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Experiencing burden is particularly common for carers of people with dementia, and is associated with a range of negative outcomes for carers and people with dementia themselves. Caregiver stress theory outlines the importance of understanding the factors associated with caregiver burden so that these factors can be addressed in interventions. It is possible that caregiver burden may differ in frontotemporal dementia and Alzheimer's disease due to the differences in the two conditions. The current systematic review of the literature aims to determine whether caregiver burden is higher in frontotemporal dementia compared to Alzheimer's Disease, and to compare factors predicting caregiver burden across the two conditions. Six databases were searched, which resulted in eighteen papers being included in the final review. The majority of papers found that caregiver burden was higher in frontotemporal dementia compared to Alzheimer's Disease. Of the papers showing that carers of frontotemporal dementia had higher burden, these carers were older and more likely to have a spousal relationship. Due to the heterogeneity of predictors of caregiver burden measured, no clear conclusions could be drawn about the factors predicting caregiver burden in frontotemporal dementia and Alzheimer's disease. Strengths and limitations of the papers are discussed, and recommendations for future research are outlined.

Service Improvement Project

Over 42,000 people are living with young-onset dementia (YOD) in the United Kingdom, however there has been relatively little research on how to support this client group. This service improvement project explored the extent to which Northamptonshire Healthcare NHS Foundation Trust's Young Person's with Dementia team was meeting the needs of people with YOD, and to determine what further support could be offered. Five staff

members of the Young Persons with Dementia Team took part in a focus group, and nine people with YOD took part in semi-structured interviews, all accompanied by their carers. The thematic analysis demonstrated that most people with YOD are satisfied with support from the team, however there was scope for further input in a number of areas, such as specialised input for rare dementias, more social support and more tailored support for carers. Limitations and areas for future research are discussed.

Theory Driven Research Project

Background and Aims

Opiate misuse is a serious problem within the UK, with the relapse rate reported as over 90%. It is important that clinicians have an understanding of psychosocial factors associated with substance use so that these can be incorporated into interventions. Previous research has demonstrated the importance of social network in recovery and interventions, but loneliness is often not taken into account within social network research with opiate users. The study aimed to understand whether loneliness could predict opiate use at baseline and six months, when controlling for social network size, depression, anxiety, engagement and baseline substance misuse.

Design

The study used both a cross-sectional and longitudinal questionnaire design.

Setting

Recruitment took place in a Tier 3 NHS Substance Misuse Service.

Participants

Participants were 178 service users who were receiving opiate substitution treatment from the service. 122 participants completed the follow-up questionnaires after six months.

Measurements

Participants filled out the following questionnaires: University of California Los Angeles Loneliness Scale; an adapted Treatment Outcomes Profile; Social Network Index; Patient Health Questionnaire; Generalised Anxiety Disorder Scale. Participants also indicated the three most important contacts in their social network from a pre-determined list. The amount of times participants visited the service over a six month period was also measured.

Findings

The results demonstrated that only baseline substance use predicted substance use after six months, and that loneliness did not predict substance use at either timepoint.

Conclusions

The findings suggest that simply focusing on loneliness or social network size may not be beneficial for opiate users, and service users may benefit from an approach tailored to their individual circumstances. It may also be possible that reducing substance use may also impact levels of loneliness, which may not have been captured by only measuring baseline levels of loneliness.

Systematic Review of the Literature

Caregiver burden in frontotemporal dementia and Alzheimer's Disease: A Systematic Review

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Proposed Journal

Dementia is an international journal that aims to publish a wide variety of research on how to improve dementia care, including systematic reviews. As well as papers focusing on the wellbeing of people with dementia themselves, the journal also publishes research on how to improve the wellbeing of carers and family members of those living with dementia. Author submission guidelines are presented in Appendix A.

Acknowledgements

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Abstract

Experiencing burden is particularly common for carers of people with dementia, and is associated with a range of negative outcomes for carers and people with dementia themselves. Caregiver stress theory outlines the importance of understanding the factors associated with caregiver burden so that these factors can be addressed in interventions. It is possible that caregiver burden may differ in frontotemporal dementia and Alzheimer's disease due to the differences in the two conditions. The current systematic review of the literature aims to determine whether caregiver burden is higher in frontotemporal dementia compared to Alzheimer's Disease, and to compare factors predicting caregiver burden across the two conditions. Six databases were searched, which resulted in eighteen papers being included in the final review. The majority of papers found that caregiver burden was higher in frontotemporal dementia compared to Alzheimer's Disease. Of the papers showing that carers of frontotemporal dementia had higher burden, these carers were older and more likely to have a spousal relationship. Due to the heterogeneity of predictors of caregiver burden measured, no clear conclusions could be drawn about the factors predicting caregiver burden in frontotemporal dementia and Alzheimer's disease. Strengths and limitations of the papers are discussed, and recommendations for future research are outlined.

Introduction

Dementia is characterised by a “significant cognitive decline” (American Psychiatric Association, 2013). There are currently over 850,000 people living with dementia in the UK (Prince et al., 2014). Whilst some people with dementia (PWD) receive residential and/or social care, the majority are being cared for by a loved one, with an estimated 700,000 informal dementia carers in the UK (Lewis et al., 2014). Carers of people with dementia often face challenges including depression (Schoenmakers et al., 2010), loneliness (Victor et al., 2020) and a lower quality of life (Argimon et al., 2004).

A particular challenge faced by carers is that of caregiver burden, which can be defined as “the extent to which carers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative” (Zarit et al., 1986). A review of the literature linked caregiver burden to a number of adverse outcomes for caregivers such as depression, anxiety, poor self-care, and death (Adelman et al., 2014). Some research has also demonstrated that caregiver burden can have a negative impact on the PWD themselves (Torti et al., 2004), with caregiver burden associated with a higher likelihood of the person being institutionalised (Sahadevan et al., 1999) and in extreme cases dying earlier (Brodaty et al., 1993).

Caregiver stress theory (Tsai, 2003) outlines that caregiver stress is predicted by objective burden alongside contextual factors (Appendix B). The theory states that certain factors are likely to increase burden, such as stressful life events, social support, social roles and demographic variables, which in turn increase caregiver stress, leading to depression. This process can then result in negative outcomes such as lower self-esteem, physical functioning, role enjoyment and marital satisfaction. It is important to identify which factors within caregiver stress theory are contributing to caregiver burden so that interventions can

be better tailored to address these factors. This would lead to less stress and depression among carers, which in turn may mean that they experience fewer negative outcomes.

