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Couples affected by dementia and their experiences of advance care planning: A grounded theory study

Dr Tony Ryan*, School of Nursing & Midwifery, University of Sheffield.

Barber House Annexe

3a Clarkehouse Road

Sheffield

S10 2LA

t.ryan@sheffield.ac.uk

Dr Jane McKeown, School of Nursing & Midwifery, University of Sheffield.

(address as above)

j.mckeown@sheffield.ac.uk

***Corresponding author**

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Author Contribution

Dr Tony Ryan: conception and design, data collection, analysis and interpretation of data, drafting of the article and approval of the final version.

Dr Jane McKeown: conception and design, analysis and interpretation of data, critical review of the article and approval of the final version.

Conflict of Interest

None to declare

Abstract

Global policy places emphasis on the implementation and usage of advance care planning (ACP) to inform decision making at the end of life. For people with dementia, where its use is encouraged at the point of diagnosis, utilisation of ACP is relatively poor, particularly in parts of Europe. Using a constructivist grounded theory methodology this study explores the ways in which co-residing couples considered ACP. Specifically it seeks to understand the ways in which people with dementia and their long-term co-residing partners consider and plan, or do not plan, for the future medical and social care. Sixteen participants were interviewed. They identified the importance of relationships in the process of planning alongside an absence of formal service support and as a result few engaged in ACP. The study recognises the fundamental challenges for couples in being obliged to consider end of life issues whilst making efforts to 'live well'. Importantly the paper identifies features of the ACP experience of a relational and biographical nature. The paper challenges the relevance of current global policy and practice, concluding that what is evident is a process of 'emergent planning' through which couples build upon their knowledge of dementia, their networks and relationships and a number of 'tipping points' leading them to ACP. The relational and collective nature of future planning is also emphasised.

Keywords

Dementia, Advance Care Planning, Family Caregiving, Palliative Care, Grounded Theory

Introduction

Global estimates suggest that there are over 35 million people living with dementia (Prince et al. 2013). With expectations of a further rise in prevalence, national policies in developed nations has placed emphasis upon early diagnosis, improved information and support as well as greater coordination of services, but limited attention to end of life care transitions (Fortinsky & Downs 2014). Such transitions, it is argued, are greatly enhanced by the use of Advance Care Planning (ACP). The focus of this paper is to explore the ways in which people with dementia and their long-term co-residing partners engage with ACP and the ways in which this might influence planning for future health and social care and medical decision making at the end of life. Indeed the quality of end of life care for people with dementia has, for some time, been exposed to critical commentary within the international literature, much of which has

emphasised the need to extend palliative and supportive care opportunities (Moens, Higginson & Harding 2014). A significant thread within these literature has been the exposure to life extending treatment options, such as artificial feeding (Candy, Sampson and Jones 2009); use of systemic antibiotics (van der Maaden et al. 2015), to the detriment of quality of life (Small, Froggatt & Downs 2007). Sub-optimal pain management and a failure to make transition to palliative services have also been noted (Hendriks et al. 2014; Ryan et al. 2013). Furthermore, a number of studies have explored explanations for the failure to facilitate palliative and supportive care for this population, such as the reluctance to accept death and dying as part of the dementia trajectory (Ryan et al. 2012); the challenges associated with recognising the dying phase (Kennedy et al. 2013) and organisational characteristics (Carter et al. 2015). Alongside these systemic barriers it has been noted that the prevalence of Advance Care Planning (ACP) remains low within the population of people affected by dementia (Harrison-Dening 2011).

Advance Care Planning (ACP) is considered a significant feature of the service landscape in seeking to achieve good quality care at the end of life, specifically a tendency to realise hospice care at the expense of hospital admission for the general population (Brinkmann-Stopelberg 2014) and people with dementia in particular (Robinson et al. 2013). Despite such claims, the utilisation of forms of ACP is limited. Those studies that have assessed its usage in the general population suggest take up could be as low as 5 per cent (De Vleminck et al 2015), with a similar adoption identified among an Australian nursing home population (Bezzina 2009) and 11 per cent prevalence found in a study of German nursing homes (Sommer et al 2012). Supporting people with dementia and family carers to engage with advance decision making at the earliest opportunity is identified within policy-making circles as a standard of high quality service provision and forms a central component of the European Association of Palliative Care White Paper on dementia (Van de Steyn et al. 2013).

The policy and professional discourse around ACP, particularly in the field of dementia care, maintains that it is both necessary and in the long term interests of the person with the condition to engage in future planning, the implication being that ACP can mediate the possibility of a 'bad death'. As such there have been a number of studies seeking to demonstrate ACP effectiveness via the development and testing of novel clinical and educational interventions. Poppe et al (2013) found that people with dementia and their carers valued ACP discussions and that they contributed to a sense of relief. ACP counselling demonstrated an increased likelihood to engage in future planning around the medical care for people with dementia and

their family carers (Ali et al. 2012; Awan et al. 2010), whilst others have noted improved engagement with ACP following the provision of video information (Vollandes et al. 2007). Modest reductions in hospital admission following engagement in ACP have been highlighted (Vandervoot et al. 2012), whereas others have noted postponement as a feature of the qualitative literature (Ryan et al. 2017). Indeed it is this latter point which appears to be a characteristic of the ACP planning literature in the field of dementia care. A systematic review of the take up of ACP in a range of clinical contexts has highlighted that, when compared with conditions such as cancer, people with dementia are far less likely to participate in any form of ACP (Lovell & Yates 2014). A number of studies have confirmed this observation (Laakkonen 2008; Harrison-Dening 2011). This in part may be attributed to the absence of any resource within formal services to facilitate meaningful ACP. Robinson et al (2013) draw attention to the lack of integration of ACP interventions within the service landscape, the reluctance among health care professionals to discuss these matters and importantly a predisposition amongst families to *'take one day at a time'* (Dickinson et al. 2013).

