance of home in older couples' experiences of living with dementia. We define 'couples' in this scoping review to include coresiding partners in marital and non-marital (i.e., civil, same-sex and cohabiting) relationship types, excluding siblings. While any definition of the meaning of home can be questioned in terms of situation, location, setting and personal embodiment, it is a concept that attracts multidisciplinary approaches (Mallet 2004) and our understanding of 'home' reflects this breadth.

We outline the methodological framework for the review in the next section, alongside an explanation of how we selected relevant literature. In the findings section that follows we present a thematic analysis of reviewed literature revealing three overarching inter-related themes of '*home as an enabling and constraining space*'; '*home as a place for doing relationships*'; and, '*home as an emotional milieu*'. Findings suggest interactions of couplehood, home and unique dementia behaviors in shaping a conscious response by both partners to conserving familiarity and continuity of relationship. Given that Bourdieu's work (1977) is concerned with individual reason

and action as shaping and being shaped by social influences, we turn to the Bourdieusian concepts of *field, capital, practices and habitus* to guide our review. We use these concepts to further discuss the complexity of people, place and action noted in reviewed literature. We conclude by reflecting on the published empirical literature and identifying areas for additional research. Throughout this article we use the term 'spouse' to refer to the partner without dementia.

## METHOD

In this section, to examine the role and significance of home in older couples' experiences of living with dementia in published empirical research, we employ the methodological framework for scoping literature as suggested by Arksey and O'Malley (2005). This comprises five non-linear stages including identifying the research question and relevant studies; selecting studies; charting the data; and collating, summarizing and reporting the findings.

### Search Process

Searches were conducted between February 2018 and April 2019 using online databases *Psychinfo, Pubmed, Academic Search Complete, Medline, Social Sciences Citation Index, Cambridge Core, Scopus* including online search engine *Google Scholar* using a combination of search terms: couple aspect (*Couple\* OR spouse\* OR partner\* OR married OR cohabitation OR husband\* OR wife\* heterosexual OR homosexual*); AND late life aspect (*old\* OR elderly OR senior OR aged OR geriatric*); AND home (*home OR housing OR aging in place OR neighbourhood OR place*); AND condition (*Dementia OR memory loss OR cognitive\* OR Alzheimer\**). We used a broad time frame to include studies published between 2000 – 2019 because following Kitwood's (1997) work on personhood in dementia, people with dementia began to be actively included in research, and since mid-2000s couplehood became an explicit focus in dementia research (e.g. Svansson and Dahlberg, 2004).

The search yielded 5 studies that explicitly focused on some aspect of home or place. Given the lack of explicit focus on home for couples *and* dementia we widened

the 'home' search keywords to (*AT home OR Community\* NOT nursing homes OR residential care\* OR long-term care\* OR institutional care*). Since we now had results on community dwelling older couples living with dementia we set out 'home' related themes (Table 1) against which to review selected literature. Our understanding of 'home' as set out in the themes is multi and interdisciplinary, broad and capacious.

< Table 1 here >

### Screening and Selection

In screening studies, we included only peer reviewed empirical research available in English that:

- a) Focused on more economically developed countries to include UK, USA, Scandinavian countries, Europe, Australia and New Zealand;
- b) Involved older couples aged 60 and above where one partner had a diagnosis of dementia of any type, with both living in a community setting.

Studies were excluded if:

- a) pertaining to interventions and residential or nursing home settings.
- b) it was not possible to separate couple dyads from adult children-parent dyads in the findings;
- c) focus was primarily on impact of caregiving on spouse's health and wellbeing rather than on the relationship or experiences of caring.

The search returned 1813 results. After scanning the title and abstract to exclude irrelevant topics, duplicates, and using inclusion/exclusion criteria, 60 articles were selected. These were assessed fully by first author to identify 'home' related themes as agreed by all authors drawing upon prior research on 'home' and as set out in Table 1. 29 studies were included in the final review. Where studies comprised of mixed dyads, only findings and themes pertaining to couple dyads were included. Exceptions were made to include studies where some 'home' related theme was discussed but research was carried out with either partner and not both (e.g. Chung et al: 2017; Boyle 2017) or where research from a couple or partner perspective was limited, (e.g., late life re-marriage).

## Charting the Data

Table 2 presents the main characteristics of the included studies by: first author, geographical context of study, first author discipline, sample, and methods.

< Table 2 here >

Of the 29 studies, 10 focus on UK followed by Sweden (9), Canada (5), USA (4), and Australia (1). Literature on late life couplehood at home in context of dementia is multidisciplinary: first authors' disciplines included: nursing, health sciences, occupational therapy, family relations, social sciences, sociology, psychology and architecture. These studies are qualitative and cross-sectional except for two longitudinal studies (Hellstrom et al.: 2007; Keller et al.: 2015) and involve small samples except for Roland and Chappell (2017). Most comprise couple dyads except 6 that include other family members (e.g., Forbes et al.: 2011; Keller et al.: 2015; Heron and Rosenberg, 2017; Roland and Chappell, 2017; Chung et al.: 2017; Ward et al., 2018).