Alzheimer's Disease (AD) is the most common type of dementia, accounting for around 60% of dementia diagnoses in the UK, and is associated with difficulties such as memory loss and confusion (Dementia UK, 2021). Due to the high occurrence of this condition, it is unsurprising that this is most dominant within the caregiver burden literature. However, there is increasing awareness of the impact of burden for carers of people with frontotemporal dementia (FTD) (Diehl-Schmid et al., 2013). FTD is more likely to be diagnosed in people under the age of 65, and is associated with symptoms such as disinhibition and personality changes (Dementia UK, 2021). FTD is associated with high caregiver burden (Diehl-Schmid et al., 2013), with some research demonstrating that carers of FTD score higher on caregiver burden measures compared to carers of AD (Riedijk et al., 2006; Uflacker et al., 2016). Considering the differences between FTD and AD, it is possible that carers of people with FTD may be in a different stage of life, and experiencing different challenges in their caring role and relationship with their loved one, compared to carers of AD. They may have other care needs such as caring for children or older parents, or managing additional stressors such as work. Likewise, it is also possible that carers of people with AD face unique challenges that are not as common for carers of FTD. For example, carers of AD are generally of an older age, which means they may be more likely to have their own physical health problems and a smaller social network on which to draw on. The contrasting factors in FTD and AD are likely to mean caregivers experience different types of stressors within caregiver stress theory (Tsai, 2003), which could result in different consequences such as changes in self-esteem, role enjoyment or physical functioning.

Whilst the above studies indicate that there is a large body of literature around the predictors of caregiver burden for both FTD and AD, the heterogeneity of the methodology

and findings makes it difficult to form any conclusions about any predictors of caregiver burden, and whether these are different across different types of dementia. A recent paper (Cheng, 2017) brought together caregiver burden literature and concluded that disruptive behaviours are most predictive of caregiver burden, and are most common within FTD, however the authors did not specifically define how they classified disruptive behaviours in the paper. The authors also did not conduct any systematic literature searches to arrive at their conclusions, meaning that some literature may have been overlooked, which could have led to inaccurate findings. There is a need for a critical systematic review of all available literature comparing caregiver burden for both FTD and AD, so that objective conclusions can be formed about whether certain carer groups are more likely to suffer from burden, and the predictors of burden for both groups. This will ensure that carers are better supported by receiving interventions that are best targeted to their specific situation and needs.

The current study is a critical systematic review of literature exploring caregiver burden in both FTD and AD. The review will aim to answer the following questions:

- Is caregiver burden higher in FTD compared to AD?
- What are the predictors of caregiver burden in FTD and AD?

Method

Searches

The review was registered on Prospero (CRD42021269643). Searches were conducted in line with the Preferred Reporting Items for Systematic Review and Meta-Analyses guidelines (Moher et al., 2009). Title and abstracts containing the following search terms were conducted in CINAHL, Embase, Medline, Psycinfo, Pubmed, and Scopus (Appendix C) on 7th October 2021:

Caregiver burden OR Carer burden OR Caregiver stress OR Carer stress

AND

Frontotemporal dementia OR Fronto-temporal dementia OR Pick's disease OR Picks disease OR Semantic dementia OR Progressive nonfluent aphasia OR Progressive non-fluent aphasia OR Progressive non fluent aphasia

AND

Alzheimer's OR Alzheimers

The inclusion and exclusion criteria are outlined below:

Inclusion Criteria

- Empirical studies comparing caregiver burden for both carers of FTD and AD
- Any variant of FTD
- Any measure of caregiver burden
- Any stage along the dementia journey
- Any study design
- Any type of unpaid carer relationship

Exclusion Criteria

- Papers that did not directly compare FTD and AD
- Papers where the caregivers were caring in a paid capacity
- Papers that are not in English
- Posters; abstracts; book chapters; conference presentations

The papers were then imported into Rayyan (Ouzzani et al., 2016) and their titles and abstracts screened for eligibility using the inclusion/exclusion criteria. Twenty percent of the papers were screened by two authors (EC & EG). One author (EC) then completed the screening for the remaining 80% of the papers. The included papers' full-text were then screened – one author (EC) screened 100% of the full-texts, with a second author (EG) screening 25% of the full-texts. Within all stages of the systematic review, any disagreements

between the two authors were resolved by discussion, and in the event that a disagreement could not be resolved by discussion, a third author (KE) was consulted.

Data were extracted from all included papers using a pre-piloted proforma on Microsoft Excel (Microsoft Corporation, 2018), which included information on demographic characteristics of carers and PWD, sample size, study design, statistical methodology and findings regarding which carer group had higher caregiver burden, and what factors were found to affect caregiver burden in each group. One author (EC) extracted the data for 100% of the papers, and a second author (EG) extracted the data for 50% of the papers. All papers then underwent a quality assessment, using the Standard Quality Assessment Criteria (Kmet et al., 2004) (Appendix D). Each paper was rated on a variety of criteria (14 dimensions for quantitative studies; 10 dimensions for qualitative studies), and given a final score between 0-1, with higher scores reflecting a higher quality paper. One author (EC) completed the quality assessment for 100% of the papers, and a second author (EG) completed the quality assessment for 33.3% of the papers.

Once all data were extracted and the quality of each paper was assessed, the authors conducted a narrative synthesis of all the papers to determine any themes regarding caregiver burden across all papers.

The authors reran the searches to screen for any further publications between 8th October 2021 and 31st January 2023. The flowchart of included studies can be found in Appendix E.

Results

The initial database search resulted in 1,208 papers, of which 115 were duplicates. Of the 1,093 papers screened, 30 papers were included for full-text screen, and 1,063 were excluded. The main reasons for exclusion were papers focusing more on the neural correlates of dementia, and not comparing FTD with AD. Of the 20% abstracts that were double-screened, the two authors reached 100% agreement (kappa=1). The remaining 30 papers then

underwent a full-text screen, resulting in 12 papers being included. Of the 25% of full texts that were double-screened, the two authors disagreed on one paper which was discussed and subsequently included in the review (kappa=0.75). The authors then hand-searched the reference lists of the 12 included papers, which resulted in 3 additional papers being included. The authors reached 96% agreement for the data extraction, and 87% agreement for the quality assessment, all of which were resolved to 100% agreement through discussion. The repeated database search returned 179 additional papers, of which 3 were included in the final review. Therefore, a total of 18 papers was included in the final review.