To focus on the challenges in establishing the use of ACP and to consider policymaker's failure to embed the practice within populations of older people is, however, to miss the point. Kaufman (2010) draws attention to the complex ethical questions facing older people within the broader dilemmas which centre upon life prolonging medical interventions. Furthermore, Kaufman points out that the subjective older self is obliged to make such decisions in a context of immediacy: *'where the foreseeable future is foreshortened towards the present'* (Kaufman 2010:pp227). These ethical complexities are furthermore extended when we begin to consider the notion of autonomy. It has already been noted that constraints upon choice are cited as an explanation for failing to engage with ACP. Kaufman helps still further with her work on the ways in which systems and structures inhibit the choice older adults are able to make at the end of life (Kaufman 2005). Borgström (2015) notes similar restrictions within UK hospital environments, suggesting *'the uncertainties of how dying unfolds and the caring responsibilities it can require problematizes the 'choice as goal' rhetoric of policy'* (pp708). Under neo-liberal conditions there is also the idea that responsabilisation has itself begun to inhabit end of life care decision making, with the concern that growing individual responsibility for the adherence to the 'good death' will lead to state relinquishment of its duties.

Notwithstanding these debates, there remain key questions about the ways in which families consider ACP and engage, or indeed fail to engage, with it as a process. In the UK around two-

thirds of those people with a diagnosis of dementia living in the community reside with a spousal partner (Rafnsson et al 2017; Marioni et al 2015). The significance of the dyad in the dementia literature is such that the focus is now shifting from individual person-centred to relationship centred approach (Whadham et al 2016; Ryan et al 2008). Our theoretical starting point is couplehood. Couplehood helps in recognising that ACP cannot be viewed as a single isolated tool through which one's wishes for the future are recorded, but rather as a part of much broader set of changes occurring within the lives of couples affected by dementia. The couplehood literature are helpful in enabling us to begin to identify the social relations within which couples might make decisions about future medical and social care. Hellström et al (2005) suggest that it is necessary to move beyond personhood, for example, to adopt a position which recognises the ways in which couples co-construct their lives together, come to terms with dementia and consider their futures. Further, couplehood theory in dementia emphasizes the ways in which dyads might work together to ensure participation in daily life and decision making Hellström et al (2007). Subsequent work in the field of couplehood has enabled us to understand more about family life as it is affected by dementia, and it is worthwhile here considering the literature as it relates to couples and in particular how this intersects with notions of future planning. In doing so we can begin to recognise that future planning is closely related to couple biography, where achievements of the past are privileged and thoughts about the future are distanced (Wadham et al. 2016). Hellström et al (2007) also give insight into the ways in which couplehood is sustained, despite increasing impairment. Part of this process alludes to ways in which thoughts about the future might be suspended whilst couples '*make the best of things*' (Hellström et al. 2007). We can also note the extent of loving relationships built upon a past together and how they might make thoughts about the future 'unbearable' (Daniels et al. 2007). In short the couplehood literature allows us to apprehend ACP from a broader perspective and consider the ways in which couples engage in future planning together, recognising the relational basis of the activity. Subsequently we set out to explore the ways in which co-residing couples considered ACP following a diagnosis of dementia. Specifically we set out to understand more fully the ways in which people with dementia and their long-term co-residing partners consider and plan, or do not plan, for the future medical and social care in the light of a recent diagnosis.

Methodology

The study utilised a constructivist grounded theory approach (CGT) (Charmaz 2014). CGT provided an appropriate set of tools in this context for a number of reasons. First, it takes as its starting point the role of agency in shaping meaning and reality. Future planning for people with dementia and their families is a highly complex process where families will seek to try to understand what is happening post-diagnosis, whilst also considering the future. Couples will vary in the extent to which they may or may not think about their future and the specificity of the planning they undertake (Rodwell 1998). CGT allows the possibility that these realities are shaped through the ways in which families talk about such matters and problem solve in the face of changes to impairment and in the context of their own lives. Second, CGT provides the researcher with a set of tools to allow for the systematic and comprehensive analysis of interview data. The stages of CGT analysis are well described and include specific methods of coding; categorisation and theory development (Corbin & Strauss 1990). Third, CGT seeks the development of a substantive theory. In the context of this study we would be seeking to develop theory in the specific area of co-residing couples and the ways in which they consider and plan for their future (Charmaz 2014). This we understand would go some considerable way to gaining new insights in the field and, importantly, assist in the future development of health and social care practices, methods and interventions. Fourth, CGT places emphasis upon social and psychological processes (Corbin & Strauss 1990). We do not think that the experience of future planning can be understood via a thematic or structural account, especially given the recognition and subsequent diagnosis of dementia is a dynamic experience for all family members. Place on top of this the consideration; conversation and interpretation in the context of the future and the importance of process and action become clearly apparent. Original GT was focused very much on understanding social processes within a particular context with a view to developing a substantive theory of such a process, including causes and possible explanations for variation.