Nearly half the studies explicitly mention married partnerships. The remaining half do not, using instead the terms 'cohabiting' and 'coresiding', although within these references have been made to husbands and wives. Calasanti and King (2007) and Sinclair et al. (2018) reported having 1 couple in same-sex and another 3 in second marriage partnerships. Otherwise, McParland and Camic (2018) is the only study comprising of non-heterosexual couples. Most of these studies comprise co-resident couples, although many do not report on the length of partnerships or co-residence. Samples in most are predominantly Caucasian with Calasanti and King (2007), Beard et al (2012), and Boyle (2013) each reporting one ethnic minority couple or partner in their samples. Botsford's et al. (2012) sample comprises only ethnic minority coupled partners.

Most couples and partners are over 65 years of age. Out of 29 studies, 18 do not report on income, occupation or education profiles: the remaining 11 report either both income or occupation and education, or only education profiles of participants. All studies mention Alzheimer's and/or dementia but not all report the latter's stage or

severity. Different tools and approaches to screen for dementia have been used. Where stage or severity of dementia is reported, most comprise partners with dementia in mild-moderate stages. 9 studies report having some participants experiencing 'severe' or 'advanced' dementia, although no study exclusively focuses on this group. A few explicitly mention the geographical context e.g., urban, rural, metropolitan etc.

Following Arksey and O'Malley (2005) and guided by our research question, we employed a thematic and iterative approach to synthesize and report findings. Synthesis produced three overarching inter-related themes: '*home as an enabling and constraining space*'; '*home as a place for doing relationships*'; and, '*home as an emotional milieu*'.

## FINDINGS

### Home as an Enabling and Constraining Space

While form, shape and design of 'home' dwellings can be diverse, 'home' is the context where daily and personal life is lived and played out (Morgan 2011). Everyday life is invariably managed and accomplished through routines planned by its occupants. Depending upon life course stage, routines can vary but the sense of familiarity and security that is often associated with the home and neighbourhood is partly shaped by habitual activities.

#### *Everyday routines within home*

In dementia, sustaining normalcy of everyday life as a couple becomes associated with maintaining and nurturing everyday routines as far as is possible (Beard et al.: 2012; Chung et al.: 2017; Bielsten et al.: 2018). Everyday customs may relate to household roles and responsibilities (e.g. cooking, cleaning, sleep routines, household maintenance, financial decision making and management,) and leisure activities of the couple either done together or apart (e.g., walking, socializing). Our review indicates that home in generating routine domestic and household work that demands attention and doing, gives each couple the opportunity to maintain their

roles. In so doing it enables normalcy of everyday life and continuity of couple identity and relationship.

Familiarity and performance of routines in known and recognizable settings of home and immediate neighbourhood (McGovern 2017; Ward et al.: 2018), further reinforces the couple's abilities to perform and maintain such roles and responsibilities. For the partner beginning to experience memory loss and disorientation, familiarity supports levels of independence and enables a sense of self-worth despite dementia (Chung et al.: 2017). Qualitative research in the UK (Boyle 2017) and Sweden (Hellstrom et al.: 2015) notes value attached by married partners with dementia to engagement in household roles and responsibilities, that may be gendered and/or established early in the marriage. Notwithstanding reproduction of gendered roles, these studies show that everyday routines enabled a sense of (gendered) self value in that it supported resisting the dementia identity. Research with seven older couples in same-sex partnerships aged 70 and over, and in partnerships spanning 3 to 54 years, suggests similar themes around continuity of habituated roles and maintaining normalcy in the valued non-heterosexual relationship (McParland and Camic 2018).

### *Beyond the home*

Our review reveals that for some, places beyond home may gradually become disquieting, leading to a centering of use of space on the home itself and immediate neighbourhood. For some, handling the potential risks associated with physical safety, wandering, socially unacceptable and uncontrollable behaviors in public spaces, e.g., restaurants, museums (Svanstrom and Dahlberg 2004; Forbes et al.: 2011) may lead to reorganization of rights of access to outdoors for the partner with dementia (Olsson et al.: 2012). In other instances, partners with dementia are likely to withdraw from valued routine social life and spaces beyond the home to avoid potential socially embarrassing situations (e.g., not being able to remember things) that negatively impact on sense of self. Research suggests that this is more likely for people especially in early to mild stages of dementia who may be more aware of loss of intellectual abilities (Roland and Chappell 2017). Subsequently, life for both partners

may become more home-centered, leading to the invisibility of couple identity. Being outdoors individually and together as a couple too may become constrained. Home, in this instance, while offering some level of privacy, comfort and safety, may also be felt to constrain valued freedoms or represent confinement.

Reviewed literature suggests that 'home' may be experienced as a dull place by some couples (Bielsten et al.: 2018). In this context habituated and/or valued routine activities such as going out and about individually (e.g., fetching mail or groceries; going for a walk) or together (e.g., walking, greeting and meeting neighbors) in the immediate neighbourhood enable activity and visibility outside the home (Womack et al.: 2016). Some as a couple may seek new social spaces beyond the home, such as support groups e.g. faith or dementia groups (Beard et al.: 2012; Donnellan et al.: 2017). Our review further indicates that where partners with dementia do not exhibit aggressive behaviors, continuity in social life beyond the home is likely to continue as part of a couple.

Other spouses may use assistive technologies to monitor the activities of their partner with dementia when going out themselves, or while sleeping, enabling safe experience for their partner who may wander or wish to go outdoors. In wider literature, increasing evidence shows acceptance (Gibson et al.: 2015) and effectiveness of assistive technologies in enabling spatial separation for both people with dementia and their caregivers (Øderud et al.: 2015), thereby contributing to a sense of security for caregivers of people with dementia. Yet affordability, knowledge and level of comfort in using technology can constrain use and uptake - alongside major ethical concerns amongst spouses about monitoring their partners without consent (Olsson et al.: 2012).