Tables 1.1 and 1.2 outline the data extracted for each paper, including the demographic characteristics of participants, design and methodology of all studies, their findings relating to caregiver burden and quality appraisal scores for each paper.

Table 1.1: Characteristics of papers

Paper (Country)	**Carer demographics** ***Mean age*** ***% female*** ***Relationship to PWD***	**PWD demographics** ***Mean age*** ***% female***	**Design**	**How ppts recruited**	**Sample** ***N*** ***Response rates (when reported)***	**Carer burden measure**	**Statistical test**	**Group with higher caregiver burden**	**Effect size** ***P-value***	**Quality Assessment Score**
(Boutoleau-Bretonnière et al., 2008) (France)	61.2 (FTD=60.2; AD=62.2) NR NR	65.6 (FTD=68.0; AD=63.5) 48% female	Cross-sectional questionnaire	Referred by health professional in neurological memory centre	FTD=26 AD=28	Zarit Burden Inventory (Zarit et al., 1985)	Mann-Whitney U	FTD	NR p=.0004	0.77
(Brodaty et al., 1993) (Australia)	NR 65.2% female 71.8% spouse; 21.1% child; 7.1% other	77.8 48.7% female	Longitudinal questionnaire	Referred by health professionals from memory and dementia clinics	FTD=26 AD=413 21% (155/732)	Zarit Burden Inventory (Zarit et al., 1985)	Linear regression	6 months: FTD 12 months: FTD	6 months: Coefficient t=12.99, p<.001 12 months: Coefficient t=11.57, p=.003	0.91
(De Vugt et al., 2006) (Netherlands)	66.6 (FTD=58.5; AD=71.3) 58% female 100% spouse	67.1 (FTD=59.5; AD=71.5) 42% female	Cross-sectional questionnaire	FTD=consecutive referrals from Department of Neurology AD=baseline data from other studies recruited from memory clinics and community mental	FTD=27 AD=47	Visual analogue scale of distress	T-test	FTD	t=3.4 p=.001	0.77

				health centres						
(Diehl et al., 2003) (Germany)	NR (FTD=46-69) NR (FTD 100% female) NR (FTD 100% spouse)	NR (FTD=51-70) NR	Qualitative reports from facilitators of dementia support groups	Feedback from dementia support groups	FTD=8 AD=NR	Accounts from support group facilitators	N/A	N/A	N/A	0.1
(Huang et al., 2022) (Taiwan)	57.9 NR 17.6% spouse; 58.6% child; 23.8% other	11.9%<70; 36.7% 70-80; 51.4% <80 63.5% female	Retrospective cohort study (baseline data only)	Consecutive people who were assessed in a dementia centre within a Christian hospital	FTD=16 AD=369	Zarit Burden Interview (Zarit et al., 1985)	Generalised estimated equations and Walds X^2 statistic	No difference	Beta=0.99 p=.712	0.59
(Hvidsten et al., 2019) (Norway; Denmark; Iceland)	57.0 59% female 70% spouse; 18% child; 12% sibling/friend	63.0 45% female	Prospective cohort study	NR – conducted in memory clinics	FTD=38 AD=50 (20%)	Relatives' Stress Scale (Greene et al., 1982)	Multiple generalised linear model	No difference[1]	OR=0.2 p=.159	0.77
(Küçükgüçlü et al., 2017) (Turkey)	55.9 (FTD=52.7; AD 57.4) 73% female 40% spouse; 53% child; 6% other relative	73.6 (FTD=67.4; AD=76.7) 57% female	Cross-sectional questionnaire	NR - Non-probability convenience sample in dementia outpatient clinic	FTD=44 AD=90	Caregiver Burden Inventory (Küçükgüçlü et al., 2009)	T-test	No difference	t=0.271 p=.780	0.81
(Kumfor et al., 2016) (Australia)	NR 86.7% female 77.1% spouse; 11.4% child; 8.6% sibling; 2.9% friend	62.9 (FTD=60.5; AD=67.4) 20% female	Cross-sectional questionnaire	NR – conducted in young-onset dementia clinic	FTD=23 AD=12	Zarit Burden Inventory (Zarit et al., 1985)	ANOVA Chi[2]	No difference	F=1.148 p=.330 χ^2=0.732 p=.693	0.68
(Lima-Silva et al., 2015) (Brazil)	53.3 (FTD=59.6; AD=50.93) 82% female 44% spouse 24% daughter 32% other	68 (FTD=67.1; AD=68.7) 40% female	Cross sectional questionnaire	NR – conducted in outpatient clinics	FTD=20 AD=30	Short Zarit Burden Inventory (Bédard et al., 2001)	Mann-Whitney U	No difference	NR p=.150	0.86

(Liu et al., 2017) (China)	59.5 (FTD=75.5; AD=61.0) 51.6% female 18.2% son; 18.7% daughter; 30.2% husband; 28.1% wife, 4.7% other	69.6 (FTD=68.3; AD=70.5) 56.8% female	Cross-sectional questionnaire	NR – conducted in memory clinic	FTD=82 AD=110	Zarit Burden Inventory (Zarit et al., 1985)	ANOVA	bvFTD	F=14.092 p<.01	0.91
(Mioshi et al., 2009) (UK)	64.7 (FTD=62.3; AD=69.9) 76% female NR	68.6 (FTD=67.9; AD=70.4) NR	Cross -sectional questionnaire	Postal questionnaires sent to members of Picks Disease Association and Alzheimer's Association	FTD=79 AD=29	Perceived Stress Scale (Cohen et al., 1983)	T-test	FTD	NR p<.05	0.77
(Mioshi et al., 2013) (Australia)	59.75 (FTD=59.3; AD=61.1) 74.9% female 79.2% spouse; 20.8% other	64.9 (FTD=64.2; AD=73.7) 32.9% female	Cross-sectional questionnaire	NR – took place in Research Clinic	FTD=57 AD=19	Short Zarit Burden Inventory (Bédard et al., 2001)	ANOVA	bvFTD	F=8.199 p<.001 (post hoc p<.05)	0.86
(Nicolaou et al., 2010) (Australia)	62.75[2] (FTD=58.5; AD=67.0) 81.5% female 82% partner; 18% child/parent	70.25[2] (FTD=64; AD=76.5) 31.5% female	Cross-sectional questionnaire	Referral from Alzheimer's Australia and health professionals	FTD=30 AD=30	Zarit Burden Inventory (Zarit et al., 1985)	Regression	No difference[3]	Wald[1]= 0.61 p=.44	0.64
(Riedijk et al., 2006) (Netherlands)	60.86 (FTD=57.1; AD=63.5) 61.3% female 64% spouse 36% child	71.0 (FTD=60.6; AD=78.2) 59.8% female	Cross-sectional questionnaire	FTD=outpatient clinics; AD=part of a longitudinal research study	FTD=63 AD=90	Visual analogue scale of caregiver burden	ANCOVA	FTD[4]	FTD Mean= 5.6; SD=0.46 AD Mean= 4.2; SD=0.28 p<.01	0.64
(Sato et al.,	NR	67.7	Cross-sectional	Consecutiv	FTD=66	Japan Zarit	Kruskal-	bvFTD	H=13.3	0.81

