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THE EXPERIENCES OF SHARING A DIAGNOSIS OF YOUNG ONSET DEMENTIA WITH OTHERS

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Summary of MRP

Section A reviews research literature on experiences of self-disclosing a life-limiting illness to others. It summarises the complex processes that frames self-disclosure as a series of ongoing events across a range of relationships: how people self-disclose, motivations for self-disclosure and concealment, helpful and unhelpful experiences and gender and age differences in self-disclosure. Among clinical implications is the need for a balanced view between self-disclosure and concealment for individuals to cope with difficulties and maintain a sense of control and their sense of self when faced with vulnerability from a life-limiting illness. Only a few studies suggest or recommend support for self-disclosure. Research implications include a need for longitudinal research to follow the evolution of self-disclosure decision making and relationships, to incorporate quantitative facets within studies of disclosure process, and to examine disclosure for different life-limiting illnesses.

Section B explores, from the perspective of individuals with young onset dementia (YOD), what happens to relationships when individuals share their YOD diagnosis, and the re-negotiation of relationships with others as dementia progresses. The journey from pre-diagnosis to living with YOD was examined. Grounded theory methodology was used analyse the processes of receiving and understanding a diagnosis, sharing the diagnosis to others, negotiating a shared understanding with others and living with dementia. The findings revealed complex challenges faced by individuals with YOD as the condition progresses. The impact of self-disclosure on relationships and the sense of self was considered. The distinct experiences of YOD due to overlapping life stages and dissimilarities to chronic mental and physical health conditions suggests the need for YOD specific services. Clinical and research implications were discussed based on the findings and existing literature.

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Section A: Literature review

Disclosing a diagnosis of a life-limiting illness to others: a literature review

Word count: 7136

Abstract

Existing literature on diagnosis disclosure focuses on investigating how professionals disclose to patients, patient and carer preferences around disclosure, and experiences of receiving diagnosis. In contrast, this review synthesises research on self-disclosing a life-limiting illness to others, concentrating on the motivations and factors that influence an individual's decision to disclose or conceal their diagnosis. A systematic literature search on four databases identified 15 studies with four different life-limiting illnesses that complied with inclusion criteria. The review identified shared experiences of self-disclosure across illnesses. Motivations to disclose included a perceived obligation to share and manage illness-related information within social circles, and to explain visible symptoms. Individuals reported both supportive and dismissive responses to self-disclosure. It was found that individuals self-disclosed to raise awareness and to offer peer support to those with similar conditions. Motivations to conceal diagnosis include previous experiences of responses (dismissive, stigmatised or excessive sympathy), to protect others from emotional distress, and to establish personal privacy boundaries. The main limitations of the literature were the narrow methodological variation and the lack of self-disclosure studies that made it difficult to draw conclusive findings. There is a need to explore the relationship between one's experience of receiving a diagnosis and the impact of disclosing to others, which can influence personal relationships and how one perceives themselves.

Keywords: Self-disclosure, concealment, life-limiting illness, relationships

Introduction

Disclosure is the process of revealing personal information and an important phenomenon within human social interaction. It provides “an opportunity to express thoughts and feelings, develop a sense of self, and build intimacy within personal relationships” (Chaudoir & Fisher, 2010, p236), and to achieve social goals. Within this general term are different types of disclosure that differ mainly in purpose and audience.

The study of disclosure is multidisciplinary spanning across social, clinical and counselling psychology. Interest in the topic began in the 1960s firstly as a personality construct and in relation to individual and cultural differences (Cozby, 1973), and secondly within the context of relationships and the understanding and treatment of psychological distress (Derlega & Berg, 1987). Subsequently, research progressed into areas of self-disclosing personal information such as sexual orientation (Mohr & Fassinger, 2003) and of significant events including abuse (Sorensen & Snow, 1991), physical illness (Greene, 2000), and mental health issues (Corrigan & Rao, 2012).

Current research on health-related disclosure

The majority of medical and psychological research to date has focused on professionals’ disclosure of diagnosis to patients. There has also been research on therapists’ self-disclosure to clients (Henretty & Levitt, 2010; Knox & Hill, 2003) with corresponding ethical considerations (Barnett, 2011; Peterson, 2002), and the clients’ views on therapist self-disclosure (Farber, Berano & Capobianco, 2004; Knox, Hess, Petersen & Hill, 1997).

The 1990s saw an increase in research on diagnostic disclosure (i.e. professionals informing patients of their diagnosis) and educational models. Examples of this are the SPIKES Model (Baile et al., 2000) on disclosing cancer diagnosis to patients; and clinical guidelines on communicating a dementia diagnosis (Murphy & Gair, 2014). This gave rise to research efforts on medical professionals' perspectives, and experiences of "breaking bad news" for both cancer (Bousquet et al., 2015, p.2437) and dementia (Werner, Karnieli-Miller, & Eidelman, 2013).

There is also literature on individuals' preferences on diagnosis disclosure from medical professionals, such as individual and family experiences of receiving a diagnosis of dementia (Robinson et al., 2011). A recent systematic review found that the majority of participants preferred to be informed of their dementia diagnosis (van den Dungen et al., 2014). The main reasons were linked to autonomy and enabling "the possibility to plan one's future" (van den Dungen et al., 2014, p.1). Recently, studies explored dyadic and triadic perspectives in disclosure of dementia (Karnieli-Miller, Werner, Neufeld-Kroszynski, & Eidelman, 2012), highlighting the common occurrence of professionals communicating directly with family members instead of the person with dementia, and the possible implications on the sense of self for the person with dementia.

Theories of health-related self-disclosure

Surprisingly given the above research base, there is a lack of corresponding investigation on personal disclosure from people with a diagnosis to others. Several models, however, have been proposed to understand how, when and why people disclose. The Disclosure Decision-making Model, DD-MM (Greene, 2009) proposed that individuals weigh up their decision to disclose a health diagnosis based on three domains: nature of the diagnosis, disclosure receiver, and perceived ability to disclose (efficacy). The disclosure is considered based on five factors: stigma, prognosis, symptoms (visibility and progression), preparation (diagnosis anticipated by others or unexpected), and relevance to the receiver (e.g. transmittable or genetic illness). From the receiver's perspective in making decisions, the model accounts for relationship quality, anticipated reaction (i.e. immediate response to disclosure), anticipated (relational) outcome and confidence in response. When a diagnosis was more severe with more visible symptoms, individuals tended to anticipate negative relational outcomes post-disclosure, and feel less able to disclose. Individuals felt more able to disclose when they anticipated positive responses and outcomes, particularly with those whom they shared a close relationship and when they felt more confident about their own predictions. The model was tested on university students with nonvisible health conditions (Greene et al., 2012). Although results were promising, it is difficult to verify its ecological validity, given the specific age group; critically, the study did not state the criteria used to define nonvisible health conditions.

Chaudoir and Fisher (2010) proposed the Disclosure Processes Model (DPM) to consider when and why disclosure happens. It models disclosure as a single but ongoing dynamic process, specifically applicable to people perceived with a stigmatised yet concealable identity. The model assumes that people in such situations frequently encounter issues with disclosure and nondisclosure. The model has been applied to studies on HIV serostatus (Chaudoir, Fisher, & Simoni, 2011), and on mental health related issues (e.g. suicidality; Pisani et al., 2012), past abuse, and sexual orientation disclosure. There are three components that influence outcomes on social support, disclosure reservations, and information related to social position: (1) antecedent goals mark decision-making driven by different motivational factors, (2) disclosure event defined as a verbal communication of previously concealed information, and (3) mediating processes and outcomes, characterised by individual, relational and social contextual factors. These components form a feedback loop as time elapses and builds on one’s disclosure experiences.

Petronio (2010) developed Communication Privacy Management theory (CPM) to understand how decisions are made about disclosing personal information. It has been applied to a range of different topics, including family communication (Petronio, 2010, 2017) and family planning (Durham, 2008), but less so on health-related topics. It is based on the premise that disclosure is accompanied by a sense of vulnerability. Nevertheless, sharing can improve one's coping and "foster relational closeness" (Broekema & Weber, 2017, p.1576). The theory comprises of three principles: privacy ownership (individuals own their private information and allows others access by directly sharing); privacy control (individuals want control of how information is shared); privacy turbulence (when shared information is co-managed by multiple people and violations occur, for example, information is shared without consent). Motivation behind disclosure influences the management of the information.

While these models do well to describe the range of components relevant to self-disclosure, only DPM attempts to explore processes involved within self-disclosure. However, none of the models clearly address issues relevant to the clinical implications of health-related self-disclosure.

Rationale

Research on self-disclosure of health conditions is important because it looks at how individuals appraise information about diagnosis, and the implications this may have on appraising others' responses to disclosure, coping, support and the perceived possibility for future and further disclosure (Greene et al., 2012).

There has been some research on experiences of self-disclosure of physical health conditions such as epilepsy (Benson, Lambert, Gallagher, Shahwan, & Austin, 2017), cancer diagnosis or survivorship, and HIV serostatus (Petrak, Doyle, Smith, Skinner, & Hedge, 2001). Self-disclosure of chronic illnesses in the workplace was linked with obtaining adjustments and support to retain employment (Gignac & Cao, 2009). However, apart from cancer, there is relatively little research on self-disclosure of life-limiting illnesses such as dementia. Berterö, Vanhanen, and Appelin (2008) in their study of individuals with a diagnosis of inoperable lung cancer described the multiple tasks they faced, including maintaining autonomy, addressing ‘life questions’ (Erikson, 1959) such as anticipatory loss and impeding death, and maintaining relationships. While not unique to life-limiting illnesses, there may also be accompanying stigma. Moreover, current models are mostly theoretical and have not been applied to a wide enough range of clinical populations. Reviewing current literature on self-disclosure in different life-limiting conditions may potentially add to the extant theories and bring more clarity to how these models are relevant and applicable to clinical practice.

Aims

The review aimed to summarise and integrate findings of individuals’ experiences of disclosing/sharing a diagnosis of a life-limiting illness with others. The definition of life-limiting illness is broad as illness trajectories differ but is generally characterised by irreversibility, shortened lifespan; either progressive or non-progressive. The latter may lead to other life-threatening complications. Specifically, the following questions were asked:

- How do people disclose to others?
- What are their considerations and motivations when deciding on disclosure?
- What do people consider as helpful and unhelpful experiences of self-disclosure?
- What are the reasons for not disclosing?
- Are gender and age differences relevant to disclosure?

Literature search

Search strategy

Searches were conducted on several databases (Web of Science, EBSCO (includes CINAHL and MEDLINE), PsycINFO). Google Scholar was used to capture relevant articles in the grey literature. Articles found through databases were forward and backward cited to locate articles not found during the initial database searches. The last search was conducted in June 2019.

Figure 1 shows the number of articles identified at each stage. The initial search combination of "life-limiting illness" with "self-disclosure* OR break bad news OR disclosure*" provided very few relevant results. The search strategy was therefore modified, pairing a specific life-limiting illness with the disclosure search string. As a comprehensive list of life-limiting illnesses could not be located, a list was derived based on the definition and examples given by the Palliative Care Curriculum for Undergraduates Project (Palliative Care Curriculum for Undergraduates (PCCU), 2010).

The search string used was: [illness – see Table 1] NOT depress* NOT anxiety NOT abuse, combined with self-disclosure* OR break bad news OR disclosure*.

Table 1. Literature search terms

Illness list
Cancer
Dementia
Cystic Fibrosis
Sickle cell disease
Parkinson's disease
Huntington's disease
Motor neurone disease

The inclusion and exclusion criteria for the search were as follows:

Inclusion criteria:

- English language peer-reviewed journal articles
- Studies of adults with a life limiting illness disclosing a confirmatory/working diagnosis of their condition to someone in their social/support system e.g. family, friends, work, other connections such as acquaintances.
- Any research designs

Exclusion criteria:

- Main focus of the study was on survivorship/general coping with illness
- Non illness disclosure such as, sexual orientation, abuse etc.
- Studies on transmittable health conditions[1], such as HIV/AIDS

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[1] The nature of transmission can mean that the condition is understood in a significantly different way by society. As such, disclosure to others may carry different meanings.

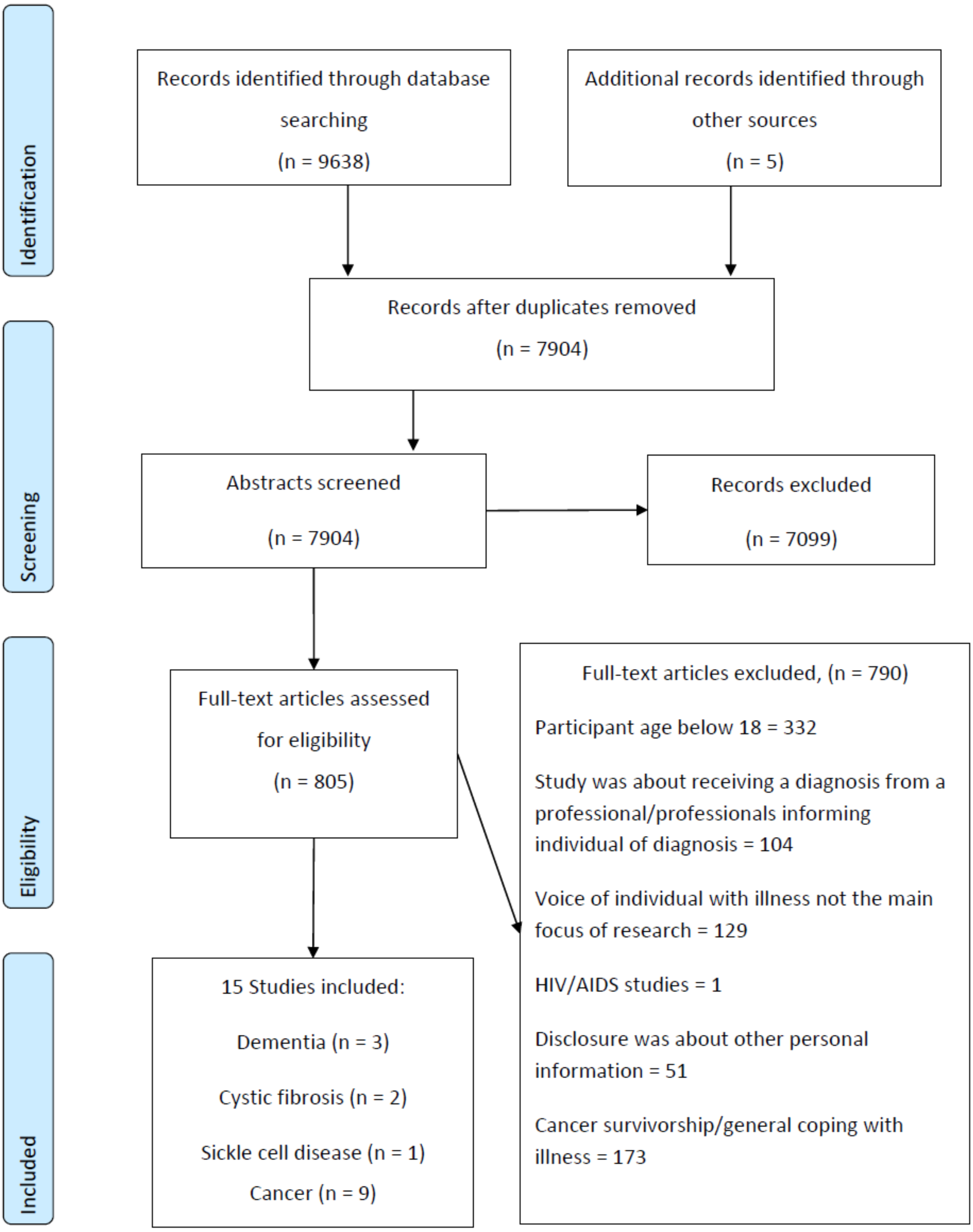

Figure 1. Prisma diagram for literature search

Findings

Summary of studies

Fifteen studies about self-disclosure that were summarised and reviewed: three studies examined dementia, nine cancer, two cystic fibrosis (CF), and one sickle cell disease (SCD). There were no relevant results for common neurological conditions such as multiple sclerosis, Huntingdon’s disease, and Parkinson’s disease, or for cardiac conditions such as congenital heart disease. Studies were largely conducted across North America and Europe, with four studies in the UK and a single study from Iran.

In terms of methodology, there were three cross-sectional studies, three grounded theory studies, two ethnographic studies, two thematic analyses, one framework analysis, one participatory action research study, and three qualitative studies employing different analysis methods not listed above. The studies are described in Table 2, followed by a summary.

Table 2. Features of studies reviewed and main findings

Authors and country	Aim	Sample demographics	Methodology and data collection	Approach to data analysis	Main results
Hellström & Torres, 2012, (Sweden)	To explore preferences in disclosing a dementia diagnosis for PWD and their spouses.	n = 20 (50% male, 50% female) PWD and their spouses. Age: 61 - 80. AD was the most common diagnosis	Qualitative Semi-structured interviews, mostly conducted individually (7 joint interviews)	Qualitative	Five disclosure patterns identified (p.160-161): 1. Want to know and tell (no reservations) 2. Want to know and tell (some reservations) 3. Want to know, do not want to tell 4. Want to know, undecided about telling 5. Cannot agree on either knowing or telling
Weaks, Wilkinson, & McLeod, 2015, (UK)	To explore the experiences of PWD and family on how they informed others of a dementia diagnosis	n = 5 (40% male, 60% female). Age: 68 - 79. 2 participants had a diagnosis of AD; type of dementia unknown for other participants.	Qualitative Interviews and observations	Grounded theory	Regardless of preferences around sharing diagnosis, participants acknowledged that it was helpful to discuss how they felt about the diagnosis
O'Connor, Mann, & Wiersma, 2018, (Canada)	To “extend understanding around the diagnostic disclosure process for PWD, in relation to stigma, discrimination	n = 8 (75% male, 25 female%). Age: 57-82. Type of dementia diagnosis unknown	Qualitative Participatory action research		Disclosing was useful in bringing about understanding and tolerance from others. However, it also hampered with opportunities for active participation and meaningful activity. Having discussions around the experiences of diagnosis disclosure is important as it allows the “naming and normalising of discriminatory experiences” (p.45).

	and social citizenship” (p.46)				Decision to disclose is “strategic and well-considered” (p.50) and communicates a level of awareness. Disclosure was used as a form of empowerment for self and others with dementia, in addressing stigma and creating a sense of community. Disclosure can challenge one’s rights to social citizenship, as well as means for claiming active citizenship
Munro, Scott, King, & Grunfeld, 2015 (UK)	To identify degree and patterns of disclosure in cancer patients and factors associated with disclosure	n = 120 (63% male, 37% female). Age: 29-86. Participants had different types of cancers: skin (18%), Lung (38%), Colorectal (44%)	Cross-sectional Measures (standardised and Likert scales developed by researchers)		Individuals disclosed the most to medical personnel, followed by family and friends Degree of disclosure was positively correlated with higher levels of perceived social support. Those who had surgery reported less disclosure than those who had other treatments such as chemotherapy. 91% rated disclosure as helpful overall. 38% thought disclosure helped “gain reassurance and support”, 26% thought it “allowed emotional expression” which was cathartic, fear-relieving and released pressure (p.511-512). 40% gave reasons for which disclosure could be unhelpful, such as when the other had poor understanding (11%), fearful of being a burden (7%), evoked pity (6%), or that the level of

					uncertainty prevented useful discussions (3%) (p.512).
Lynne Robinson, Kocum, Loughlin, Bryson, & Dimoff, 2015 (U.S)	To gain a deeper understanding of how women manage the process of communicating their cancer diagnosis within the workplace	n = 19 females. Age: 42.2 - 57.5.	Qualitative Semi-structured interviews	Thematic analysis from a realist perspective	Challenges to control disclosure and information about one's cancer, especially when the cancer became, or was expected to become visible. Control was challenged when disclosure was done on their behalf, or when emotional responses were received. Women managed information by either being quite open or very selective. Helpful responses included those who offered support, kept in touch during their absence from work. Responses that lacked empathy, triggered fear, or unaccommodating were perceived as unhelpful and unsupportive.
Johansen, Andrews, Haukanes, & Lilleaas, 2014 (Norway)	Ethnographic study of the experience of freedom in being open (or closed) about their illness in women with breast cancer	n = 5 females. Age: 41-62.	Qualitative Open thematic interviews based on ethnographic approaches of Smith (1987, 2005) and Spradley (1979).		Disclosure was to receive support and influence others' attitudes about cancer. Decision not to disclose is often interpreted as a sign of "not coping", excluding support from others, obstructing public enlightenment "Practicing openness about one's illness should not be treated as the only acceptable option" of coping (p.121)

Najmabadi, Azarkish, Latifnejadroudsari, Shandiz, Aledavood, Kermani & Esmaily, 2014 (Iran)	Determining the level of self-disclosure of breast cancer diagnosis in employed Iranian women	n = 175 females, employed. Age: 20-60.	Cross-sectional Questionnaire survey	Descriptive analysis and chi-square tests	> 66.7% disclosed to friends, immediate and extended family, bosses and supervisors 61% disclosed to colleagues, 67% to boss. Reasons for non- disclosure included pity (41%), disappointment speech (7%), shame and embarrassment (5%), constant questioning (4%); or all of the above (43%).
Ewing, Ngwenya, Benson, Gilligan, Bailey, Seymour & Farquhar, 2015 (UK)	Multi-perspectives gathered from individuals with a lung cancer diagnosis, companions and professionals on the experience of diagnosis sharing	n = 20 individuals with a lung cancer diagnosis (70% male, 30% female). Age: 49-79); 17 companions, 27 professionals	Qualitative Semi-structured interviews conducted separately with individuals with diagnosis and companions; professionals took part in focus groups or individual interviews	Framework analysis	Six elements of ‘sharing bad news’ identified
Gray, Fitch, Phillips, Labrecque, & Fergus, 2000 (Canada)	To understand decisions on whether diagnosis is disclosed for men with prostate cancer	n = 34 couples. Age of men: 50 – 68; age of spouses: 42 - 72.	Qualitative Interviews at three time points (pre surgery, 8-10 weeks post-surgery, 11-13	Constant comparison approach from grounded theory.	Identified factors that contributed to limiting disclosure were men’s low perception for support needs, fear of stigmatisation, reducing the illness risk to cope, pragmatic requirements of the workplace, and the desire to prevent inconveniencing others

			months post-surgery).		
Hilton, Emslie, Hunt, Chapple & Ziebland, 2009 (UK)	Gender similarities and differences between how and why adults self-disclose a cancer diagnosis	n = 37 (43.2% male, 56.8% female). Age: 18-34.	Qualitative Narrative interview	Constant comparative method (Lincoln & Guba, 1985)	Both genders concealed own distress in order to protect loved ones Both experienced sorrow and guilt towards the pain family felt upon learning the cancer diagnosis. There were more men than women in those who wished to conceal diagnosis. Men feared being excluded or treated differently; women were concerned about associated stigma and perceived judgement about sexual activity. Cancer directly challenged identity as a young person Used humour in self-disclosure to relieve tension.
Donovan-Kicken, Tollison & Goins, 2012 (USA)	To investigate the nature of communication during cancer, specifically with diagnosis disclosure of diagnosis and other illness-	n =40 (30% male, 70% female). Age: 21-74. Caucasian majority (85%)	Qualitative All took part in focus groups except for 4 individually interviewed participants	Grounded theory (Strauss and Corbin, 1990)	Communication of diagnosis took place during a stressful period of feeling physically unwell and undergoing treatment. There is a felt sense of duty or obligation to communicate diagnosis with others, which is sometimes shared with a significant other in order to manage demands and emotions.

	related information				Communication was carefully planned, and included anticipation of others’ responses, the actual content and method of communication
Yoo, Aviv, Levine, Ewing & Au, 2009 (USA)	Managing emotions of self and others in self-disclosure of breast cancer	n=176 females. Age: 31-83. Ethnicities: 31% Caucasian, 14% Latina, 25% African American, 30% Asian American, 1% mixed.	Qualitative In-depth interview with open-ended questions	Grounded theory	Self-disclosure occurred at the same times as treatment decisions were being made. Strategies used in disclosure involved some form of emotion management, such as managing others’ worry by delaying or concealing disclosure;
Derlega, Maduro, Janda, Chen & Goodman, 2018 (USA)	To explore the reasons for disclosing or not disclosing a diagnosis of SCD	n=24 (25% male, 75% female). African American ethnicity. Age: 24.8 – 42.4.	Qualitative Interviews	Coding system developed by the researchers. No further details on epistemological/ methodological approach.	Talking about diagnosis may be a form of support in coping with stresses associated with SCD, with further benefits of demystifying inaccurate beliefs others may have (“educating others”) and preparing others for future decline in the individual’s health. Non-disclosure was related to perceived stigma, concerns of rejection and protecting others from worry/fear.
Borschuk, Everhart, Eakin, Rand-Giovannetti, Borrelli &	An examination of associations between disclosure of SCD and psychosocial	n=163. Age: 16-63	Cross-sectional Questionnaire, measures	Descriptive statistics; Spearman’s rho correlations and t-tests.	97% disclosed to their romantic partners; 70% disclosed to all close friends. This was followed by boss and colleagues. Speculated that disclosure at the workplace was driven by visibility of symptoms or absence due to hospitalisation.