McGovern's (2017) qualitative research with seven couples living with dementia in New York's metropolitan area highlights how couples actively use features of neighbourhood and city (e.g. shared knowledge about living in a specific neighbourhood and city, affordability of transport, recreational activities and amenities within walking distance, and neighbourhood bonds) to maintain life together as a couple, in turn nurturing the couple relationship and identity. Amenities and facilities that urban living may offer can be appreciated relative to rural settings, where services,

facilities and amenities might be under-developed, inaccessible or unavailable (Heron and Rosenberg 2017).

### *Space, time and activities*

Empirical findings unequivocally suggest a commitment to ‘doing things together’ amongst older couples despite dementia and its impacts on the couple’s relationship (Hellstrom et al.: 2007; Beard et al.: 2012). Gradually and over time, as literature suggests, the spouse may become increasingly responsible for shouldering the day to day organization of home and care for the partner with dementia (Hellstrom et al.: 2007; Vikstrom et al.: 2008). However, despite this trend, evidence from heterosexual and very limited non-heterosexual relationship research indicates that spouses actively manipulate and reconfigure undertaking of household and outdoor activities that are meaningful to partner with dementia (Chung et al.: 2017; Sinclair et al.: 2018; McParland and Camic 2018). Spouses bring their intimate knowledge of the partner developed over time in the relationship to ensure and enable meaningful participation and involvement. In so doing, spouses work towards maintaining personhood of their partner as well as sustaining long established relationship practices and couplehood.

Male spouses of women partners with dementia, and some in same-sex partnerships, are likely to organize formal care (personal and household) if they can afford it (Calasanti and King 2007; McParland and Camic 2018). Yet, increasing need for scaffolding and supporting the partner suggests that most couples end up spending a considerable amount of time together to manage everyday routines and personal care (Hellstrom et al.: 2007; Chung et al.: 2017). Partners may be thrown together at home more frequently than before. Finding space and time for personal relaxation for the spouse of a partner with dementia therefore may become difficult. For some spouses this new practice may be experienced as constraining (Calasanti and King 2007) and challenge pursuit of interests integral to maintaining personal identity (Vikstrom et al.: 2008; Forbes et al.: 2011; Womack et al.: 2016). Spending some time apart may come through accessing respite (e.g. day care center, support groups) or pursuing valued solo hobbies or interests at home. How ‘me time’ or ‘our time’ (Gabb and Fink 2015) is valued by the partner with dementia remains unclear.

Some evidence shows that both partners' experience of spaces within the home may diverge. As McGovern (2017) observes, for the partner with dementia a small sized home may enable easier navigation. But for the spouse, the home, now possibly modified to include mobility equipment and live-in support from family (McGovern 2017) - may intensify feelings of confinement and constraint. Soilemezi et al (2017b; and X this Special Issue) show that, if there is enough space the spouse many make an 'escape' room – somewhere in their home for their own activities (e.g. to use a computer) and to obtain intermittent solitude to relieve stress and feel less constrained (Hellstrom et al.: 2013). Spatial improvisations and modifications to shape comfort and 'me time' depend however to a large extent upon availability of space within the house which is, in turn, linked to a couple's socio-economic position and command over material resources. While Bielsten et al (2018) and McParland and Camic (2018) make references to concerns about physical safety within the home (e.g., falls while using stairs) leading to reorganization of space, the implications of home modifications for the couple and each partner remains under-explored. Here housing type and tenure may be of significance in shaping home adaptations.

### **Home as a Place for Doing Relationships**

Our second theme on home suggests an ongoing reconstitution of social membership of couples' and home in dementia. Home is also defined in relation to family and social relationships (Allan and Crow 1989). The social environment of the home involves not only the couple but also interaction with a wide variety of others, from family – immediate and distant – including children and siblings, to friends, neighbors and different professional care visitors.

#### *The Couple*

It must be noted that shifting of roles and responsibilities together with caregiving occurs in the context of a well-established couple relationship. Intimacy and knowledge about the partner, their likes and dislikes developed over a lifetime supports maintenance of the self-identity of the person with dementia (Kitwood 1997;

Down and Lord 2017). As Chung et al. (2017) observe in their research, spouses not only actively strived to engage their partners with dementia in meaningful pursuits but sought to ascertain the wishes of their partners in making such decisions. It is interesting to note that their sample comprised primarily of female spouses of partners with dementia.

Reviewed literature however suggests that a gradual shift in responsibility for managing the home may upset the existing balance of power relations between married couples. Relinquishing long held habituated and/or gendered roles and responsibilities by the partner with dementia may be marked by tensions and conflicts in the relationship (Boyle 2013). As her research in UK shows there are however gendered differences. Male partners with dementia are more likely to disagree with shifts in gendered roles while female partners are more likely to acquiesce with their spouses wishes to avoid conflict.

Furthermore, her research indicates that gendered patterns of caregiving can undermine doing of gender for women partners with dementia, more than men (Boyle 2017). She notes that male spouses are more likely to take over decision making roles without considering the wishes or participation of partners, and despite women partners with dementia retaining some capacity. Taking over decision-making roles may be rooted in internalized notions of male authority and privilege in marital relationships, which as Calasanti and King (2007)'s research in USA notes is actively used by male spouses to seek compliance of partners with dementia in personal care (e.g., bathing, toileting, dressing). Literature in the Swedish context however suggests some contradictory findings - male spouses may support female partners with dementia in maintaining valued roles (Hellstrom et al.: 2017). Both studies (Boyle 2017; Hellstrom et al: 2017) have small samples. The difference in findings may be cultural but this needs further investigation.