2021) (Japan)	NR NR	(FTDbv=63.9; SD=68.1; AD=69) 65.8% female	questionnaire	e patients visiting dementia clinic	AD=43	Burden Inventory (Arai et al., 1997)	Wallis		p=.0013	
(Uflacker et al., 2016) (USA)	NR NR NR	58.1 (FTD=58.6; AD=57) 47% female	Cross-sectional questionnaire	NR – took place in FTD clinic	FTD=48 AD=21	Short Zarit Burden Inventory (Bédard et al., 2001)	ANOVA	bvFTD	F=3.29 p=.026 (post hoc p=.053)	0.73
(Velilla et al., 2022) (Colombia)	53.4 (EOAD=46; LOAD=58; FTD=55) NR NR	NR NR	Cross-sectional questionnaires	University Neuroscience Group members	FTD=51 AD=100 (EOAD=45 ; LOAD=55)	(Zarit et al., 1985)	ANOVA	FTD and EOAD	F=3.707 p=.026	0.95
(Yadav et al., 2020) (Indonesia)	NR NR NR	71.4 (FTD=66.8; AD=74.05) 36.6% female	Cross-sectional questionnaire	NR - took place in psychiatry department	FTD=15 AD=26	Zarit Burden Interview (Zarit et al., 1980)	NR	FTD	NR p<.001	0.36

ANCOVA=Analysis of Covariance; ANOVA=Analysis of Variance; EOAD=Early Onset Alzheimer's Disease; FTDbv=behavioural variant of frontotemporal dementia; LOAD=Late Onset Alzheimer's Disease; NR=Not reported; SD=semantic dementia

[1]The results reported are for the quality of life, as the caregiver burden scores were not reported. However, the study found that higher caregiver burden was significantly associated with poorer quality of life (p=0.013)

[2]Median age reported

[3]No difference after controlling for age and gender

[4]Burden higher in home environment, compared to nursing home environment

Table 1.2: Factors predicting caregiver burden for each paper

Paper	**Variables measured (formal measure used)**	**Statistical test**	**Associates of Burden for FTD**	**Associates of burden for AD**
(Boutoleau-Bretonnière et al., 2008)	Behavioural impairment (NPI) Functional Disability (DAD) Cognitive function (MDRS & MMSE)	Correlation	Behavioural impairment (r=.70322, p<.0001)	Behavioural impairment (r=.34504, p=0.0721) Cognitive function (r=0.45160, p=.0158)
(Brodaty et al., 1993)	None.	Not applicable.	Not applicable	Not applicable.
(De Vugt et al., 2006)	Behavioural problems (NPI total	Descriptive statistics	Apathy (mean=2.4. SD=1.6)	Anxiety (mean=1.7, SD=2.0)

	score and subscales)		Disinhibition (mean=2.0, SD=1.7)	Apathy (mean=1.6, SD=1.8) Depression (mean=1.6, SD=1.9)
(Diehl et al., 2003)	Not applicable (Qualitative)	Not applicable (Qualitative)	Loss of a loved one Mourning Role reversal Social isolation Financial burden PWD being younger Changes in behaviour and personality Relative lack of cognitive impairment Disease less obvious and comprehensible No established pharmacological treatment Little information on natural cause Disease is not known to the general public Behavioural changes less well accepted as an expression of disease	Loss of a loved one Mourning Role reversal Social isolation Financial burden
(Huang et al., 2022)	None.	Not applicable.	Not applicable.	Not applicable.
(Hvidsten et al., 2019)	None.	Not applicable.	Not applicable.	Not applicable.
(Küçükgüçlü et al., 2017)	Activities in daily life (FAQ) Neuropsychiatric symptoms (NPI) Cognitive function (MMSE)	Logistic regression	FAQ score (Beta=.467, p=.002) NPI score (Beta=.322, p=.012) Hallucinations (NPI subscale) (p=.010) Euphoria (NPI subscale) (p=.005) Sleep disturbance (NPI subscale) (p=.046)	FAQ score (Beta=.480, p<.01) NPI score (beta=.205, p=.050) Aberrant motor behaviour (NPI subscale) (p=.043)
(Kumfor et al., 2016)	Autobiographical memory (AI) (Levine et al., 2002) Behaviour change (CBI-R)	Correlation	Semantic dementia Behavioural change (r=.740, p=.011)	Behavioural change (r=.512, p=.045)

	Functional impairment (FRS)		Functional impairment (r=.518, p=.040) <u>bvFTD</u> No significant associations	
(Lima-Silva et al., 2015)	Cognitive status (ACE; EXIT-25) Functional performance (DAD; DAFS) Patient anxiety (GAI) Patient Depression (CSDD)	Correlation	ACE (r=-.649, p=.005) EXIT-25 (r=-.697, p=.002) DAFS (r=.744, p=.001)	No significant associations
(Liu et al., 2017)	Behaviour and Psychological Symptoms of Dementia (NPI total score and subscales) Cognitive function (MMSE; CDT; MoCA) Caregiver age Relationship to patient Patient age Age of dementia onset Activities of daily living	Logistic regression	NPI total score (OR=1.186; p<.001) Agitation (NPI subscale) (OR=0.654, p=.006) Aberrant motor behaviour (NPI subscale) (OR=1.1429, p=.013)	NPI total score (OR=1.059, p<.001) Apathy (NPI subscale (OR=1.132, p=.013) Activities of Daily Living (OR=1.049, p=.010) Patient onset age (OR=0.930, p=.029)
(Mioshi et al., 2009)	Behaviour change (NPI) Activities of Daily Living (DAD) Carer depression (CES-D) High contact roles (SNI)	Linear regression	Carer depression (Beta=.739, p<.001)	Carer depression (Beta=.689, p<.001) High contact roles (Beta=.310, p=.025)
(Mioshi et al., 2013)	High contact roles (SNI) Caregiver depression (DASS) Caring relationship (IBM) Controlling relationship (IBM) FTD severity (FRS) Abnormal behaviour (CBI-R) Stereotypical behaviour(CBI-R) Apathy (CBI-R)	Stepwise multiple regression	FTD severity (Beta=0.416, p<.05) Caring relationship (Beta=-0.353, p<.05) Carer depression (Beta=0.247, p<.05)	Not reported
(Nicolaou et al., 2010)	None.	Not applicable	Not applicable	Not applicable
(Riedijk et al., 2006)	Duration of having dementia Whether patients were at home or residential setting (FTD only)[1]	ANCOVA	Longer dementia duration for people living at home (mean 5.2, SD=0.76, compared to mean=6.0, SD=0.76), but	NR