Method

We set out to recruit people who have recently been diagnosed with dementia and their co-residing partner. By this is meant that the diagnosis will have been given by a medical practitioner in the past five years. The term partner refers to the person who co-resides with the person with dementia in a long-term relationship, spousal or otherwise. This excludes those adult-child offsprings who may be the main co-resident of the person with dementia. All participants were identified and first contacted by a support worker based within a voluntary

organisation providing advice and support to people with dementia and their families. Initial contact was in the form of a telephone call, followed up with outline written information and covering letter. This contact was subsequently followed up with a further telephone conversation after one week to allow for consideration of consent. Those who had agreed to take part were subsequently contacted by a member of the research team (TR) who arranged to meet with each couple and complete further formal written consent. Dewing's approach, which centres on an inclusive process consent model was used (Dewing 2007) and the team underpinned this approach by implementing CORTE methodology. CORTE recognises the importance of ongoing CONsent, maximising Responses through the recognition and provision of a supportive environment, enabling people with dementia to Tell their story and the significance of Ending on a high (Murphy et al. 2014). Eight couples were contacted and all consented to take part in the study.

Data collection

Data were collected via face-to-face interviews with participating couples with a joint interview as the preferred approach. Alongside the idea that interviews enable co-construction, they provide and allow for flexibility for both interviewer and interviewee to raise and explore ideas and areas of discussion as they arise (Charmaz 2014). The idea of conducting joint rather than separate interviews is well-established and underlines the importance of the 'relational self' in the interview context (Bjørnholt & Farstad 2014). Furthermore, the joint/couple interview provides a 'reflective space' for couples when discussing their decision making in an interview context (Bjørnholt & Farstad 2014). Indeed Molyneaux et al (2012) add that the joint interview is a means of observing and learning about the interaction within couples where one person has a diagnosis of dementia. Interviews were conducted in the family home. In addition to the face-to-face interviews, all participating couples were subsequently invited to take part in a group discussion to reflect upon our initial analysis of the data. During this group discussion early findings were presented and an extended discussion centred on theoretical insight took place.

Data Analysis

Interviews were transcribed verbatim. The authors read through each of the transcripts independently before undertaking initial coding. Coding allows the analyst to begin to see

theoretical possibilities within the data (Charmaz 2015). By approaching each segment of the interview the analyst ‘codes’ text through the conceptual naming of significant aspects of the data. These initial codes are often presented in short-hand form and should emerge out of the data. The authors met to discuss how each had proceeded such coding. Codes were shared and discussed and we were able to identify shared meanings within the data. Agreements were reached to undertake more focused coding around emergent patterns. Focused coding required the categorising a larger amounts of data and was achieved through the selection of codes which both summarise the data conceptually and steer the direction of the analysis, providing ‘theoretical reach’ and centrality to the processes experienced by participants. One of the authors (TR) proceeded to undertake focused coding before the meeting once again to agree on an approach to theoretical coding. Theoretical coding enabled the bringing together of focused codes into a coherent analytical story. Theoretical codes were used with caution in this study. When imposed upon the data the resultant theory can become too abstract and isolated from the experience of participants. Nonetheless such coding can provide a potent tool in beginning to provide a comprehensive theory of the process of future planning in dementia. We sought to ensure that such coding was rooted in the experiences of participants by meeting with people with dementia and their spousal caregivers at a final workshop where the theory was presented (see data collection above).

Ethics

The project was approved by the University of Sheffield Research Ethics Committee in September 2015 (University of Sheffield UREC 0002646). Fieldwork was undertaken between October 2015 and March 2016.

Findings

Eight spousal couples were recruited to take part in the study, 16 participants in total. Table 1 provides information on age, relationship, time since diagnosis and previous occupation.

The circumstances within which couples were able to consider future planning can be said to have been contextualised by two features, both of which played a significant role in determining the pace and direction of actions taken to plan for the future. The first one was relational in nature and bounded by the couple’s way of working with one another. The second

largely service related and determined by the low level of assistance provided by the formal health service sector. It is against this backdrop that couples made decisions about how to plan for their future. Largely it should be noted that there was a distinct absence of engagement with formal ACP planning processes. This is not to say, however, that they were not thinking or indeed planning for their futures, making decisions and putting things in place. We identify two approaches to future planning, one which focuses on its avoidance, especially ACP. A second approach we have called 'latent planning', referring to thinking and discussing the future and beginning to envisage what might address the challenges ahead and to put into place the conditions that will assist carers in particular to make decisions more easily. Finally, we did identify evidence of more formal approaches to planning, including ACP. These actions were prompted by a number of 'tipping points' of a relational, functional and temporal nature. The main theoretical contribution of the paper rests on the notion of 'emergent planning', whereby couples develop through their experience and knowledge of life with dementia and benefit from the social networks that they become part of to help in their ACP endeavours.