Riekart, 2016 (USA)	and health outcomes				Disclosure correlated with positive psychosocial outcomes such as social support, employment and medication adherence.
Broekema & Weber, 2017 (USA)	How individuals with CF manage illness-related information when sharing this within a romantic relationship	n=13 (23% male, 77% female). Age: 24-43.	Qualitative Semi-structured interviews	“interpretive approach” (Corbin and Strauss, 1990).	Participants decided to share when they wanted to further develop relationship with partner. Motivated by the need for support from partner.

Abbreviations:

PWD	Person with dementia	AD	Alzheimer’s disease
CF	Cystic Fibrosis	SCD	Sickle Cell Disease

All cross-sectional studies aimed to quantify rates of self-disclosure: Munro et al. (2015) investigated the rates of diagnosis disclosure to different people for individuals with colorectal cancer, lung cancer and skin cancer (45%, 37% and 18% of the sample respectively; 120 participants in total) and identified disclosure-related factors and degree of helpfulness experienced in self-disclosure. Borschuk et al. (2016) quantified self-disclosure of individuals with CF and the associated health and psychosocial outcomes. Najmabadi et al. (2014) quantified self-disclosure rates of Iranian women with breast cancer to family members and colleagues, and reasons for non-disclosure. There were 423 participants across the three studies. 248 of which were from the first two studies, pre-dominantly Caucasian of ages between 16 and 86. The third study consisted of 175 participants with the mean age at diagnosis of 44 years old.

Grounded theory studies explored (1) male disclosure of prostate cancer and related information to others besides their spouse (Gray et al., 2000), (2) communication work in individuals with a cancer diagnosis (Donovan-Kicken et al., 2012), and (3) emotion work in women self-disclosing breast cancer (Yoo et al., 2010). The number of participants for each study ranged from 13 to 176; giving a total of 223 participants. It should be noted that Yoo et al.'s (2010) study consisted of an unusually large and ethnically diverse sample. A fourth study explored how individuals with CF shared illness-related information with romantic partners, employing grounded theory techniques for data analysis (Broekema & Weber, 2017).

One ethnographic study focused on women with breast cancer and how open they felt they could be about their cancer (Johansen, Andrews, Haukanes, & Lilleaas, 2014). Another examined how individuals with an AD diagnosis approached the task of disclosure in the first six months post-diagnosis (Weaks, Wilkinson, & McLeod, 2015). There were five participants per study.

Both thematic analyses studies were on cancer. Hilton et al. (2009) explored young adults' experiences of cancer diagnosis disclosure and gender differences. Robinson et al. (2015) studied illness communication in the workplace for individuals with a cancer diagnosis. There were 56 participants in total.

Using framework analysis, Ewing et al. (2015) examined the perspectives of individuals who disclosed their lung cancer diagnosis to adult family members and friends. O'Connor et al. (2018) conducted participatory action research over 16 months on the process of self-disclosure of dementia and its relationship to stigma, discrimination and social citizenship. The remaining qualitative studies were on self-disclosure and concealment of SCD (Derlega, Maduro, Janda, Chen, & Goodman, 2018), and couples' disclosure preferences of a dementia diagnosis (Hellström & Torres, 2012). Both studies described their data analysis process: the former developed their own coding system, whilst the latter adopted qualitative analysis methods from Creswell (1998) and Silverman (2001) but did not describe the adaptations in detail.

Appraisal

Qualitative studies were appraised using the Critical Appraisal Skills Programme (CASP, 2013), with further reference to discussions raised by Mays & Pope (2000). The Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (National Heart, Lung, and Blood Institute (NHLBI), 2014) was used for appraising cross-sectional studies. Details of the appraisals can be found in Appendices B (qualitative studies) and C (cross-sectional studies).

Most qualitative studies generally fulfilled CASP's criteria, although several studies were ambiguous about the researchers' positions in relation to their topic of study. Some did not state epistemological positions. Cross-sectional studies mostly satisfied the criteria recommended by NIHLBI; some questions on exposure (independent variable) were not applicable as the diagnosis status was the variable. All participants were individuals with a specific diagnosis aligned with the respective research scope.

Strengths and limitations of studies

The wide range of participants' ages, ranging from 18 to mid-80s, allowed for a comprehensive overview of self-disclosure across the lifespan and in the context of identity development.

Due to the limited amount of studies in cystic fibrosis, sickle cell disease, and dementia, it was difficult to draw illness-specific conclusions. Participants primarily had common forms of dementia (Alzheimer disease, vascular dementia, or mixed), resulting in an under-representation of individuals with frontotemporal degeneration and other forms of dementia in the studies reviewed.

For cross-sectional studies, the exploration of self-disclosure to healthcare professionals was limited to doctors and nurses (Munro et al., 2015). It was unclear whether disclosure was active or prompted by professionals, who might have already been informed via medical correspondence. Self-disclosure with other allied health professionals remains relatively unreported. Although Weaks et al.'s (2015) study was in itself extended self-disclosure with a researcher also trained in counselling, the findings could not be generalised owing to the small sample size.

There may also be recruitment and volunteer bias as research participation is a form of self-disclosure and participants may have been relatively open to discussing their illness. The views of those who did not take part remain unknown.

There were more female participants than male in most studies, except for Gray et al.'s (2000) study on prostate cancer. There was a lack of ethnic diversity within most studies, with the majority of participants being Caucasians. Only two studies had sizable proportions of non-Caucasian participants: 70% of participants in Yoo et al.’s (2010) study on women with breast cancer were non-Caucasian, 44% of whom were African American; and Derlega et al.’s (2018) SCD study where all participants were African American.

Synthesis

How do individuals disclose?

All qualitative studies reported to some degree how their participants disclosed their diagnosis. Methods varied across studies on how participants disclosed. Most commonly it occurred as verbal conversation in person, but studies also reported more indirect forms such as telling several people at once via smartphone messaging, email, using social media in order to reduce repetition and the emotional upheaval that would cause (Ewing et al., 2015; Donovan-Kicken et al., 2012; Yoo et al., 2010). At times self-disclosure was prompted, such as that on application forms for volunteering opportunities (O'Connor et al., 2018).

Some people asked a significant other, such as their spouse to share the diagnosis on behalf of themselves. Men with prostate cancer specifically avoided sharing to avoid becoming emotional in front of others (Gray et al., 2000), and as such some spouses (and in one case, the individual’s adult child) were left with the responsibility to disclose without having been asked directly (Weaks et al., 2015).

Some casually dropped the information in during social meetings and responses were in a similar manner. Gray et al. (2000) pointed out that the method of delivery often set the tone for subsequent discussions (or lack thereof) of the illness.

The use of humour was evident, usually of a self-deprecating nature in men with prostate cancer, who joked about possibilities of incontinence or erectile dysfunction (Gray et al., 2000). Some individuals with dementia also employed humour when responding to cognitive impairment “with levity” (O'Connor et al., 2018, p.48). The strategies used involved an element of control by joking about themselves first before others.

Only one study reported means of self-disclosure that were less commonly reported elsewhere, such as public self-disclosure through a newspaper article (Johansen et al., 2014): the individual wished to tell “an optimistic story” (p.113) about breast cancer and the female body. This was interpreted as an expressive act of openness towards one’s diagnosis in order to exercise control over her situation. It also reported situations whereby individuals had little or no control over the privacy of their diagnosis, such as being part of a small and tight knit local community and having the news of their diagnosis overheard on a hospital ward and spread by others.

Considerations when self-disclosing

Deciding about disclosing

Nine studies (two were cross-sectional) were relevant to this question. Three qualitative studies covered cancer (Ewing et al., 2015; Robinson et al., 2015; Gray et al., 2000), two on dementia (O’Connor et al., 2018; Weaks et al., 2015), one on CF (Broekema & Weber, 2017), and one on SCD (Derlega et al. 2018).

The two cross sectional studies comprised of measuring comfort levels in disclosing CF to different people (Borschuk et al., 2016), and the degree and helpfulness of disclosure in cancer individuals (Munro et al., 2015). Almost all participants in the CF study disclosed to their spouses (97%), close friends (94%), as opposed to bosses (71%) and co-workers (53%). Comfort levels in SCD disclosure were positively correlated with social support, employment and self-efficacy in medication adherence (Borschuk et al., 2016). On the other hand, more individuals with cancer disclosed further information to medical professionals compared to family and friends. Despite using a rating scale from a previous study, self-ratings (i.e. “talked very much", Munro et al., 2015, p.509) can be subjective and hence, the breadth and depth of the reported self-disclosure remains unknown.

Deciding who to tell

All studies formally reported targets of self-disclosure. Individuals reported disclosing to a range of people: parents, immediate family, friends, doctors and nurses, others with the same diagnosis, people in the workplace (Ewing et al., 2015; Munro et al., 2015; Najmabadi et al., 2014) or potential romantic partners (Broekema & Weber, 2017). People in the workplace were often told out of necessity. Others with the same diagnosis were encountered through self-help or peer support groups (Gray et al. 2000). Only studies regarding dementia reported self-disclosing to strangers. It was found that for some individuals, it was easier to share with strangers compared to family and friends (O'Connor et al., 2018); or with people encountered in the community such as hospital staff. Interestingly, when individuals disclosed to medical professionals, they spoke less about feelings and thoughts associated with their illness (Derlega et al., 2018).

The decision to disclose was also based on perceived right or need to know. Often, participants felt obliged to inform family to prepare them for a negative prognosis, such as death (Gray et al., 2000) or genetic risks (Broekema & Weber, 2017; Weaks et al., 2015). Some participants explicitly expressed the need to share information about the illness to the family (Gray et al., 2000).

Timing

There was a consensus among studies on readiness to share a diagnosis. Both Gray et al. (2000) and Weaks et al. (2015) reported individuals with cancer or dementia delaying self-disclosure as time was needed to process the diagnostic process and the emotions and shock from receiving a diagnosis. It was recognised that planning and making decisions about self-disclosure amidst feeling physically, mentally and emotionally compromised was a major challenge. In contrast, there were individuals with cancer who immediately informed people with whom they were relationally close (Ewing et al., 2016). The nature of timing for those with CF and SCD in disclosing to romantic partners differed and depended on the (anticipated) onset of an episode of ill health or health-related life events such as childbirth.

Motivations for disclosure

As means of information management and control

In this context, diagnosis was considered information owned by the individual with the illness that required some degree of guarding to maintain ownership. The amount of control exerted by individuals may reflect the sense of control lost on maintaining one’s health and emotions, and self-disclosure was a way to recover control (Robinson et al., 2015). Active disclosure was used to avoid rumours or having the diagnosis publicised by others without the individual’s knowledge (Gray et al., 2000). This type of disclosure was particularly common especially within workplace settings and often used in anticipation of stigmatised responses from others. Similarly, individuals with dementia self-disclosed to prevent others from guessing (Hellström & Torres, 2012), but there was also reluctance to inform those who had previously denied the possibility of dementia.

Individuals with CF strived for a balance between “being upfront” (Broekema & Weber, 2017, p.5) about CF and not overwhelming a romantic interest with details of the illness. It was also an implicit way of negotiating a future of the relationship. This was referred to as the “risk and benefit ratio” (Broekema & Weber, 2017, p.5), or “forewarning”- reported by individuals with SCD (Derlega et al., 2018, p.105).

Self-disclosure due to illness progression

Individuals shared their diagnosis more readily when firstly progression of the illness became unconcealable through visible symptoms and side effects (Broekema & Weber, 2017; Weaks et al., 2015), and secondly the impact on others became more evident, for example, within the workplace (Robinson et al., 2015). Furthermore, self-disclosure was employed as a "self-protective measure" to explain "unusual behaviour" for individuals with dementia (O'Connor et al., 2018, p.47; Weaks et al., 2015). This allowed individuals to differentiate between their selves and the uncontrollable symptoms of dementia. For individuals with CF, the visible symptoms were a demonstration of the illness akin to non-verbal disclosure, which at times provided information to others (Broekema & Weber, 2017).

To educate and spread awareness

Intentions to educate others and spread awareness have often led to self-disclosure, across illnesses. Individuals with SCD hoped to challenge assumptions such as dying young and being frequently hospitalised until death (Derlega et al., 2018). Those with cancer hoped to influence public attitudes towards cancer (Johansen et al., 2014) and raise awareness about the importance of routine screening (Gray et al., 2000). These efforts often led to others asking for more information.

Self-disclosure empowered individuals with dementia to challenge and resist stigma and discrimination (O'Connor et al., 2018). A common stigma faced by individuals with dementia was the misconception that dementia was a mental health disorder (O'Connor et al., 2018; Weaks et al., 2015). This motivated some individuals to name dementia through self-disclosure (O'Connor et al., 2018) and educate others, even though the individuals anticipate and worry about the stigma. It transpired that individuals with dementia could potentially be dismissive of one's perceived experience of stigma, and hence be emotionally invalidating. Individuals also self-disclosed to newly diagnosed persons to share their experiences in responding to stigma.

To elicit and/or provide support

Individuals with dementia self-disclosed to elicit support and generate understanding and tolerance from others. Some individuals used a badge or card to reduce the stress of explaining a complex condition, particularly when verbal communication abilities are compromised (O'Connor et al., 2018). Individuals with CF self-disclosed to romantic partners not just to seek support, but to find someone who could share the burden and "co-own" CF-related information (Broekema & Weber, 2017, p.3). The accumulation of self-disclosure experiences led some people to disclose to newly diagnosed individuals as a form of emotional support and encouragement (Derlega et al., 2018).

To gain information and practical advice

Individuals disclosed their illness to medical professionals in order to gain information and advice (Derlega et al., 2018; Munro et al., 2015). Those with colorectal cancer disclosed more information to nurses and others with cancer (Munro et al., 2015). Talking to others with the same diagnosis or other chronic health conditions (Derlega et al., 2018; Gray et al., 2000), family members who were medical professionals and/or carers for an individual with a life-limiting illness (Derlega et al., 2018) also served this purpose.

Helpful and unhelpful experiences of self- disclosure

Overall, individuals found self-disclosure most helpful when aims for self-disclosure were achieved, such as the exchange of information and practical planning, and when others' responses matched their preferences (Robinson et al., 2015). Expressing feelings and thoughts widened perspectives and provided reassurance that may facilitate adjustment (Munro et al. 2015). Both expected and unexpected offers of support were experienced as helpful and normalised the individual's distress during self-disclosure (Weaks et al., 2015; Yoo et al., 2010). Crucially, individuals with dementia were able to come to terms with their diagnosis through "facilitative listening" by others (Weaks et al., 2015, p.780). Consequently, this enabled a co-construction of a different sense of self.

Responses from others who were patronising and lacked both empathy and tact in their words or actions were viewed negatively. Occasionally, such experiences resulted in concealing the diagnosis (Weaks et al., 2015). Noteworthy is the significant impact of stigmatising comments from "outsiders" who were connected to the recipient of disclosure, that led to others ending romantic relationships with the self-disclosing individual (Broekema & Weber, 2017, p.7).

The lack of knowledge about the disclosed illness was suggested as a reason for others not knowing how to be helpful. Whilst some people may be curious and willing to raise awareness of the illness, it inadvertently burdens individuals into feeling compelled to explain their illness. Responses that are emotionally incongruent with the self-disclosing individual can be experienced as unhelpful. Attempts from others to comfort, reassure or enliven the individual, together with being overly sympathetic have come across as dismissive (Gray et al., 2000).

Within the workplace, individuals with cancer found self-disclosing most unhelpful owing to a sudden surge in demands prior to sick leave for treatment or requested to return to work prematurely. One explanation for such incidences is the low awareness of the effects of cancer treatment (Robinson et al., 2015).

What are the reasons for concealing a diagnosis?

Ten qualitative studies and one quantitative study on cancer (Munro et al., 2015) across a range of conditions reported a range of reasons for concealment. All studies reported that concealment was often attributed to interpersonal concerns. A common concern was being an emotional burden to others, causing distress or upset, and thus drove the decision to conceal the diagnosis in an effort to protect family and friends (Derlega et al., 2018; Hilton et al., 2009; Munro et al., 2015; Yoo et al., 2010). For illnesses with a higher occurrence at a particular life stage, such as prostate cancer in older men, Gray et al. (2000) found that some men avoided sharing their diagnosis as they felt it may overwhelm people, particularly since cancer was closely associated with loss and death.

Stigma was another reason for concealment (Derlega et al., 2018; Gray et al., 2000) to avoid others' negative judgements and misunderstanding. For example, the association between cancer and death led one to inform his social circle that he was "off on holiday" during a prostatectomy (Gray et al., 2000, p.279). Individuals with SCD recounted experiences of others' stigmatizing responses such as misunderstanding SCD as contagious, or explicitly relating pain episodes to drug addiction (Derlega et al., 2018). Similarly, for individuals with dementia, concealment tended to occur when others were perceived to have little awareness or understanding of dementia (Hellström & Torres, 2012).

Furthermore, individuals concealed to avoid unwanted responses from others, such as questioning, pity, being treated as ill, vulnerable and weak (Derlega et al., 2018; Gray et al., 2000), or being treated differently within their peer groups (Hellström & Torres, 2012). Younger individuals with cancer feared being excluded from their peer groups if they revealed their diagnosis (Hilton et al., 2009). Individuals often preferred the nature of relationships to retain "pre-illness character" (Gray et al., 2000, p.277) given the potential perceived negative impact self-disclosure has on relationships. The decision to conceal also arises from previous experiences of others distancing themselves (Ewing et al., 2016) or cutting ties (Gray et al., 2000).

Non-disclosure is commonly deemed detrimental to relationships and emotional wellbeing, increased isolation (Weaks et al., 2015), and associated with maladjustment to the illness. However, Johansen et al. (2014) suggested that concealment also served to establish necessary boundaries between private and public life for women with breast cancer. Berlin's (1958) concepts of positive and negative freedom (as cited in Johansen et al., 2014, p. 108) were applied to understand choices of disclosure and concealment, in which the former referred to self-related attributes of mastery, determination and actualisation, whereas the latter is concerned with the absence of hindrances, coercion or interference from others; or according to Frey (2000), the right to keep personal information private (as cited in Johansen et al., 2014, p. 109). Whilst there is conventional belief of a right to privacy, preferences as to what is kept private depends highly on the individual and hence, social conflict may arise from perceived expectations to share certain information. However, a conscious choice to privacy/concealment as means of coping currently remains subjugated due to expectations of social sharing.

Gender and age differences

Gender

Only one out of 15 studies explored gender differences at any length (Hilton et al., 2009); one study had all male participants (Gray et al., 2000), and three studies had all female participants (Johansen et al., 2014; Robinson et al., 2015; Yoo et al., 2010). Munro et al. (2015) reported some gender related- statistics.

Men, in contrast to women, disclosed more to people they deemed as trustworthy within their immediate circle such as spouses, colleagues and doctors (Munro et al., 2015). Hilton et al. (2009) reported that young men were inclined to conceal their cancer diagnosis. This was interpreted as being associated with social expectations of men being more stoic. As such, disclosure may be expressed humorously, and the reciprocation of humour from receivers was an indication that the individual with the illness was still accepted within the group (Gray et al., 2000; Hilton et al., 2009).

Women tend to take on responsibility of maintaining social roles and relationships through eliciting and caring for others' emotions within the system ('emotion work'; Yoo et al., 2010). They may adhere to norms around certain types of feelings to maintain their own roles. Hence, women may anticipate reactions to disclosure differently than men, and delay disclosure to prioritise others' feelings. Women with cancer interviewed by Robinson et al. (2015) preferred to be offered rather than request support, and experienced hurt due to lack of contact/concern from the workplace during treatment.

Age

People face different developmental tasks associated with both age and life stage alongside diagnosis and living with a life-limiting illness. Not surprisingly. these topics were reflected in people's accounts of disclosure. Hilton et al. (2009) focused on gendered identity in young adults who were grappling with their identity with respect to their social world and seeking to establish independence. People in middle adulthood focused on romantic relationships (Broekema & Weber, 2017) and maintaining roles within the workplace (Robinson et al., 2015). Concerns about the latter often extended to individuals in their 60s with increasing life expectancy and retirement age. The studies indicated that hesitation in self-disclosure became more apparent as individuals matured and accumulated multiple roles in different social systems.

Discussion

This review summaries and draws attention to the highly complex processes that make up self-disclosure as a series of ongoing events across a range of relationships. There was recognition amongst all studies that having a life-limiting illness is a highly emotional experience and in combination with accompanying stigma (from others and self), significantly influenced one's relationships with others.

The review highlighted several influential factors in the self-disclosure process: 1) the nature of the illness (trajectory, progression, stigma and other pre-conceptions); 2) illness as a life event and its interaction with the person's life stage and social context, and 3) the range of possible motivations that can drive self-disclosure, which at times were out of necessity to inform and to fulfil a sense of responsibility (e.g. handing over tasks within the workplace).

Of the aforementioned theories, only Greene's (2012) DD-MM considered properties of illness (e.g. symptoms and prognosis) as factors within the self-disclosure process; and only Petronio's CPM theory (2002) captured the fragility of privacy for individuals who may be feeling quite vulnerable in their confrontation of a life-limiting illness and the co-ownership (and potential breach of privacy) of illness-related information after sharing the diagnosis. Both DD-MM and DPM assumes that individuals with the diagnosis has full control over the privacy of the diagnosis, and that self-disclosure are discrete dyadic interactions, although DPM also suggested that self-disclosure outcomes are aggregated to form a feedback loop that informs the individual in managing potential stigma related to their illness. Both DD-MM and DPM acknowledge individuals' use of disclosure and concealment as means of managing perceived stigma related to the illness. Evidently all three theories have their strengths; and joining the theories together provides a more comprehensive picture of the self-disclosure process. An amalgamated theory might include the following contributing factors: perceived nature of illness (as outlined by DD-MM); motivations for self-disclosure (DPM); anticipated response

(DD-MM, DPM); expectations, or rules around privacy and co-ownership of the disclosed information (CPM); self-stigma and perceived stigma (DD-MM, DPM); relationship with the recipient (DD-MM, DPM). These factors could apply to both the person disclosing and the recipient. The process of self-disclosure is expected to repeat itself as the illness progresses over time, and new decisions around further disclosure are made.

It was observed across studies (except for Johansen et al., 2014) that the act of disclosure was reported as the dominant social narrative, in other words, acts of concealment were perhaps subjugated. A plausible contributing factor to the narrative is the considerable amount of supporting literature on the benefits of self-disclosure. Therefore, data may have been analysed and reported in a certain light. If both disclosure and concealment were equally regarded as valid and socially accepted responses to a diagnosis, this may encourage more balanced conclusions.

The large proportion of cancer studies can be attributed to the way it has been socially framed and understood in current times and the decrease in stigma. In contrast, there are only a few studies on dementia despite it being a major illness affecting many people in their older years, and even a minority of younger people in mid-adulthood. It is possible that the enduring stigma towards dementia (Garand, Lingler, O’Conner, & Dew, 2009), the progressive nature of the condition, and the relative delay in directly engaging individuals with dementia in research until the last decade may have slowed research efforts in this area.

There were no studies found on cross-cultural differences in self-disclosure. Apart from two studies, the samples of all other reviewed studies were Caucasian. Whilst there could be cultural differences between different Caucasian communities, these were not reported by any of the studies. Different cultures could understand an illness differently, such as certain Asian communities perceiving dementia symptoms as a normal part of aging (Liu, Hinton, Tran, Hinton, & Barker, 2008). Certain cultural norms on roles within family or social circles can influence how people cope with life-limiting illness, and hence influence people's priorities in self-disclosing.

Except for Weaks et al. (2015) who collected data on multiple occasions over a six-month period for each participant, there was a lack of follow up for all other studies. The data collected was mostly retrospective self-reported data which runs the risk of recall bias and makes it difficult to follow the temporal changes within relationships.

While there is a directory of life-limiting illness for children and adolescents (Hain, Devins, Hastings, & Noyes, 2013), a comprehensive list is yet to be developed for adults. Using definitions from PCCU to derive search terms may have led to a limited list of illnesses and runs the risk of overlooking literature specific to other life-limiting illnesses not included in the list.

Clinical Implications

The majority of the reviewed studies advocated for disclosure as helpful; coupled with dominant social narrative that talking openly is the preferred method of coping with difficulties, alternatives such as concealment and its justifications can be easily overlooked. Johansen et al. (2014) highlighted the lack of ideology to fall back on for concealing diagnosis. It is therefore important for professionals to note that concealment does not equate to maladjustment and that the enforcement of personal boundaries can affirm individuals in preserving a sense of self and a sense of containment and control. Ultimately, a balanced approach that allows for both self-disclosure and concealment may be more beneficial.

Only four studies mentioned the need for, or proposed suggestions on support for self-disclosure (Borschuk et al., 2016; Munro et al., 2015; Robinson et al., 2015; Weaks et al., 2015). Based on their findings, Robinson et al. (2015) created a list of communication tips for individuals with breast cancer, their employers and co-workers on talking about cancer in the workplace. Weaks et al. (2015) and Borschuk et al. (2016) suggested role-playing strategies with health professionals as means of rehearsing the disclosure with someone who is assumed to be relatively unaffected by listening to the disclosure. Weaks et al. (2015) also thought that health professionals should be more attuned to patients' intentions on wanting to talk about their diagnosis.