			shorter dementia duration for people in residential settings (mean=8.8, SD=1.50, compared to mean=5,5, SD=0.46), (p=.04)	
(Sato et al., 2021)	Behavioural and psychological status (NPI) Stereotypic behaviour (SRI) Cognitive function (MMSE) Dementia severity (CDR) Activities of Daily Living (LIDL & PSMS)	Multiple regression	bvFTD: NPI total score (Beta=0.558, p=.002) Right side SD: NPI total score (Beta=0.567, p=.009) LIDL (Beta=-0.426, p=.037) Left side SD: NPI total score (Beta=0.520, p=.004) MMSE (Beta=-0.351, p=.041)	Not reported.
(Uflacker et al., 2016)	Neuropsychiatric symptoms (NPI)	Regression	High NPI scores (OR=0.942, p=.003) (bvFTD only, but not lvFTD)	None.
(Velilla et al., 2022)	None.	Not applicable.	Not applicable.	Not applicable.
(Yadav et al., 2020)	Psychopathology (NPI) Cognitive impairment (HMSE)	Correlation	High psychopathology (r=.535, p=.008) High cognitive impairment (r=0.628; p=.012)	High psychopathology (r=.714, p<.001)

ACE=Addenbrooke's Cognitive Examination-Revised (Carvalho et al., 2010); AI=autobiographical interview; bvFTD=behavioural variant of frontotemporal dementia; CBI-R=Cambridge Behavioural Inventory-Revised (Wear et al., 2008); CDR=Clinical Dementia Rating (Morris, 1993) CDT=Clock Drawing Test (Shulman, 2000); CES-D=Centre of Epidemiological Studies Depression Scale (Radloff, 1977); CSDD=Cornell Scale for Depression in Dementia (Gélinas et al., 1999); DASS=Depression Anxiety and Stress Scale (Lovibond & Lovibond, 1995); DAD=Disability Assessment of Dementia (Gélinas et al., 1999); DAFS=Direct Assessment of Functional Status (Pereira et al., 2010); EXIT-25=Executive Interview (Matioli & Caramelli, 2010); FAQ=Functional Activities Questionnaire (Pfeffer et al., 1982); FRS=Frontotemporal Dementia Rating Scale (Mioshi et al., 2010); GAI=Geriatric Anxiety Inventory (Pachana et al., 2007); HMSE=Hindi Mental Status Examination (Ganguli et al., 1995); IBM=Intimate Bond Measure (Wilhelm & Parker, 1988); LIDL=Lawton Instrument of Daily Living (Lawton & Brody, 1969); lvFTD= language variant frontotemporal dementia; MDRS=Mattis Dementia Rating Scale (Folstein et al., 1977); MMSE=Mini Mental State Examination (Mattis, 1976); MoCA=Montreal Cognitive Assessment (Nasreddine et al., 2005); NPI=Neuropsychiatric Inventory (Cummings et al., 1994); Physical Self-Maintenance Scale (Hokoishi et al., 2001); SD=Semantic dementia; SNI=Social Network Index (Cohen et al., 1997); SRI=Sterotypy Rating Inventory (Shigenobu et al., 2002)

[1]Unclear whether there were more factors measured as paper only reported significant results

Study characteristics

The papers studied a total of 2,226 carers (719 FTD; 1,507 AD) – this does not include the number the people with Alzheimer's dementia in Diehl et al., (2003), as this value was not reported. The number of participants in each study ranged from 8-439. Response rates were reported in 2 studies (Brodaty et al., 1993; Hvidsten et al., 2019), and were 21.2% and 20% respectively. The mean reported carer age was 54.7, and the mean reported PWD age was 70.6. For the studies that reported ages for FTD and AD separately, carers of people with FTD were younger than carers of people with AD in 8/10 (80%) papers, whilst people with FTD were younger than people with AD in 11/13 (85%) papers. The majority of carers (66.1%) were female and were the person with dementia's spouse or partner (55.8%), and 52% of the people with dementia were female.

The studies took place in a range of locations around the world, including Asia, Australasia, Europe, North America and South America. Whilst it was planned that data for ethnicity were to be extracted, no paper reported ethnicity of the participants. One paper (Yadav et al., 2020) reported the religion of the participants, but this was not explored in any further in relation to caregiver burden.

The most common ways for participants to be recruited was through referrals from healthcare professionals and within the memory clinic setting, 8/18 studies (44%) did not specify how participants were recruited. The majority of studies (94%) used a quantitative methodology, with one study (Diehl et al., 2003) using a qualitative methodology. Of the seventeen papers that used quantitative methodology, fifteen were cross-sectional, one was longitudinal, and one was a prospective cohort study where it was unclear whether the data had been collected cross-sectionally or longitudinally. All quantitative studies used questionnaires to measure caregiver burden and other factors related to this.

Group with higher levels of burden

Of the eighteen studies included in the review, eleven studies (61%) reported greater burden to be found in FTD (4/11 [36%] of these studies specified behavioural variant of FTD specifically) six studies (33.3%) found no difference in carer burden across dementia types. No study found AD to have higher carer burden, but one study found early-onset AD had higher carer burden than late-onset AD. One study did not specify which had higher burden, although they compared burden across the two different types of dementia.