The Planning Context

It has been noted that we observed two important contextual or environmental features of future planning for the couples participating in the study. The first we might call the service environment. All of the couples participating here had experienced the assessment and diagnosis of dementia within a local memory service. A common feeling of abandonment was observed by participants during the post-diagnosis period and in particular in relation to the ways in which couples affected by dementia might begin to consider the future and plan for it. Couples described a situation where diagnosis and post-diagnosis services were organised in an episodic manner, where there was limited continuity and where close working relationships with nursing and medical staff were difficult to foster. This relative absence of relationships had implications for the degree to which information about ACP could be provided, leaving couples feeling that they did not know which way to turn, where to seek help and what help they may have expected. This was often put down by participants to the financial pressures present within the service system, where the competing demands of providing care to an increasing population of service users meant that it was inevitable that staff '*did not have the time*'. The carer (Margaret) below highlighted this feeling of abandonment during the post diagnosis period for her and her husband:

Margaret: Yes we saw a consultant there. [Husband] had a scan, head scan, and erm he just *said erm right you've got dementia, can't do anything about it sort of on your bike a little bit.*

Interviewer: Ok, ok

Margaret: *I wasn't particularly impressed can I say. I know they was you know, I realise with dementia that there's not a great deal you can do, there's nothing in the way of medication I realise that, but and I was half expecting that diagnosis, but I just found it a little bit I don't know, there's your diagnosis (gesturing). It was just right erm yes this scan shows this, yes that, yes right, yes you've got dementia erm I can't do anything ok you know and you come out thinking right, right ok, what, what do we do from now?*

A second contextual feature of the interviews with couples relates to the idea that the future holds a singular meaning. It has already been noted that it was our intention to interview couples together in order that we would be able to identify a shared articulation of the process of planning. Interviews did reveal this to some degree, but what was also apparent was the extent to which ideas about the future were in a state of constant negotiation. Couples were at times discussing their differently held perspectives on the future within the interview setting, revealing the dynamism of the subject but also the compromises and conciliation that is inherent within the process. These were often revealed as clear lines of tension between partners and very different notions of what constituted the present and future were being observed. Interviews stressed the importance of this, specifically in how couples could make progress towards planning, decisions around care and how it is organised in the future. The couple below were discussing their differences in relation to his perceived levels of independence and how carer and person with dementia appraised the situation very differently:

Alfred: I can do quite a lot on my own. I mean I think you could go out more than you do and leave me at home. *I don't see that as a problem.*

Rose: You forget to eat, you forget to drink.

Alfred: *No I don't forget to eat. Nothing makes me forget to eat.*

Rose: No I must admit the two stones has just about gone on that you lost.

It is against this backdrop that couples affected by dementia are encouraged to consider what they may want from the provision of medical and other health services in the future.

Postponing Planning: Living for today

We embarked upon this work to help identify the measures taken by couples affected by dementia to consider and record wishes as part of the formal ACP process. The context within which this took place for them is highlighted above, but another overriding feature of the data was the relative absence of engagement with the formal ACP process. Just one of the eight couples had worked to put any form ACP in place (Do Not Actively Resuscitate order). Three had been through the process of setting up Lasting Power of Attorney (Finance). This should not have been a surprise given the evidence suggests that the population as a whole does not engage with ACP. Nonetheless ACP remains a mainstay of policy and guidance within the field of dementia and as such continues to be regarded as the best model. We identified three particular barriers to approaching formal planning within our data.

'Tomorrow never comes'

A number of couples could be described as being in a state of postponement when it came to planning for their future, particularly in respect of ACP. Within such a situation couples downgraded the importance of the future in favour of the present and were actively seeking to focus on day to day life. This was despite recognising the temporal nature of dementia and the possibility of significant change in terms of cognitive status in the future. We were able to discern a number of key features within the stage at which some couples could be said to be postponing under the understanding that *'tomorrow never comes'*. The couple below had an approach which was fully consistent with the way in which they had always lived their lives:

Tom: No, no er they (medical *professionals*) *know roughly you know sort of thing what's going to happen er erm but they don't know ... we haven't made any definite plans. As I say we've never done all our married life, we live for today and tomorrow you know you might not be here.*

Elizabeth: Tomorrow never comes.

The inevitability of cognitive and functional decline is apparent in the way the above carer regards his wife's illness, but the rate at which this will occur is somewhat uncertain. Under such circumstances the couple feel that continuing to live a 'normal' life is the right approach. For others, a positive decision to delay any consideration of what was to happen was the

product of unease about ensuing cognitive change. There is, however, a sense that participants were rejecting prescribed notions of ‘the good death’ as determined by stated policy and practice guidelines. The ‘good death’ is underpinned with planning, choice and the clarification of end of life practices for the professionals who might be in a position to care for the dying person. Our data suggests that there is an absence of any adoption to such an approach. The person with dementia below indicates his reluctance to plan for the precise detail of his future social and medical care:

William: *If I can't look after myself and no one else can look after me, somebody will take me somewhere and shove me somewhere and that's it. Erm and I'm quite sure they'll be kindly enough and er no I'm quite resigned to the future. ... the problem isn't it you know you plan all these things and then the other person dropped off their perch don't they and they're left and you know anything could happen to your son and daughter, what happens then but I suppose realistically well it's in the lap of the gods if that happens.*

‘Living well with dementia’

A significant constituent part of global dementia policy in recent years has been that of ‘living well’. The focus of living well has been to contest the assumption that dementia can only impact upon the person and the family in a negative way. Living well suggests that following diagnosis a healthy and happy life, with some degree of continuity in terms of activities, lifestyle and relationships is possible and to an extent should be facilitated. Participants in this study embodied the living well code. They were demonstrably active in seeking to maintain a lifestyle which was consistent with the past. They sought multiple opportunities to participate in social life and to retain a sense of physical activity and engagement. Adherence to the living well doctrine was something that participants felt was worthy of investment, but at the same time participants noted some discord with an approach to life which appeared to place importance on decline, further impairment and death. The carer below and her husband pride themselves in being fully engaged in the life of the community. The importance of this was threatened by the spectre of future decision making:

Bridget: *You know there's enough going on and we are keeping ourselves active and busy, I don't think you want to go down the route of 'well what we're gonna do if this, that and the other' and get all depressed about it.*

Keeping busy for this couple occurred within a context of uncertainty. Whilst this uncertainty persisted it was important to live one's life to the full, a sentiment that can be detected within contemporary dementia policy discourse.

