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**Exploring the fruitful darkness of liminality: Informal caring for  
elderly family members and the impact on the self**

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## **Introduction**

One in eight people class themselves as informal carers in the UK, saving the economy £132 billion per year (Carers UK, 2018). In the UK, advances in health and medical care have led to an increase in life expectancy (Public Health England 2016) with approximately 10 million people in the UK over 65 years old and this figure is expected to rise to 19 million by 2050 (Cracknell 2010). However, *healthy* life expectancy is not predicted to increase as fast, resulting in proportionally greater demands on public services (Mendelson and Schwartz 1993; Higgs and Gilleard, 2015; Public Health England 2016) and this is a reflection of global trends. This mismatch between life expectancy and healthy life expectancy has serious consequences in terms of planning for formal care and, given that there has been a £160 million cut in elderly social care funding over the five years to 2015/16 (Age UK 2017), this means that informal care options need to be utilised to fill this gap. This has had an enormous impact upon the family unit as adult children are now increasingly involved in the informal care of their elderly relatives, while many adult children are still parenting their own children.

Informal care has been the subject of a number of studies in an attempt to investigate how much informal care provision is being used, by whom and how this care provision affects the informal carer and family unit. Various aspects of informal care have been studied including gender differences (see for instance Campbell and Martin-Matthews 2003;), sibling differences (Tolkacheva, van Groenou, and van Tilburg 2014), effects of employment (Henz 2006), marriage (Kraijl, Brouwer, de Leeuw, Schrijvers and van Exel 2011), ethnicity (Lee, Peek and Coward 1998), and social status (Laditka and Laditka 2000). However, there has been scant research

focusing on the transition from independent family member to informal carer, their capacity to care and how it affects the carers' identity, which has led to calls for further research (Bédard, et al. 2004; Dwyer and Miller 1990; Goins et al. 2009; McKenzie et al. 2010; Tommis et al. 2007). This research forms part of a wider phenomenological study that looked at the life experiences of informal carers in East Yorkshire. However, the focus of this paper was to understand how the transitional role of informal carer affected their identity; and explore the “fruitful darkness” of liminality (Cody and Lawler 2011) in the lived experiences of informal carers. Our contribution is to extend the debate on informal care by highlighting how this affects the informal carer, their identity, their relationship with their family members, and how this relates to the wider issues of elderly care social services.

### **Informal care**

The growth in care needs has increasingly been covered by informal care (Bolin, Lindgren and Lundborg 2008) and this is most frequently provided by relatives of the elderly family member (Checkovich and Stern 2002, Szinovacz and Davey 2007). Indeed, Henz (2006) argues that approximately three quarters of British frail elderly people receive some form of informal care and it is predicted that the number of informal carers in the UK will reach 9 million by 2037 (Carers UK 2017). However, changing demographics are worrying as birth rates in the UK are falling, meaning there are fewer adult children to provide informal care to their parents (Tolkacheva, et al. 2014) and increasing divorce rates have resulted in fewer spouses willing to provide care (Gans, Lowenstein, Katz and Zissimopoulos 2013). Nevertheless, the majority of informal carers for elderly relatives are either adult children or spouses (Hoff 2015; Akgun-Citak, et al, 2019; Jeong, et al, 2019). Moreover, care provided

by spouses is on the increase (Hoff 2015) and may be the only informal care option for couples who do not have children (Allen, Lima, Goldscheider and Roy 2012). Spouses are better placed to provide informal care as they generally co-reside with their partner but may also struggle to provide care due to their own age-related health issues. Informal care has also been shown to be affected by other aspects of the carer's life such as their employment, geographical proximity, marital status and age (Checkovich and Stern 2002, Leinonen 2011). Informal care is occasionally extended to wider family members including aunts, nieces and grandchildren (Vincent et al. 2006) providing what Barnhart and Peñaloza (2013) call an elderly consumption ensemble. There are also respite facilities provided by local authorities (Leonard, R., Horsfall, D., Noonan, K., and Rosenberg, J. 2017), however, there is significant guilt in informal carers' ability to care (Prunty and Foli, (2019) difficulty in accessing these facilities (Phillipson, et al, 2019). However, with both formal and informal care provision there is a view that for end of life care, remaining in the home is the best option for the cared for (Horsfall et al, 2017). Historically informal carers have tended to be female (Finley 1989; Hiedemann and Stern 1999; Laditka and Laditka 2000) this also increases when they are unmarried (Stoller 1983). However, today female workers are still more likely to be informal carers than male workers (ONS, 2019).