The majority of studies (N=12) used variations of the Zarit Burden Inventory to measure caregiver burden across the two groups, and the remaining studies used different measures of caregiver burden including the Caregiver Burden Inventory (N=1), Perceived Stress Scale (N=1), Relatives Stress Scale (N=1), visual analogue scales (N=2), and accounts from support group facilitators (N=1). Of the studies that used the Zarit Burden Inventory, 8/12 (66.7%) found FTD to be associated with greater caregiver burden, which is a similar proportion to the total number of papers.

There was some difference in the demographic variables of papers that reported higher burden in FTD compared to papers that reported no difference. Papers that reported higher caregiver burden for FTD were more likely to have slightly older carers (ages 60.1 vs 54.7) and a higher likelihood of the carer being the spouse (70.6% vs 55.8%). However, there was no substantial difference in the papers that reported higher caregiver burden for FTD compared to all papers in terms of PWD age (ages=71.1 vs 70.5), percentage of female carers (63.4% vs 66.1%) or percentage of female PWD (48.7% vs 52.%). There were no identifiable differences in the country that the study was conducted and the caregiver burden group.

Factors associated with caregiver burden in FTD and AD

Of the eighteen included studies, thirteen examined the factors associated with caregiver burden for FTD, and ten of these also reported factors associated with caregiver

burden for AD. There were a vast range of questionnaires used to measure factors associated with burden across the two types of dementia, and a variety of tests used including regression (N=6), correlation (N=4), descriptive statistics (N=1), ANCOVA (N=1) and qualitative data analysis (N=1).

The most common questionnaire to measure factors associated with dementia was the neuropsychiatric inventory, with 8/13 of the studies using this measure. Seven of these studies (87.5%) had at least one subscale on the NPI that was associated with carer burden for FTD, and five of these studies (71.4%) had at least one subscale on the NPI that was associated with carer burden for AD. However, for both types of the dementia, the specific factors on the NPI associated with burden varied between the studies, and there was no clear factor that was more associated with caregiver burden.

Quality appraisal

The Standard Quality Assessment criteria (Kmet, 2004) was applied to all studies; the quantitative version was completed for seventeen studies and the qualitative version was completed for one study (Appendix F). The quality scores ranged from 0.1-0.95, with higher scores indicating a higher quality study. The mean quality score was 0.72. Two papers scored substantially lower than the remaining papers. Without the two lower-scoring papers, the mean quality score was 0.78, ranging from 0.59-0.95.

Quality of quantitative studies

The majority of papers scored highest on factors related to outcome measures, with 86% of papers using fully defined and robust measures to examine caregiver burden. The papers also generally scored highly on the design criterion, with 88% papers fully describing an appropriate design and the remaining 12% papers partially describing the design. The papers were also scored highly for describing the sample characteristics of the participants

(71% of the papers fully described the sample characteristics, including the age and gender of the participants).

The most common reason that papers lost points on the quality appraisal was for not fully describing the method of participant selection, with only 35% studies providing detailed information about how their participants were recruited. Lower scores were also given for not providing estimates of variance, with only 41% studies reporting this information. Most of the studies could have also better controlled for confounders, as only 41% papers fully controlled for confounding variables in their analysis.

Quality of qualitative studies

Only one study was assessed using the qualitative assessment criteria, but this study scored substantially lower than all of the other studies in the review. Whilst this paper clearly outlined the ways in which caregiver burden was different in FTD due to the challenges associated with the condition, the study did not use a defined qualitative methodology or analysis to arrive at this conclusion. There was no data analysis description of any kind, and it therefore appeared that the conclusions of the paper were largely speculative. Additionally, whilst the paper reported the recruitment of people with FTD in some level of detail, they did not mention how they recruited any of the participants with AD, and therefore scored low for this criterion. The only aspect in which the study scored full marks was describing the context of the study, which took place within a support group for carers of people with dementia.

Quality of studies and caregiver burden

When examining the findings of the papers in the context of their quality appraisal score, there was a slight trend towards higher quality studies showing that FTD had higher burden, however these findings should be interpreted with caution. The three highest scoring papers (scoring between 0.91-0.95) indicated that caregiver burden was higher for FTD, however the highest scoring paper also reported that caregiver burden was higher for early-

onset AD. The next two high scoring papers (both scoring 0.86) reported no difference in caregiver burden across FTD and AD. Considering that more papers reported higher burden for FTD, it is possible that the three highest scoring papers reporting higher burden for FTD is due to chance. There were no clear patterns in any of the demographic characteristics of participants in the higher scoring papers, or any of the factors associated with caregiver burden.

Discussion

This systematic literature review aimed to compare caregiver burden for FTD and AD. Eighteen papers were included in the analysis; seventeen were quantitative and one was qualitative. The review found that burden was higher among carers of FTD compared AD for the majority of studies. Papers finding that FTD was associated with higher burden had carers that were older, and more likely to have a spousal relationship with the PWD, compared to papers reporting no difference in burden. There was little difference in other demographic variables between papers reporting higher burden in FTD compared to papers reporting no burden. The relationship between burden and ethnicity could not be assessed as none of the papers reported ethnicity in their findings. Due to the heterogeneity of factors that were shown to predict caregiver burden between the papers, it is not possible to conclude which factors most strongly predict caregiver burden for either type of dementia, although it is likely that there are differences in predictors of caregiver burden between FTD and AD.

Our findings that FTD is associated with a higher amount of caregiver burden can be examined in the context of caregiver stress theory (Tsai, 2003). Caregiver stress theory highlights the impact of objective stressors and social support in predicting stress of carers. Caregivers of people with FTD receive less support over time (Riedijk et al., 2008), which may increase stress and perceived burden of caring. Additionally, carers of people with FTD experience more stigma in social settings (Oyebode et al., 2013), which is likely to be a

stressor for the carer, and has been shown to be associated with high burden (Velilla et al., 2020).

Whilst the predictors of caregiver burden across FTD and AD could not be fully synthesised due to the heterogeneity of the methodologies, one study (Diehl et al., 2003) outlined a number of factors in FTD that are less present in AD. Many of these factors are indicative a lack of certainty in FTD (for example, the disease being less comprehensible, little information on cause and treatment, and the disease not being known to the general public). Uncertainty has been linked with higher levels of caregiver burden and stress in caregivers of other conditions (Byun et al., 2016; Unson, 2016) and it may therefore be beneficial to address levels of uncertainty in carers of FTD in interventions.