Carer Burden

One final characteristic that could be detected within this phase of the process relates to efforts undertaken by caregivers. Caregivers described the efforts, particularly physical, that they made across a number of aspects of daily life. These daily efforts were often enough in themselves to prevent investment in considering the future. For those who were just about managing their caregiving role planning, and ACP in particular, were viewed as an additional burden. Caregivers also described the work undertaken to 'manage' the day to day anxiety of the person that they cared for, noting that this was an element of their work which often went unseen. Nonetheless the anxiety of the person they cared for was a significant burden in itself and a threat to normality and day to day life. Caregivers described this highly skilled work which involved monitoring for signs of upset, distracting the person and helping them to work through anxious moments. A particular threat to the people with dementia in the study was that of the future and what was to become of them as individuals and as a couple. Discussing the future had become forbidden territory for some, as it invoked deeply held fears for the person with dementia. At best some couples had to '*agree to disagree*' about attempts to talk about the future. The couple below, aware of the anxiety experienced by the person with dementia, had made a decision not to talk about specific plans including ACP. This did mean that a 'positive' approach to day to day life was all the more possible for them both:

Stan: *I think you do try and do it, do it that way [avoiding talking about the future] 'cos it's another point of looking positive isn't it, you don't want to ...*

Sylvia: You shove that to the back of your mind.

Stan: *You shove it, yes subconsciously it's in the back of your mind but you don't want to bring it to the forefront because you want to carry on to a certain extent living your life and being together and er as normal, well as what you've always done.*

These data demonstrate an absence of plans to engage in formal ACP. Furthermore, they point to a range of potential barriers to this happening. It would be wrong to assume, however, that couples were not considering the challenges that lay ahead and actively working, however implicitly, to prepare for change.

Latent planning

Although involvement in formal planning was absent, discussions with participants within interviews and the group meetings revealed that a number were making efforts to organise, prepare and consider the challenges which might lie ahead. Some of the efforts described by participants were not understood to represent formal planning, and certainly did not take the form of ACP, but were nonetheless essential to couples in making preparations. As such, activity of this nature was viewed as a way of maintaining independence, providing the means with which couples could address challenges as they arose or declaring long-term aspirations about the nature of care and how it might impact upon them as a couple. Part of the planning that is undertaken by couples is centred on the realisation that there is limited post-diagnostic support and a recognition that planning and making decisions, especially in the absence of such support, is very much an entrepreneurial practice. The identification of sources of support, the garnering of information and seeking potential solutions to problems is highly dependent upon a couple's own efforts. These efforts were often supported by the accumulation of contacts and helpful sources of help support, often new found friendships, but also from of the third sector. The caregiver below described being particularly anxious about the present and the future. She sought out the advice of a friend who put her in touch with an advisor at a local charity who she now communicates with regularly. Having put such a network of support in place means that concerns about the future are somewhat mediated.

Margaret: *I don't know what help I will, would need. I am, it worries me witless about the house. That does worry me should we get to that point in time, that really worries me. Erm but I don't know what I will need 'til I'm there.*

Interviewer: Yeah absolutely.

Margaret: *But having got that contact of people I can speak to I'm actually less worried about that than I was before I went to speak to [name] and different other people.*

Interviewer: *That's really interesting. So the mere fact that you've kind of got this new network*

...

Margaret: *I've got that conduit that I can go down if and when I need it which is part of why I'm a little bit more chilled about everything....That's my centre, that's the centre, that's my centre now of where I go. That's where I will you know, that's, that's and I feel quite, quite comfortable about that.*

The use of the word centre here refers to a pivotal source of support where information and advice can be sought, but importantly an ongoing comfortable relationship with the charity and a particular worker is apparent. Margaret makes the effort not to undertake formal planning in the present, but recognises that the work done to form the relationship has created the conditions to make things easier when the time does come to take actions, 'if and when' she needs it. Peer support was also highlighted by participants as a means for gaining access to information alongside a feeling of belonging.

Barbara: *Yeah it makes you feel that little bit better ;cos there's not only me here because as you are now you're on your own, I know I've got her but you still feel that you're on your own and then you go and meet them and some of them are alright aren't they? We meet up with one or two ...*

Eric: Get to know a lot of things from other people.

Barbara: *and people saying things and you think oh I've never thought of that.*

Eric: You get to know more than what you get from the memory Clinic.

Barbara: *And you listen to people don't you talking and saying things and oh I never thought about that, or that's summat and you think oh there is somebody else in the same boat as I'm in it makes you feel that little bit more, at least you're talking to people what's in that area, same as you so you're not thinking it's only me here.*

Despite living with his wife, Eric concedes that his dementia has rendered him sometimes isolated and alone. Meeting others with the condition gives access to a collection of people whom he can relate to, allowing him to gain further insight and helping him to think about ways of managing day to day. Both of the above resonate with a need to extend the reach of available networks and develop relational capital.