The challenges of multiple roles affect the quantity and quality of informal care provided to care recipients (Stephens and Franks 1999) but also affects the wellbeing of the carer (Bevans and Sternberg 2012). This has also affected carers' relationships with other family members and the wider family unit (Dooghe 1992, Leinonen 2011). Tensions emerge as new caring responsibilities are assigned, family rituals are altered, financial changes are worked through and self-identities change (Dean, Kellie and

Mould 2014; Leinonen 2011; Trees and Dean 2018). The propensity for a carer to provide care is motivated by many factors, including love, affection, duty and obligation. There is usually a pre-requisite level of affection that encourages helping to care (Engster 2005; Leira 1994) but more importantly a sense of moral duty or familial obligation has the greatest impact on care (Daly 2002; Oudijk et al 2011) Moreover, some studies showed that the greater the perceived obligation, the greater the amount of care given and the emotionally closer the familial relationship (Cicirelli 2000, Engster 2005, Stuifbergen, Van Deldem and Dykstra 2008, White-Means and Hong 2001). The declining health of a family member and the need for informal care necessitates the coming together of two previously autonomous family units where the adult child helps to care for the ageing parent along with the concomitant tensions and negotiations (Dean et al. 2014). For Miller (1998) love is “the ideological foundation for the complex relations that exist between family members” and providing informal care for an elderly relative increases these complex relations. This can exacerbate long standing family tensions or conversely build deeper loving relationships (Trees and Dean 2018) illustrating that the disruptions, negotiations and practices which form a continually evolving family assemblage Huff and Cotte (2016). We respond to Phipps and Ozanne’s (2017) call to build a deeper understanding of how family practices adapt to this disruption and change, and in particular examine how this affects the informal carer and their identity during this transitioning lifestage.

## **Identity**

The concept of self-identity is widely assumed to be unique to each individual and is based on who we are, where we belong and how we fit in. However, Hogg and

Michell (1996) suggest that the 'self' is made up of a number of macro and micro levels of identity and for Schwartz, Luyckx, and Vignoles, (2012, p5) "identities are inescapably *both* personal *and* social". Shankar, Elliott and Fitchett (2009) proposed that the concept of self-identity is changing, from being a fixed construct of social position to a dynamic construct, which can be assembled, changed and influenced by a variety of other aspects. Al-Abdin, Dean and Nicholson (2016) described individuals with a number of 'selves' – social, domestic and extended which are shaped by both major and minor events in a person's life. This notion concurs with both Ahuvia (2005) and Belk (2014a). Both Schwartz et al (2012) and Ahuvia (2005) suggested that a self can be made up of a number of different identities and questions Belk's (1988) concept of a core and an extended self because the existence of a core self suggests the existence of a 'true' or 'real' self that individuals must endeavour to discover. Rather, Ahuvia (2005, p180) suggests that the self is more fluid in nature, responding to changes over time. Crucially, Kleine and Kleine (1993) also make the distinction between a self-identity and identity roles which is an important consideration when looking at the transitional role of informal carers. Belk (2014b) reviewed alternative formations to the extended self and confirmed they acted as "an enriched and enhanced set of perspectives for construing the relationship between people and things" (Belk 2014b p.253). The alternative formulations considered included the expanded self – essentially viewing other people as part of self; the extended mind, which allowed the inclusion of technological advances into our concept of self; the multiple self; the narrative or dialogic self, which confirms the existence of multiple identities; and actor network theory which recognises that multiple objects and multiple people both work together as actants in a network to formulate behaviours. All these characterizations illustrate the dynamic, fluid nature

of self-identity and McAdams (1993) argues that “we create a self that is whole and purposeful because it is embedded in a coherent and meaningful story” but stories are “works-in-progress” (McAdams, 2012). As individuals are exposed to new experiences through their life course the stories are amended and if experience does not fit the narrative then tension occurs in identity transition.

### Identity transition

Identity transition is a social act, which requires recognition from those around us to validate the new identity (Shankar et al 2009), however this recognition (or lack of recognition) by others can also become a source of discontent. Our identities are socially constructed to provide “archetypical identities” (Shankar et al 2009 p.80) or role models of identity to demonstrate who we are and how we behave, which remain theoretical until put into practice by the individuals around us. As these archetypical identities are reproduced over generations, the characteristics of those identities become deeper ingrained, supported by our society and becoming increasingly static (Shankar et al 2009). Therefore, identity transition can create tensions because the desired or changed identity may not conform to the expectations within our milieu (Schwartz et al, 2012, p6), indeed, a new identity is not *assigned* by others but *validated* by others (Shankar et al 2009).

### Liminality

In periods of dramatic change in the family (such as the inception of care) changes to the self can be extreme and occur quickly. Noble and Walker (1997) suggest that



identity transition takes place through three distinct phases. Firstly, 'separation' whereby an individual detaches from their previous identity and roles; secondly 'liminality' whereby individuals exist between identities, somewhere between the relinquishment of their previous identity and the development of a new identity, "Liminality is evidenced by solitude, alienation from social existence and withdrawal from the present social structure" (Noble and Walker 1997 p.31). Thirdly, 'aggregation' whereby a new identity and its associated roles are identified and accepted. Prolonged existence in the liminal period may have severe negative emotional consequences for the individual involved and result in "profound and disruptive effects on our innermost self-perceptions" (Noble and Walker 1997 p.32) by increasing the gap between our actual identity and our ideal or desired identity. For Cody and Lawler (2011),

"the liminar is understood as experiencing a suspension of identities in which commitment to the definable and social categories from which they left and towards which they gravitate to cannot be made".