In current times, healthcare services are set up with a heavy focus on healthcare professionals providing assessment, treatment, and indeed information for the person with illness. In contrast there is relatively less thinking and wondering about what may happen beyond the treatment room, which might include how an individual might share their diagnosis and information about their illness with others. It is essential for professionals to have a good understanding of this, if they are to work with people as they continue living with that life-limiting illness, which, as highlighted by the review's findings, influences their interpersonal relationships, impacts on their emotions, and on the simultaneously managing their own emotional wellbeing and others' emotional responses to the disclosure. In addition to providing facilitative listening (Weaks et al., 2015) to individuals who wish to talk about their diagnosis, professionals may consider facilitating discussion with individuals around:

- Identifying people in the individuals' network who can listen in a similar manner
- Making informed decisions around self-disclosure and considering concealment as a viable option
- Pacing self-disclosure conversations with others and managing "burnout"
- Practicalities around workplace adjustments

Research Implications

There is a relative lack of quantitative studies on self-disclosure. There are possibilities for quantifying some of the findings in the reviewed studies, such as the degree of openness within self-disclosure and its predictability of different attitudes towards life-limiting illness. By quantifying different facets within the self-disclosure process, this may also address the "overly simplistic 'positive/negative' evaluation" on perceptions of health diagnoses and the influences on disclosure decisions (Greene et al., 2012, p.364).

Longitudinal research to trace the evolving of self-disclosure decision making and its interaction with readjustment and relationships is required (Weaks et al, 2015). The experience of receiving a diagnosis from a health professional and how that may influence subsequent self-disclosure to others, has not been investigated. It may be worthwhile exploring responses from 'listeners' (recipients of one's self-disclosure) and the possible effects these responses have on relationships afterwards.

There is a lack of research concerning disclosure for various life-limiting illness, for example, progressive neurological conditions such as motor neurone disease, Huntington's disease and Parkinson's disease. Most surprisingly, there are only three dementia studies on self-disclosure given the relatively high prevalence of the illness in older age and the widespread attention it has received as a global epidemic (WHO, 2015). The area of self-disclosure and dementia is important given the substantial number of people with dementia whose main carer is a family member (Schulz & Martire, 2004). Further exploration of the process of self-disclosure of dementia is required, including individuals with different types of dementia and with an earlier onset age. A single study (Hilton et al., 2009) considered the impact of life-span development of young adults in self-disclosure of cancer, and so there may be scope to explore the relationship between self-disclosure of Young Onset Dementia and the corresponding developmental tasks.

The findings of the review imply that disclosure is an ongoing process, not a one-off event, where individuals and those around them are continuously and constantly making decisions on disclosure and related aspects. This corroborates with previous critique that extant models, with its focus on disclosure as a standalone behaviour, fail to address factors that mediate the consequences of disclosure on different domains of well-being and interpersonal relationships (Chaudoir, Fisher, & Simoni, 2011)

As such, it may be useful to conduct further research in a way that focusses more on evolving processes and systemic factors, and to do so for life-limiting conditions that are less researched, such as CF, dementia and other progressive neurological conditions, where progression of the illness will correspond to changes in self-disclosure over time. This more process-oriented focus is likely to inform clinical practice and how individuals can be supported over time and in the context of multiple relationships.

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Section B: **Research study**

How people with young onset dementia share their diagnosis with others

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Abstract

Dementia is commonly associated with older age. A younger person's experience of dementia may differ due to differences in life stage. However, there is a relative lack of literature with younger individuals with dementia as the 'main voice' and receiving and sharing a diagnosis of Young Onset dementia (YOD; diagnosis before the age of 65) influences relationships beyond that of the family. Using Grounded Theory (GT) methodology, this study aimed to gain an understanding of how relationships with others are re-negotiated by people with a diagnosis of YOD. Semi-structured interviews were conducted with 15 individuals (mean age at diagnosis=57) with a diagnosis of YOD, transcribed and analysed. An emergent theory detailed the temporal unravelling of events and the relational changes that occurred alongside, resulting in three main categories: making sense of change in self, coming to terms with changes, and living with intention. Findings specific to YOD include experiences of a long convoluted diagnostic process and stigma and disbelief from others due to the association of dementia with old age. Findings also indicated the benefits of peer support groups in enabling connection with others with YOD and meaningful engagement outside of family and immediate peer groups. The study points to the emotional, relational and lifespan complexities faced by individual with YOD.

Keywords: Young-onset, dementia, relationships, adjustment, sense of self

Introduction

Dementia

Dementia covers a wide range of neurodegenerative conditions. As the fifth leading cause of death in modern times it was recognised as a public health priority by the World Health Organisation (WHO, 2015). Of the 850,000 people diagnosed with dementia in the UK, an estimated 5% are diagnosed before 65 years old (Alzheimer's Society, 2014), or commonly referred to as young onset dementia (YOD). The age demarcation is based on traditional separation of working age and old age psychiatric services. Atypical dementias such as behavioural-variant frontal-temporal dementia and posterior cortical atrophy are more prevalent in the younger population whereas Alzheimer's disease and vascular dementia are more common in older people (Alzheimer's Society, 2014).

Due to its relative rarity, research interests in YOD only started developing in late 1990s (Greenwood & Smith, 2016), with an initial focus on epidemiology, aetiology, diagnosis, and a small number of case studies. This subsequently expanded to studies on service provision, diagnosis disclosure, experiences of YOD from different parties, and emergent aspects alongside progression, such as coping and adjustment, changes to identity, and loss (Sansoni et al., 2016).

The following introduction provides an overview of different models of dementia, UK care policy and YOD in the context of lifespan development. A short review of self-disclosure literature on dementia provides the rationale for the current study.

Models of dementia

The traditional biomedical understanding of dementia is based on observable symptoms, neuropsychological testing and confirmation from brain imaging. It primarily focuses on individuals' cognitive deficits (memory, attention, executive functioning, language and communication) and negative changes in personality and behaviour. Sabat (2014, p.25) criticised the disregard for “intact cognitive and social abilities” and the overemphasis on performance within clinical testing.

Several psychosocial models have since been proposed to conceptualise dementia, most notably Kitwood’s concept of personhood (1997), defined as “a position or social relationship that is bestowed on one human being by ‘others’.”, through “recognition, respect and trust” (Kitwood, 1997, p.8). These correspond with psychological needs of comfort, attachment, inclusion, occupation, and identity. Wellbeing is enhanced when these needs are addressed, together with the presence of recognition, respect and trust within relationships. Conversely, devaluing, dehumanising and diminishing behaviours (‘malignant social psychology’; Kitwood, 1990) undermine personhood and thus wellbeing. Malignant social psychology is driven by two deep rooted anxieties, relatable to many individuals: “fear of becoming frail and highly dependent through memory loss”, and fear of prolonged dying in old age (Dewing, 2008, p.7). These fears were thought to be experienced by both individuals with dementia and their caregivers.

Within a social constructionist framework, Sabat expanded on Kitwood’s idea of malignant social psychology through malignant positioning: how “persons with dementia are socially positioned affects how they are related to, considered and conceptualised, which in turn affects how persons with dementia are as persons, their personhood, behaviours and interactions with others.” (Dewing, 2008, p.4; see also Sabat, 2002).

Growing studies on selfhood (having a sense of self) and identity in people with dementia have emerged (Bevins, 2008; Kelly, 2010; Kontos, 2005) under the influence of Kitwood’s work and the importance placed on person-centred care in dementia. Harris and Keady (2009) were among the first to investigate selfhood in YOD and found that both the person with dementia and carers experienced changes in multiple aspects of their identity (occupation, family member, sexual being) from diagnosis; and expressed feelings of loss, fear and abandonment.

Clinical Practice and Care Policy

Although there are different approaches in conceptualising dementia, there is a gap in how these are integrated and utilised within policy making (Innes & Manthorpe, 2013). Dementia in the UK remains predominantly conceptualised as a medical condition, with healthcare services located across several disciplines: geriatrics, older adult mental health (which memory services often fall under), and specialist neurology; this can be confusing for the public in orienting their understanding of dementia.

The Prime Minister's challenge (Department of Health and Social Care, 2015) proposed to focus efforts on providing timely diagnosis, funding research for medical treatments, improving person-centred care and addressing social stigma by increasing community awareness, but made no mention of age-specific services. This is at odds with a recent review (Sansoni et al., 2016) which reflected a consensus on the need for YOD-specific services due to different needs compared with later onset dementia (LOD). A comprehensive diagnostic pathway is crucial due to the amount of time required to confirm diagnosis (Murphy & Gair, 2014). Delayed diagnosis can be attributed to a range of factors such as misdiagnosis and stigma, leading to delayed help-seeking and unwillingness from professionals to make onward referrals (van Vilet et al., 2011; Vernooij-Dassen et al., 2005).

Recent evidence briefing (BPS Dementia Advisory Group, 2018a) called for a systemic approach in including and supporting the entire family system experiencing dementia. Yet, the focus was on support for family caregivers and neither other family members nor people outside the family system were sufficiently considered. As with all individuals, there are multiple social systems (both family and wider contexts) with members significant to the person with dementia and whom should be included in their care (Harris, 2013).

YOD and Lifespan Development

Age is a significant aspect in the experience of YOD (Tolhurst, Bhattacharyya, & Kingston, 2014). A younger person's experience of dementia may differ from that of an older individual due to differences in life stage and events, in which the task of adulthood is often generativity and 'making life count' (Erikson, 1959). Those in middle adulthood may play multiple roles within family, work, friends and the wider community, whilst striving for a sense of productivity and accomplishment. These roles typically contribute to the construction of one's sense of self (Slater, 2003). The dominant understanding within society of dementia as an 'old age disease' thus presents a challenge. When dementia "occurs 'off time'" (Harris & Keady, 2009, p.442), the impact on one's physical health, cognitive abilities and behaviour can significantly affect how individuals engage in these roles, relationships and environments. As younger people tend to be part of a broader range of systems and relationships, the impact of YOD on relationships and social roles may be more prevalent compared to that of LOD (Holdsworth &McCabe, 2018; Hoppe, 2019).

In line with psychosocial approaches to understanding illness-related changes, Hopson and Adams (1976) proposed seven stages to the process of psychosocial transitions: 1) initial immobilisation (shock, negative emotions), 2) reaction (elation, despair, minimisation), 3) self-doubt, 4) accepting reality and letting go ("severing" the old and entering the unknown), 5) testing (of new relationships), 6) searching for meaning (through reflective thinking) and 7) integrating the transition into the life space. However, for progressive conditions like YOD where deterioration occurs over time but its course unpredictable, transitions may never be "complete" (Riegal, 1976, p.697). It is therefore unclear how much integrating might be achieved before further deterioration occurs. Relevant to understanding one's complex journey of YOD is Bronfenbrenner's (1979) ecological systems theory, which proposes that an individual’s development takes place in and is guided by five interconnected social systems. Notably, the theory includes a temporal element (chronosystem) that reflects influences from environmental events and transitions throughout the lifespan. A diagnosis of YOD as a major life event would entail continuous transitions as the condition progresses, affecting one’s functional abilities to roles and relationships across systems. The social aspects of self-disclosure are pertinent across these interconnected systems (O'Connor, Mann, & Wiersma, 2018) - through self-disclosure, individuals with YOD may begin to relate to family and friends in different ways to prior to diagnosis (Patterson, Clarke, Wolverson, & Moniz-Cook, 2018).

YOD and Self-disclosure

Self-disclosure is the process of sharing personal information with another individual. Interest in the topic began in the 1960s (Derlega & Berg, 1987) but investigations into self-disclosure of physical illness (Greene, 2000) only occurred four decades later. It remains a growing research topic, with emphasis on HIV/AIDS (Petrak, Doyle, Smith, Skinner & Hedge, 2001) and cancer (Munro, Scott, King & Grunfeld, 2015). To date, there are only three studies on self-disclosure of dementia (Hellström & Torres, 2012; O'Connor, Mann, & Wiersma, 2018; Weaks, Wilkinson, & McLeod, 2015). The studies report that diagnosis sharing was a difficult decision. Although majority of individuals recognised a need to tell others, some hesitated due to reasons such as perceived stigma and potential risks to relationships. Perspectives on sharing and how to share often differed between couples (Hellström & Torres, 2012) and within families (Weaks et al., 2015). The decision to share may change over time and may be used strategically to address stigma, as means of self-empowerment, community building and in claiming active citizenship (O’Connor et al., 2018). Nevertheless, these studies did not focus on the experiences of YOD individuals which is critical given that self-disclosing a dementia diagnosis may impact on one’s self-perception and how they are socially perceived and positioned by others (Sabat, 2002).

Rationale and aims for current study

There is a lack of studies on YOD and relationships particularly with individuals with YOD as the ‘main voice’. To date, research has focused on dyadic relationships, such as couples or client-professional, without consideration for the myriad of relationships across systems. From a psychosocial perspective, understanding relationships is essential in elucidating how these interactions affect one’s sense of self as dementia progresses.

In addition, studies typically focused on people with LOD, overlooking the unique perspective of those with YOD. Whilst Erikson’s (1959) theory of psychosocial development provides a comprehensive overview of tasks and dilemmas across life stages, complexities of modern life could be overlooked. Rather than assigning people to a particular life stage based on age, life events and transitions offer more flexibility. Hence, it is crucial to consider the lifespan perspective to understand the unique narrative of those with YOD, as the tasks, responsibilities, and relationships will differ from those with LOD.

Existing research rarely considers the connections between successive events within the dementia journey (from pre-diagnosis to living with dementia) within its temporal frame. This study intended to address several issues missing from the literature and explore, from the view of the person with YOD, how relationships with others are re-negotiated amidst dementia progression, and the influences of diagnosis sharing on relationships and sense of self.

Aims

The study aimed to understand the process of how relationships with others are re-negotiated by people who receive a YOD diagnosis, specifically

a. What do people take into consideration when deciding on sharing their diagnosis?

b. How does their experience of receiving their diagnosis influence their decisions on disclosing, and how they then share this with others?
c. How does the information disclosed differ depending on the relationship the individual with dementia has with the other person?

Method

Participants

Fifteen individuals participated in the study (Table 1). The mean age at diagnosis was 57 years old. All participants attended a peer support group in their geographical area. One group was run by an NHS memory service whereas the other two were organised by local branches of a third sector organisation. All groups provided space for discussion of dementia related topics, informative talks, and socialising. Members of the NHS-run group had access to more opportunities for research, self-advocacy and conference speaking.

Table 1. Participant demographics

Gender	Diagnosis (reported by participant)	Time since diagnosis (years)	Age at diagnosis	Age at interview
F	AD with signs of VaD	2.1	61	63
M	Mixed (AD and VaD)	2	63	65
F	VaD	1.2	57	58
F	FTD	2	55	57
F	VaD	3.5	53	57
M	FTD	5	61	66
F	Mixed (AD and VaD)	2.2	63	65
M	FTD	2.5	51	53
M	FTD	2.9	58	60
M	Mixed (bvFTD and AD)	7	53	60
F	Mixed (FTD and AD)	3	55	58
F	PCA	1.7	54	55
M	AD	4.9	54	58
M	FTD	3	58	61
M	bvFTD (genetically inherited)	3.8	59	62

Notes: AD= Alzheimer's disease; VaD= Vascular dementia; FTD= Frontaltemporal dementia; bvFTD= Behavioural-variant frontaltemporal dementia; PCA=Posterior cortical atrophy

Design

This study used grounded theory (GT) methodology. GT studies people's actions, interactions and interpretations within their social context from which their understandings of the world are derived (Charmaz, 2014, p.54), thereby developing and conceptualising an explanatory account grounded in people's experiences. It recognises the dynamic and temporal nature of social phenomena, as opposed to discrete static events. This dynamic focus corresponded well with the progressive nature of dementia and the inevitable changes people with dementia and their social network encounter. In addition, no previous study has explored multiple social relationships for people with YOD, and hence no theorising thus far on the topic. GT was considered the most appropriate approach because it allows for theory building across multiple experiences.

Charmaz's (2006) social constructivist approach to GT was adopted, assuming co-construction of data and its meanings by participants and researcher and acknowledges researcher subjectivity in the collection and interpretation of data. This stance resonated with the researcher's epistemological position and was used as a guiding principle throughout.

Procedure

Recruitment

Recruitment took place through NHS memory services, third sector organisations and peer support groups. Permission was sought to advertise the study via Alzheimer's Society's online forum and presentations at several peer support groups. Any individual diagnosed with dementia (regardless of type) before 65 years old, able to verbally express themselves and maintain conversation, was eligible to participate. The only exclusion criterion was severe comorbid mental health disorders, which may introduce other influencing factors to a person's functioning, communication, and relationships.

Sixteen people expressed interest and were given further information. This was followed up by a phone call to confirm interest, and individuals were asked for their dementia diagnosis and age at diagnosis. The telephone conversation provided an indication as to whether inclusion criteria was met. One individual had significant semantic difficulties that affected their ability to understand basic information and maintain conversation; hence it was agreed that it was inappropriate to recruit them onto the study.

Ethics

The study was approved by the local NHS NRES committee panel (Appendix D). Before commencing the interview, participants gave consent either verbally or by signing a consent form (Appendix F). Participants were informed via an information sheet and verbally before the interview, that they were not required to answer questions that caused too much discomfort. They were reassured that the interview could be stopped at any time without them needing a reason. The researcher remained observant of participants' emotions and focus throughout the interview and checked in to see if breaks were needed. Participants were debriefed at the end of the interview through a brief conversation on how they found the interview process, and information with sources of support (Appendix F).

Data Collection

All participants were interviewed in their own homes, except for two in a community setting, and two at the researcher's university. Participants were given the option of having photographs or items with them as memory aids or visual prompts. These items were discussed with participants and used to facilitate conversation. Several participants had photographs, one participant had written notes with help from their carer, and one participant utilised objects to help them talk about different people.

A semi-structured interview schedule (Appendix H) was devised based on the research aims and discussions with supervisors. It was used as a guide during interviews to address the main questions whilst allowing space for a participant-led process. Follow-up questions depended on interviewees' answers. Interviews were audio recorded and ranged between 60 and 90 minutes.

Data Analysis

Interviews were transcribed and read several times for familiarisation purposes. Atlas.ti (qualitative analysis software) was used throughout the coding process. Line-by-line coding was used in the initial stages to remain open to the data. Memo writing took place alongside coding to keep track of how data was understood, document emerging ideas and concepts from the comparison of the data and reflections on the analytic process. Focused coding and constant comparison of written memos enabled the development of conceptual categories and subcategories. Emerging relationships between categories were then captured through theoretical coding. Theoretical sufficiency (Dey, 1999), reaching "a sufficient depth of understanding" for a theory to be constructed (Nelson, 2017, p.3), was considered more appropriate than the classical stance of theoretical saturation given the scope of the study.

Quality Assurance

In examining her own epistemological position, the researcher questioned assumptions such as the researcher-participant relationship, and her positioning in relation to dementia, using questions from Birks and Mills (2015); from this a positioning statement was generated (Appendix P). Personal observations and reflections written after each interview and during the analytic process were documented in a research diary (Appendix K). Separate notes on participants' background and social contexts were compiled, based on participants' descriptions and the researcher's understanding, and were constantly referred to in the analysis process. Throughout analysis, conversations with supervisors enabled further development of relationships between categories (diagrammatic representations shown in Appendix J). The researcher's assumptions and possible biases were considered through discussions with supervisors.

Hence, the following analysis is a single interpretation of the data, a co-construction of participants' recounted experiences through interactive inquiry with the researcher, and the researcher's understanding of the experiences alongside her own biases and assumptions. This is aligned with Charmaz's (2014) stance on an interpretive approach to theory that is built from "specifics" and developed into more abstract understanding whilst situated "in the context of their construction" (Charmaz, 2014, p.232).

Results

Data analysis led to development of three overall categories, each with corresponding subcategories. *Making sense of changes* characterised the pre-diagnosis period when participants seek explanation for unusual changes to their functioning. A long diagnostic process hindered understanding of ongoing changes, whereas a confirmed diagnosis facilitated this process of understanding. A better understanding of changes provided the basis for participants to adjust to the impact on themselves and on relationships.

The second and third category are interlinked processes encompassing *coming to terms with change* and *living with intention* illustrating post-diagnosis adjustment. The former involved coming to terms with dementia-related changes, negotiating an understanding with family and friends and dealing with changes in relationships. The latter was concerned with on staying socially included and meaningfully occupied. Acceptance of changes and mutual understanding often entailed more inclusion and meaningful engagement, whereas conflicted perspectives may be linked with feelings of isolation and distress. Figure 1 illustrates how different concepts make up these three categories within the journey from pre-diagnosis to living with dementia, followed by a detailed analysis with illustrative quotes which are denoted by transcript number and quote number respectively. All names are pseudonyms.

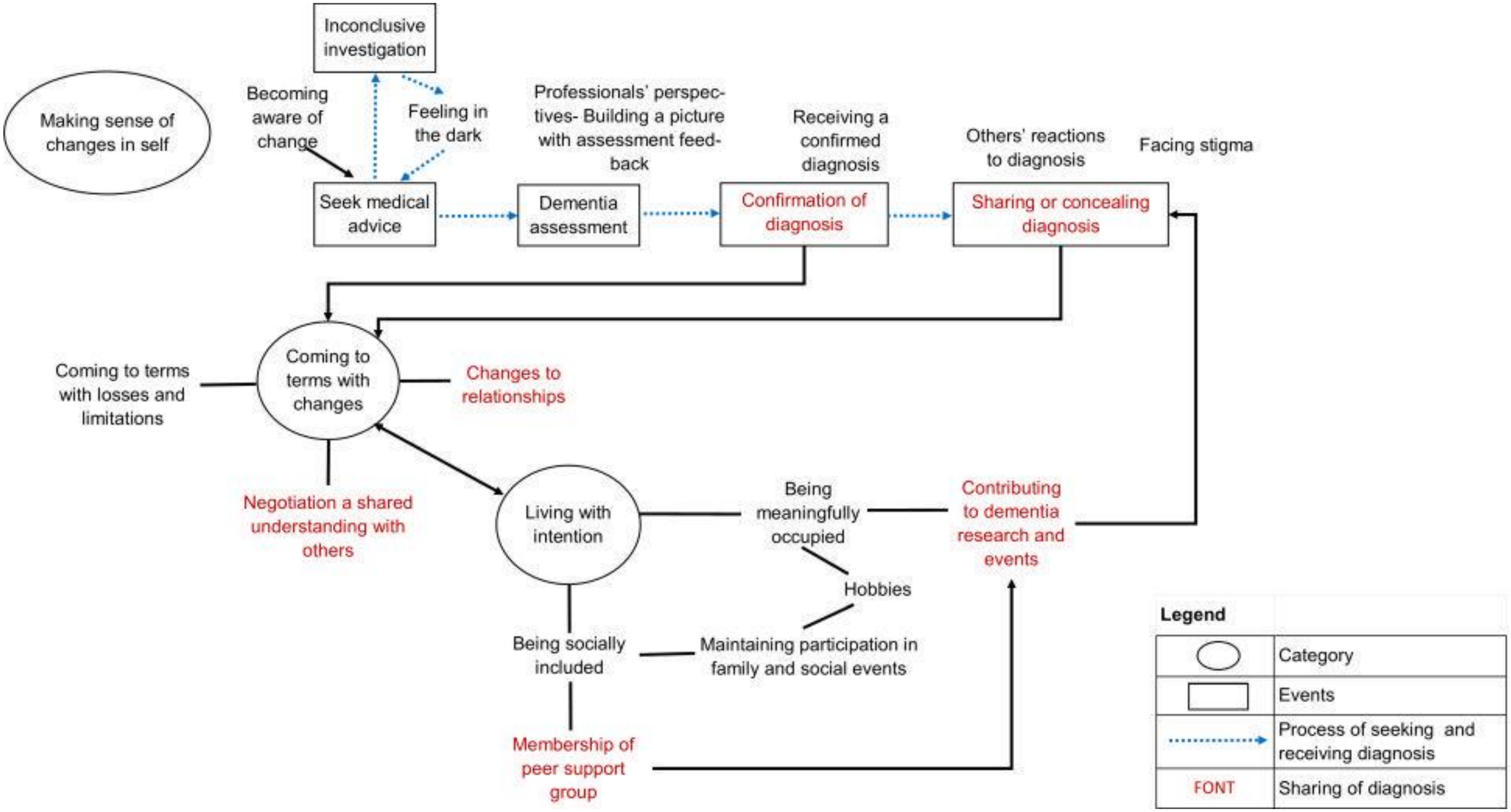

Figure 1. Conceptual model on negotiating relationships and shared understandings of YOD with others – from pre-diagnosis to living with YOD. Text in red indicates diagnosis sharing.

Making Sense of Changes in Self

Becoming aware of change

Participants noticed changes in work performance ("Deadlines were becoming difficult. I was forgetting appointments," Ivan 17:36), emotions ("I've always been in control of my emotions but now they really run quite a riot," Bob 14:23), physical health and orientation. These were interpreted as signs that something was unusually wrong.