Others were also adamant that they had done very little formal planning, but articulated very clear ‘non-negotiables’ in anticipation of a change in cognitive status. It was evident that couples had gone to some length to discuss with one another these future aspirations and importantly what they wished to preserve. These plans centred on maintaining couplehood itself in the face of changing capacity. One couple outlined their wishes to move into the same care home, promising never to be separated from one another. Another couple had vowed that neither would end their days in a nursing home. They had gone some way to costing a domiciliary provider alternative. Finally the caregiver below spoke about his commitment to his wife and how he had an essential need to continue to care for her whatever the changing circumstances:

Stan: *Touch wood I will always be there for [wife] and I wouldn't want [wife] to ever go anywhere else other than me to see to her but it, it, it would be nice to know that if I need assistance that it's there, that I can get assistance, but I can still be there and take control to a certain extent of looking after [wife]. And that's what, that's my one aim is to be in that situation.*

Interviewer: *That's your, that's your kind of long term plan?*

Stan: *That's my goal yeah, that I'm always there and that she's always with me and that we're always together even though it may be that sometimes she doesn't know that I'm there but I know I'm there and I know ..*

Sylvia: Shut up (upset)

Stan: *Yeah I know it's hard to talk about isn't it because [Wife] doesn't want to be in that situation.*

Sylvia: *Can't stop it can you?*

Stan: No

Sylvia: *Can't stop it, help it to be a bit better.*

Stan: *But I would always want her to know that that's my goal that I'm gonna be there, yeah, whatever.*

Maintaining couplehood is essential for this caregiver and his intention to do his best to ensure that the two remain together is set in the context of ‘whatever’ happens. He also alludes to the formation of a care scenario where he is on control, directing things on her behalf.

The Time is Right

The dynamic nature of the planning process is evident in that not all couples remained in a state of postponement, indeed as already noted some couples were beginning to actively plan. We were keen, however, to explore why some couples began to change in their approach to planning and ACP in particular. This change from postponement to planning was prompted by four observable ‘tipping points’: temporality and a change in cognitive status; the potential for changes in carer’s health status; others having a say and ‘seeing the relevance’.

Dementia had brought with it a range of challenges, one such being the provisional nature of daily life. Couples had become used to the notion that things, as they stand, are temporary for them and that day to day life is dynamic. Once reconciled, couples were prompted to begin to think about the decisions they may have to make, this in itself became a cue for investment in planning activities. For the person with dementia below the time between diagnosis and the present had allowed him to consider the challenge of dementia. For his wife there was an element of regret that the actions they were considering had not happened earlier:

William: *This is to my mind a good time because you’re in plenty of time to swallow the idea in my case that I’d got Alzheimer’s, there’s been plenty of time for me to understand because it’s progressing in my case. I’ve had to surrender to [wife] all the decision making so there’s been big changes in my thing so it’s been a good time for you know this sort of general discussion.*

Mary: I would have done it earlier when I could cope better thinking about it.

Interviewer: Ok

William: We had less understanding of the problems then.

This excerpt demonstrates that the experience gained since diagnosis has led to valuable insight and despite the regret on behalf of the caregiver, it may not have been possible to begin planning without a greater appreciation of the challenges. One couple had gone some way to undertaking detailed ACP, indeed these being the only such participants to have a record of a DNAR order put in place. For them the man’s mental and physical capacities were such that the ‘tipping point’ around a change on cognitive status had occurred some considerable time prior to interview. The couple had sought the advice of a solicitor who had assisted them in making the plan.

Engagement with future planning was also initiated by changes in carer's health status. Such episodes prompted discussion about care arrangements, in particular, but also foreshadowed a wider set of concerns and led to discussions about how participants with dementia might manage. These discussions often exposed very different ideas about who would be able to assist the person with dementia and where they might go for support. It has already been noted that future planning was being undertaken in a context of negotiation. The example below draws attention to such concern and how the prospect of carer ill health or death has initiated discussion:

Alfred: *I mean if anything happens to me then it's a big problem.*

Rose: *But I think, I hate saying this, but I think we've got enough in our family to be able to make decisions.*

Alfred: Yes but are you going to want to have the decisions they made?

Rose: *I think I'm sensible enough and hopefully I will remain so to accept, to accept things. I know I can't go on living here forever, I'm not stupid.*

Alfred: *I mean while ever I'm here that, that ... if I can cope that's fine, that's what we'll do but if anything, if I were to be, if I were to go then you've got to be prepared. I know they will do their best for you but we can't expect them to give their lives up for us.*

A further 'tipping point' discernible within these data relates to the existence of the wider family as the source of future planning. This is concerned with both the avoidance of burden in the future for family members and the interventions of others to stimulate discussion and action around the future. Not wishing to 'burden' a son or a daughter had become the origin of the initiation of funeral plans, wills, and in some cases early discussions about care arrangements, although not ACP. It was, however, the conversations that had been instigated by family members that had a powerful influence. One caregiver spoke of the ways in which his eldest son and daughter had begun to 'look into certain things' and were openly monitoring their parent's engagement with activities where information is shared and accessible, such as dementia cafes. For another couple the professional role of one their daughters gave her a particular legitimacy to become vocal on matters around planning for the future:

Interviewer: *So she's a sort of driving force between both of you?*

William: *Well she's a very good guide, she knows her way around things.*

Mary: *You know she'll say things well why don't you try this person and go there and listen to what they're saying and I'm glad she does because it's made me realise that I've got to get my skates on (laughing) and get something done.*

The excerpt above demonstrates the role of an external 'facilitator' in the planning process, but there were also examples of others actively inhibiting any consideration of the future. A social work practitioner, who had been in touch with one couple, convinced the caregiver to try not to think too much about the future as it was causing additional anxiety. This highlights the significant role that those trusted by the participating couples might have on influencing the planning process.