Shifts in gendered household roles and responsibilities have been observed amongst black (African Caribbean) and ethnic minority (Greek Cypriot) couple relationships (Botsford et al.: 2012). While this limited research does not offer insights into power relationship shifts among couples it does suggest a role for wider family in managing shifting roles and responsibilities as outlined below. Limited research on

non-heterosexual couple relationships in dementia does not indicate power shifts suggesting an easier sharing of household responsibilities. But, in line with heterosexual couple relationships, it indicates annoyance and resentment on the part of the partner with dementia where spouses may become overprotective or begin making decisions for them (e.g., deciding to limit their engagement in activities) (Chung et al.: 2017; McParland and Camic 2018).

#### *Adult children and wider family*

Couples may manage their shifting roles and responsibilities through the involvement of family members, especially adult children. Gender and cultural differences however exist in patterns of support expected and accessed from adult children (Botsford et al.: 2012; Donnellan et al.: 2017). Donnellan et al (2017) in a qualitative study involving white British spouses of people with dementia observe that while practical support is valued from adult children, cultural norms dictate avoidance of over reliance. Amongst spouses of partners with dementia of Greek Cypriot origin, support from family, especially daughters is expected and considered normal; and for African Caribbean spouses not burdening the children was important (Botsford et al.: 2012). Notably, family relationships are emphasized over and above the couple relationship in Greek Cypriot couple relationships. Some evidence suggests that where visits from siblings of partners were routine prior to dementia, these may continue as usual, or stop due to the insistence of partner with dementia or where siblings are finding it difficult to engage with an impaired partner (Donnellan et al.:2017).

The above findings may not be applicable to couples in late life remarriages whose relational and family histories may be more complex. Sherman et al (2013) conducted research with 9 female spouses of partners with dementia in the context of late life remarriage (defined as a second marriage when both partners' children are over 18 and no longer living at home). Their findings suggest that assistance from partner's or own adult children may or may not be forthcoming. Additionally, step children may challenge spouse's decisions in relation to everyday life, finances and care for partner with dementia. This research however does not consider the

perspective of the partner with dementia on expectations of support from adult children, despite 7 partners being in mild-moderate stages of dementia. Wider literature on non-heterosexual people notes both distance and closeness with family of origin (Heaphy et al.: 2004) but further research is needed to explore non-heterosexual older couple relationships in dementia in contexts of wider family involvement.

### *Neighbors and friends*

Living in proximity can make neighbors a valuable source of help especially during a crisis (Donnellan et al.: 2017; Ward et al.: 2018). Maintenance of activity in the neighbourhood may enable other people to understand issues of wandering and dis-orientation for a person with dementia. For instance, some spouses, to maintain activity participation of partners with dementia, may communicate about their partner's condition to neighbourhood shopkeepers (Boyle 2013; Chung et al.: 2017).

However, spaces and places that couples remain connected to or withdraw from, including re-evaluation of social membership of home, may, to some extent, depend on couples' disclosure of dementia to neighbors and friends (Hellstrom and Torres 2013). Some may be more reluctant than others to reveal. Perceived stigma associated with dementia and in many instances, coupled with negative situational social encounters (e.g., avoidance by others, over-helpfulness, scrutiny of dementia behaviors) shape whether existing social relations are maintained or not (Bielsten et al.: 2018). Difficulty in maintaining existing friendship circles too has been reported as similarities in experience and activities diverge (Donnellan et al.: 2017). However, as these studies also note, opportunities to participate in social life as a couple remain important and couples may selectively choose with whom and where to socialize.

Reviewed literature also highlights that concealing diagnosis is not a universal experience. Some couples favor disclosure to maintain social relationships and to raise awareness (Womack et al.: 2016; Bielsten et al.: 2018). We note that Womack et al's (2016) research was conducted with white middle class educated couples suggesting links to social contexts and locations (Jones 2017). Disclosure amongst

non-heterosexual couples in context of neighbors and friends remains under-explored and needs further investigation.

### *Formal carers*

Formal carers offering personal care or home care may be regular visitors. How far the couple accept and adapt to carers coming into their home will depend on the changes that dementia may bring, perceived appropriateness and acceptability of need for this care by both or either partner (Olsson et al.: 2012; Heron and Rosenberg, 2017) and sexual orientation (McParland and Camic, 2018). The spouse's own health, knowledge about and affordability of available services, and eligibility via formal recognition as a 'carer' are important considerations (Forbes et al.: 2011). African Caribbean spouses are more likely to seek formal care as are male spouses with adequate financial resources while for Greek Cypriot partners, formal care is seen as supplementary to care provided by family (Botsford et al.: 2012).

Although a well-developed body of literature exists on blurring of private-public boundaries when formal care comes home (Twigg 1999; Milligan 2009), research into formal home care in context of couplehood and dementia remains under-explored. Some qualitative research on dementia care networks comprising couple, family and home workers in rural Canada note the lack of a familial approach amongst dementia home care services (Forbes 2011). Heron and Rosenberg (2017) further observe the need to consider gender and cultural norms of rurality in the design of services as lack of gender-sensitive services may delay the use of formal services, especially by male partners with dementia. McParland and Camic (2018) observe that for same-sex partnerships in dementia, the interplay of sexuality and dementia offer challenges related to issues of discrimination and mistreatment that may prevent some from disclosing and seeking formal care. One couple in their study organized formal care but bought this to ensure control over care interactions.