Some participants became aware of changes through family members either by being directly informed or by overhearing conversations. Agnes recalled overhearing her husband and daughter discuss changes and who should accompany her to the GP. Others were given upsetting feedback by family members, as they had not noticed it themselves: "I have always been caring, but she said I wasn't caring anymore." (Doug 5:50)

Although personality changes were often perceived as negative, Francis, who described himself as having always been "shy" was pleased with becoming more sociable: "I count it as a blessing honestly because [laughter] I talk to more people now." (16:4)

Changes were accompanied with different emotions. Feeling depressed, frustrated, angry and worried were frequently mentioned, but were not always obvious to participants: "My wife says if a spanner gets thrown in the works, I get depressed. I don't feel depressed, but she said I go inward, and I don't realise that" (James 18:2).

Some described themselves as being "in denial" in the early stages: "Everybody around me kept saying there's something wrong, you're not yourself…I used to say to them…I've just had major surgery, and they kept saying there's something else." (Julia 7:85)

Feeling around in the dark

Most participants experienced a convoluted search for diagnosis, involving multiple GP visits and repeated requests for investigation. Some understandably felt negative when investigations returned with inconclusive results:

> One of the reasons why people appear to be depressed or very fed up is because they can't get anybody to believe the problems they're having[...], when you see there are things you can't do and you don't know the reason why that is. (Bob 14:2)

This was especially the case for participants who initially experienced physical symptoms (e.g. repeated infections, extended periods of fatigue, falls), resulting in investigations that were not dementia-targeted. Often, participants and family members had to make repeated requests for further examination. Physical symptoms were also dismissed as signs of stress and depression.

Other participants described additional complications with existing health conditions. Ted had an accident previously resulting in memory and concentration difficulties, which were attributed to PTSD; nevertheless, he continued to search for an explanation until the possibility of dementia was investigated. Bob spoke of others noticing changes in him, but not voicing their observations until he shared his confirmed diagnosis. Whilst he understood their reservations, in retrospect he preferred honesty to validate his own concerns and to "drive" him to pursue investigations more intently.

Professionals' perspectives: building a picture with assessment feedback

Participants perceived memory clinic referrals as acknowledgement that changes they had noticed were "real". Regular feedback from professionals throughout assessment assisted individuals to understand and recognise what had changed about their functioning: When I drew it I thought it looked alright. Then when I looked at it after I said, "Who drew that, looks like a little kid's done that." [clinical psychologist] said, "You've done it." (James 18:14)

For some participants, the possibility of dementia was discussed before neuropsychological testing started. Both this prospect and ongoing feedback helped prepare participants and family members for the possibility of dementia and reduce distress: "… by the time we sat down in her office, it wasn't a shock to be told." (Bob 14:33)

Receiving a confirmed diagnosis

A confirmed diagnosis was usually communicated to individuals by a professional involved in the assessment process. The diagnosis served as an explanation for unusual changes that had caused feelings of uncertainty: "oddly enough…it was a relief. I wasn't happy about being diagnosed with it, but it took a lot of pressure off… now we know the reason why." (Bob 14:3)

Those who were not expecting the diagnosis were shocked, upset and angry. Brenda questioned "why me?". Amidst anger, the diagnosis prompted Jo to self-reflect; feelings of fear emerged as she understood the significance of her behaviour:

> Eventually…I analysed things. Like I would go into the bedroom pull out a pair of knickers, and then I would come back and pull out another pair... That's when I began to think something's not quite right. I was frightened... (Jo 11:5)

When the diagnosis was communicated without explanation, accompanying information or focused on losses, it became increasingly emotionally taxing: “He said you’ve got FTD, you’re not allowed to work, not allowed to drive, that was it.[…]Without any explanation whatsoever.[…] Very disheartening, I really felt down as a result of that.” (Francis 16:1)

Some participants felt ill-informed. Julia was unsure about what help she needed when asked immediately after receiving her diagnosis. She reported receiving no information from professionals and having to search for it with her husband.

Others’ reactions to diagnosis

Participants reported various responses from others around them; from relief, sympathy to shock, upset, and disbelief. “She was a lot worse than me…‘Cause it was a blow to what we'd planned for retirement” (Stan 9:4). Family members involved in the diagnostic process sometimes shared the same emotions with the participants. Bob’s colleagues were also unsurprised by the diagnosis as they had observed changes in his work.

Reactions of shock were typically followed by sympathy (“poor you”, “I’m so sorry”). Jo found it comforting as she thought it showed that people cared about her, whereas Bob preferred “empathy”- an understanding and accepting attitude towards the diagnosis and specific difficulties for the individual. Likewise, for Thomas: “I don't want them to be sorry. I want them to be aware because there's lots of other people around like that.” (Thomas 6:61)

There was disbelief about the validity of the diagnosis, perhaps due to the common belief that dementia was an ‘old age’ condition. This was frustrating for some participants:

> Some people just get [to] you… “There’s nothing wrong with you. You haven’t got dementia” …They just don’t know.” (Julia 7:9). James described his father’s refusal to

> accept the diagnosis because of James' age: "He's old school, you know, push it away. (James 18:22)

Another typical reaction was others claiming to be similarly forgetful, possibly to downplay the perceived grimness of the diagnosis, which left participants feeling dismissed. This suggested that others did not understand the variability of dementia symptoms. Mary felt misunderstood and unheard when friends asked if she had "gotten better". Subsequently she stopped talking about her condition and instead said she was "fine" when asked.

Several participants (Doug, Ivan, Bob) were told "you don't look like you've got dementia". Some took it as a compliment that implied a degree of wellness and capability; others thought such comments reflected others' understanding of dementia as an absence of wellness and ability.

Facing stigma

Participants discussed how stereotypical beliefs of dementia affected them emotionally. Dementia was mostly associated with social rejection and diminished control of bodily functions: "you are going to be sitting in the corner dribbling." (Bob 14:6); being emotionally and cognitively unresponsive, requiring hospitalisation in mental institutions. This led to shock and fear of being ousted by society: "The idea of Alzheimer's scares people because they think they are going to end up in the funny farm...I was scared." (Jo 11:29)

Julia's sibling had concerns about her children visiting Julia because she thought people with dementia were violent, illustrating the significant impact of stigma and how one's vulnerability can be overlooked:

> I’ve become very moody but not violent, I would hurt myself before I hurt anybody else[…]it’s easy for people to misunderstand…someone told me it was a mental illness and because of that you could become violent. (Julia 7:41)

Julia’s account of her sibling’s perspective also demonstrated how others may understand dementia as a mental illness. Ted also expressed detest for being associated with having a “mental health issue” (implied he was “going loopy”) and being “senile”. Because of these assumptions he was initially “in denial” about his condition and concealed his diagnosis.

Coming to terms with changes

Coming to terms with loss and limitation

One of the major losses was employment and employability; an unexpected ending to participants’ working lives, with different implications depending on how the ending was marked.

Some participants had the opportunity for closure: Bob returned to his workplace to inform his colleagues whereas Ivan was supported to gradually hand over his responsibilities. It was less smooth for Francis, who had to dissolve his own company; and Thomas who felt he was “gently pushed away” (6:1). Ruth’s job ended abruptly after a period of sick leave. For her there were multiple losses of role, purpose, relationships with colleagues and a sense of belonging: “I would have liked to have had a last day, not to be told to clear my locker and go…they said they’d keep in touch…they didn’t. It makes me think I’m not worth it.” (Ruth 10:45)

Unemployment clashed with personal values, particularly for those who strongly valued work and productivity:

> [spouse] keeps telling me that my working life is over, but I don't feel an invalid. I have a problem with my memory, but that doesn't mean I can't still function […] I was always brought up that...you have to work and earn what you want in life. (Ruth 10:4,43)

Several participants had their driving licenses revoked, impeding their mobility. They described an immediate withdrawal ("straight away it was signed and there was me with no car.", Thomas 6:53), despite having driven themselves to the appointment to receive their diagnosis. Crucially, none of the affected participants mentioned going through a driving assessment to determine whether dementia had affected their driving skills.

For Mary, the emotional impact of losing employment and her driving license due to visual difficulties was significant. Because of her diagnosis, the local authority deemed her unable to care for her foster children and rehomed them, splitting up her family. There was much despair and frustration: "the only thing I can do is play with my grandchildren…God, that's all I can do." (Mary 15:6)

Individuals also gave up certain interests due to low energy levels and difficulty concentrating for extended periods of time. In Ted's case, he stopped attending football matches as he easily lost track of the game.

Negotiating a shared understanding with others

Participants attempted to establish a shared understanding of their abilities and needs with others and on how to adjust to changes. Bob described his family reminding him when he was "illogically bad tempered" or "out of order"; "They will point it out because you can't allow people to charge around willy-nilly. So it does keep me slightly on track. They are accepting the fact that it isn't me, it's perhaps part of my condition…" (14:36)

There were situations where it was difficult to establish mutual understanding, leading to friction within relationships. Ted, whose executive function was affected by dementia, found it essential to follow his routine closely to keep track of household chores, personal care and meals. Although his rigid routine caused problems with family, prioritising routine enabled him to live relatively independently.

Negotiating entailed accepting differences in coping styles. Bob and Ivan preferred to learn as much as possible about dementia in advance so they could anticipate and plan, whilst their spouses preferred to focus on other aspects of life, or to obtain new information about dementia alongside its progression. They managed these differences by empathising and respecting differences in coping.

Thomas found others trying to "reverse" the effects of dementia, but wished they could accept what he could still do:

> They're trying to get me to be where I used to be. I'll never be there but I'll be able to hover in the middle where I can take bits and pieces myself and feel comfortable with it…I hope they can feel comfortable with my situation as well. (6:72)

Several participants felt their grandchildren were more accepting of changes and felt supported by them. Doug suggested that the younger generation may not share aforementioned assumptions of senility and age. He believed that it was important to engage them in conversation.

Where dementia affected cognition (e.g. forgetting, word-finding difficulties) communicating needs with others became difficult. Mary discussed how it could help if others suggested possible words when she struggled to express herself, because if she “takes too long then it’s gone” (15:20).

A lack of shared understanding of one’s abilities and needs can lead to others over-helping, instead of providing support to enable independence. Mary, whose eyesight was significantly affected, felt frustrated at having to wait for her carer do tasks for her, rather than be supported to do tasks at her own pace: “It is horrible really because when I go out, they say oh wait a minute, wait a minute…I can’t stand it anymore. I’ve always been a person that can do everything [independently]”. (Mary 15:2,9)

Changes to relationships

Coming to terms with dementia-related changes and attempting to seek mutual understanding with others meant facing possible relational changes. Stan drifted apart from his wife, as his character and behaviour were affected by FTD: “We're not as close as we used to be. I think it's a lot to do with me…I'm not spontaneous. I don't start conversations…I mean we're still friends but…it's a shame.” (9:13)

Participants spoke about others becoming distant. Doug was disappointed when interactions with a neighbour dwindled from long conversations to simply greeting each other. In contrast, Jo interpreted distancing as a sign that others “didn’t know how to cope with” the diagnosis; she empathised that others may have different ways of coming to terms with it and that it was not her “problem”.

Experiences of stigma can discourage individuals from sharing their diagnosis, hindering shared understanding with others and relationship maintenance. Brenda avoided romantic relationships as she thought that her diagnosis “would put him off”. Ted chose to conceal his diagnosis because of previous experiences of others' disbelief and debating with people who had fixed views about dementia as an old age condition. It is plausible that his negative experiences deterred him from communicating his needs and negotiating a shared understanding with others.

When mutual understanding cannot be established, the effects were often reflected in relationships. Mary described a strained relationship with her son and breakdown of communication: "He's not a horrible person. But he doesn't know what to do. He doesn't want to talk to me about anything."

Ivan had always been "the rock" whom others approached for advice and support. Whilst the change from being a rock to needing a rock was drastic for Ivan, he continued to care for his family whilst being supported by them. He reflected: "The last year, I've needed a rock. And that's been quite different. I don't want to be a burden upon the kids and [wife]."

Living with intention

A shared understanding with others about the abilities, needs, and values enabled participants to live according to their own intentions. Participants mentioned the significance of staying meaningfully occupied, being socially included, and the values that motivated them.

Being socially included

Support from family and friends

For some participants, their family and close friends prior to the diagnosis remained as their main social circle. With support from her immediate family and determination in not letting dementia "define" her, Jo maintained regular activities such as running chores, accompany her husband to sports competitions, and going on holiday. Julia talked about being invited to a party and how it was a respite from dementia.

Membership of peer support group

Participants developed supportive relationships from joining their local peer support group. Meeting others with dementia was a positive experience for many as it provided another platform to form shared understanding:

> My friendship network is better now than it was before the diagnosis, but it’s largely people in the dementia world […] I’m really comfortable with that because they are the only ones who understand. (Ivan 17:5)

Opportunities offered in peer support groups played a significant role in constructing the individual’s understanding of dementia and own identity. Groups with a strong focus on enabling members to discuss and deliberate their views aided members to build group identity, and to validate their own experiences. They were also informed about research participation, self-advocacy roles, and local and national events. Participants from such groups appeared more confident in challenging people’s assumptions by pointing out discrepancies between others’ views of dementia and their own lived experience:

> “If I hear somebody talking as if they have got the wrong impression of dementia, I sometimes will correct them. Similarly, around the words used, if I can correct them to perhaps not use the word “demented”. (Bob 14:15)

Participants without access to such groups or who belonged to groups that offered “remedial” or socially oriented activities were equally vocal and formed own opinions, but tended to challenge others less: “In the end you just say ‘you believe what you want to believe’ and carry on” (Julia 7:82).

Being meaningfully occupied

Participants stayed meaningfully occupied through developing and maintaining interests aligned with personal values, energy levels and abilities. As Francis enjoyed helping others, he volunteered as a health walk leader and took up a ministry role to stay socially active. With assistance, participants returned to previous interests. James resumed recreational fishing with support from friends:

> I haven't been out in the boat for a couple of years and they want me to go back and I said, “Well, if I come…I might need some help”. So, they're going to help me. I'm looking forward to that.” (18:8)

Contributing to dementia projects, events and research

Some participants took part in dementia projects, such as research, awareness training for various settings and post-diagnostic groups. Motivations included supporting others with dementia by sharing their experiences, educating others through initiating conversations and addressing stigma or common misconceptions. “A lot of people like to keep it under wraps. But I’m all upfront with it. I think it’s better…, not only are you telling people, you’re teaching them about it...” (James 18:23). It also affirmed participants that their perspectives were sound and valued by others:

"…what you people are doing in your studies and the realisation by other people that I'm not silly, I'm not a mad man." (Thomas 6:33)

James talked about participating in an online audio diary research project, through which he recorded his experiences and concerns. He listened to recordings from other participants, which contributed to developing an understanding of FTD from a collection of lived experiences, going beyond a textbook description.

Messages for others with YOD

To end of the interview, participants were asked if they had any messages for others with YOD. Participants sent messages of comfort, encouraged others to stay active, persevere in order to stay hopeful, and to accept the condition. They also wished to connect with others with YOD. Full messages in Appendix O.

Discussion

The findings depict a three-part emergent theory of a journey of YOD from pre-diagnosis to living with the condition, mediated by ongoing reciprocal influences between diagnosis sharing, negotiations of a shared understanding of dementia, relationship changes and life events. The breadth and richness of the interviews resulted in exploration of areas that had not been predicted by the initial research questions. Examples of this include the interaction of the relationships between participants and their systems, and the dynamic nature of the process; and the unexpected finding of participants feeling disbelieved (see following paragraph for elaboration). The process of discovery and surprise in qualitative methodology is one of its strengths: as Strauss and Corbin suggested “one does not begin with a theory then prove it. Rather one begins with an area of study and what is relevant to that area is allowed to emerge.” (Strauss & Corbin, 1990, p.23).

In terms of the diagnosis search, while screening and referrals were relatively swift for older people (Campbell et al., 2016), younger individuals underwent multiple inconclusive investigations before dementia-specific referrals were made. Critically, and not mentioned in previous research, was the experience of feeling invalidated and disbelieved whilst searching for a diagnosis and disbelief and dismissiveness from others when the confirmed diagnosis was shared because of the association of dementia with old age. This highlights the impact of YOD on one’s social identity prior to a confirmed diagnosis, and possible ambivalence from healthcare professionals in early dementia screening (Verooij-Dassen et al., 2005).

When contemplating diagnosis sharing, participants considered the nature of the relationship with the recipient and whether there was enough of a connection (as Agnes and James had eluded to their experiences of disclosing to strangers). This inevitably led to distress when others responded in a stigmatising way, distanced themselves or responded so differently that it led to relationship rifts. The anticipation of others’ reactions prior to self-disclosure is reflected in other life-limiting conditions (Derlega et al., 2018; Broekema & Weber, 2017). Interestingly, some participants welcomed disbelief (an indication of intact abilities) and some disapproved (they felt their difficulties were being dismissed).

The need to stay socially included and meaningfully occupied resonate with several studies on living and coping with Young-onset AD (Clemerson, Walsh, & Issac, 2014; Pipon-Young, Lee, Jones, & Guss, 2011). This is evident in Erikson’s (1959) understanding of mid-adulthood during which the main task is generativity versus stagnation. All participants strived to avoid stagnation through exercising a routine to participating in self-advocacy and education; in situations where stagnation could not be avoided, this resulted in distress. Moreover, people with YOD and families may encounter tensions in ensuring that sufficient attention is given to older age ‘life tasks’ (integrity versus despair; immortality versus distinction). This might be reflected in couples using different coping strategies.

Relevance with existing theories

Findings were relevant to certain aspects of extant self-disclosure theories. Greene’s (2009) Disclosure decision-making model listed stigma, symptoms and illness relevance (to the recipient) as factors in the decision process. Participants tended to share their diagnosis as an explanation to visible symptoms (e.g. Ruth when she struggles with shopping); Stan and Francis informed family to involve them in genetic counselling. Petronio’s (2010) CPM theory describes co-ownership of private information when diagnosis is shared and that individuals form criteria in selecting co-owners. For example, Brenda’s criteria for her co-owners (two neighbours in her block) was that she could trust them in treating her normally despite knowing her diagnosis; in contrast she concealed from other residents who were too “gossipy”. However, these models focus on self-disclosure as a discrete event that occurs within dyadic interactions, and do not consider the wider impact of the diagnosis search process and the managing of relationships. Current findings suggest that these models would benefit from expanding on the social and emotional consequences of self-disclosure and on the dynamic nature of self-disclosure, for example, where others’ reactions to the diagnosis disclosure influences subsequent disclosure (and concealment).

Bronfrenbrenner’s ecological systems theory (Figure 2) provides a basis for mapping social systems around people with dementia. Diagnosis sharing occurred mainly within the microsystem where relational changes were frequently reported. Existing research reports similar changes in spousal relationships (Wawrziczny, Pasquier, Ducharme, Kergoat, & Antoine, 2015). In particular, people with YOD recognised changes in emotional intimacy (Stan was aware he and his wife had drifted apart) and roles (Bob feeling like a "kept man" with his wife as the sole earner). Whilst previous findings report the loss of ability to empathise with others in individuals with dementia, especially FTD (e.g Dermody et al., 2016), participants with FTD in this current study demonstrated that this was not always the case. Bob was able to understand and respect his wife's way of coping with the inevitable progression of dementia. That said, others struggled or did not have the awareness of the changes themselves (Doug feeling hurt when his wife said he was no longer caring), although they acknowledged others' reports of the changes.

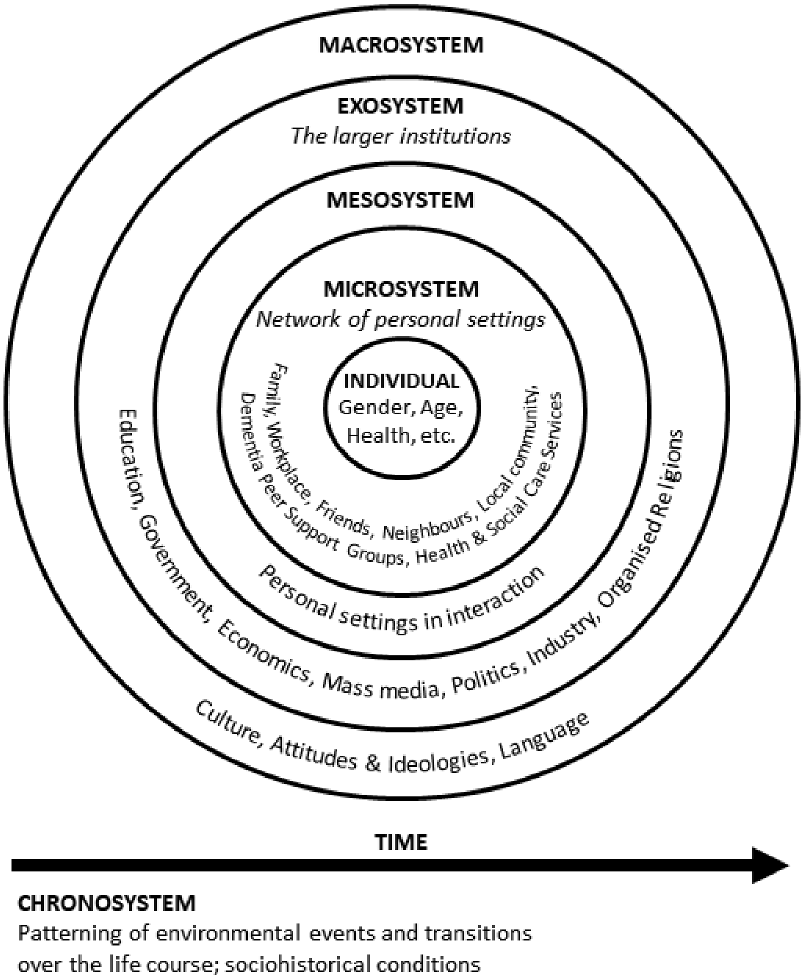

Figure 2. Ecological systems theory – social circles that person with dementia is situated in.

Compared to individuals with other life-limiting illnesses (Munro et al., 2015), participants seemed more likely to share their diagnosis with strangers in a social setting (mesosystem), having encountered and established a degree of connection through conversation and as self-affirmation. These motivations directly address and break the assumption of dementia as an old age condition, coinciding with previous research whereby individuals with LOD share their diagnosis to combat stigma (O'Connor et al., 2018).

The findings also encapsulate Hopson and Adams' (1976) stages of psychosocial transitions. This was experienced by participants and members within their microsystem, albeit in a slightly different order. For example, doubt was experienced at different times– by participants whilst searching for a diagnosis (and family members who were closely involved), and by others not involved in the search process when they learnt of the confirmed diagnosis. In coming to terms with YOD-related changes, participants reflected on the changes and accepted losses and limitations, but there did not seem to be a severance of past selves. Instead, personal values were actively integrated so they could continue to live meaningfully. In terms of testing relationships both new and old, the former occurred in peer support groups, and the latter in the process of negotiating shared understandings of dementia-related changes.

Few studies on understanding relationships within dementia have referred to systemic models; this may also reflect the dominant narrative of dementia as a condition assigned to an individual. One exception is the family systems illness model (Rolland, 1987), a framework for capturing the familial experience of chronic illness over time and its impact on family development, including cross-generational influences. Specifically, the interactions between the family's illness beliefs, the illness itself, the members, and the family life cycle mediate closeness and disengagement within the system. This is particularly relevant to the process of negotiating a shared understanding of YOD. When there is sufficient shared understanding, including mutual acceptance of different coping styles between family members (Bob and Ivan's families), the family system tends to be closer. In contrast, disbelief and conflict between family members' understandings of YOD may lead to disengagement (Mary and Julia's families). Roach et al. (2014) reported similar narratives in families' attempts to manage YOD. Hence systemic approaches in clinical and community settings are worth exploring to support families and other systems in understanding their beliefs about YOD, and how the systems could be supported as dementia progresses.

Clinical Implications

The uniqueness of the YOD experience, corresponding life events and its progressive trajectory compared to that of chronic physical and mental health, suggests that YOD may be a specialist area separate from older adult and working age mental health and neurorehabilitation services. YOD-specific services may need to consider the variability in individuals' lifespan development, which may directly affect their approach to diagnosis sharing, post-diagnostic support and peer group membership.

The gradual building of a picture of dementia during the assessment process was perceived as helpful and recommended in clinical guidance (Murphy & Gair, 2014). Explicit naming of dementia as a possible outcome during early stages of assessment facilitated discussions, destigmatising dementia to some extent. After diagnosis confirmation, participants' experiences suggest that "facilitative listening" (Weaks et al., 2015, p.780) offered by professionals may be beneficial in supporting individuals with YOD and their families process their own and others' reactions to the diagnosis.

Clinicians could consider supporting individuals in how managing their diagnosis as privately-owned information, such as possible outcomes of sharing and concealing specific to the individual’s familial, social and work context and community. If employment is terminated, individuals could be supported in planning and finding closure with their work and colleagues (Alzheimer’s Society, 2014). The above may require multi-disciplinary input beyond clinical psychology, such as occupational therapy.

Findings support the use of systemic approaches in working with individuals with dementia and their families. Since dementia impacts the whole family across generations, including the wider family could be beneficial (Fisher & Lieberman, 1994). In situations where families contemplate concealing the dementia diagnosis from the individual with dementia (or the individual themselves from their family), systemic approaches may open conversations about reservations, fears, and the rights and wishes of the person with dementia (BPS Dementia Advisory Group, 2018b). The use of systemic practice could provide a means to include people with dementia in decision-making, dilemmas of care provision, and restructuring of family roles.