One final 'tipping point' for participants was the prerequisite in seeing relevance to any proposed formal approach to planning. It has already been noted that participants approached the challenges of the future through attempting to maintain normality and live for today. Nonetheless some examples of formal ACP planning have already been described. Other forms of future planning such as funerals, recording financial affairs and power of attorney were approached when participants discerned that such actions would solve a particular problem or address a specific concern. This approach to future planning led many to use an incremental approach. The couple below had taken some limited steps in making plans around their financial affairs, but these had occurred as and when they felt appropriate. They were some way from recording and ACP, if ever.

Stan: I think the planning bit is you adjust to the circumstances as and when they arise and I *think in probably most cases it's not where these things alter overnight, you keep at a certain level for so long don't you so you adjust your life to that situation as and when these things and then if it comes to a situation where you think well I need, I just need some help here 'cos I'm finding that I can't do what I think I need to do that you know that you can go to the [Organisation] first of all and then they will say well this is what you need to do or we can put you in touch with [Organisation].*

These data suggest that ACP is anything but a simple process for couples following a diagnosis of dementia. We have identified a protracted period of 'postponement' in beginning to engage with ACP, or indeed any major planning. We have also identified, however, a 'latent' period

whereby participants undertake preparations to enable planning to happen at a later point. This ‘latent planning’ is characterised by identifying formal sources of support, meeting and talking with others with the condition and making explicit the ‘non-negotiables’ present in the couple’s lives. A small number of ‘tipping points’ have also been highlighted to indicate a dialectical element to the process, from a stage of postponement to the full participation in ACP via a series of enabling factors or further disruption via the person’s cognitive and functional capacity. This overall process we identify as ‘emergent planning’ and provides us with the main theoretical contribution of this paper. In doing so we can bring together the observations made within the findings section and as such ‘make sense’ of this entire process. Understanding ACP for couples with dementia through ‘emergent planning’ enables nuanced insights into the processes involved in coming to terms with the condition, planning for the future alongside maintaining a determination to ‘live well’. Emergent planning helps in understanding the series of phases faced by the participants here. Each dyad appraised these phases in their own way, relying upon a wealth of biographical and relational reserves. Phases are marked by the aforementioned ‘tipping points’ which might be understood as mini-revelations within the experience further underlining the need for considering further planning or making the decision to undertake ACP. Furthermore, ‘emergent planning’ enables an understanding of the ways in which the experience of dementia can contribute to better decision making, and belies the notion that as dementia progresses the potential make decisions is diminished.

Discussion

In this paper we have presented the findings from a CGT study exploring the ways in which co-residing couples considered ACP following a diagnosis of dementia. Specifically we set out to understand more fully the ways in which people with dementia and their long-term co-residing partners consider and plan, or do not plan, for the future medical and social care in the light of a recent diagnosis. The relative absence of formal ACP planning within the study sample is not unusual in the UK context (Harrison-Dening, Jones & Sampson 2011) as well as other parts of Europe (vandervoort et al. 2012). Similar studies have emphasized this reluctance within the dementia population (Lovell & Yates 2014). Alongside a number of barriers to engaging fully with ACP activities, the study recognises the fundamental juxtaposition that couples wish to consider end of life issues whilst making efforts to ‘live well’.

The study highlights service system and relational characteristics of life after a diagnosis as being important in the ways in which couples do or do not engage with ACP. Those accessing health services, such as memory clinics, identified a dearth of support in relation to long term advice. Where research around the needs of professionals have been undertaken, practitioners are able to identify the skills required. Professionals view the capacity and skills to initiate and facilitate complex conversations as being at the heart of a competent service infrastructure. The skills used to provide families with assurance, direction and peace of mind when addressing hugely sensitive topics, such as the potential withdrawal of medical treatment, has been noted elsewhere (Ashton et al. 2016, Poppe et al. 2013). Studies involving health care professionals have also indicated a lack of clarity around when such conversations should be initiated and by whom, alongside an absence of confidence in the ACP process, undermining the degree to which professionals are able to intervene (Robinson et al. 2013). This absence of action to facilitate ACP and the confidence to support families is recognisable in our data, and outside of the dementia field (Lund, Richardson & May 2015) and runs counter to policy and practice guidance (van der Steen et al. 2014). Furthermore, the retraction of formal service support in the facilitation of ACP represents a transfer of responsibility onto the individual and their family at a time when daily life is characterised by multiple unknowns.

This absence of formal health service support means that the informal relationships become all the more noteworthy in future planning. Indeed social relations are influential in determining the ways in which ACP planning plays out within families and contributes to our theory of ‘emergent planning’. It is noted here that there is a dynamic quality to planning within couples, with negotiation occurring against the backdrop of the temporal experience of dementia. The notion of couplehood (Hellström 2007) is a central feature within our data, where voice is given to future caregiving roles as a form of planning. Additionally family biography is used as a form of knowledge to inform likely practice and medical scenarios. Other family members are cited as being instrumental in prompting, advising and orchestrating resources, an observation that has been made elsewhere (Hirschman et al. 2008). Furthermore, in the absence of assistance from formal services, couples describe a strategy which seeks to work to construct networks and relational capital as particular form of what we have called ‘latent planning’. As with similar studies, in these instances the voluntary or third sector proved to be the more fruitful option (Dickenson et al. 2013).