### **Home as an Emotional Milieu**

Our third theme suggests that emotions and bodily co-presence interact to shape experiences of home. Behavioral changes in a partner with dementia are likely

to disrupt established communication practices including talking, listening, reciprocity and emotional validation between couples and for some, may bring about a shift in a spouse's perception of their partner's identity with implications for being intimate (Hayes et al.: 2009; Holdsworth and McCabe 2018). Despite the context of a well-developed relationship for many, relationship standards previously held are transgressed with regards to personal care (Calasanti and King, 2007). The range and ambivalent nature of emotions experienced can include loss, grief, anger, love, anxiety, guilt, sadness; aggression on the part of the person with dementia and abusive behavior by the spouse without dementia, all of which may be totally out of character or relate to difficult experiences prior to dementia (Svanstrom and Dahlberg 2004; Forbes et al.: 2011; Hellstrom et al.: 2013).

### *Co- presence*

Reviewed literature both on heterosexual and non-heterosexual couple relationships indicates that home can be experienced as a 'lonely' place for the spouse of the partner with dementia, especially where emotional reciprocity and communication in the relationship gradually diminishes (Svanstrom and Dahlberg 2004; Calasanti and King 2007; Roland and Chappell 2017). These spouses may find it difficult to sustain meaningful emotional contact with the affected partner, generating feelings of loneliness and isolation in the relationship and at home. In contrast, little is known about the emotional experience of home for partners with dementia, although some (Roland and Chappell 2017, Bielsten et al.: 2018; McParland and Camic 2018) hint that the couple relationship itself together with the known context of home may constitute safety, security and comfort for the partner.

Living together and caregiving-receiving in the private sphere of the home suggests ambivalent experiences of co-presence. For some spouses, being co-present entails dealing with aggressive behaviors of partner with dementia (Svanstrom and Dalhberg 2004; Hellstrom et al.: 2013). Co-presence however might be vital to establishing new practices of communicating in the relationship through non-verbal gestures and expressions to sustain emotional intimacy. Some partners may communicate using non-verbal embodied cues (e.g., hugs, touch, kisses), however occasional this may be (Chung et al.: 2017; Bielsten et al.:2018), and these non-verbal

gestures furnish their spouses with much needed clues to interpret their moods and wishes. Joint endeavors of engaging in activities such as sharing cooking and other household chores (Johansson et al.: 2014) that constitute everyday practices associated with home may offer ways to sustain emotional contact and intimacy in the relationship.

Being co-present, however, also means engaging in emotion work. The couple as a unit to varying degrees may engage in emotion work and, especially, in relation to their future as a couple together at home. This emotion work may take the form of, for instance, not talking about future, avoiding making plans in form of advance directives (Ryan and McKeown 2018) and externalizing dementia (Hellstrom et al.: 2007). In so doing, staying together at home as a couple is prioritized. While many avoid a discussion about future living arrangements, Sinclair et al's (2018) research with couples offers some insights suggesting that partners' views on the matter may diverge, with potential for disagreements and conflicts. Some partners with dementia thought that moving into a care home would protect their couple relationship, others did not and associated respite care with care home admission.

### *Shared knowledge and memories*

In literature on older adults, it is well established that home becomes infused with personal and social meanings that are kept alive and enacted through valued possessions or objects (Sherman and Dacher 2005) and memories (Hockey et al.: 2001; Young 2005). McParland and Camic (2018) note that some couples used photographs and objects to reminisce and connect. The symbolic dimension of material practices of homemaking and living together for couples in dementia and its role in facilitating identity maintenance and couplehood, however, remains under-explored.

Having presented key themes on role and significance of home for couples living with dementia, in the next section we turn to Bourdieu to aid discussion of findings.

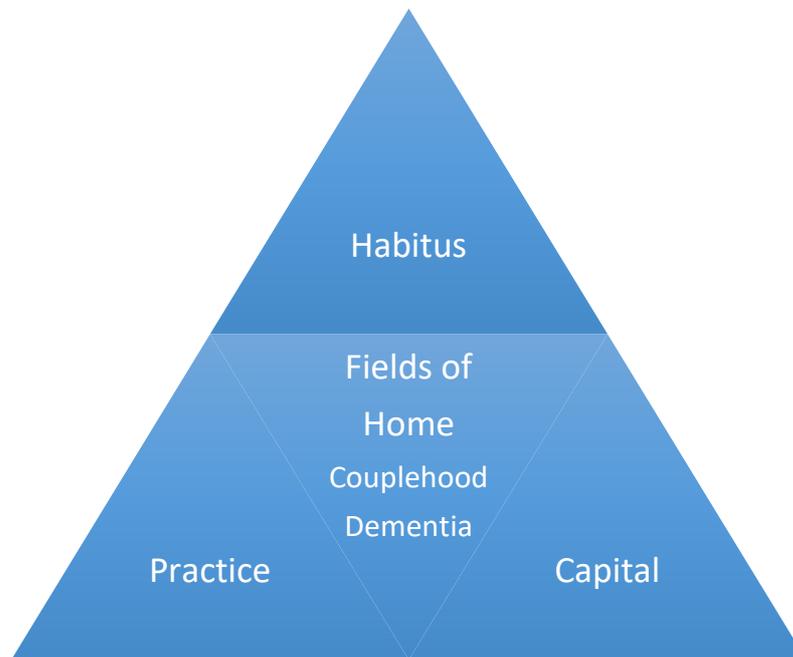
## UTILISING BOURDIEU TO FRAME THE DISCUSSION