Informal carers are in this liminal position 'betwixt and between' their former identity (whether a work identity, social identity, spousal identity or child identity) as they transform to informal carer. This transition is complex and depends on the family relationship, if there is a warm, loving connection or if there are tensions in the relationship. Therefore, the notion of liminoid is also useful, for Turner (1974; 2008), a liminoid position is voluntary, as identity is chosen to be temporarily suspended. Al-Abdin et al (2016) suggests that there are three parts to liminal transition "history, happening and hopes" which produce a 'transitional self' that is liminal, in a constant state of flux and "expressed through rituals, symbols and artefacts". In addressing self-identity tensions, Ahuvia (2005) introduced the idea of three methods for reconciling self-identity crises. Firstly, "demarcating" whereby one identity is rejected

in favour of another, secondly, “compromising” whereby an identity is formed part way between two alternative identities, and thirdly, “synthesizing” whereby aspects of each alternative identity are taken out to formulate a new third identity (Ahuvia 2005 p.181). Rindfleish’s (2005 p.345) utilized the notion of sythesization in religious choice with the “spiritual supermarket” whereby individuals can select a belief system to complement their identity transition. In considering future identity Belk (1990) highlights the importance of considering the past. Belk (1990) argues that a sense of past is of particular importance during times of transition, stress and identity tension arises when futures are uncertain and that possessions provide a sense of support as well as a “stimuli for future reflections, communication and consolidation of self” (Belk 1990 p.670).

#### Rituals and artefacts

As a person’s life evolves, rituals, artefacts and personal possessions help to secure and stabilize the transition of the self (Rindfleish 2005). For Turner (2008) in times of uncertainty and conflict, not only are rituals more frequent but rituals and artefacts help to provide an anchor and enable a structure to be followed to prepare for what is unknown to those entering a liminal situation. These provide a mechanism for enabling the rite of passage movement. For example, possessions can act as conduits for transporting the ‘self’ during a geographical relocation (Noble and Walker 1997). Even possessions which are utilitarian in nature, such as televisions and radios can hold significant emotional value as vessels of symbolic meaning during the liminal phase and can be used in two ways; acting as replacements for absent social and personal relationships; and acting as facilitators for the development of a new identity (Noble and Walker 1997). Shankar et al (2009) agrees that consumption can be an

empowerment tool to assist in the creation of an individual's ideal self-identity, that possessions can become a "personal archive" for the recollection of memories (Shankar et al. 2009 p.78). Personal consideration of these possessions then becomes the "cultural construction of subjectivity" in that tensions may emerge between the individual's current or desired self-identity and the social constructs enforcing stasis or an undesired change in self-identity (Shankar et al. 2009 p.78). Conversely, Ahuvia (2005) claims that love and happiness are intrinsically linked to objects of emotional attachment and that these objects help shape the transition. For this research, identity is defined as a transient construct consisting of a narrative identity (McAdams, 1993) – the 'who am I?'; the 'what do I value?' and the 'who do I connect with?' (Abma et al. 2012). Together, these narratives form an individual's 'normative expectation' (Abma et al. 2012), a self-identity constructed according to these personal narratives. This research supports the idea of multiple identities which may co-exist (Ahuvia 2005; Al-Abdin et al. 2016) and consist of multiple roles.

## **Methodology**

This phenomenological research was part of a wider study on ageing and the family and sought to understand how this new caring role affects the identity of the informal carer. As elderly family members transition from the *third* to the *fourth* age (Higgs and Gilleard 2015) we sought to understand how the changing social interactions and dynamic family relationships affect the informal carers perception of their own self (Adams, 1993; Belk, 1988; Belk 1989; Berger and Luckmann 1966/1991; Cunliffe 2008, Edvardsson, Tronvoll, and Gruber 2011; Schwartz, et al, 2012). The meanings of care, love and identity are derived from the lived experience and social interactions articulated through conversation (Peñaloza and Vekatesh 2006). Indeed, for van

Manen (1990, p27), “A good phenomenological description is collected by lived experience and recollects lived experience – is validated by lived experience and it validates lived experience”. Phenomenology is helpful as it illuminates interpersonal interactions and the individual and collective experiences in order to construct meaning (Moran 2000; Kvale 1996). It takes into consideration the perspectives and interpretations of the informal carer and the researcher so meaning is constructed “*prior to, during and after the actual exchange and use(s) takes place*” (Peñaloza and Vekatesh 2006). Phenomenology seeks to get to the essence of the phenomenon to be studied and we share the view that family behaviour is intersubjective, dialogic and shaped by the family, the ‘collective we’ which creates understanding (Cunliffe, 2003). Adopting the phenomenological interview as a research method confirms the epistemological position of the research which:

Allows that a legitimate or meaningful way to generate data on these ontological properties is to talk interactively with people, to ask them questions, to listen to them, to gain access to their accounts and articulations.  
Mason (2002 p.63/64)

The interview process was reflexive and considered the impact that the researcher has on the research process (Cunliffe 2008). As an interview was completed, we noted that “*you cannot separate the interview from the social interaction in which it was produced (because you cannot separate ‘facts’ from contexts)*” (Mason 2002, p 65). This intersubjective approach is supported by Cunliffe (2008) who asserts that meaning is created with others, with no one person directing the interpretation of reality and is experiential, relational and interactive on a micro-level and cannot be separated from others as “*we are always in relation to others whether they are present or not*” (Cunliffe 2008, p 28). Moreover, quality interviews can only be achieved when power relations are equal, and that the identification of some level of

‘shared identity’ and therefore ‘shared experience’ is necessary to prevent barriers to understanding (Oakley, 1981, cited in Tang 2002). In order to facilitate a shared experience the researcher shared some personal information with the participants, such as the fact that she had children, had elderly parents and a relative with dementia, which the researcher felt assisted in creating a ‘shared identity’ as suggested by Tang (2002) which formed the basis for the sharing of experiences. Interview location was an important aspect of the research Tang (2002) suggests that interviews taking place at the the participants home tend to be more relaxed thus providing an added richness to the data because the participant feels more confident on their home turf, despite the researcher’s power in directing the conversation. All interviews conducted were conducted in the participants own home, or the care recipient’s home.