Caregiver stress theory also outlines that race, age and gender all impact carer stress, which may explain the finding in our review that carers of FTD experiencing more burden are likely to be older and have a spousal relationship with the PWD. The fact that older spouses reported more stress in FTD could be due to the fact that older people are also experiencing their own difficulties associated with later life, for example role transitions or physical health problems, which may place more pressure on the caring relationship. Spouses of people with young-onset dementia report particularly high amounts of depression, fear, and worry that their partner will become dependent on them, and this is particularly true of spouses of people with frontal degeneration (Kaiser & Panegyres, 2007).

Of all four papers that split FTD into subtypes, all noted a significant increase in burden for carers of people with the behavioural variant of FTD. Carers have previously reported that behavioural changes are most difficult to manage in FTD (Caceres et al., 2016), and it is therefore possible that behavioural factors associated with FTD may explain the higher burden in this carer group.

There were no papers finding that carers of AD had higher burden than FTD. Whilst the predictors of caregiver burden in AD varied substantially across the studies, behavioural changes and apathy were the most commonly reported as predictors of burden. These symptoms are also common in FTD (Bathgate et al., 2001; Merrilees et al., 2013) which may be why these stressors did not result in carers of AD having higher burden. Whilst there were no papers that reported higher burden for carers of people with AD overall, one paper reported substantially higher burden for early-onset AD compared to late-onset AD. The symptoms of early-onset AD present differently to the symptoms of late-onset AD (Koedam et al., 2010), which may account for these differences in carer burden. However, whilst the papers did not demonstrate burden in AD to be higher than FTD, it is nonetheless important to acknowledge that burden in AD is still high, and is associated with a range of negative outcomes for carers (Mahoney et al., 2005; Markowitz et al., 2003). Due to people with AD generally being older than people with FTD, this may result in carers experiencing different challenges, for example there may be more children caring for their parents than in FTD, and spousal caregivers may be more likely to need support for physical health problems themselves.

Strengths and limitations

To our knowledge, this is the first study to systematically bring together the literature comparing caregiver burden in both FTD and AD. This review examined a range of databases, and therefore was likely to capture the vast majority of literature examining caregiver burden in FTD and AD. Examining the reference lists of the included studies also increased the likelihood of all relevant literature being captured for the review. The review did not place any exclusions on any demographic characteristics of the carer or PWD, which allowed a comparison of different demographic characteristics and how they were associated with caregiver burden.

However, the current study has a number of limitations that must be acknowledged. There was a high amount of heterogeneity in the design and methodology of the studies, leading to a large range in quality. Whilst our review indicates that caregiver burden is higher in FTD compared to AD, many of the included studies did not report estimates of variance or control for confounding variables when reporting these results. Additionally, the majority of studies did not report how participants were recruited, and therefore it is possible that studies used a biased sample that is not representative of the general population. Due to the lower quality scores in some studies, their findings must be interpreted with caution. The heterogeneity of the studies also made it difficult to firmly conclude which factors predicted caregiver burden in FTD compared to AD, and therefore further research needs to be conducted in this area to form recommendations about this.

The majority of the studies used the Zarit Burden Inventory (Zarit et al., 1985) to measure caregiver burden. Whilst the Zarit Burden Inventory has been validated in the population of dementia carers (alpha=0.93) (Yap, 2010), it has not been validated in a group of carers of FTD specifically. As AD is the most common type of dementia (Dementia UK, 2021), it is highly likely that the majority of carers completing the questionnaire will be carers of people with AD. Due to the differences in burden for FTD outlined above, it is possible that the Zarit Burden Inventory may not be as valid for carers of people with FTD. However, to our knowledge there is currently no pre-validated questionnaire specifically for carers of FTD, so it is likely that the Zarit Burden Inventory is the best possible questionnaire to measure burden within this client group.

There were also a number of factors that were not examined in the studies included in the review. None of the papers reported the ethnicity of the carers – research has previously shown that attitudes to caring for family members can greatly differ across ethnicities (Zontini & Reynolds, 2007), and race is also a factor outlined in caregiver stress theory (Tsai,

2003). It is possible that the ethnicity of carers may have impacted their perception of caring, and in turn, the burden that they experienced. Additionally, the majority of papers did not split FTD into subtypes. As research has found that behavioural difficulties are particularly challenging for carers (Krishnamoorthy & Anderson, 2011) and the studies that did examine FTD subtypes found that the behavioural variant was associated with more burden, it is possible that the higher burden in FTD found in the review is skewed by carers with the behavioural variant only. Finally, all the studies apart from one examined carer burden cross-sectionally. Caregiver burden has been shown to be on a trajectory, as opposed to a static construct (van den Kieboom et al., 2020) and therefore it is possible that burden may change as the PWD progresses.

Recommendations for future research

This literature review indicates a number of directions for future research. It is important for future research to address the gaps in the current literature, primarily by examining how carer ethnicity impacts caregiver burden in both AD and FTD. It would also be useful for burden in AD to be compared separately with each sub-type of FTD (behavioural variant, semantic variant and progressive non-fluent aphasia) to determine whether there are certain types of FTD which have higher burden when compared with AD. There is also scope to continue research exploring the differences in carer burden for early-onset compared to late-onset Alzheimer's disease to determine whether the differences in the presentation of the illnesses may contribute to carer burden. There is also a need for more longitudinal research to examine burden among carers of FTD and AD over time, taking into account the disease progression of the PWD. Whilst the evidence suggests that caregiver burden is higher among FTD, it is important to acknowledge that carers of AD still have high levels of burden, and ensure that the factors contributing to burden in both FTD and AD are understood as separate constructs.

It is also important that future research conducted is of high quality. This can be achieved by explicitly reporting how participants were recruited, and ensuring the sample is representative of the population. Additionally, quantitative studies should ensure that results are reported in a high level of detail, including reporting all estimates of variance, and controlling for confounding variables were appropriate. When confounding variables are adequately controlled for, this will allow for a clearer picture of which factors are associated with caregiver burden, and whether this is different for carers of FTD and AD. Additionally, there is currently a lack of qualitative studies within the field, therefore further qualitative research could be conducted to obtain a richer understanding of the challenges associated with caring for people with FTD and AD.

Implementing the above changes are likely to allow for a better understanding of what type of dementia is most predictive of caregiver burden, and what factors are likely to impact this. Understanding the predictors of caregiver burden will allow for carers to be able to receive timely, targeted support that it is adapted to their needs, therefore allowing a higher quality of life for both carers and people with dementia themselves.