Finally, the need for purposeful activity in preserving a sense of self and dignity was indicated in the findings and increasingly recognised within clinical and research arenas (Roach, 2014). The range of opportunities available has widened over time beyond the traditional day centre set-up, such as arts interventions (Young, Camic & Tischler, 2015) and singing groups (Unadkat, Camic & Vella-Burrows, 2016). While such groups may facilitate social engagement, individuals with YOD might view productivity as a crucial task in accordance with their life-stage. Hence it is also important that options to work-based projects or meaningful volunteering opportunities are offered (Robertson & Evans, 2015).

Limitations

The current study captured dementia experiences pertinent to those in their mid to late 50s, nearing retirement, adjusting to children leaving home, but retained financial commitments like mortgages. Findings may not be fully generalisable to younger individuals in their 30s and 40s whose life tasks and responsibilities may be different, such as parenting younger children, caring for parents and demanding work commitments.

Volunteer bias is plausible as participants were forthcoming in speaking to another person about dementia. In contrast, people might not participate in this type of research if they are less likely to talk about their dementia, consider dementia as a private matter not to be shared, or do not have access to a peer support group. Moreover, although the recruitment strategy covered NHS services, service setup differed across. Some did not have memory clinics and therefore prospective participants were more difficult to locate once discharged after assessment. Sampling from those who were neither attached to a health service nor a peer support group may have added different perspectives to the data.

Despite efforts to recruit from several localities, including that of a culturally diverse inner city, the ethnically homogenous (white British) sample meant that cross-cultural differences could not be fully examined. The experiences of non-white British individuals with YOD may differ due to cultural expectations of the role of family when an individual is diagnosed with a long-term condition (Liu et al. 2008), as well as nuanced social understandings of dementia and how that is constructed by individuals with YOD and their surrounding systems (Cipriani & Borin, 2014).

The majority of participants talked more about their personal journey of YOD and less specifically about how relationships were re-negotiated. The inclusion of other parties, such as caregivers, spouses, friends and other close relationships in the interviews could provide a broader perspective on possible changes that may have taken place within those relationships (Eisikovits & Cohen, 2010).

Research recommendations

The current study could be extended to include individuals with YOD from minority ethnic backgrounds. Recent evidence briefing outlined the need to reach ethnic minority communities in order to provide the appropriate support that consider cultural-based understandings of dementia and care giving, potential barriers to services such as language and increasing prevalence of the condition (BPS Dementia Advisory Group, 2018c).

It was observed that individuals involved in self-advocacy, dementia awareness raising and policy making were more open about their diagnosis and prepared to challenge stigma. This warrants further quantitative investigation between aspects such as social engagement, openness, and peer support group set up.

As proposed by Benbow and Sharman (2014), outcome studies for interventions should report change in systems, as opposed to following the conventional focus on changes in the individual or single caregiver. Further research could consider methodologies that focus on developing dialogue (e.g. participatory action research; Pipon-Young et al., 2011) which include individuals with dementia and others beyond the family system, such as friends, colleagues and members in the local community.

Conclusion

This GT study investigated self-disclosure of YOD diagnosis, how relationships with others were re-negotiated and changes that took place over time as dementia progressed. An emergent theoretical framework from the data, incorporating key events in the illness trajectory, and processes of making sense of change, negotiating a shared understanding of change, the subsequent maintenance of relationships and life with dementia was constructed. Findings highlight the complexities in discerning self-disclosure, the potential impact on relationships and how relational changes can in turn impact on sense of self, subsequent decisions of disclosure and how one lives with YOD.

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Section C: Appendices of supporting material

Appendix A. Literature search terms

Search	**Search term**	**CINAHL**	**Web of science**	**PsychINFO**
1	"("self-disclose* OR break bad news OR disclose*)	10484	93082	72038
2	“dementia NOT depress* NOT anxiety NOT abuse”	18236	125573	50333
3	""cancer NOT depress* NOT anxiety NOT abuse""	191510	2151460	45674
4	""cystic fibrosis NOT depress* NOT anxiety NOT abuse""	5187	64179	1044
5	""sickle cell disease NOT depress* NOT anxiety NOT abuse""	28	20992	1027
1&2	Limiters - Full Text; Peer Reviewed; Language: English	131	474	668
1&3	Limiters - Full Text; Peer Reviewed; Language: English	799	4951	2329
1&4	Limiters - Full Text; Peer Reviewed; Language: English	37	117	55
1&5	Limiters - Full Text; Peer Reviewed; Language: English	7	36	34

Appendix B. Critical Skills Appraisal Checklists – CASP

Screening questions/ Authors	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Hellstrom & Torres, 2013, (Sweden)	Y	Y	CAN'T TELL	Y	Y	Y	Y	Y	Y	Y
Weaks, Wilkinson, & McLeod, 2015, (UK)	Y	Y	Y	CAN'T TELL	Y	Y	Y	Y	Y	Y
O'Connor, Mann, & Wiersma, 2018, (Canada)	Y	Y	Y	Y	Y	IN PART	Y	Y	Y	Y
Robinson, Kocum, Loughlin, Bryson, & Dimoff, 2015 (USA)	Y	Y	Y	Y/IN PART	Y	CAN'T TELL	Y	Y	Y	Y
Ewing, Ngwenya, Benson, Gilligan, Bailey, Seymour, & Farquhar, 2015 (UK)	Y	Y	Y	Y	Y	IN PART	Y	Y	Y	Y
Gray, Fitch, Phillips, Labrecque, & Fergus, 2000 (Canada)	Y	Y	Y	Y	Y	CAN'T TELL	CAN'T TELL	Y	Y	Y
Donovan-Kicken, Tollison & Goins, 2012 (USA)	Y	Y	Y	Y	Y	Y	Can't tell	Y	Y	Y
Yoo, Aviv, Levine, Ewing & Au, 2010 (USA)	Y	Y	Y	Y	Y	Can't tell/no	Can't tell	Y	Y	Y
Derlega, Maduro, Janda, Chen, & Goodman, 2018 (USA)	Y	Y	Y	Y	Y	CAN'T TELL/NO	CAN'T TELL	Y	Y	Y
Broekema & Weber, 2017 (USA)	Y	Y	Y	Y	Y	CAN'T TELL	Y	Y	Y	Y
Hilton, Emslie, Hunt, Chapple, & Ziebland, 2009 (UK)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Ewing et al- researcher's role not examined

O'Connor et al- researcher's role not examined

Robinson et al- not explained why selected participants were most appropriate; not discussed saturation;

Critical Appraisal Skills Programme (CASP): Qualitative Research Checklist

Screening questions

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims for the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between the researchers and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

Appendix C. Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies

	Criteria	Munro, Scott, King & Grunfeld, 2015	Najmabadi, Azarkish, Latifnejadroudsari, Shandiz, Aledavood, Kermani & Esmaily, 2014	Borschuk, Everhart, Eakin, Rand-Giovannetti, Borrelli & Riekart, 2016
1	Was the research question or objective in this paper clearly stated?	Y	Y	Y
2	Was the study population clearly specified and defined?	Y	Y	Y
3	Was the participation rate of eligible persons at least 50%?	Y	CD Authors noted 75% participation however also wrote that not all questionnaires were complete. It was not stated how incomplete questionnaires were dealt with.	Y
4	Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	Y	Y	Y
5	Was a sample size justification, power description, or variance and effect estimates provided?	N	N	N
6	For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	N	N	N
7	Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	N	N	N

8	For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	N	N	N
9	Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Y	Y	Y
10	Was the exposure(s) assessed more than once over time?	N/A	N/A	N/A
11	Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Y	CD (see answer to question 3)	Y
12	Were the outcome assessors blinded to the exposure status of participants?	N/A	N/A	N/A
13	Was loss to follow-up after baseline 20% or less?	N/A	N/A	N/A
14	Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	Y		Y

Y = YES N = NO CD = cannot determine N/A = not applicable NR = not reported

Appendix D. Ethical approval and insurance cover for current study

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Insurance cover

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Letter for funding

Canterbury
Christ Church
University

Salomons Centre for Applied Psychology

Miss K Siu
2 Victoria Way
LONDON
SE7 7RE

Date: 18th June 2014

Direct line 0333 0117114
Direct fax 01892 52088
E-mail paul.camic@canterbury.ac.uk
Our Ref PC/vc/083/dissertations

Dear Miss Siu

I am writing to inform you that the Independent Research Review Panel has approved your research project proposal. Please include a copy of this letter in your ethics application.

Information for Ethics Panels and R & D offices: I am writing to confirm that funding has been secured for the doctoral-level research project of Katherine Siu who is a clinical psychology trainee at our institution. This research project is in partial fulfilment of the Doctor of Clinical Psychology degree awarded by Canterbury Christ Church University. Each trainee is assigned a Lead and Second Supervisor who will closely monitor the scientific and ethical components of this research project.

All research in the clinical psychology doctoral programme at Canterbury Christ Church University is carried out in accordance with the Research Governance Framework for Health and Social Care 2005. The University provides insurance coverage, against negligent harm, for our postgraduate students while undertaking research. A copy of our insurance letter is attached and this is automatically renewed each year. .

All doctoral dissertation proposals are independently vetted by two members of the clinical psychology programme faculty before being given approval. Only those research projects that are deemed to be of significant clinical and scientific merit are approved.

The above mentioned clinical psychology trainee is employed full-time by Surrey and Borders Partnership NHS Trust and is bound by the requirements of the Research Governance Framework (RGF). They are also required to adhere to the *Code of Ethics and Conduct* of the British Psychological Society.

Department of Psychology, Politics and Sociology
Faculty of Social and Applied Sciences

Canterbury Christ Church University
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Professor Rama Thirunamachandran, Vice-Chancellor and Principal

Appendix E. R&D approval

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Appendix F. Participant consent form, information sheet and de-brief letter

Canterbury
Christ Church
University

Salomons Centre for Applied

Centre Number:
Study Number:
Participant Identification Number for this study:

CONSENT FORM

Title of Project: How people with young onset dementia share their diagnosis with others
Name of Researcher: Katherine Siu

1. I confirm that I have read and understand the information sheet dated.................... (version............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time before the interview without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that data collected during the study may be looked at by the researcher's supervisors, Professor Paul Camic and Mr Reinhard Guss. I give permission for these individuals to have access to my data. ☐

4. I agree for my interview to be audio-recorded. ☐

5. I agree that anonymous quotes from my interview may be used in published reports of the study findings ☐

6. I agree to take part in the above study. ☐

Name of Participant_____________________ Date_________________

Signature ____________________

Name of Person taking consent _______________ Date______________

Signature _____________________

Salomons Centre for Applied Psychology

Information about the research
How people with young onset dementia share their diagnosis with others

My name is Katherine Siu and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in the above research study. Before you decide it is important that you understand why the research is being done and what it would involve for you.

Talk to others about the study if you wish.
(Part 1 tells you the purpose of this study and what will happen to you if you take part.
Part 2 gives you more detailed information about the conduct of the study).

What is the purpose of the study?
We hope to learn more about how people communicate their diagnosis of dementia to others, and how their experience of receiving their diagnosis influences how they share their diagnosis.

Why have I been invited?
We are looking for individuals with a diagnosis of 1) young onset dementia, *and* 2) who do not currently have a severe and ongoing mental health problem, such as psychosis or major depressive disorder, to participate in this study. This is the main reason that you have been invited. We are hoping to interview around 15 people to help us get a clearer idea on how a diagnosis of young onset dementia is shared with others, and what might influence this.

Do I have to take part?
Taking part is voluntary- it is up to you to decide. This is an independent study and is not linked to any care you receive. As such, your decision on whether you take part or not will not affect the standard of care that you receive now and in future. If you agree to take part, I will ask you to sign a consent form. You are free to withdraw at any time before the interview takes place. Again, this would not affect your care.

What will happen to me if I take part?

You will be given the opportunity to ask any questions you may have about the research study. After this, I will ask you for some personal information and we will set a date and time for an interview session.

An interview session usually lasts up to 90 minutes. We may meet for one session, or two shorter sessions, depending on what you feel more comfortable with. The sessions can be done at the NHS service you receive support at, or at your home. At your first interview session, you will be asked to sign a consent form for the study.

The interview is done with yourself, but if you would like your carer or a family member to be present, we can discuss this further. The interviews will be audio-recorded.

Expenses and payments
We can reimburse up to £10.00 for any travel expenses you make.

What will I have to do?
On the day of the interview, I will have some topics that I am interested in knowing more about. I will start off the interview by asking you to talk a bit about yourself so I can get to know you better. We will then talk a bit more about the following topics:

- How you were told about your diagnosis
- How you decided to share your diagnosis with other people
- What the actual sharing was like
- After sharing your diagnosis, what was it like being with those people

  I may ask questions from time to time. Before the end of the interview, we will spend a bit of time thinking about what it was like to talk about these experiences. If needed, we will arrange to meet for a second time.

What are the possible disadvantages and risks of taking part
There are no known risks to taking part. Sometimes, people find that talking about past difficulties can make them feel sad or upset.

What are the possible benefits of taking part?
There is research to show that some people find it helpful to talk about their experiences of dementia. This has also been reported by people who have taken part in research studies, during which they were asked to talk about their experiences because it gives them an opportunity to make sense of what has happened.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes part 1.
If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2 of the information sheet

What will happen if I don't want to carry on with the study?
If you decide that you no longer want to take part, we will stop conducting any planned interviews. However we would like to use the data collected up to your withdrawal.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to answer your questions (*contact details have been removed from the electronic copy)*. If you remain unhappy and wish to complain formally, you can contact Prof. Paul M. Camic, Lead Research Supervisor (*contact details have been removed from the*

electronic copy) at Canterbury Christ Church University.

Will my taking part in this study be kept confidential?
Yes. The interviews you take part in will be kept strictly confidential. The interviews will be audio recorded, and then transcribed into a written script for data analysis. All names will be anonymised. No one else will be able to read these scripts apart from myself and my research supervisors.

I may also read out small sections of the script to an advisor who also has a diagnosis of young onset dementia, to make sure that I am understanding the data correctly. Please be reassured that your name and any identifiable information will be removed before doing this.

After the study is completed, all recordings will be kept on a password protected CD and stored for 10 years at the Salmons Centre of Applied Psychology, Canterbury Christ Church University, after which it will be destroyed.

Will my GP or other professionals involved in my care be informed of my participation in this study?
We will not be informing your GP or other professionals of your participation. You may wish to inform them yourself if you would like them to know.

What will happen to the results of the research study?

The results will be written up as part of a doctoral thesis (a piece of academic work). They will also be published as an article in an academic journal. Quotes from our interview may be used but they will be made anonymous. You will not be identified in any report or publication unless we have your consent.

If you are interested in the results of the study, please contact Katherine Siu (*contact details have been removed from the electronic copy*)).

Who is organising and funding the research?
Canterbury Christ Church University.

Who has reviewed the study?
A university independent research review panel has approved this study. In addition, all research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by IRAS (NHS) Research Ethics Committee.

Further information and contact details

For general information about this research study:
Katherine Siu, Trainee Clinical Psychologist (*contact details have been removed from the electronic copy*))

Advice as to whether I should participate:
You may wish to speak to a professional involved in your care and support. This could be your GP, your carer/support worker, or a healthcare professional who is working with you.

If you are unhappy with this research study and wish to make a formal complaint:
Prof. Paul M. Camic, Lead Research Supervisor (*contact details have been removed from the electronic copy*))

Debrief letter

Canterbury
Christ Church
University

Salomons Centre for Applied Psychology

Dear [*name of participant*],

Thank you for participating in the research study, and for sharing your experiences in the interview.

We understand that sometimes these experiences may be difficult to talk about, and some people can feel distress after talking about such experiences. This is not unusual, and you may find that the upset feelings fade after a while. However, if you find that these feelings stay with you for a prolonged period of time, or if you feel you would like further support, you can contact:

1. Your General Practitioner
2. A healthcare professional involved in caring for you: this may be someone at your local memory clinic or mental health team

If you would like any additional information, or a confidential discussion, please contact me on *[contact details removed from electronic copy]*, or leave me message on *[contact details removed from electronic copy]*. Please specify that the message is for Katherine Siu and it will be forwarded to me promptly.

Thank you again for your participation in this study.

Yours Sincerely

Katherine Siu
Trainee Clinical Psychologist
Canterbury Christ Church University

Supervised by
Professor Paul Camic
Research Director, Salomons Centre for Applied Psychology, Canterbury Christ Church University, Tunbridge Wells, Kent TN3 0TF

and

Mr Reinhard Guss
Consultant Clinical Psychologist
Kent and Medway NHS and Social Care Partnership Trust

Appendix G. Consent, process and flow chart

Assessing capacity to consent to research study

The chief investigator will assess capacity with reference to the process consent method (Dewing, 2007). This method is used by researchers to support people with dementia in considering their preferences to take part in research. The method encourages researchers to recognise of consent can be situational and variable. As such, when assessing capacity, the chief investigator will

1) present information about the study in a way that is easy for the potential participant to understand;

2) take notice of non-verbal communication (e.g.: body language, behaviour) that may convey their preferences; and

3) bear in mind how one's emotional state can influence their preference to participate.

The chief investigator will also take into account the conditions set out by the mental capacity act for determining mental capacity. That is, the individual can show that they understand and retain information about participating in the study, and they understand what participation may or will lead to. For example, they might feel emotional when talking about past experiences and that their experiences will go towards academic research to be published.

In the case that the individual is unable to express their preferences about participation or do not show an understanding of it, the chief investigator will take this as an indication that the individual is unable to consent to the study. The chief investigator will explain to the individual, that, the individual does not seem to understand the study, and it will not be the right thing to do to have them take part in the study.

Please refer to the flowchart (Fig. G1) on the next page for the consent process.

Reference: Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia*, 6(1), 11–25. doi:10.1177/1471301207075625

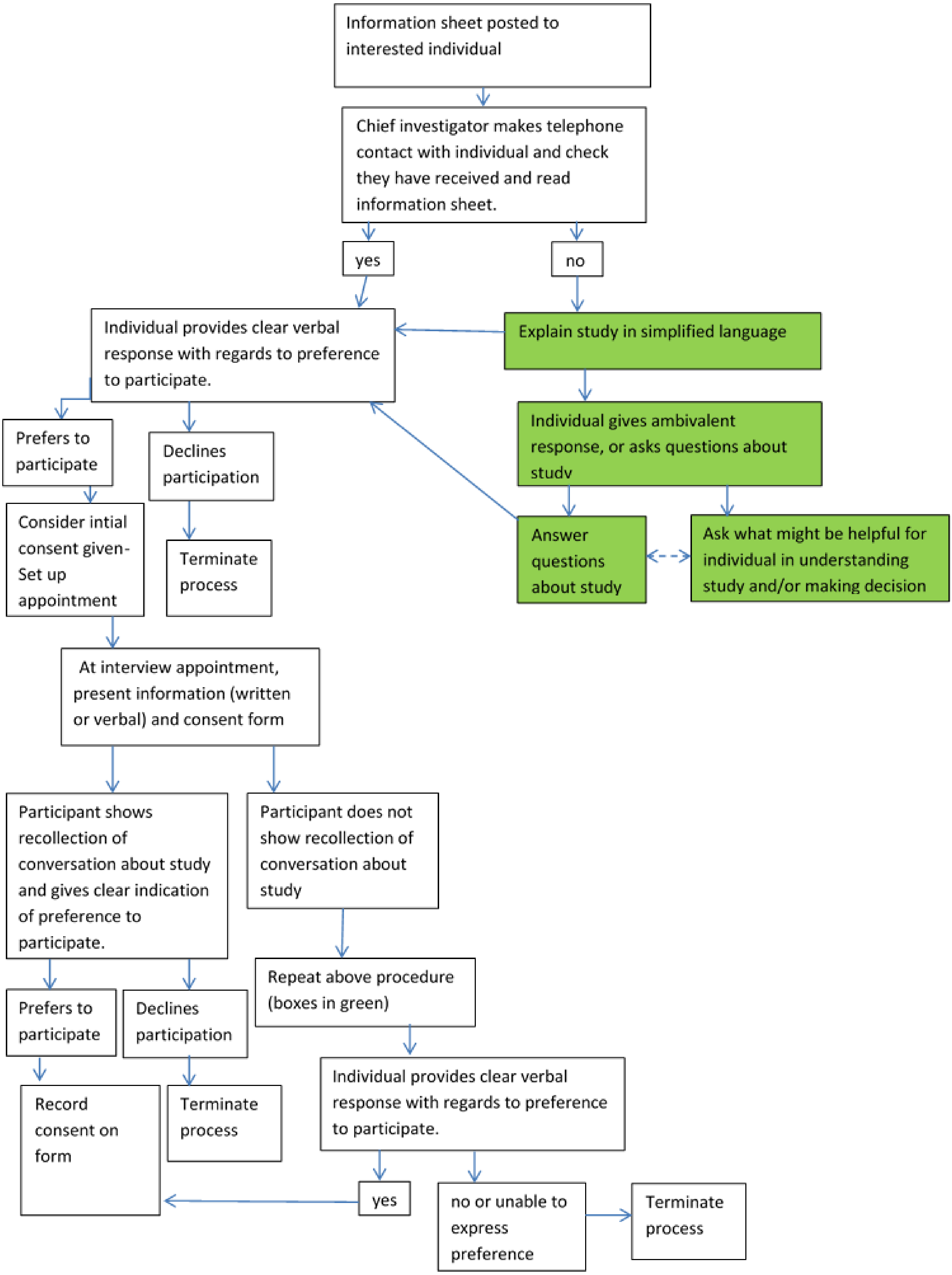


Figure G1: Flow chart of consent process for individual to participate in study

Appendix H. Interview schedule

Introduction

Please tell me a bit about yourself…what are some of the things you enjoy doing?
Since receiving a diagnosis of dementia, has your interest in those things changed?

Receiving a diagnosis
How you were told about your diagnosis/how your diagnosis was communicated to you?
What happened/what was it like?
Was there anyone with you at the time?
How did that leave you (feeling/thinking)?

Making a decision on disclosing

Did you think of sharing your diagnosis with others?
What went through your mind as you decided who you would share/not share with?
When did you decide to share your diagnosis with others?
Who did you feel needed to know first? What is your relationship like between you and the person?
What was it like, thinking/planning on how share this piece of news with them?
Did you decide to do the sharing yourself, or have someone else support you in doing so?

Disclosing

Did the sharing happen as you had planned it?
How did they react?
Then what happened?...

Post-disclosure

Could you tell me what it was like being with [the person] after you shared your diagnosis with them?
Was it comfortable being with them this way?
What made it comfortable/uncomfortable? Why?
How would you have liked it to be instead?
Is this person now involved in supporting you in living with dementia? How?

Appendix I. Example theoretical memos

Making sense of how others are understanding observed deterioration [Agnes]
seems like it can be extremely confusing for person with dementia to make sense of the conversations surrounding them with regards to changes/deterioration.

in this case, Agnes sensed that husband had noticed, which she seemed to dread.

she picked up that her husband had spoken and persuaded the daughter to accompany her to seek a diagnosis, as he sensed her uneasiness in having him accompany her.

did these roundabout conversations cause feelings of hurt, embarrassment and inferiority? ---people have to talk about what to do with me, but no longer directly with me

remarkable how she saw herself being in the middle, between husband and doctor. she goes on to say how she feels less than her husband, now that she has dementia and her abilities have deteriorated.

“oh my God, there she is”- it's like having a spotlight, having unwanted attention…feeling exposed?

Julia
“I enjoy doing colouring”
I was surprised when she said that; I took it that she meant she could colour (and unable to do other things). She did not "look" disabled. She looked pretty able. I thought colouring was a "low level" activity. I wonder if she ever felt patronised by others, and by herself.

“the toilet’s usually an issue…I have had to the occasional accident, and that’s..horrible. to get into a shock but can’t move because you want to go so bad…it’s all those feelings, you don’t know you want to do it, but you do. It’s horrible.”

reminded me of the scene in Still Alice when Alice suddenly starts running frantically through their holiday home, opening doors, looking for something. But couldn't seem to find the right door...or the right room? until her husband caught her by the arms and she looked so shaken. And he said, it's ok, it's ok, let's get you cleaned up. she was tearful, and embarrassed. almost ashamed.

Others’ assumptions about dementia
People with dementia wanting to preserve skills
a lot of people can’t seem to understand that there is still the desire to persevere and do things. why don't you go and sit down and relax? sitting down and relaxing= the better, more sensible option for dementia? what is the function? is it about

- protecting,
- asking them to staying out of trouble

- gentle way of pushing aside/out casting
- a communication of them and us "you're different, you can't do what we can"

Familial dementia

It seemed that what came to mind first, when asked who the diagnosis was first shared with, was the fact that there had already been experience of dementia within the family. Participant described dementia as a pressure of the family; watching his parents deteriorate and "knowing" this could happen to him one day (?); for people who come from families with familial dementia, perhaps pre-empting deterioration starts even before any dementia-related change reveals itself. Decline was discussed across generations within the family.

technology as helpful...the development of "tablets" (a hopeful cure? counteractive object) tablets give "confidence"...placebo effect? a peace of mind? a sense of hope that one day the family may be able to break out of this pressure? a communication of "i'm being responsible for my illness, i'm doing what I can"?