In this relational and system context we have identified a number of barriers to the commencement of formal planning. These barriers coincide with the observations made within previous studies. Hirschman et al (2008) characterised this unwillingness to engage with formal ACP planning as both ‘passive’ and ‘active’ avoidance. In their work ‘passive’ avoidance is noted as the result of a failure to engage with ACP, viewing it as a relatively unimportant activity. Active avoidance on the other hand is recognised as a strategy born out of fear for the future. Gott et al (2008) identify the rejection of engaging in revivalist notions of a ‘good death’ amongst older people as a barrier to future planning. Furthermore, Dickinson et al (2013) identify a ‘living for today’ perspective as a barrier to ACP, where finding the right time to undertake future planning is identified as a major challenge to families. There are elements of both studies in our data, but we would add a clear line of tension which exists in the conversations within families in relation to the ‘living well’ discourse and ACP planning. ‘Living well’ with dementia appears most explicitly in the policy statements in the UK (DoH 2009), but promoting a good quality of life after diagnosis is a feature of national strategies around the world (Rosow et al. 2011, Fortinsky & Downes 2013). Specifically in the UK maintaining independence, activity, social production and enhancing self-esteem are prominent features of the policy discourse. Our participants perceived these to be worthy goals and had framed their approach to post-diagnosis life in as much as these were feasible and possible. Reminiscent of those critical perspectives of the successful ageing paradigm (Timonen 2016) participants recognised their own limitations in maintaining active and social participation with advancing dementia. Participants also note a tension with the ‘living well’ enterprise and consideration of end of life plans, and were challenged in attempts at the reconciliation of both. People with dementia are compelled to make explicit their end of life plans whilst relatively healthy and in the very early moments after diagnosis. We might speculate that this is indeed a difficult transition to make and what we have observed here is the use of the ‘living well’ objective as a means of resisting active steps to consider the end of one’s life. Compelled by policy, and in the absence of support, the individual (in this case couples) are left to invest time, effort and resources to consider future medical and social care options and create a plan around these. Kaufman (2010) notes the challenges faced by older people as they are increasingly bound to consider ‘time left’ in the context of difficult in the moment medical decisions, stressing the degree of individual responsibility in shaping one’s ageing experience. Couples affected by dementia clearly find it perplexing to address these questions far in advance of their perceived need to do so, despite the apparent urgency and despite the lack of evidence supporting it as being effective in the context of the condition (Robinson et al. 2013). As such

a process of ‘emergent planning’ is useful as a means of understanding this nuanced and complex process and will, we hope, contribute to a more informed policy context.

The data here demonstrates that when planning is undertaken it is very much formed by a degree of entrepreneurship. Families themselves in this study felt abandoned by formal services and, aside from limited advice, they felt required (albeit reluctantly) to invest time in seeking information, support and advice in isolation from health professionals. This emphasis on the family to create, maintain and enact formal ACP resonates with the idea that the shaping of one’s death experience is, it seems, based upon profound interdependency as opposed to a project of the self (Seymour et al. 2004). Importantly, however, the relational significance of our data points to a requirement to focus on the collective and interdependent nature of the ‘emergent’ process. In the US recently the relational imperative has led to funding for joint physician and patient conversations about ACP (Abele & Morley 2016). Furthermore, the importance of trusting relationships with professionals can yield a supportive experience for families in their attempts to come to terms with decisions about future medical treatments. Our data points to a need to provide such assistances to families of those affected by dementia when making such plans. It should be noted, however, that this can be achieved alongside the ‘emergent planning’ occurring within couples and their growing engagement with future planning. We view the notion of ‘emergent planning’ as the main theoretical contribution of this paper. In promoting the idea that ACP contains temporal and dialectical qualities, and that the scope of planning being undertaken by couples is broader than the current foci on the medical decision making sphere, we recognise the need to re-consider current policy and practice guidelines. Further work is required to consider ACP against a backdrop of ‘emergent planning’ which we feel will be more aligned with the lives of those affected by dementia.

Notwithstanding other limitations of the study in relation to the size of the sample and our capacity to make generalisations, we should also briefly reflect on our understanding of the involvement of people with dementia in this qualitative research. One of the explicit aims of the study was to engage with co-residing couples in seeking their shared perspectives on the matter of ACP. As such we undertook to interview people with dementia and co-residing partner together. There are, however, challenges in seeking out the voice of the dementia within such shared interviews. Others have noted the possibility of ‘self-silencing’ within interview settings when the conversation is shared in this way (Wiersma et al. 2016). There is also the possibility that individual concerns of both remained unspoken. As such we request that the

reader bears these potential limitations in mind. This being said, the degree to which participants were engaged with as part of the study should be viewed as a particular strength. Further to this, and also an element of the CGT approach, efforts to undertake systematic and rigorous analyses of these data in order to promote an authentic account of participant experience should also be regarded as strength of the paper.

Conclusion

This paper has focused on the experiences of ACP with a small cohort of people with dementia and their co-residing partners through a constructivist grounded theory study. The study explores the context within which ACP exists, noting that couples continued to struggle in their future planning in the absence of formal support. A number of challenges are also noted, principally the perceived burden and a propensity to defer such decisions, but notably a feeling that the consideration of the end of life was inconsistent with the idea of ‘living well’ with dementia. The paper rejects the notion that ACP is an individual practice, instead highlighting the relational approach taken within families and their demands for further support from trusted others. Further, our notion of ‘emergent planning’ helps in establishing a more nuanced understanding of the ways in which couples consider these issues, promoting the temporal and dialectical means with which to consider future policy and practice.

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