### **Sampling**

The health and quality of life in this region is lower than the English national average, however, there are more elderly people supported by social care and 70% of those receive Self Directed Support (Public Health England 2017). The notion of SDS is to encourage independent living (and of course to save money) and frequently includes the introduction of informal family care. There were two main study groups, one rural and one urban. The research took place over a two year period in Hull and East Yorkshire, England. Participants included family members (sons, daughters, husbands and wives) who all described themselves as informal carers.

<b>Participant Name</b>	<b>Relationship to Care Recipient</b>	<b>Gender</b>	<b>Age</b>
David	Husband	Male	64
Ashleigh	Wife	Female	71

Francine	Wife	Female	74
Bob	Husband	Male	68
Jill	Daughter	Female	48
Jayne	Daughter	Female	56
William	Husband	Male	N/K
Harold	Husband	Male	72
Gary	Husband	Male	N/K
Yvonne	Wife	Female	N/K
Vivienne	Wife	Female	65
Tracy	Wife	Female	N/K
Carol	Wife	Female	70
Susan	Wife	Female	N/K
Neil	Son	Male	49
Ian	Husband	Male	81

Table 1 List of Participants

Participants were recruited using a judgmental sampling strategy identifying care support groups in both Kingston upon Hull and an East Yorkshire market town. We selected the two regions to identify if there were any differences between the formal and informal support in the ‘elderly consumption ensemble’ (Barnhart and Penalosa, 2013). We attended the support group sessions and recruited participants from there, however, participants also identified other informal carers known to them so we used snowball sampling to increase our sample size and this contributed to the evolving theory (Creswell 1998). Participants continued to be recruited until theoretical saturation was reached (Kvale 1996). Sampling was organized through the following criteria, that the care recipient must be over 65 years of age, must reside in the study area (although the participant, the informal carer, could be any age over 18 and could reside anywhere); that the participant was willing and able to provide consent; and that the care recipient received informal care from at least one source (See Table 1).

### **Data Collection and analysis**

The phenomenological research adopted the ethical guidelines followed by the researchers' institution and were approved before the outset of the data collection. The discussions were wide ranging and included discussions on their lived experiences, their family, their family relationships, their work, children, when the caring commenced; how long it had been going on for, what informal caring includes for them, what activities they engage in, whether they engage in personal care, the challenges and what has changed. The second section of the discussion included how the informal carer tried to maintain balance in their lives, what rituals are continued, and which are newly initiated after a crisis point, what artefacts are no longer used and which are now included. Embedded in the discussions was their feelings about caring and how they coped. The data source was the narrative description provided through fifteen semi-structured interviews with the informal carers within the family, including spouses, sons and daughters, discussions were supported by memos and notes taken by the researcher (Glaser, 2014). The interviews were digitally recorded and transcribed verbatim soon after in order to identify any emergent themes that could be developed in later discussions. The discussions were conducted in the participants' family home and were from two to three hours in duration. In order to protect the safety of the researcher, a practice of text in and text out was followed. Interviews took the form of a conversation but it was semi-structured, as Kvale (1996) suggests it is a professional interview, so although an informal atmosphere was created there was some direction in the discussion. The data was transcribed by the researcher after each field visit, using the notes taken from the interview, which helped to revise the discussion guide where necessary and then later visited the participants again to co-create the findings (Cunliffe, 2008).

Data analysis followed the guidance of Shutz (1967) and Kvale (1996), all material including transcripts, notes and memos were read and re-read by the researchers to identify emergent themes (Glaser 2014). Using the notion of theoretical reading (Kvale1996), the data was examined through the lens of identity seeking to uncover perceptions of identity, any changes, and tensions.

### **Findings and discussion**

Themes that emerged through the data (See Table 2) were that the *carers' needs were overlooked* in terms of health, personal wellbeing; not having their own time and a lack of recognition of the sacrifices of their caring role. *The transition to carer*, created tensions in the family as the balance of focus shifted towards the cared for to the detriment of other family members; placed the carer in a liminal position; that their character changed; they had new roles and responsibilities which they were frequently unprepared for; the loneliness; and how their relationships changed with the cared for. *Possessions and rituals* provide links to their previous identity and were used for reducing the tension between the informal carer and the cared for. It emerged that there was no road map or guidance in how to transition to an informal carer, particularly given the frequently traumatic events of a crisis point that triggers the need for care.

The transition from their previous life as an employee, friend, and husband/wife to that of informal carer, changed not only their physical appearance but their mental state due to the lack of control they had over their own lives and the guilt they felt when wanting the situation to end. William felt that he was no longer centre-stage in his own life but he had to fit around his wife's needs.