Ted

Ted's interview was a difficult one. He had so much to tell, and much of his answers were preceded by descriptions of several events that…a lot of the time did not seem to be linked to my initial question. There were some moments where I think both of us felt we were going around in circles (me trying to ask the same question again but phrased differently, and him giving the same answer). Out of all the transcripts I probably revisited his the most. The following are examples of memos I wrote as I tried to make sense of Ted's experiences for myself:

Ted seemed to describe a time when he decided to withhold the dementia diagnosis from his family, as to him the diagnosis was attributed to "going silly", "going senile", "go out in the rain...and water plants cause he did it regular 24/7". As he described himself as a capable man prior to his work accident and dementia diagnosis, and dementia to him meant the opposite of that ("uselessness"?), he described being in denial in order to cope with the diagnosis. This links up with what he described repeatedly about attempting to do many things at once, mostly for others, but being unable to complete tasks due to a change in maintaining attention.

Through completing neuropsych tests Ted seemed to realise that he was not "senile" or "stupid" (qualities he attributed to dementia). he recognised that he was retaining information though in an un-structured format; as was his verbal reasoning when pointed out to him. He seemed to take that as a sign that he was still "functioning", and that the person who administered the test also recognised this. Others recognising his ability may have meant quite a lot for Ted.

"because she works with them and because she thought I would turn like that violently when I'm giving her a cuddle or something and I get, I finally know. I have never hurt a woman in

54 years and I have got no intention at all of doing it. So that is why I back off relationships."

I felt heartbroken, hurt and angry for Ted. After learning of his diagnosis, Ted thought his partner distanced herself from him as she thought he would become unpredictable and violent, because this was she had encountered in her work as a carer. This was also one of the moments when James spoke with relative clarity- " that is why I back off relationships". Ted wanted no one to be hurt, including himself. It seemed that some things were better off when remained unspoken.

Mary

Foster/adaptive parent. Had more recently adopted a young child but she started becoming unwell – couldn't drive ("I don't know what to do", when describing a chaotic situation on the road).; turning to one side all the time (attentional/visual neglect); can't go to the toilet,

Can't do paperwork: She described spending hours trying to do it, but it didn't work.

Needs help in removing clothing in order to use the toilet. If felt as though she could see all of this happening in her mind as she recalled this and tried to as best as she could relay to me what had happened. "It was horrible, I hate it."

Tried to get an assistance dog but 'they' wouldn't do it for her. It seems that dementia was somehow reduced interactions between people into 2 categories:
'Person in need of help' and 'Person who is asked to help'

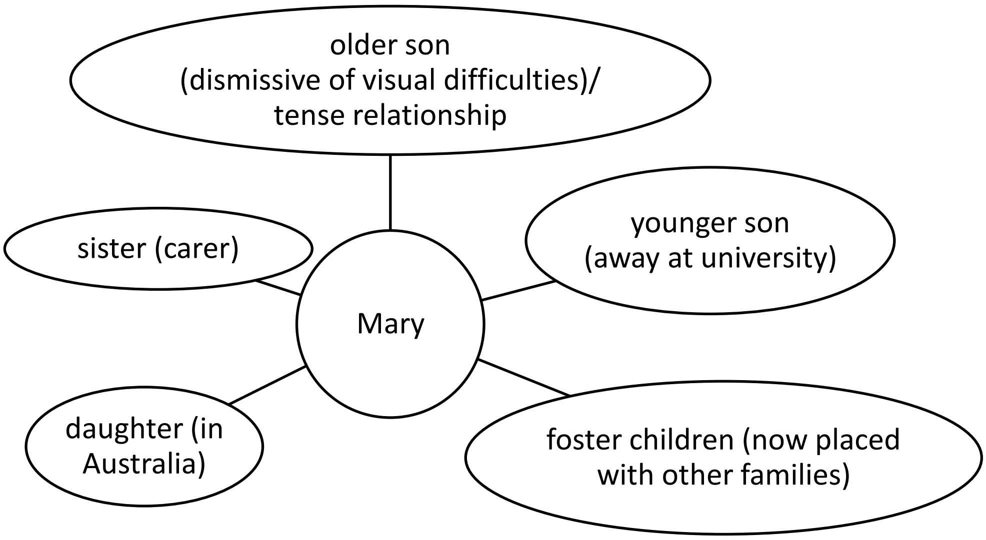
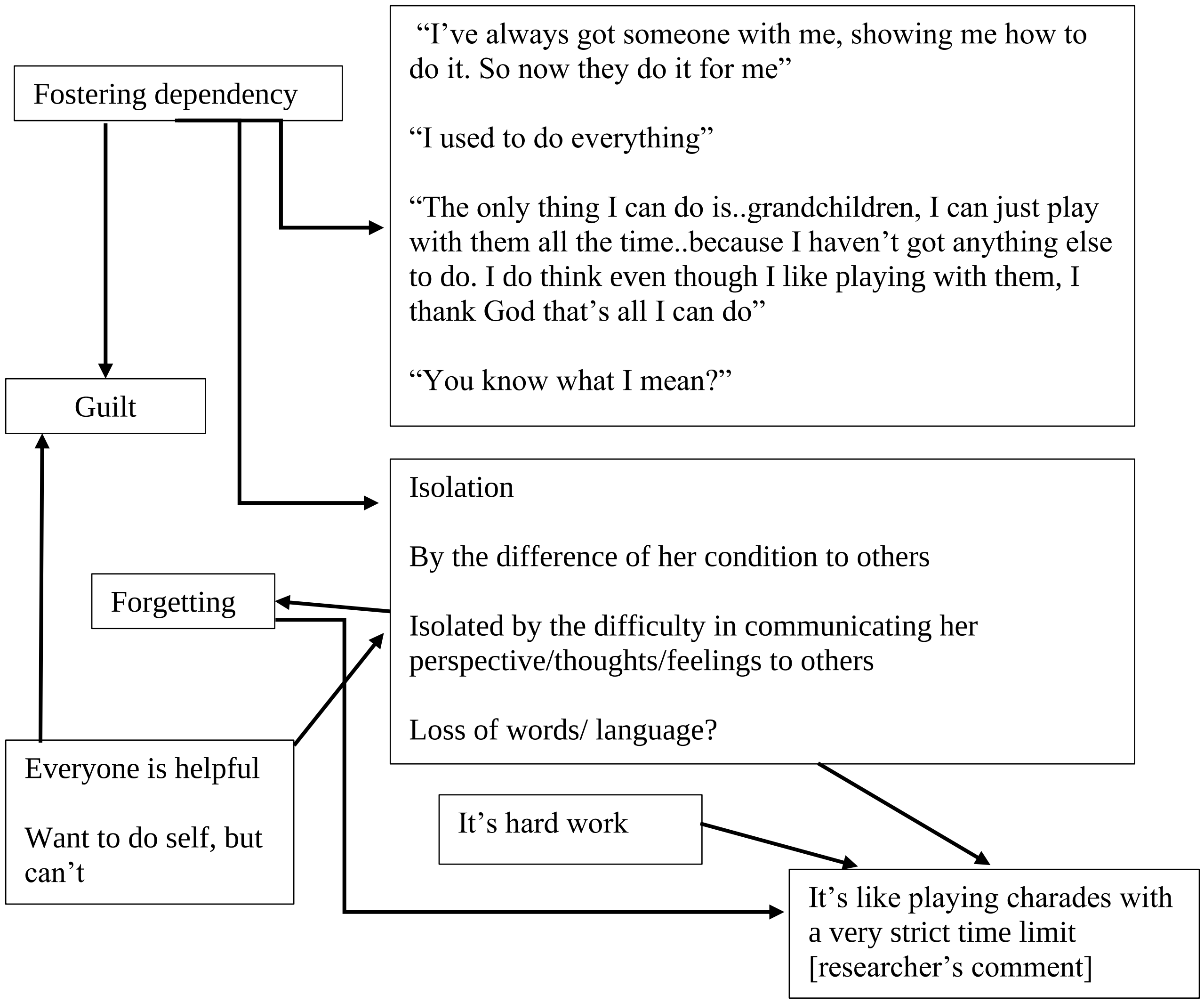


Figure I1. Mary's family circle

Visual difficulties: Taking someone else's shopping items instead of her own



"I've always got someone with me, showing me how to do it. So now they do it for me"

"I used to do everything"

"The only thing I can do is..grandchildren, I can just play with them all the time..because I haven't got anything else to do. I do think even though I like playing with them, I thank God that's all I can do"

"You know what I mean?"

By the difference of her condition to others

Isolated by the difficulty in communicating her perspective/thoughts/feelings to others

Loss of words/ language?

It's like playing charades with a very strict time limit [researcher's comment]

Figure I2. Mary's experiences with dementia

Re: Disabled foster son – "I wanted to keep him...because no one understood him…"
It feels very confusing, there isn't a coherent narrative. Others are on opposite poles, on one hand there are people who do their utmost to help and even over-help by doing it for the person instead of supporting. On the other hand, there are people who minimise the impact of dementia or dismiss it by doing so invalidate the struggles that person with young onset dementia has to live day in day out.

Ability

Some people go through multiple, significant losses as a result of identity and social role but other tangible things such as property, which can lead to other losses such as access to hobbies (e.g. gardening). Then it is not just about a “simple” psychological emotional adjustment; the struggle becomes very real in order to find meaningful occupation

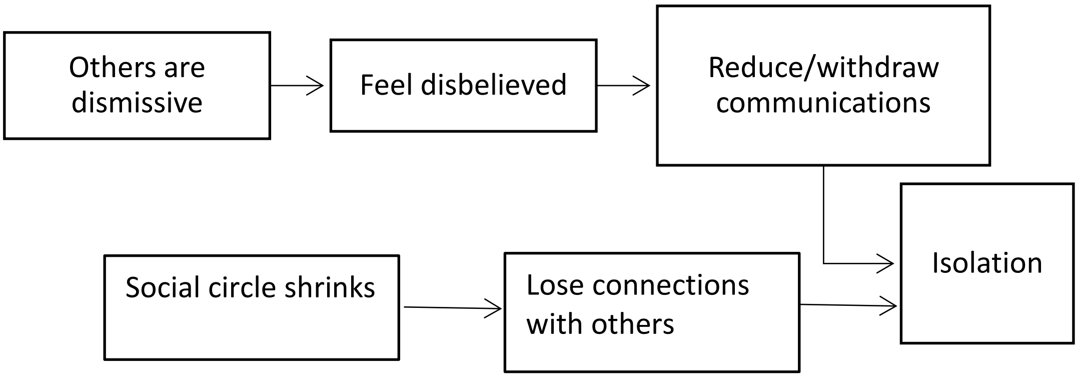
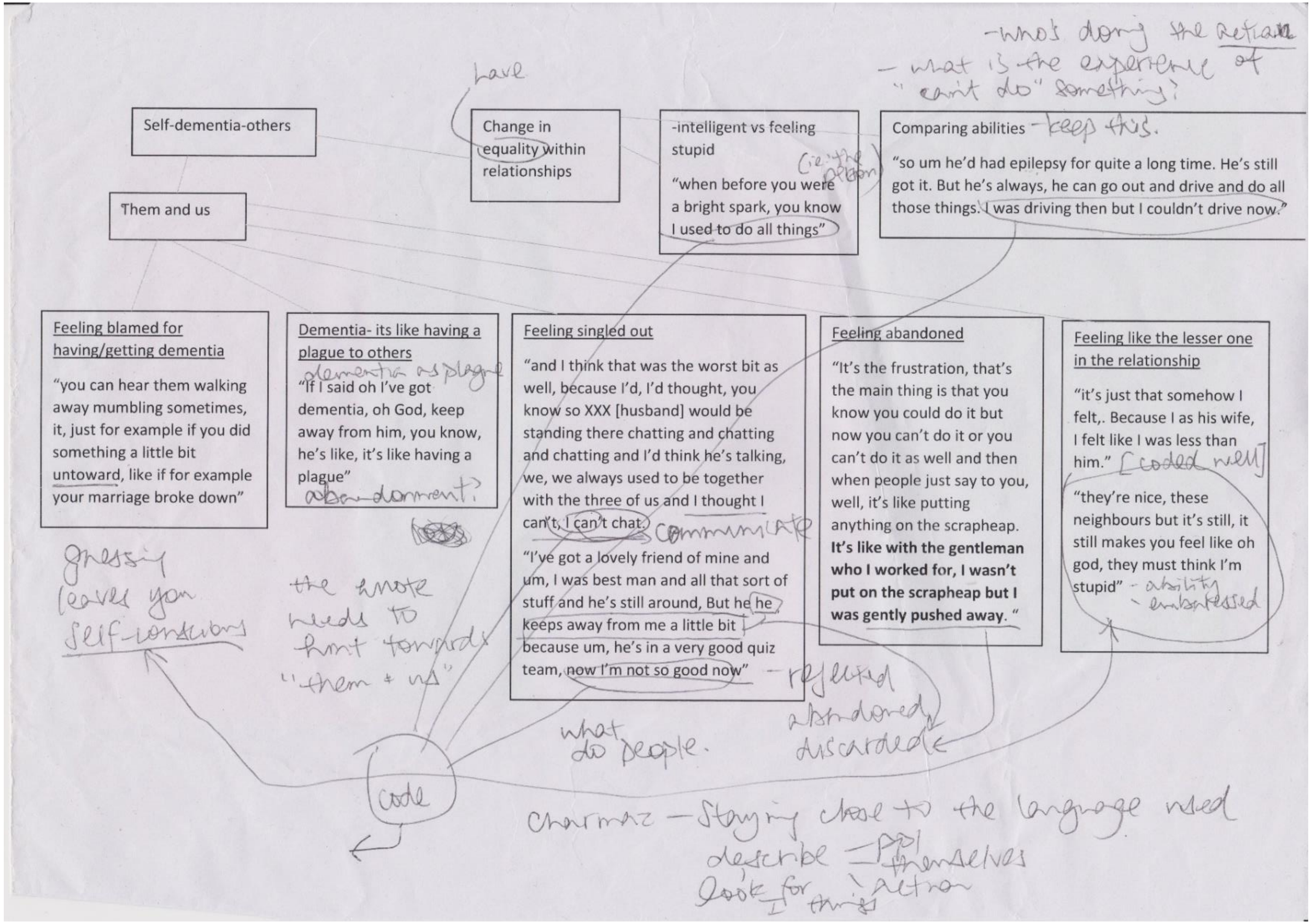


Figure I3. Example of an experience of a person with YOD leading to feelings of isolation

This links into discussion is important to the variety of activity offered in peer support groups to support people in finding in a sense of purpose (*I did not ask her what she talked about to have a break from the “hard work”*)

Appendix J. Example theoretical diagrams



Self-dementia-others

Them and us

Change in equality within relationships

-intelligent vs feeling stupid

“when before you were a bright spark, you know I used to do all things”

Comparing abilities

“so um he’d had epilepsy for quite a long time. He’s still got it. But he’s always, he can go out and drive and do all those things. I was driving then but I couldn’t drive now.”

Feeling blamed for having/getting dementia

“you can hear them walking away mumbling sometimes, it, just for example if you did something a little bit untoward, like if for example your marriage broke down”

Dementia- its like having a plague to others

“If I said oh I’ve got dementia, oh God, keep away from him, you know, he’s like, it’s like having a plague”

Feeling singled out

“and I think that was the worst bit as well, because I’d, I’d thought, you know so XXX [husband] would be standing there chatting and chatting and chatting and I’d think he’s talking, we, we always used to be together with the three of us and I thought I can’t, I can’t chat.

“I’ve got a lovely friend of mine and um, I was best man and all that sort of stuff and he’s still around, But he he keeps away from me a little bit because um, he’s in a very good quiz team, now I’m not so good now”

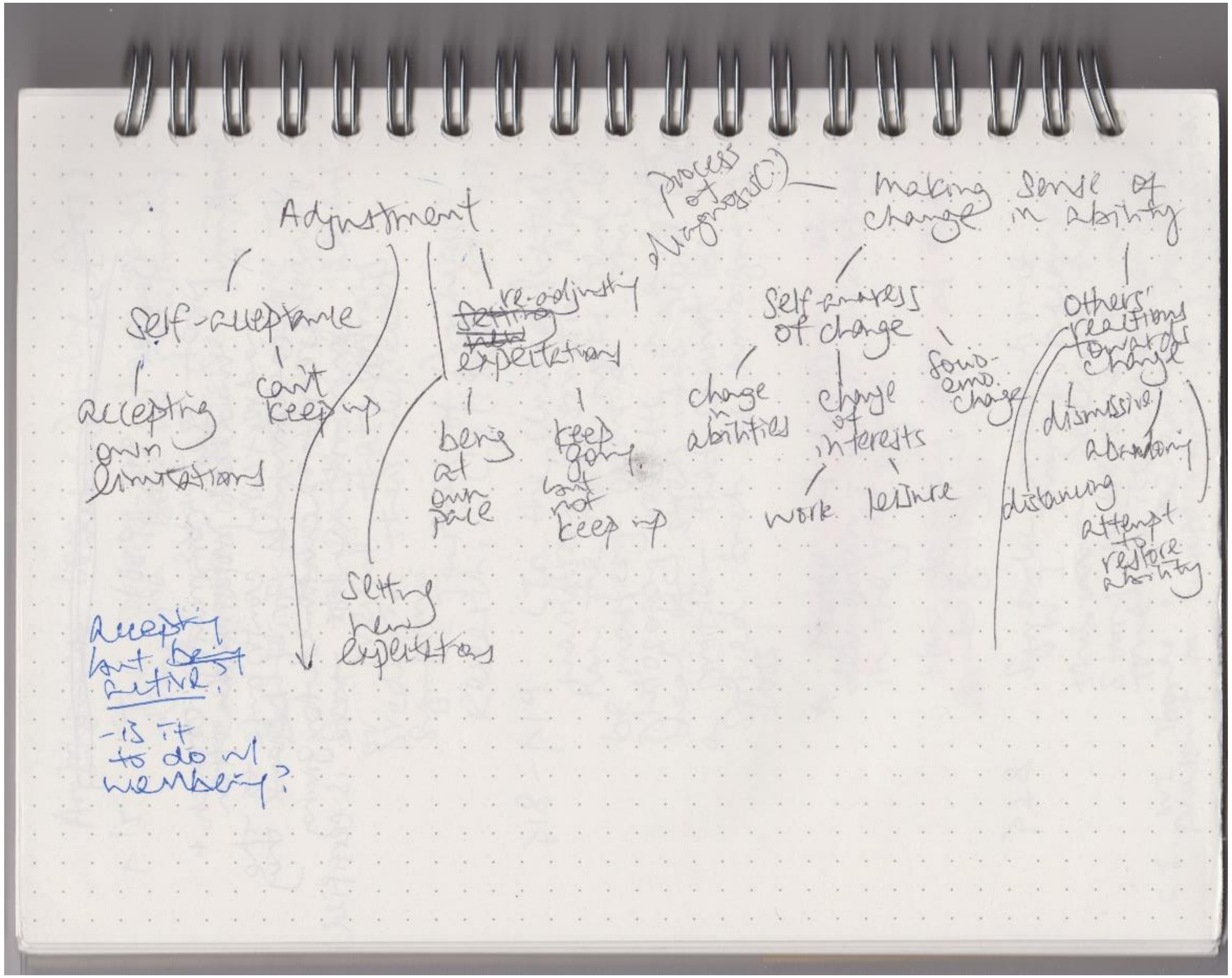
Feeling abandoned

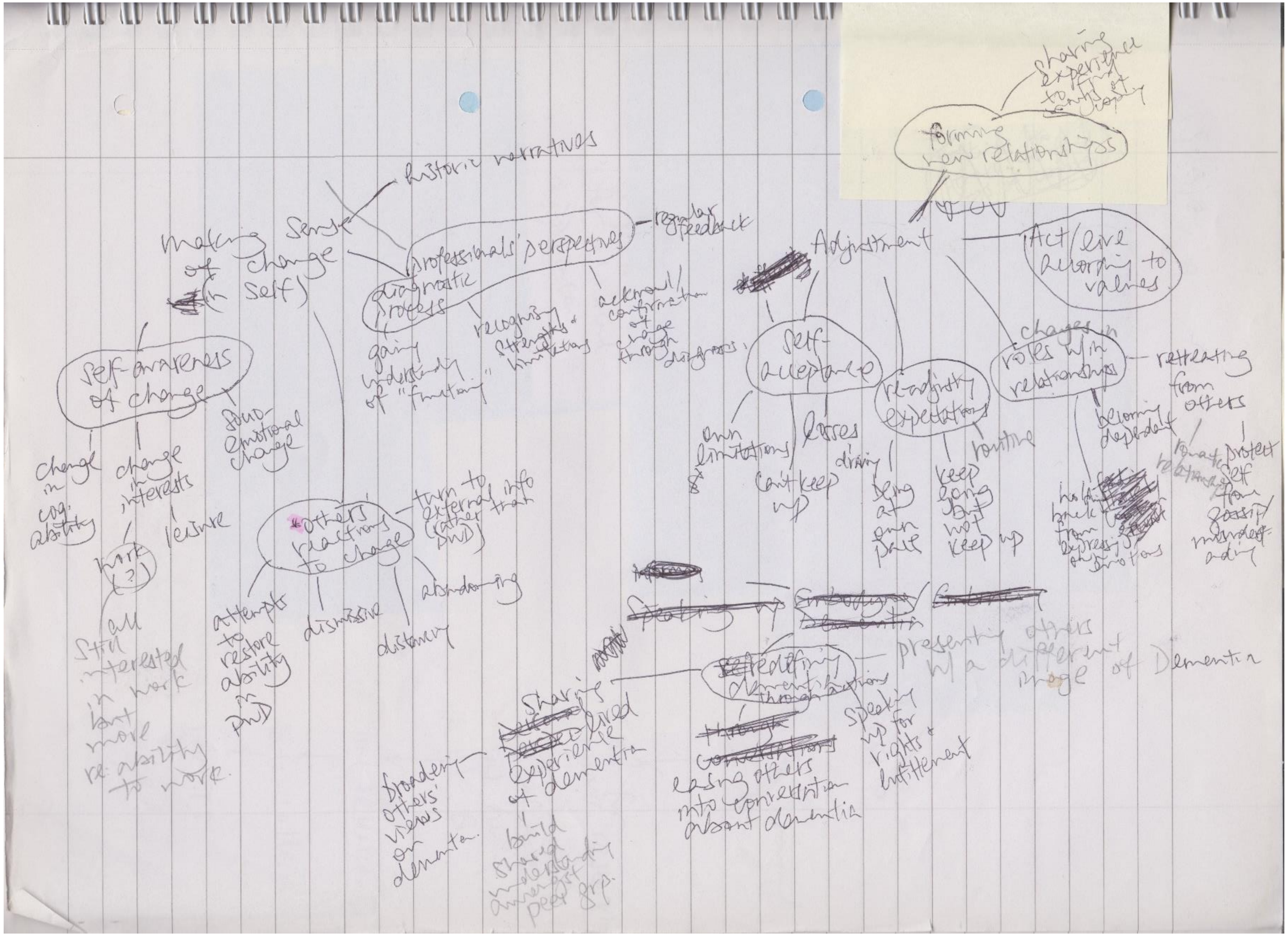
“It’s the frustration, that’s the main thing is that you know you could do it but now you can’t do it or you can’t do it as well and then when people just say to you, well, it’s like putting anything on the scrapheap. **It’s like with the gentleman who I worked for, I wasn’t put on the scrapheap but I was gently pushed away**. “