The three themes as set out in the previous section reveal two key findings:

1. Experience of home in dementia for the couple and each partner becomes marked by ongoing changes, ambivalences and divergences. Dementia gradually influences what is known, familiar and taken for granted, i.e., everyday life as a couple situated within the home and feeling of at-homeness;
2. Conserving familiarity and continuity of relationship and home becomes important for couples facing dementia. The interdisciplinary nature of the literature reviewed strongly suggests interactions of couplehood, home and unique dementia behaviors including perceptions of dementia in shaping a conscious response by both partners to conserving familiarity and continuity.

To address this complexity of people, place and action within our discussion we turn to the concepts of *field*, *capital*, *practices* and *habitus* developed by Bourdieu (1977; 2000). These concepts are utilized by Peace, Holland and Kellaher (2006) and Angus et al (2005) in earlier studies of environment and aging in later life. We use these concepts as they enable: an analysis of the complexities of doing couple relationships at home that are rooted in couple history and biography, and in the ongoing context of dementia; taking account of the social influences of gender, ethnicity, class and sexuality on individuals' understanding, feelings, and agency, while recognizing fluidity and change. These concepts (Figure1) are outlined briefly before being used in further discussion of the findings.

**Figure 1:** Representation of Bourdieu's concepts



*Fields* are primarily social spaces where actors enter and engage with each other, each according to the social position they occupy within the field, the assets they possess and their ways of living (Bourdieu and Wacquant 1992). For the purposes of this article, we have outlined home, couplehood and dementia as the three overlapping fields of interest. Within these fields, *Capital(s)* are the resources that actors possess in varying amounts and are in turn tied to social positions (Skeggs 1997). Bourdieu discusses three kinds of capitals, namely, economic, social and cultural, of which symbolic capital is a part and is defined by the collective value social actors within a field assign to it. Capitals are inter-connected, and one form of capital can be transformed into another (Bourdieu 1986).

The idea of *Habitus* offers an important sense of how we understand places we call 'home' and is also useful when examining familiar interpersonal relationships. *Habitus* is a person's embodied, taken for granted way of thinking, being, and acting, operating at a pre-conscious level (Bourdieu 1977). It represents and is realized in all that is taken for granted, deeply familiar, known; surfacing into consciousness only when that familiarity is threatened or disrupted (Dovey 2005). As a fluid construct, it can adapt, modify or evolve in response to new experiences thus reproducing the predictability of everyday life. *Capital* is linked to both habitus and field in that an

individual's response to an encounter (field) is shaped by habitus, which in turn is underpinned by possession of relevant capital(s). Possession (or not) of capital shapes actors' position in the field as well as their ability to accumulate capital.

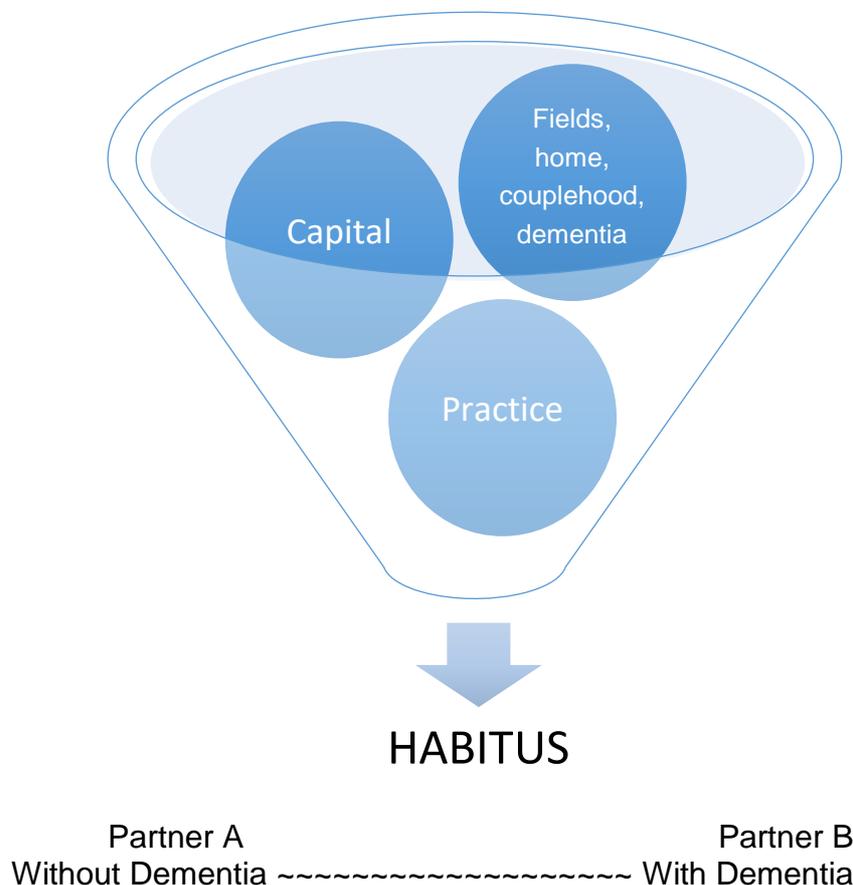
*Habitus* that is shaped by the dynamic interplay of history, structures and biography over a period of time is the lens through which the individual makes sense of the world (Bourdieu and Wacquant 1992). In his work on domestic settings Bourdieu (1977) sought to understand everyday life through observation of *Practices*, or 'ways of doing things', as the interplay of habitus, capital and field manifests itself in behaviors or responses. *Practices* are situated and performed in social contexts (fields) and are constitutive of the deep familiarity in form of habitus. Bourdieu, however, acknowledges that under certain circumstances *habitus* can change radically - especially when it encounters new situations or *fields* which are very different from the ones that were previously encountered (Bourdieu 2002).