Everything has totally changed and now everything revolves around her so I really don't have a life of my own anymore

For Tracy, her personal appearance changed as she stopped wearing makeup, just “throwing on” casual clothes because she felt invisible, and she now felt isolated and undervalued

I am not allowed to be sick or feel like staying in bed for an extra hour or so because I am expected to be at their beck and call - no one gives any thought to how I might be feeling or if I am having a rough day.

While for David he felt trapped and said that

I can't walk away from it, it's not like a paid carer or a job where you go home at night. Its 24/7 full on and I don't think it's right. There's got to be changes. We can only live in hope

A number of participants revealed that the lack of physical space when families lived together created tensions for the informal carer. For Susan, she found her husband was always there and the lack of physical space was frustrating as

He likes to ‘help’ so will stay with me while I sort laundry, load the washer or dishwasher, fold clean clothes and put them away. Since he cannot be left alone there are many things which I cannot easily do

Francine's life increasingly revolved around her husband and she felt her freedom was dictated by his physical and mental needs. However, he tried to maintain his control over her and the household by dictating what activities needed to be completed, which ensured that he was involved in some way, despite being unable to move from his chair.

Theme	Premise	Supporting Statements
Carer needs over-shadowed	Health needs	“I am not allowed to be sick or feel like staying in bed for an extra hour or so because I am expected to be at their beck and call - no one gives any thought to how I might be feeling” – Tracy
	‘Me time’	“I feel as if there is no free time for myself and that no one appreciates the efforts I make. Sometimes I barely do cope” – Carol

	Lack of acknowledgement of sacrifices	"I think it would be nice sometimes to be able to just, you know, not do it all...like he says to me, I don't know what you want to go on about caring for, all you ever do is an hour in the morning and half an hour at night, that's the way he sees it you see!" – Francine
<b>Transition to carer</b>	Tensions within the family	"I have tested my wife more than I should have. We have had many a 'last chance'" - Neil
	Carer identity unwanted trapped in liminal position	"I could have very easily have driven my car into a tree most mornings" – Gary "Life gets very frustrating at times. You get a feeling of being trapped in a situation you can do nothing about, sometimes you just want to cry or give up but you can't. And yes you can think suicidal thoughts at times and even wish your partner would die so you can actually have a life." – William
	Carer identity accepted	"I don't mind, I don't feel no pressure...I don't feel obligated, my family have always done everything they can for me, I do whatever I can for them. I've never felt obliged to my parents at all. I just feel like I should do it, but not that I have to do it. I want to do it." - Jill
	Character changes	"I barely do cope and have discovered at nearly 70 years old that I have a bad temper. I never thought I had. I was always laid back and happy" – Carol
	New roles and responsibilities	"All responsibilities are now for me to do, including washing and dressing my wife as well as taking her to toilet, also cooking, shopping etc. Life gets very frustrating at times" – William
	Loneliness and isolation	"It's easy as well to feel so alone, not getting much support from family or friends as they could not manage my wife on their own" – William
	Relationship label changes	"My feelings towards my husband are now that of a carer and at times I feel like I am living with a child and not someone I used to be able to talk to and discuss day to day problems with. We are not 'husband and wife' now" – Tracy
<b>Possessions and rituals</b>	Tools to try to retain links to their previous lives	"And we even used the wallpaper in here, the same as she'd had in the other house... I went back and we got the same wallpaper, so that was the same... same layout as her house. So we tried to keep everything as emotionally undistruptive as possible." – Jayne
	Links to previous identity	"We had a caravan, well we still have one, its been parked up and not used because Sylvia can't get in and out of it really. I keep saying we are gonna sell it but we never just get round to selling it... It was freedom, to go where we wanted to go, when we wanted it. That's probably why we haven't sold it. We keep saying, but we never do anything seriously about selling it." - Bob
<b>Reasons for acceptance of identity change</b>	Love and affection	"I would not change a thing, even though it is hard work looking after her. She is my whole life." - Harold
	Duty, obligation and moral code	"It's an admission that'll resonate with many people caring unexpectedly for loved one. We never chose to be in this position and we certainly never trained for it, yet here we are, unable through our moral consciences or love to do anything other than care." – Yvonne
	Piety, self-sacrifice and martyrdom	"So many come out with "I don't know how you do it" or "I couldn't do it". One woman in the village asking about Mum ending the conversation with the parting shot "...ruining your life". I have the completely opposite view - how can you not do it?... In the real world, "How's your Mum?" is as much as you get before they glaze over and rush off. My guess is embarrassment from recognising they don't want to do the same. Their willingness to offer excuses kind of gives it away." – Neil

Table 2 Supporting examples from the data

### Transitions and Liminality

The notion of being trapped or unable to escape from the informal carer position was evident for a number of participants. Francine felt both physically and emotionally controlled and on top of the pressure of caring, this was overwhelming for her and

often she would go out into the garage and cry as this was the one place where he couldn't hear her. Her sons lived away and while they visited their father insisted that they didn't need any help, either formal or additional informal care.

Vivienne shared the same view:

It's not easy looking after someone - your life is no longer yours... When things get on top of me there's *nowhere* I can go to get away. Sometimes I just want to run away.

There were feelings of frustration and the sensation of being trapped by their caring role, a role from which there was no escape as she could not wish for the inevitable to happen sooner, again reflecting the guilt of the informal carer (Prunty, et al, 2019).