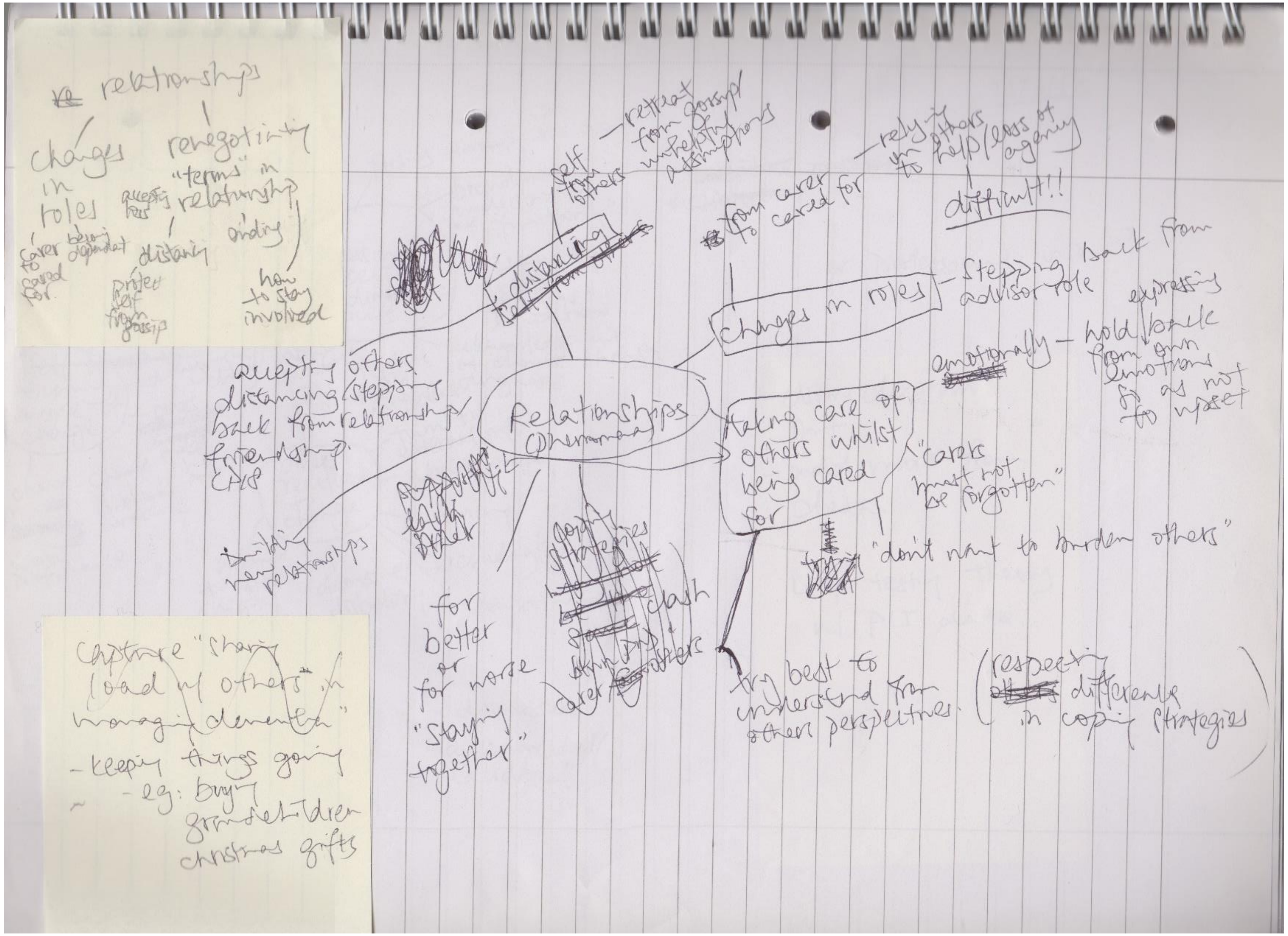
Feeling like the lesser one in the relationship

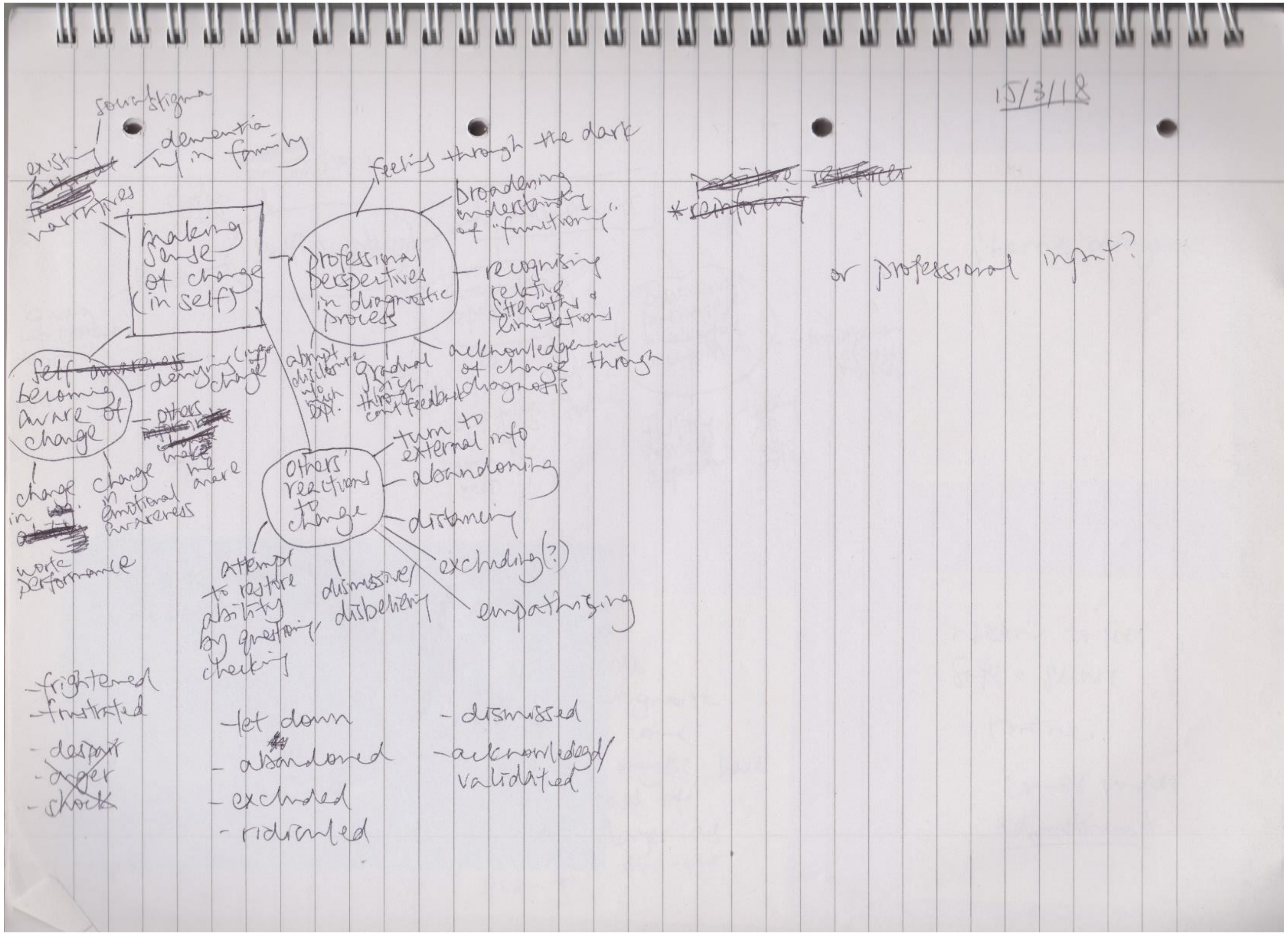
“it’s just that somehow I felt,. Because I as his wife, I felt like I was less than him.”

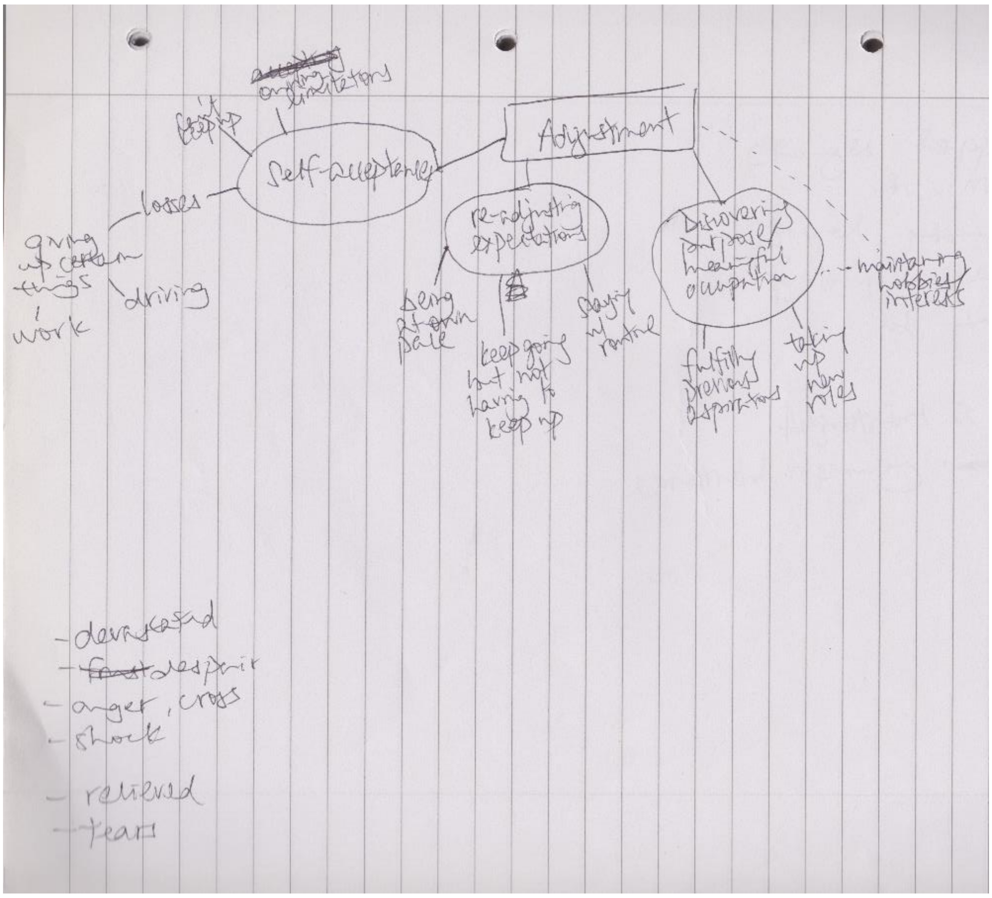
“they’re nice, these neighbours but it’s still, it still makes you feel like oh god, they must think I’m stupid”

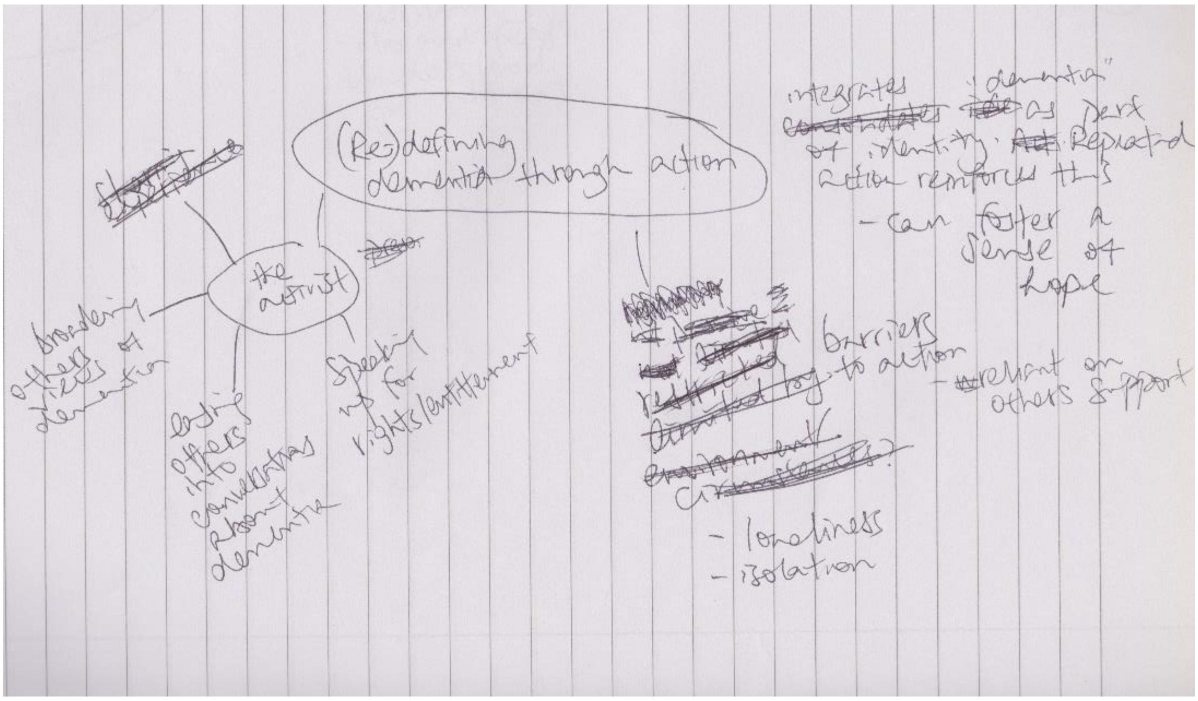

Adjustment
self-acceptance
accepting own limitations
can't keep up
re-adjusting ~~setting new~~ expectations
being at own pace
keep going
can't not keep up
setting new expectations
Accepting but ~~being~~ active?
- is it to do w/ wellbeing?
process of diagnosis(?)
making sense of change in ability
self-awareness of change
change in abilities
change of interests
work
leisure
socio-emo. change
others' reactions towards change
dismissive
abandoning
distancing
attempt to restore ability


historic narratives
making sense of change (in self)
professionals' perspectives
regular feedback
diagnostic process
gaining understanding of "functioning"
recognising strengths & limitations
acknowl/confirmation of change through diagnosis
self-awareness of change
change in cog. ability
change in interests
socio-emotional change
leisure
work (?)
all
still interested in work but more re: ability to work.
*others' reactions to change
turn to external info (rather than PWD)
attempts to restore ability in PWD
dismissive
distancing
abandoning
forming new relationships
sharing experience to find sense of coping
Adjustment
Act/live according to values
self-acceptance
own limitations
losses
driving
can't keep up
readjusting expectations
routine
being at own pace
keep going but not keep up
changes in roles w/in relationships
becoming dependent
holding back from expressing emotions
retreating from others
romantic relationships
protect self from gossip/misunderstanding
~~Speaking up~~
~~Embodying Dementia~~
redefining dementia through actions
presenting others w/ a different image of Dementia
sharing lived experience of dementia
broadening others' views on dementia.
build shared understanding amongst peer grp.
~~Conversations~~
easing others into conversation about dementia
speaking up for rights & entitlement


relationships
changes in roles
renegotiating "terms" in relationship
accepting loss
carer to cared for
being dependent
distancing
protect self from gossip
finding
how to stay involved
self from others — retreat from gossip/ unhelpful assumptions
distancing
~~self from others~~
from carer to cared for — rely on others to help (loss of agency)
difficult!!
changes in roles — stepping back from advisor role
emotionally — hold back from own emotions so as not to upset
expressing
accepting others distancing/stepping back from relationship/ friendship.
Relationships (phenomena)
taking care of others whilst being cared for
"carers must not be forgotten"
"don't want to burden others"
building new relationships
for better or for worse
"staying together"
coping strategies clash carer/others
try best to understand from others perspectives.
(respecting difference in coping strategies)
capture "sharing load of others" in managing dementia"
- keeping things going
- eg: buying grandchildren christmas gifts


15/3/18
social stigma
existing
narratives
dementia
hx in family
making sense of change (in self)
feeling through the dark
professional perspectives in diagnostic process
broadening understanding of "functioning"
recognising relative strengths & limitations
acknowledgement of change through diagnosis
abrupt disclosure w/o much expl.
gradual shift through cont feedback
~~self-awareness~~
becoming aware of change
denying (impact of) change
others make me aware
change in work performance
change in emotional awareness
Others' reactions to change
turn to external info
abandoning
distancing
excluding (?)
empathising
attempt to restore ability by questioning / checking
dismissive / disbelieving
~~positive~~ ~~reinforcer~~
* ~~reinforcing~~
or professional input?
- frightened
- frustrated
- ~~despair~~
- ~~anger~~
- ~~shock~~
- let down
- abandoned
- excluded
- ridiculed
- dismissed
- acknowledged / validated


ongoing limitations
keep up
it
Self-acceptance
Adjustment
losses
giving up certain things
driving
work
re-adjusting expectations
being at own pace
keep going but not having to keep up
staying in control
Discovering purpose/ meaningful occupation
maintaining hobbies/ interests
fulfilling previous aspirations
taking up new roles
- devastated
- ~~frust~~ despair
- anger, cross
- shock
- relieved
- tears


(Re-)defining dementia through action
the activist
broadening others' views of dementia
easing others into conversations about dementia
Speaking up for rights/entitlement
integrates "dementia" as part of identity. Repeated action reinforces this
- can foster a sense of hope
barriers to action
- reliant on others support
- loneliness
- isolation

Appendix K. Abridged research diary

1st July 2015, 1st interview

Very different to how I imagined it to be. Not a chronological account but conversation does take its own natural course.

Questions that are too open-ended may be too vague- depends on person and their abilities.

Ask more re: relationships to get some good background info. Makes it easier to talk about the changes later on.

17th July 2015, 2nd interview

When person keeps talking about the same thing, they may be trying to illustrate or embellish a point. Look beyond the wording and into the underlying meaning.

Kept saying how they appreciated being able to take part. Fits with wanting to remain active and do what the dementia allows them to do, and to celebrate that.

3rd interview

Dilemma when disclosed taking medication for anxiety. How will that have affected their relationship with others re; dementia? At the time did not ask as it did not occur to me. Carried on with interview and found person's experiences beneficial- it was 'good' data! Person also found participation and talking beneficial. Initially appeared nervous but reported feeling relaxed in second part of interview and "ok" when interview finished. It was there first time talking about things in this way, found it therapeutic.

- Be flexible- allow flexibility in the research process…allows new knowledge to emerge!

31st July 2015, 4th interview

So surprised, person in interview versus person in their social space. So much thought, so much strength.

Not many words of emotions used. Stiff upper lip? But open about own experience.

Allowing person to "centre' themselves in their own context. For this person, it was their family, their own belief to 'keep fighting', to retain their 'occupation' of caring for others.

Their sharing was very personal…charm bracelets, things that form their identity.

Message taken away: you can still have dreams, even if you have dementia.

29th October 2015, interview

“I was at an event with X (family friend), Y (member of local community), Z (member of community, holds important position in local council). Event was related to dementia. I told them I had dementia. Do I get invited over for a cup of tea now? I don’t. People want to be at these big events and show they are involved, but they don’t want to be linked with people with the dementia diagnosis.”

Strong sense of stigma- is dementia seen as a mental health illness in society?

Contrasting views of young and old (age)

Strong sense of unfairness expressed. The right/access to work is taken away as soon as diagnosis is shared.

Person seemed to make every effort in life to preserve his self and protect people who are important to him in his life.

Sad to hear when people around them don’t understand. There is loneliness, but also a sense of perseverance to stand firm and be what and all they can.

30th October 2015, interview

After recording stopped- “I don’t know whether I would have made everything sound positive, I’m like that, if so and so read this [transcript] they would be able to tell it was me”

We talked about the “interview front”. Participant visibly tired from interview. It was almost like finishing a race, and his brain was gasping for breath.

“lately I’ve been feeling glum after taking part in research…it makes things more real, that I do have a problem and it is there. But it’s ok, because I am still taking part in it. Usually I get distracted by something and then it’s ok.”

Indeed a ‘rosy’ interview compared with others. There was a sense of mission in him. Perhaps this was his best way of living with and through dementia. Wonder what he did not give more time in acknowledging the difficult parts of dementia? Was it a strategy to manage his feelings towards dementia?

Appendix L. High level categories and example quotes

Category	Sub-category	Focused codes	Example Quotes
MAKING SENSE OF CHANGE IN SELF	Becoming aware of change	Change in temperament	she wrote to the GP and explained that (..) she'd known that I'd been a bit strange for about 10 years, you know. Forgetting things and, you know. Not talking to her, being uncommunicative. [9:1]
		Changes in abilities	I used to walk down the garden and see a little job and I'd start it and then I'd see something else so I'd, I'd go to that and then I'd see something else and I'd never actually get anything done. [9:3]
		Others notice change	My wife said I went out one day and come back a **different man 5:45**
		Self-awareness of change	I was in the middle, there were all cars coming **beep, beep**, and the two children I was looking and they were going **leave her alone**, because they were shouting at them you know. And then that's when it um, (..) I realized I can't get in the car, I can't do things. And my eyes, I would be able to talk to somebody but I would be turning that way all the time. 15:13
	Feeling around in the dark		you see there are things that you can't do and you don't know the reason why that is. 14:2 they kept saying to her, "It's you, you", and my grandchildren, they were going "it's you nan, it's not granddad". And uh, cause they said "He's always been mad" but uh and she kept saying "no it is, it's him". Cause, because obviously we were together all the time, she said "You're not seeing the things he's doing" 18:30
	Hearing Professionals' perspectives	Receiving feedback during assessment	he was very good and he drew pictures for me of my brain, and he explained my scan to me and he explained what a healthy 54 year old brain should look like and he showed me what my brain looked like, and he showed me the differences. 17:16
		Receiving a diagnosis	"he said you've got FTD, you are not allowed to work, you are not allowed to drive, bang, that was it…without any explanation whatsoever 16:1

	Receiving a diagnosis	Confirmation put people at ease/relief	it was alright to be told that because I wanted to get to the bottom of what was causing the problems 14:38
		Overwhelmed by dementia diagnosis	**Dementia**? **I haven't got dementia**. **That's, that's terrible**, you know. And I'd like, I couldn't wait to get home to **cry**. I cried in work, I was crying all over the place 13:1
		Shock/disbelief	Shock. Disbelief. Um, I'd never met anybody who was aged 54 who had had Alzheimer's, which was my age at the time 17:12
	Others' reactions to diagnosis	Shock/upset	he kind of said "Oh my god" you know, as though it was something really, really bad 7:40 It took her a while, she had to assimilate everything. But she was upset, we had a couple of sobbing sessions…It was both of us you know, she wanted some reassurance, I wanted some reassurance and we gave each other reassurance 11:63
		Others are dismissive	we told her it was the veins in my brain that aren't working properly. Erm, and she said "well I thought you was brain dead years ago" and tried to make a joke of it. And it wasn't a joke. I know you say things when you're younger but as you get older you've got something that's to do with your brain, it's not nice 7:81
		"you don't look like you've got dementia"	now when people say to me you don't look like you've got dementia I always say thanks very much you know. Um, because that means I am still, to me it means I am still functioning well enough in, in society for it not to be. 14:8 she said well you don't look like you've got dementia. So I said "well thank you very much". I said "I don't know quite honestly how people **do** look with dementia."…and that's how I **left** it… she said you know whenever I've spoken to you, you have been lucid and you know what you are talking about…so…**that's** her perspective of me.. because I am not down that line **where** they can have a conversation with me and know that I've got dementia 5:16
		Others attempt to restore ability	it's not my feet that's stopped walking, it's me mind, it's slowing down and the memory in it is so they say things like oh why don't you do crosswords everyday to occupy your mind? Why don't you do Sudoku? Why don't you do scrabble? Why don't you do this? 12:31

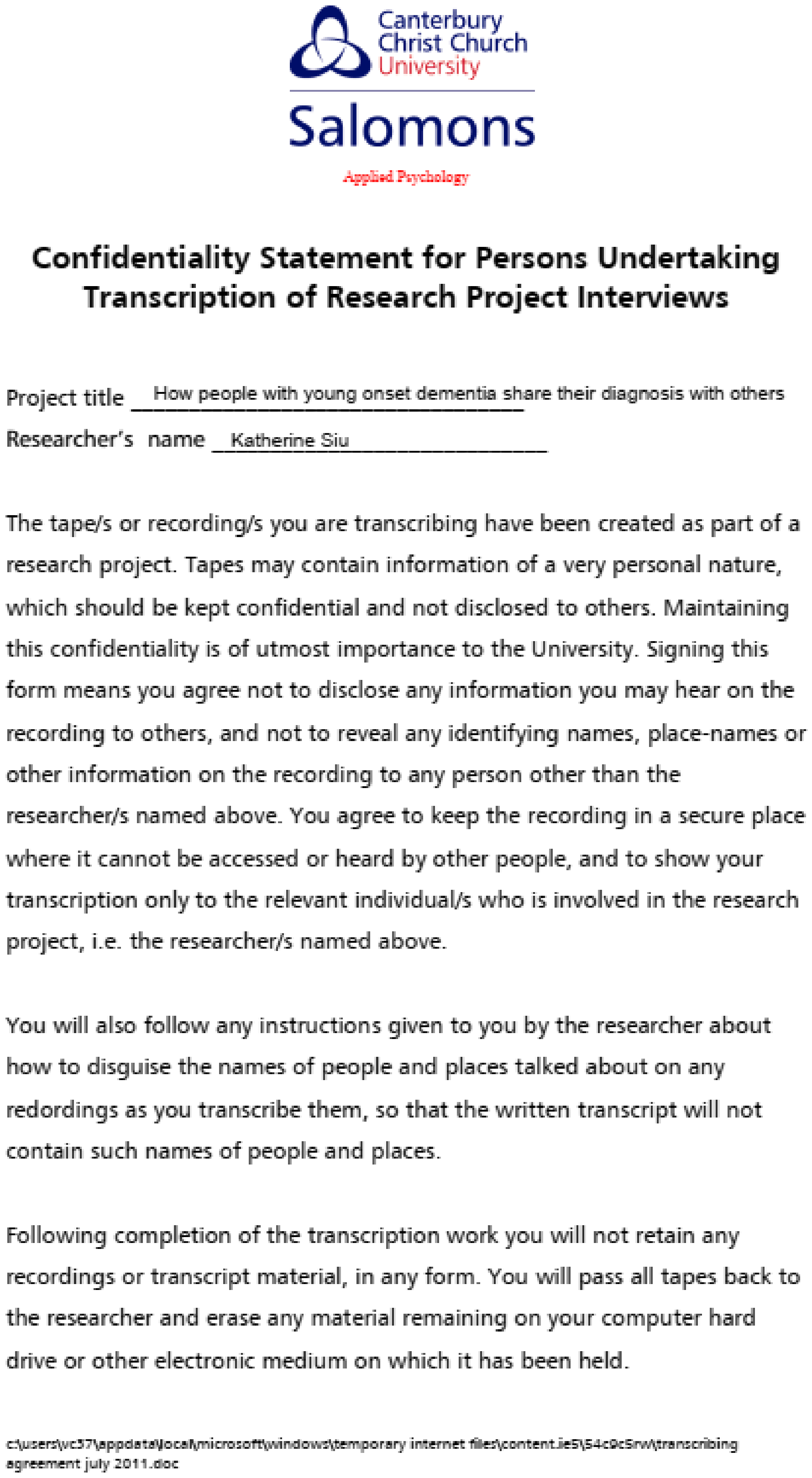
		Too young to have dementia	some of the family actually they just, say “hey you’re too young” and “don’t talk stupid you’re far too young”, erm and then we had some friends and they came and they kept saying “no you’re far too young” 7:82
		Others are accepting	the woman that was running that course, I went and told her that, I said I've got Dementia. And she said “That's fine, we don't mind. We know some people with Dementia with, some of them do like nice plots, pots so don't worry about it.” 4:148
	Facing stigma	Dementia seen as a mental illness	“The whole idea of Alzheimer’s scares people because they think they are going to end up in the funny farm or you know, in an institution or something. I mean I was scared.” 11:29
		Assuming person with dementia loses awareness	I think she's told her friends and they expect me to like go **whoa, what's your name**, you know? Like that. And I'm not like that. 13:3
		Assuming dementia entails a drastic loss of functioning	our generation, they've got this sort of push away thing and they look at it “Oh, you, they're in the corner and they're slobbering, they don't talk, they don't anything.” 18:21
COMING TO TERMS WITH CHANGES	Coming to terms with losses and limitations	Having to give up	that’s why I don’t watch television, I forgot everything now. I look at it for a while then I see, because I can’t think about it, sometimes I can’t see it properly, so I just think, just sit there [laughter]. 15:29 On home repairs- “she said “Leave it, wait until he comes home.” Anyway he did it, but I sort of helped him. Probably a hindrance but I was going to have a go and I messed it up…now I have to say right, no I'm not doing that. I can't do that now. Yeah things like that, it's a little bit frustrating…18:41
		Can’t keep up	Oh yes, when it was, cause I couldn't, it's quite hard for me to talk. What was hard was if they were talking, my brain was slowing down. So I couldn't always remember what they were saying...and I couldn't catch up with it. 4:55
		I used to be able to, but…	I love shopping. I used to love going and you know, used to go and get my granddaughter’s school clothes and things, and I used to love doing it. Not now. Erm, get what you want and get out 7:39