Having outlined briefly key concepts of *habitus*, *field*, *practices* and *capitals*, we now discuss our findings in relation to these in the next section.

## DISCUSSION

As noted, *habitus* defines a way of being that is so familiar it is taken for granted. Home, couplehood, and dementia (identified in Figure 2) increase the complexity of understanding *habitus* in different ways for the two partners; one with dementia and one without dementia. For the couple, this taken for granted deep familiarity emerges from every day interwoven relationship and domestic *practices* that are located and continually enacted in the social context (*fields*) of home and relationship. Though the reviewed literature tends not indicate how long couples have lived together in their dwellings, it does suggest that for many these are long standing partnerships. In continually challenging the existing relationship status quo, dementia threatens this familiarity (that forms and is formed by *habitus*) within the relationship (Wadham et al.: 2016). Practical responses are shaped by interplay of *habitus* and *capitals* (or lack of it) in relation to the *fields* of home, couplehood and dementia. The specific aspects of *habitus*, types of *capitals* shaping *practices* are however relational to the three *fields*, i.e., situational context of each couple.

**Figure 2:** The complexity of conserving habitus in couplehood in dementia



For many couples, despite reproducing gendered identities, 'home' may be experienced as a positive place for owning and preserving identity (Young 2005). In other instances, as feminist literature suggests (Bowlby et al.:1997) home may reproduce gender inequality. Where materiality of the home supports continuity of valued gendered identities and roles of husband, wife or partner it becomes *capital*. Gendered roles and responsibilities seem to be central to individual and couple identity making and marking in heterosexual couple relationships in dementia. This differs from literature on home in later life, where identity is commonly individualized outside dementia and tied more commonly to place, belonging and independence (Peace et al.: 2006; Oswald and Wahl 2013). Where partners experience a shift in the power balance, as both or either partner are no longer able to adapt practices to

accommodate evolving situations of risk and safety that are mutually beneficial, a fracture within *habitus* occurs.

Offering (or not) material spaces for retreat, relaxation (e.g., spare rooms, gardens) and spatial improvisations to manage emotions (McGovern 2017; Soilemezi et al.: 2017b), the resource or capital of home will be experienced differently by couples living in different types of housing. There is limited research exploring how different forms of housing and any modifications or assistive technology therein may shape the experience of home for couples in dementia. In a systematic review exploring barrier and facilitators in the home environment to dementia care and support, Soilemezi et al (2017b) note the significance of size, layout and accessibility of housing in lending itself to modifications and highlight tensions between balancing safety and independence with comfort and risk (see also X in this Special issue).

We note that differences exist between experiences of 'home' as dwelling and 'home' as community or neighbourhood. Outside the home, practice may begin to change even while the partner with dementia is coping with mild onset, beginning to affect their understanding of self. Couples may begin to do more things together - shopping, walking locally making active use of commitment to the relationship and familiarity with place - and withdraw from valued activities and spaces beyond the home. Experience of home may shift and diverge for both partners although inside the home, such fractures in terms of *habitus* may be less visible to others as the couple maintain household roles.

The review confirms that the couple and each partner for as long as possible actively strive to maintain normalcy of the *habitus* as it is gradually altered by the experience of dementia. This includes upholding their valued identities of gender and being a couple, representing a form of *symbolic capital* that is both actively valued, defended and used as a resource to support performance of normalcy. Our findings suggest that 'home', as a *context* that locates couples' lives, (Roseneil 2006) is central to understanding how the couple and each partner may engage with and respond to gradual changes. In generating everyday practices that are undertaken in a familiar context, home actively constitutes a resource for the performance of normalcy and couplehood. Where gendered practices become valued and actively utilized to resist

the de-valued dementia identity (Boyle 2013; Hellstrom et al.: 2017), they become a form of *cultural capital*. However, where the impact of dementia comes to demand changes, such as, the relinquishing of gendered or couple practices, *habitus* may become fractured and may need to be re-established.

Implicit in the notion of home, at least for this population, is co-residence (Roseneil 2006) which enables bodily co-presence (Urry 2002). The material and emotional dimensions of home offer some insights into the ambivalent experience of bodily co-presence. In enabling co-presence, home situates the use of time and space spent together and apart thus shaping *habitus* - supporting emotional communication and connection in the relationship as well as contributing to stress and distress.

The level of involvement of informal or formal care from family, friends or services sits alongside the *capital* resources of these partnerships. The work relating to family, children, neighbors and friends shows that these relationships are different forms of *capital* which may influence practice for the central partnership. Equally, diverse couple relationship types (e.g. late life re-marriages; non-heterosexual partnerships) may impact availability of such *capital* but needs to be explored further. Findings also show that there is variation in how different cultures understand family commitments to shared responsibilities in couplehood (Botsford et al.: 2012).