Yvonne made the comparison with professional carers who

have the luxury of going home at the end of the shift or bad day, putting their feet up and maybe having a bath and a glass of wine. It is much harder when you're working day has no end and the one you care for is with you 24 hours a day.

Ashleigh also felt permanently on call and tried to gain some space through moving her husband out of their bedroom into a room downstairs, ostensibly so she could manage him better during the day

We made a proper bedroom in there [in the downstairs dining room] for him but he was... it was a case of once he was down here "are you there love???" [Interviewee shouts towards the upstairs, impersonating him "Yes", "are you putting kettle on??" "No!!!" I'd sit here and think I've just been down, I've just done so and so... "What time are we having tea???" [Laughs]

Although this sounded lighthearted, the frustration was unmistakable. Even when popping out to the shops she would get a phone call

where are you now? I'd say I'm in the shop, How long are you gonna be? When are you coming home? I'd say I've left you a sandwich in the fridge,

oh well I'll wait till you come home he'd say I haven't been out an hour and he's already wanting me back home! It wasn't that he couldn't cope on his own. He was able to make a cup of tea, so he was never... but in an afternoon he used to have a good sleep and that was my time.

Gary used to have full time employment but had to terminate this when he started getting phone calls from his neighbours who told him that his wife had been wandering the streets in their village. His wife would become aggressive believing he spent time at work to avoid being with her. He saw no way out and said that "I could very easily have driven my car into a tree most mornings". These conversations not only discussed the transition from their previous lives to informal carer but also the transition in the relationships. Carol mourned the loss of her husband, close confidant and lover who had become her "dependent child". Old labels of lover or friend had been replaced with carer and dependant, the relationship had changed significantly and there was no return

Our relationship altered beyond all recognition. I feel that I am looking after a stranger and that my husband has gone ... We are no longer affectionate towards one another, we cannot share a joke, we cannot talk in any meaningful way and we no longer have a physical relationship.

For Tracy, previous bonding activities for her and her husband were the ability to discuss their minor problems, to chat with each other at the end of the day discussing good and bad and both felt a sense of shared experience. When this was lost through her husband's illness, for Tracy the change in both her identity and relationship was evident to her and she responded through feelings of bitterness and powerlessness.

I felt trapped by 4 walls...I felt like my world had collapsed around my ears. I had no one to talk to anymore...There was no empathy...There are days I could gladly walk away and let him get on with it - he doesn't care about me or my feelings, why should I bother?

The loss of physical contact changed Ashleigh's relationship with her husband and therefore her self-identity she now acted as nurse rather than wife.

In contrast, Harold believed that strength of his relationship had not changed despite his wife's illness. Harold believed he was "lucky" and his relationship with his wife was "amazing". Susan felt admiration for her husband's battle with dementia and did not reveal the bitterness and helplessness that other participants did.

He is always so thankful for the help I give him and so appreciative of everything that is done for him. I admire him tremendously the way he copes with all the confusion in his life... I am humbled by the vigorous efforts he makes to understand the troubled world he lives in and by his grateful thanks... Although our relationship has changed due to dementia it remains strong. It isn't what we expected it would be - no one expects it - but so long as we can remain together and share our love for each other then I shall feel life hasn't been all bad.

For Chris his caring role enhanced his relationship with his father and while there was a distinct change in the relationship for instance, Chris now held his father's hand but the responsibility of care was worrying

I actually cherish those days in particular because, there was one day we went to the concierge and asked to borrow a wheelchair for my dad. OK fine, you can have it for a couple of hours so I nicked it! And we then legged it from the hotel, got on a train and went to {unintelligible} just to do something different. But we've got photographs of... you know, dad had a black eye at the time {laughs} and was wearing a baseball cap! But they are to me, very precious memories...I suppose they symbolise the change in the relationship between me and Dad. You know, I had to hold his hand when he walked...I'm very glad I've got this new relationship with him... [although] I did find it hard, the worry.

This study has identified an inextricable link between pressures of caring and carer identity, however the findings have shown that re-negotiation of self-identity to the carer identity is challenging, particularly for some who remain in a liminal position,

feeling trapped and the guilt relating to wishing to escape from this is palpable. However, for others it strengthened the feelings of love and care which enhanced their relationship.

### Rituals and possessions

The investment of artefacts and objects with emotional meaning is not a new phenomenon (Belk 1988) and rituals and possessions can be imbued with memories and links to previous times, reminding carers and their care recipients of previous shared identities. Rituals also play an integral role in making people feel secure (Phipps and Ozanne, 2017) and the continual renegotiation is crucial during family transitions (Trees and Dean, 2018). However, this data reveals that possessions and rituals could be used to escape temporarily such as a car, provide a link to a previous life such as wallpaper, or lament the loss of their former life. Possessions and rituals acted as agents to reinforce self-identity or as vestiges of connections to former identities. Possessions were often used in conjunction with both familiar and renegotiated rituals as identities transition for both carers and care recipients. New rituals and possessions were acquired by some participants which reinforced their new caring identity whilst the loss of previous possessions and rituals were a source of great distress for others. Some participants attempted to transfer the emotional value of rituals and possessions into new settings, however this was not always successful, and the intrinsic value often became lost when attempted.