		Self-acceptance	I suppose I still find it hard to accept but (slight chuckle) you know, my working life is over but I didn’t, wasn’t ready (chuckles) to quit [I: yeah] and you know, but hey, got to umm where I am and got to move on from it and hopefully that's what I’m gonna try and do. 10:12
		Loss of employability	I gave up work cause I just couldn't remember what I was doing sometimes 13:6
		Difficulty expressing oneself	listening is the best thing. Interruption is the worse thing for me. If they're trying to interrupt me or trying to help me about something that I already know but I can't get it out on to the conveyor belt if you know what I mean? It's there somewhere. But I just can't access that. 6:30
		Doing things differently due to loss of abilities	I can still function to you know within my own capabilities and one of the things I like to do is keep to, have a routine. I do, because to me that err that helps. 10:2 I use to train like an **Olympian**, I used to go down to my shed for a couple of hours in the morning and train, weight lift, and then go out. I still do that…I still ride my bike for an hour and a half a day and I walk still my dog twice a day and I go out my gym twice a week. 5:53
		Being at my own pace	I just have to take longer now. Just take my time. Where before I could do it in a day, day and a half I take about 3 days now. Just take it nice and steady. If I need a break, and she makes sure I have a break. 18:9
	Negotiating a shared understanding with others	Sharing an understanding of changes	they just all treat me normal. I am normal but it's just if I do anything they don't take any notice now. Say if I went to the bar to get an order and I come out with a different order they don't, you know, it's just I forgot by the time I got there or got the wrong things 18:35
		Changes in roles	I think he probably thinks he needs to care for me more in that...I’m not very good with money. He’s got my bank card 'cause I went through a phase where I kept forgetting my pin number and things. 10:48 that is quite hard for me, not to have a job, and to see my wife go out to work every day. And I desperately want her to be with me in these years because I want to make the most of these years. And we can’t do it because if she doesn’t work then we won’t have any money coming in. She feels the same but she knows that she is going to have to carry on working which is a shame. And as a man you like to think you bring the money in and all that and it is a strange sensation to know that I am almost a kept man. 14:28
		Differences in coping styles	her coping strategies are very different from my coping strategies. Her coping strategies are to…not necessarily o bury one’s head in the sand and to pretend it doesn’t exist, but there is an element of

			that, because that's the way she deals with it and I understand that. My coping strategy is almost to confront it and to try and beat it. She feels she can't do that. Erm, and also, as I said earlier, my initial approach was knowledge is power. Her approach was, don't read about it. Don't think about it. Let's consider all the rest of life, but not the dementia. Let's put all our energies into all the fun things and all the hassles and aggravations we have, but not the dementia. So if we have – if we have fears, if we have concerns, okay, let's – let's focus on them, but not dementia. 17:45
	Changes in relationships	Drifting apart	she kept asking me things and I was going hmm, hmm, hmm and she said "I could just as well put something on the wall there and press a button and talk to that and it goes hmm, hmm." So I wasn't getting in conversation, I wasn't answering but I didn't realise[…]And so I said to her she'll have to just "Oi, I'm talking to you." for me to understand or make sure I answer. Cause it makes it lonely for her. She said she gets down about it that she can be sitting here with me but she's on her own 18:37
		Others distancing themselves	I still speak to him, I text him and stuff but I haven't actually seen him for a couple of years now. And it hurts in a way cause, I mean, if anybody else has got a problem I'm there for em. The first few times I didn't really notice, when he said oh, they had a do the other night, we didn't get an invite and then I say he never ever mentioned it, if I used to bring it up he'd move on. And so I've just left that. You can't wallow in all that, 18:38
		Distancing self from others	Now I pull myself back in relationships, pull me back on commitments on certain things. Before I used to try and help people with their problems…I try and sort out my problems now. 12:32
		Not wanting to burden others;	I don't want to put the burden on me sisters, me brothers. 12:25 I have to be mindful of her health and – and whilst I don't want to keep secrets, I also don't want to burden her and she feels the same towards me 17:44
		Friction within relationships	My eldest son is in denial to this day, there is nothing wrong with you dad, you remember things. Too much friction, too much agitation…I won't shut up. I would say come on, I would do it later on dad. Okay, I go out, come back, well, oh come on dad I will do it. I want it done-…I have noticed over the years my voice gets louder and more prompt- I've told ya. Yeah but dad you've got dementia, how can you remember? And I am on about a certain situation. So now me and him we are talking but he can only talk to me through an argument. He can't talk to me. 12:20
LIVING WITH INTENTION	Being socially included	Maintaining participation in family and social events	I've been invited to a hen party tomorrow night…I was quite amazed actually. And everybody there will know that I've got dementia, but it won't be talked about and they will let me live for the night rather than worrying about my dementia…I will feel normal and that's what I want people to do. 7:78

		Membership of peer support group	it's been beneficial for me because I am able to get information, sometimes that ordinary people with dementia don't get and I can relay information to.. people when I am talking that they don't know about. They said, thanks for telling them that because I didn't know anything about that. So from that that point of view I've found it very satisfying 5:41
	Staying meaningfully occupied	Developing and maintaining personal interests	I do very much want to continue reading, um, and I do want to try and remember as much as I can about what I read but also remember how much enjoyment I'm taking from the reading 17:8
		Contributing to dementia related projects, events and research	We're ready for it. We're quite happy to do it. it's not confrontational it's just uh, as it is. And like, it's only going to be good for them because they're going to learn and they think, oh hang on a minute, oh that, well, we'd better write that in as well, say this can happen instead of having that view from a sheet of paper. It's better to get it from us, who are living with it 18:12
		Easing others into conversations about dementia	They will talk about it if the subject comes but sometimes they don't really know what to say because in the back of their mind they are thinking Bob has got dementia and so their conversation is perhaps stilted, they don't know what to say. So if I can lead the conversation then that makes it easier for them once they know that you are alright with it then it becomes easier 14:13
		Broadening others' views on dementia	Where did the idea of educating others come from- "probably through the [peer support group] and, and um, other places I've been with uh, conferences and talking to other people with dementia" 18:39
		With help I can do what I used to do	I feel that I still have a lot left in me to do all these things and that's what I want to do. I don't want to sit in a chair knitting, that's not me [laughter]. This is more me [points to plate]. I didn't make the plate itself but I did all the decorations…It nearly drove me insane, but yeah, I go with my youngest daughter, we went together, this is the sort of thing I like doing you know, it's fun. And you see other people you know and its great and I enjoy it. 11:43

Appendix M. Transcribing agreement



Canterbury Christ Church University

Salomons

Applied Psychology

Confidentiality Statement for Persons Undertaking Transcription of Research Project Interviews

Project title __How people with young onset dementia share their diagnosis with others

Researcher's name __Katherine Siu________________

The tape/s or recording/s you are transcribing have been created as part of a research project. Tapes may contain information of a very personal nature, which should be kept confidential and not disclosed to others. Maintaining this confidentiality is of utmost importance to the University. Signing this form means you agree not to disclose any information you may hear on the recording to others, and not to reveal any identifying names, place-names or other information on the recording to any person other than the researcher/s named above. You agree to keep the recording in a secure place where it cannot be accessed or heard by other people, and to show your transcription only to the relevant individual/s who is involved in the research project, i.e. the researcher/s named above.

You will also follow any instructions given to you by the researcher about how to disguise the names of people and places talked about on any redordings as you transcribe them, so that the written transcript will not contain such names of people and places.

Following completion of the transcription work you will not retain any recordings or transcript material, in any form. You will pass all tapes back to the researcher and erase any material remaining on your computer hard drive or other electronic medium on which it has been held.

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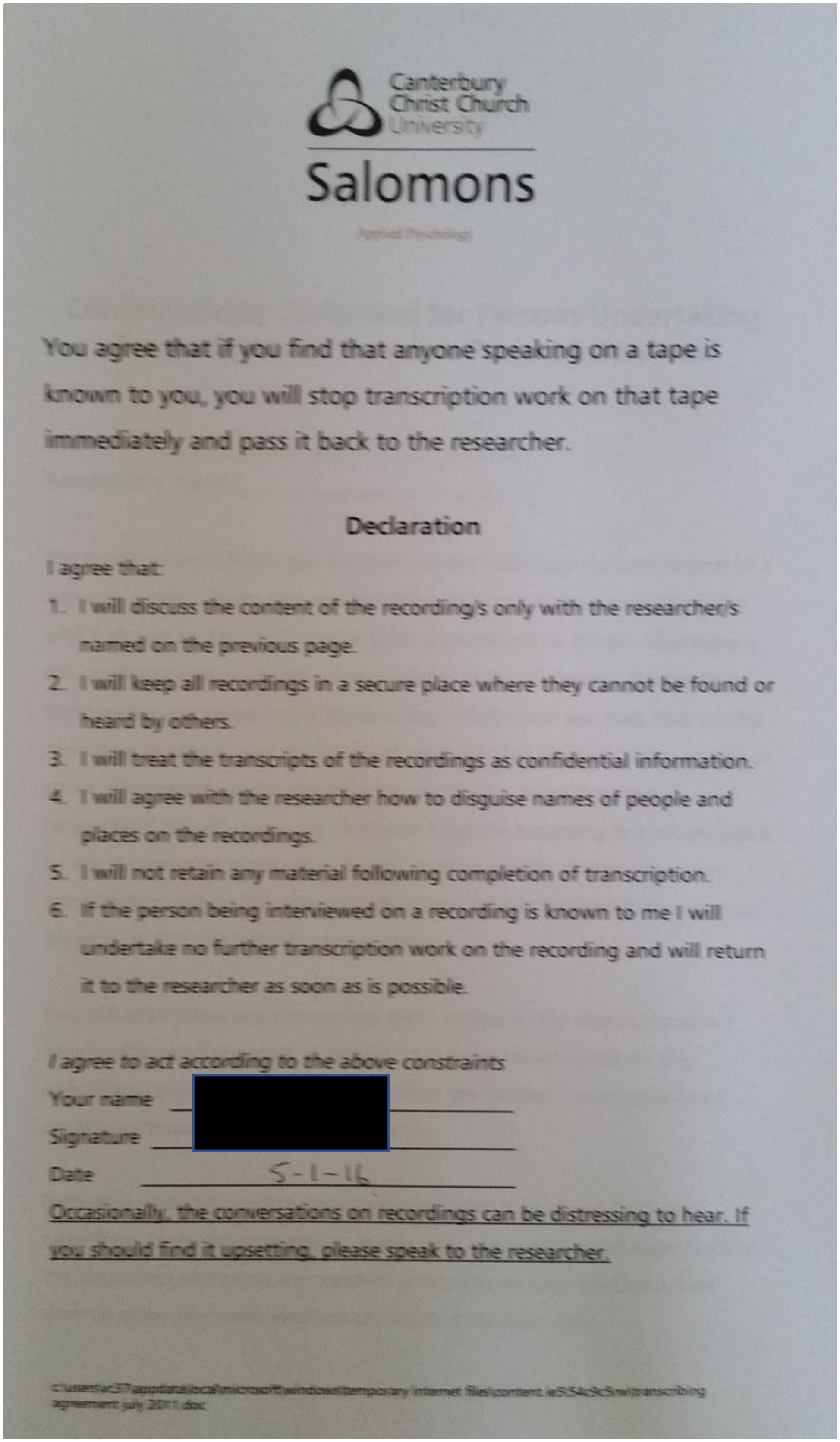

Canterbury
Christ Church
University

Salomons

You agree that if you find that anyone speaking on a tape is known to you, you will stop transcription work on that tape immediately and pass it back to the researcher.

Declaration

I agree that:

1. I will discuss the content of the recording/s only with the researcher/s named on the previous page.
2. I will keep all recordings in a secure place where they cannot be found or heard by others.
3. I will treat the transcripts of the recordings as confidential information.
4. I will agree with the researcher how to disguise names of people and places on the recordings.
5. I will not retain any material following completion of transcription.
6. If the person being interviewed on a recording is known to me I will undertake no further transcription work on the recording and will return it to the researcher as soon as is possible.

I agree to act according to the above constraints

Your name [redacted]
Signature
Date 5-1-16

Occasionally, the conversations on recordings can be distressing to hear. If you should find it upsetting, please speak to the researcher.

Appendix N. Example of coded transcript

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Appendix O. Participants’ messages for others with Young Onset Dementia

I try to (..) help people who don't understand. I don't want them to be scared. There's nothing to be scared about because what's going to happen is inevitable, whatever way it is. Whether we get blown up with a nuclear bomb or we just die a natural cause or whatever way. So, you've got to live for today…do what you can, enjoy life, and communicate with people. (Thomas)

Young people do get dementia...and they are the people coming behind me that I want to help through [peer support group], and that gives me so much pleasure that I can..give them information and talk to them about dementia..because talking about it helps me and helps them as well to deal with dementia. (Doug)

Do as much as you can. Live life to the full, keep your life as normal as you can. Obviously, it does change you, but just get on with what you’re doing and don’t stop doing anything. Because I think the more you can do, the better. (Julia)

Embrace it, don’t give up, fight on because there’s always hope. I mean, people get diagnosed with cancer..and other problems but do you give up or do you fight on? I was born to fight on, and that's what I’m going to do. (Ruth)

You can’t let the illness define you. You can’t. You’ve got to battle against it. And (..) what can I say, you definitely need a support group, you know, friends, family. (Jo)

I have learnt [to] worry about what is happening now. You can reminisce about the past, but you can’t bring it back. And that is when you get agitated, that is when you get angry with yourself and then you start getting angry with the people who you care for and you love, and you want to be close to. You can’t help yourself by doing [that]. So, I think about today and tomorrow is another day. (Ted)

You must be proud of yourself and still believe in yourself. You have to keep going. It is like custard, you know. I saw this thing where they filled a swimming pool with custard, and it is possible to walk across the surface of custard as long as you stand firmly and keep walking. But the moment you stop you sink straight away. And it is like riding a bicycle, all the time you are moving forward on the bicycle you are alright. The moment you stop you fall off. And that’s the message, just keep moving forward, keep your head high and just keep moving forward. Don’t stop because you start getting into that spiral. And once you get into it, climbing back out of that spiral is ten times harder than it is going down. (Bob)

I would like to say, tell things, I would like to talk about them and talk and they talk to me and do things like that, yeah, I would do that a bit don’t we when we are in a group sort of thing. (Mary)

Don’t panic. It doesn’t mean that you’re necessarily going to get very ill, not necessarily so don’t panic. (Francis)

Don't be afraid of it. Try and embrace it. Try and have a look at what's offered to you to help you. Live life to the full, that's what we do and um, yeah, just try and accept it. Rather than fight it, it's happened, you've got it and it's not going to change so you've got to make the most of it. You can live well with dementia. (James)

Appendix P. Notes on researcher positioning

I am a clinical psychology trainee in my early 30s, with an East Asian culture background. There has been no experience of dementia within my family. During my adolescence, dementia was not well known, and although people seemed more familiar with Alzheimer's disease (known as "Elderly senile syndrome", when directly translated from my mother tongue), layperson knowledge did not go beyond its hereditary nature and the unfortunate prognosis of "senility". In secondary school, a friend would occasionally mention that they were due a visit to their grandmother with AD who no longer recognized family members. She dreaded these visits, firstly because there was "no point"- her gran just kept repeatedly asking whether people had eaten yet (much equivalent to "you alright?" in the British sense), and more so because of the unresolved disagreements on what the best caring arrangements were for her grandmother. She felt that some of her relatives were not genuinely caring and had other motives. Filial piety is considered a high virtue within society and it is an expectation that older people are respected and cared for by the younger generation within the family. Residential care was frowned upon socially and was considered as abandonment (extremely unfilial).

I did not come across young onset dementia until my early 20s. As an assistant psychologist, I was involved in setting up a routine screening system and dementia baseline screening for individuals with a learning disability (usually with Downs Syndrome as there is an age-related risk). This was one of the first opportunities for me to deeply consider the experience of anticipating and living with a condition characterized by inevitable physical and cognitive decline. For individuals and their families, there was so much to think about even before any signs of dementia were shown. I questioned whether younger adults with Down's Syndrome would want to know, or indeed, that they had the right to know about this health risk that concerned them, but others in the team thought it would cause unnecessary distress. I was never quite comfortable with that response.

I feel that I have embarked on this project with a bit of a blank slate, not totally blank- I have my "textbook knowledge", my "clinical hat", as much empathy and "try and put yourself in their shoes" as I could gather, and an understanding of the British culture through an East Asian lens, which I often assume to be more "individualist" than my "collectivist" roots (it is not always true).

Appendix Q. Report to the ethics committee

The report below was submitted to the ethics committee.

Dear Chair of Research Ethics Committee,

Study title: How people with young onset dementia share their diagnosis with others?

I am writing to inform that the research project is completed, and a thesis has been submitted for partial fulfilment of the degree of Doctor of Clinical Psychology at Canterbury Christ Church University. The following summarises the project findings.

Self-disclosure of life-limiting conditions, particularly dementia, remains relatively unexplored. Dementia causes progressive decline in an individual's cognitive, communication and memory abilities. Young onset dementia (YOD) affects people below the age of 65 and can be difficult to recognise and diagnose given its rarity. From a psychosocial viewpoint, relationships are crucial in the construction of YOD individual's sense of self and identity as the condition progresses. Existing research typically focuses on dyadic relationships (e.g. individual & professional), lacking the consideration for the myriad of relationships across social networks. In an effort to understand the evolution of personal relationships as dementia progresses, it is important to examine the disclosure journey from the YOD person's perspective, and how they re-negotiate relationships with others based on lifestage.

The study interviewed 15 individuals (mean age= 57) diagnosed with YOD that were able to verbally express themselves and maintain conversation. Participants had the option to have photographs, memory aids, or visual prompts. These items were used to facilitate conversation during the interviews. A semi-structured interview schedule was employed to guide the interviews and enabled a participant-led process. Data was analysed using grounded theory methodology to develop an interpretive theoretical model of the journey from diagnosis to living with dementia, and the evolving changes on relationships. The model (see Figure 1) consists of three categories: making sense of change, coming the terms with change and living with intention; covering pre-diagnosis period and post-diagnosis adjustments and growth.

The findings shed light on the complexity of YOD: (1) as a condition that spanned different life stages, and (2) in negotiating relationships, work and meaningful activity over time. There is an interplay between the person with YOD and the disclosure choices that concerns others around them, and subsequently, how others' reactions influenced the YOD person's decisions in planning and living their life. There were elements from existing self-disclosure theories, based on private information ownership, ecological systems and psychosocial transitions, that were relevant to the findings. In terms of clinical implications, the distinctive experience of YOD and corresponding life stages/events suggests that YOD is a specialist area that is separate from services for older adult, working age mental health, and neurorehabilitation. YOD-specific service requires attention of the variability in individuals' life stages that will directly impact how they receive diagnosis (clinical aspects), approach diagnosis sharing, obtain post-diagnostic support (within family and workplace) and participate in peer groups. Lastly, it is recognised that YOD needs purposeful activity in preserving a sense of self and dignity through social engagement and meaningful work (e.g. volunteering to support newly diagnosed YOD/raising YOD awareness though projects) through groups or as an individual.

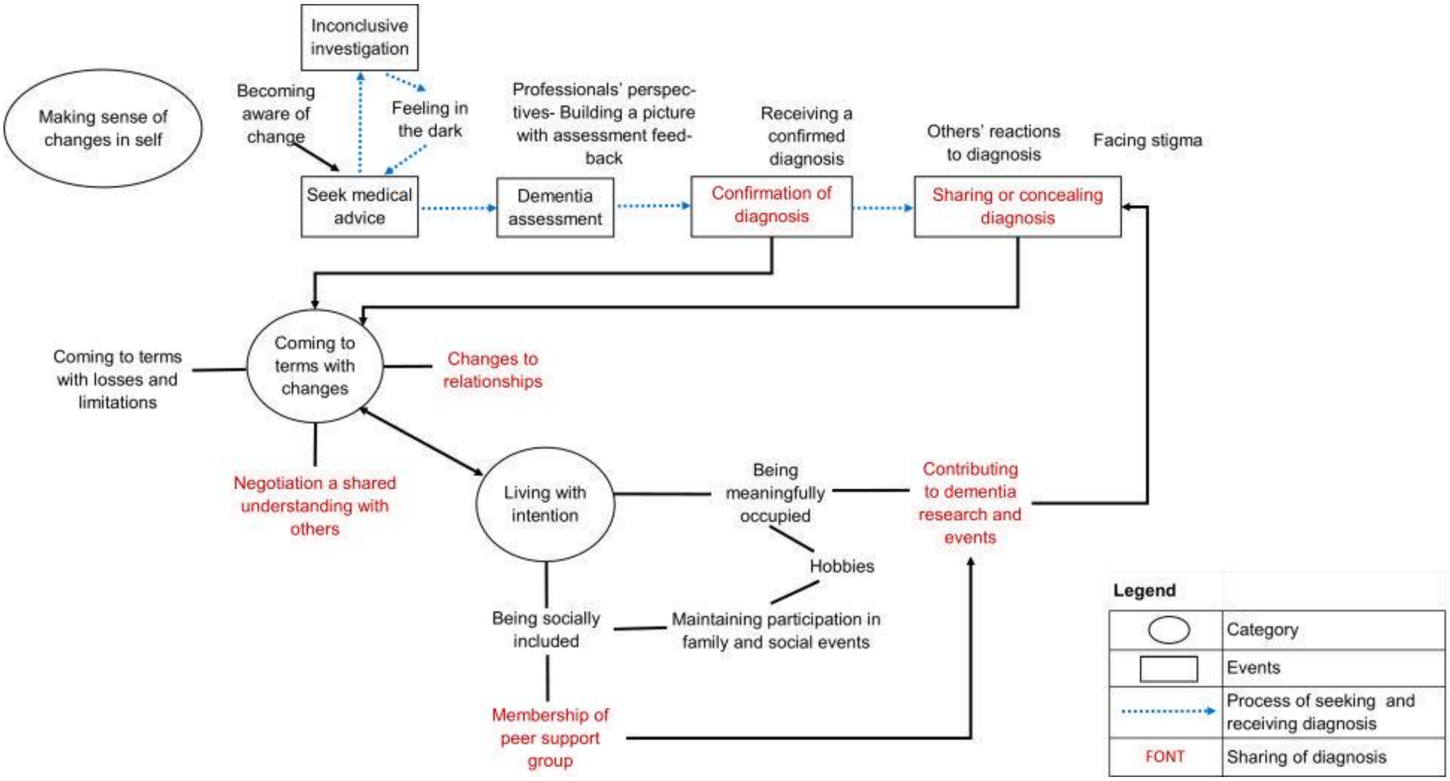

Figure Q1. Journey of a person with young onset dementia, from pre-diagnosis up to living with dementia.

Appendix R. Author guidelines for journal submission

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