Consistent with wider literature, meaningful social relations constitute an important dimension of home (Forsund et al.: 2018). Our review suggests that social membership of the home (*field*) is subject to ongoing reconstitution in dementia and notably, is partly shaped by disclosure practices of the couple (Hellstrom et al.: 2013). Wider literature indicates that social categories of race, class, ethnicity and sexuality shape understanding and perceptions of dementia, in turn affecting seeking of diagnosis and treatment (Hulko 2009; Bartlett et al.: 2016).). Our review suggests a likely role for education, gender and sexuality in shaping disclosure of dementia to friends and neighbors, but this needs further research.

By adopting Bourdieu's work to provide a conceptual framework we have seen how when considering home, couplehood, and dementia, *habitus* may become fractured -in some cases to be re-established through changed practices. Bourdieu's

work is useful because it shows that domestic and relationship practices overlap and are also simultaneously gender, sexuality and cultural practices, although Bourdieu mostly emphasized class. Morgan (2011) makes similar observations in relation to family practices. Reporting variations in income, education and occupation profiles of participants in studies that include these variables make it difficult to understand the influence of class in shaping capital or resources that each partner may bring to the partnership. Further investigation is needed to understand the impact of class and *capitals*: material - housing tenure and type – through to social and the emotional aspects of the couple relationship itself (e.g. commitment, intimate knowledge).

Most of the published research reviewed focuses on mild to moderate stages of dementia and our understanding of couples' experiences in advanced dementia is severely limited. Research by Hellstrom et al (2007) suggests that where the couple relationship cannot be maintained, partners may come to live in different places. In such instances, 'home' itself may also be fractured.

### **A COMMENT ON PUBLISHED RESEARCH AND FURTHER RESEARCH**

This review makes a unique contribution in that it offers timely and relevant insights into the role and significance of home in the context of couplehood in dementia. The review reveals that resources of home and couplehood are employed in conserving continuity in the relationship for as long as possible by the couple and each partner. It adds to our understanding of home within and beyond the dwelling with regards to interacting material, social and emotional environments (e.g. privacy, safety, comfort, use of space, attachment). Notably and perhaps, uniquely in context of home in later life, it demonstrates the significance of home in situating and supporting performance of practices of everyday couple life and the role of practices in making and remaking home and couplehood in dementia with implications for identity.

We have not assessed the quality of the included studies or explored grey literature. Yet, certain features of the reviewed research deserve further reflection. We noted great variations in reporting the couple relationship in terms of length and

type of relationships or length of time living together. Despite well placed and timely focus on couplehood in dementia, half of the reviewed research did not mention the type of couple relationship. The reason for this omission is difficult to decipher and may relate to assumptions about older adults being in long standing married relationships. As Sherman et al's (2013) research shows, diverse relationship histories and trajectories are likely to affect the social capital of couples. Couplehood in later life is now more varied with remarriage, cohabitation, civil and same- sex partnerships becoming acceptable ways of doing relationships (Koren 2014; ONS 2017), hence, relationship type becomes an important influencing variable. None of the aforementioned articles mentioned childless couples and this may be another important consideration in future research.

Whether findings highlighted in this review relate equally to marital and non-marital long-standing partnerships is an important consideration for future research, as is the need for researchers to uniformly report on type and length of partnership. With exception of Hellstrom et al (2007) and Atta Konadu et al (2011) most studies were cross-sectional. This limits our understanding of the possibilities and limits of home, couplehood practices and resources in shaping living together at home until advanced stages and indicate the need for more longitudinal research.

The complex interactions of home, couplehood and dementia demonstrate the need for further research and additional work looking at experiences of and resources available to older couples living at home including those who are from differing cultures, part of late marriages, and non-heterosexual all of which are under-researched. Given the importance of home - as the review suggests - to individual and couple identity in dementia, and to aging in place in local and policy discourse (Beard et al: 2012; Wiles et al.: 2012) questions arise about the limited interest in explicitly exploring home and its meaning for couples in dementia. This, despite a flourishing tradition of environmental and geographical gerontology in Western contexts.

Our own previous work on home in later life has also neglected these couples (Peace et al.: 2006; Peace 2015). We note that recent work on sexuality and gender at home does not relate to late life, apart from Scicluna's (2017a, b) work with older lesbian couples (Pilkey et al.: 2017) and all neglect living with conditions such as

dementia. We suggest two possible reasons for this omission to date. First, demographic shifts in longevity of both lives and relationships (ONS 2014; 2017) has only recently begun to be captured within environmental and geographical studies where there has for long been a focus on individuals. This suggests the need for extending ethnographic research on the current reality of everyday life for older couples (Chambers et al.: 2009). Secondly, an evolving understanding of the experience of dementia, particularly since the adoption of a person-centered approach to care, emphasizes issues of attachment and identity (Kitwood 1997; O'Connor and Purves 2009).

Gradual fracturing of habitus with progression of dementia suggests that continuity of relationship and home remain contingent, but this needs further investigation. We acknowledge that research on dementia has brought to fore the salience of couplehood but undifferentiated use of the term 'couple' employed in much of the reviewed research implies that research into couplehood in dementia is in early stages. It is our hope and expectation that further research in embracing nuances of couplehood will broaden and deepen our understanding of the many thousands of couples grappling with dementia and their homes futures.

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