Everyday objects such as a television, radio and the telephone became links to wider society, which became a connection to other humans, which was of particular importance at night when sleeping was difficult.

In order to manage his wife's safety, Ian bought CCTV for her bedroom room

We can pop to the shops without taking her with us - the CCTV in her room (accessed via my fancy phone) minimises the anxiety around leaving her.

Microwaves and freezers were helpful as mechanism to manage independence, Jayne installed a water boiler in her mother's house as it was safer than boiling a kettle. A radio was also useful to maintain independence and reduce the pressure on the informal carer. For Chris

I know he has his lonely moments, and I know he still finds it difficult going to bed. Now, I bought him a radio. Ermm, I think for his birthday actually, last year. Because I said, look, Radio 4 Radio 2, and it's a rechargeable thing and solar powered. I keep telling him now, if you wake up in the middle of the night, put the radio on, put the World Service on really really low, because then you're not thinking about things.

Other purchases that helped were phones were also seen as helpful as in Ian's case but a hindrance when they were constantly calling as in the case of Ashleigh.

Jayne's mother's home was the other side of the city where it was difficult for Jayne to support her mum. Therefore, she was moved her mum to a house that was closer to hers. Jayne used exactly the same wallpaper in the house, the same furniture and possessions, and tried to arrange them in the same layout as the previous house in the belief that her mother's emotional attachment to her previous home could be transferred through these objects. This was unsuccessful and that her mother still took some time to settle in her new home.

Family objects, artefacts and rituals also contributed towards the loss of an emotional connection but also helped the transition towards carer. This also supports Karanika and Hogg's (2013, p 911) notion that consumers' value in certain possessions increases over time as the object becomes "layered with meaning via personal attention". For Bob and his wife for whom he provides care, they reside in the same house but he buys Sudoku and crossword books to have some space from each other – despite sitting in the same room, their 'minds' are elsewhere.

Holidays were an important ritual, especially when couples retired, Holidays were discussed at length by participants and many revealed a great loss when they were unable to pursue them. Holidays described included two week summer breaks but also shorter trips to visit family and friends. For Gary the sale of their caravan was a time of great stress for him. Despite selling a possession, Gary described how he felt he was selling a part of his life, his freedom to explore and the opportunity to socialise with old and new friends through their caravanning trips. The loss of this possession was therefore much greater than it first seemed for him. Gary also described how he and his wife attempted to alter their previous caravan holiday rituals moving to coach trips in the UK but this also failed due to his wife's illness. The stress of attempting social interactions such as holidays or visits to restaurants and cafés became too much for him and so he stopped this type of social engagement. The sale of the caravan was therefore the beginning of a distinct shift in Gary's way of life, social experiences and social routine.

I sold the caravan because she refused to go through the door. She refused to get on a bus when we went on a coach holiday to Scotland, this impacting on



people waiting to board in the rain. We stopped going on holidays. I stopped taking Nancy to restaurants and cafes.

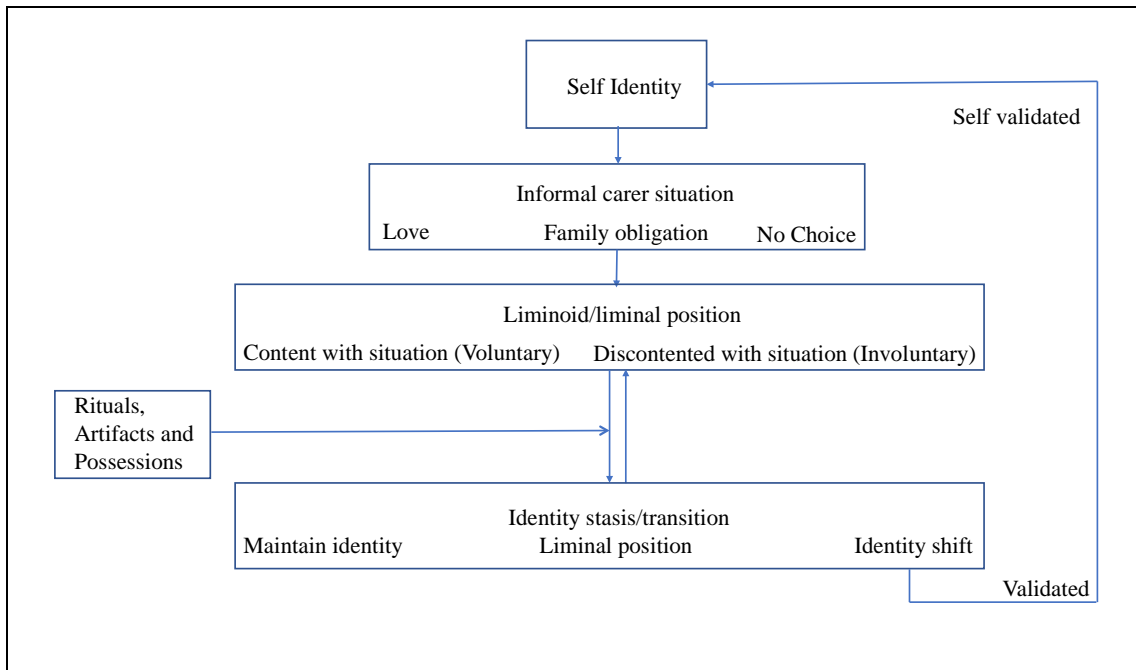
Ashleigh recounted a story of going on holiday with her husband whose illness had progressed to him requiring a wheelchair. She described how her husband enjoyed taking responsibility for the planning and organisation of the annual trip when he was well and liked to continue this practice despite his failing health. The couple purposely targeted hotels which catered for disabled individuals, however this arrangement was not always satisfactory:

I remember once we went to Ireland and he'd rung this hotel up and said to them 'can you tell me if you cater for disabled people?', 'oh yes Sir, yes Sir' they said. So he said, 'right well, have you any downstairs rooms, because I'm in a wheelchair?' 'Oh no Sir', they said, 'all rooms are upstairs' so he says, 'well how do I get upstairs to the bedrooms then?' So she says 'there's always plenty of big fellas in the bar Sir!!' So he laughed and thought, they really don't get this, so he said, 'that's fine but how do I get downstairs in the morning then?' She says, 'them big fellas will still be in the bar!!!' {Laughs}

Family rituals such as holidays are frequently curtailed such as Gary's situation, but Ashleigh still encouraged her husband to arrange the trips with her help so it was a slightly amended ritual with joint decisions rather than just her husbands.

When there is a crisis point in the family, the need to care for an elderly relative is unavoidable but as the cuts in social care continues it is increasingly necessary for the family members to take up the role. The findings illustrate that the informal carers' identity shifts as the role of carer becomes more intense. However, there are distinct differences in how this shift progresses and this is due to the informal carers situation. Figure 1 illustrates the transition from previous identity to new identity as informal carer. For some informal care is merely an extension of the family relationship with love and close family ties. For others, they adopt the informal carer role through

obligation to their elderly relative. Finally, there are those who feel they have no choice and trapped in their new role. This model illustrates the complexity and fluidity of transition articulated by Huff and Cotte (2016) as there are three stages or series of continua.



**Figure 1 Liminal/liminoid affects on self identity**

Firstly, the informal carer situation illustrates those who are placed in this position through either love or have no choice depending on their current identity and/or their relationship with their elderly relative. Second, and depending upon the family relationship, this new experience of caring moves the informal carer into either a liminoid or liminal position where they remain until they either maintain or shift their identity. For adult children and spouses who have had a close and loving relationship where activities such as shopping, cooking or holidaying together, the gradual transition into care is voluntarily accepted, such as in the case of Harold. This

liminoid position appears to be less challenging as there is comfort in caring for their loved ones. For others, where there was either geographical distance or tension in the family relationship, the transition was more difficult and participants in this liminal position experienced feelings of guilt, resentment, of being trapped and underappreciated. However, over time some informal carers who originally occupied a liminoid position on the continuum moved towards the liminal position of uncertainty and stress due to the strains of caring.

Third, is identity stasis or transition to the accepted role of informal carer. This can mean either that the informal carer is still for instance, husband or daughter and caring is still part of that identity. For other participants, their identity has been changed with a creation of a new carer identity where others recognize their new role for instance Neil's conversation with a neighbour in Table 2.

Rituals, artefacts and possessions play a key role in both preserving both the family relationship (Trees and Dean, 2018) but also illustrate how far removed the carer identity is from their former identity. Things such as caravans that not only emphasize freedom and getting away from it all, provide a stark reminder of being trapped in this identity. Possession such as TV and books, sudoku puzzles help provide some personal space, particularly for those informal carers who occupied a liminal position. However, while there is what could be described as a linear transition from the informal carer situation to the liminoid/liminal position, the transition from liminoid/liminal position to identity stasis/transition is more complex. Rituals, artefacts and possessions can for some participants illustrate a continuing, gradual process towards a shifted identity to informal carer as the care recipient

requires more care. While for others, the loss of freedom, through no longer seeing friends, having their own social identity merely emphasizes their restricted status and thus they remain in this liminal position where they are 'betwixt and between' identities. This where mental health issues may arise and support is required. Moreover, these issues are exacerbated by what Dempsey and Baago (1998) termed *latent grief* suggesting that carers who are supporting family members with dementia receive grief counselling upon initial diagnosis.

## **Conclusion**

Informal caring is an issue of increasing importance in the UK, as population demographics change, resulting in a greater number of individuals suffering from ill health, disability and frailty. Extant research has demonstrated the existence of carer identities whereby labels of carer and cared-for determine self-identity, to a greater or lesser extent, depending on individuals' circumstances. However, extant research had not considered the significance transition process in carer identities, what drives changes in self-identity and how these changes occur. This paper has addressed this gap in knowledge by identifying how carers adapt to the informal care role and how that affects their perceptions of identity and identity shift. This research has highlighted how this liminality/liminoid stage affects carers and how artefacts and rituals available to them can help to assist in this liminal position. The vital aspect revealed in this research is that in contrast to the literature on identity, this identity is imposed rather than self selected and is only self validated after the role has been validated by others in their family and their milieu. This occasionally enforced and liminal role has important implications for mental health. The most important issue is that the impact of caring for an elderly family member on informal carers has been

largely ignored, only supported by charitable bodies and support groups. However, there needs to be significant improvements in the support and resources or this fragile system will fail with increased mental illness which will impact upon the informal carers' ability to care adding to an increased cost to social care provision.

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