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Service Improvement Project

Post-Diagnostic Support Needs for People with Young-Onset Dementia

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Proposed Journal

Dementia is a high-impact international journal which publishes research on social research and dementia. The journal has previously published a wide range of studies outlining how we can improve care for people with dementia, and the current Service Improvement Project, with its focus on young-onset dementia, will add to this evidence base. Author submission guidelines are presented in Appendix A.

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Abstract

Over 42,000 people are living with young-onset dementia (YOD) in the United Kingdom, however there has been relatively little research on how to support this client group. This service improvement project explored the extent to which Northamptonshire Healthcare NHS Foundation Trust's Young Person's with Dementia team was meeting the needs of people with YOD, and to determine what further support could be offered. Five staff members of the Young Persons with Dementia Team took part in a focus group, and nine people with YOD took part in semi-structured interviews, all accompanied by their carers. The thematic analysis demonstrated that most people with YOD are satisfied with support from the team, however there was scope for further input in a number of areas, such as specialised input for rare dementias, more social support and more tailored support for carers. Limitations and areas for future research are discussed.

Introduction

Dementia is a neurocognitive disorder leading to progressive decline in a variety of cognitive domains (American Psychiatric Association, 2013). There are currently an estimated 850,000 people living with dementia in the UK, which is projected to increase by 2 million by 2050 (Prince et al., 2014). As most people with dementia are over 65 years old, the majority of dementia research has been conducted among older populations. However, over 42,000 people in the UK have been diagnosed with young-onset dementia (YOD) (classified by a diagnosis under the age of 65) (Alzheimer's Society, 2014a). Having YOD can impact the person differently compared to late-onset dementia – for example YOD can be associated with loss of income combined with an inability to claim pension payments (Mayrhofer et al., 2021), and a loss of identity and pressure to continue to act "normally" amongst their younger peers (Rabanal et al., 2018). People with YOD are also likely to be in a different stage of life compared to older adults, for example they may be in full-time employment or raising a family, and they may also have additional challenges along their dementia journey, such as perceived stigma or an overestimation of their cognitive abilities by others (Millenaar et al., 2016).

The Prime Minister's Challenge on dementia states that "every person diagnosed with dementia [should have] meaningful care following their diagnosis" (Department of Health, 2015, p7). People with dementia and their families pay an estimated £5.8 billion a year to professional care workers to ensure that the person with dementia is supported (Alzheimer's Society, 2014b), further highlighting the need for services to better support people living with the condition.

The Adaptation Coping Model (ACM) (Brooker et al., 2017) outlines that people will be confronted with a large number of situations that are constantly changing throughout their dementia journey and will need to adapt to this. The model theorises that poor adaptation

leads to higher psychological distress, and that engaging in certain adaptive tasks allows the individual to develop better coping strategies, which influences their cognitive appraisal and emotional reaction to dementia. The ACM outlines seven different adaptive tasks which, when all are performed, result in an individual coping better with the condition:

- Coping with one's own disability
- Preserving an emotional balance
- Preserving a positive self-image
- Preparing for an uncertain future
- Dealing with the day care, the care home or nursing home environment and procedures
- Developing an adequate care relationship with staff
- Developing and maintaining social relations

The way in which individuals can perform the above tasks can be influenced by their environment (Dröes et al., 2010). Therefore, it is important that services are developed to support individuals in performing these tasks to ensure that they can cope as well as possible with YOD.

There has been a large body of research outlining successful post-diagnostic support that can be provided for people living with dementia, that can allow them to adjust to the adaptive tasks in the ACM. Examples of this support includes post-diagnostic groups (Brooker et al., 2018), psychotherapy (Cheston et al., 2003) and Cognitive Stimulation Therapy (Toh et al., 2016). However, whilst this support has been successful in older populations, research has demonstrated that people with YOD view themselves as different to older people (Rabanal et al., 2018) and desire more tailored care (Carter et al., 2018). Therefore, people with YOD may need to adapt to and cope with different aspects of the ACM (Brooker et al., 2017). Research has demonstrated that people with YOD do not

perceive current services to be providing adequate support, meaning they are less likely to seek help (Cations et al., 2017). It is imperative that people with YOD have access to targeted and meaningful support, ultimately leading to better adaptation to living with dementia.

The current project was conducted in the Northamptonshire Healthcare NHS Foundation Trust's Young Persons with Dementia team. Although the service aims to provide a high standard of post-diagnostic support for people with YOD, it is currently unclear what would be most helpful for people with YOD, and what further support people in the region require. The project aims to answer three specific questions, which were considered by both team members and clients:

- What is the current level of post-diagnostic support available for people with YOD in NHFT memory service, and are people with YOD able to access this?
- What is the perceived usefulness of the current post-diagnostic support available among people with YOD?
- What further post-diagnostic support could be rolled out to support people with YOD along their dementia journey?

Method

Setting

This service improvement project took place within the Young Persons with Dementia Service. Clients are referred to the Service from their GP or from mental health teams. The team can assess and diagnose people with YOD, and can provide further individualised post-diagnostic support for as long as clients require. The service also run a number of different groups for people with YOD. The staff team consisted of a clinical psychologist (LBS), 3 community psychiatric nurses (one of whom was also the team manager), one occupational therapist, one community support worker, one administrator and two assistant psychologists.

Participants

Staff members

Five staff members employed by the Young Person's with Dementia Service in Northamptonshire Healthcare NHS Foundation Trust were invited to take part in a remote focus group in December 2021. The Clinical Psychologist in the Team (LBS) was not invited to take part as she was involved in study design.

Clients

Participants were clients living with YOD who gave consent to be interviewed as part of the research. Participants were included if they provided informed consent, were under the age of 65 at the time of diagnosis, and received their diagnosis 3-15 months prior to interview. The timeframe post-diagnosis was included after consultation with the Clinical Psychologist in the team, as this was likely to give participants enough time living with the diagnosis so that they knew what support they would need, but most participants would still be cognitively able enough to take part in the research. People with all subtypes of dementia and at different stages of their dementia journey were included, providing they were able to give informed consent and engage in an interview. Participants were also given the option for their carer to join them if they were more comfortable.

Whilst a focus group with clients was considered, it was agreed that individual interviews were likely to provide richer data as they could be adapted to support each individual's communication needs. Additionally, it was likely that the person with dementia may have felt more comfortable to articulate their difficulties and their perceptions of the team in a one-to-one conversation.

Procedure

Development of materials

A focus group for staff and an interview for people with YOD was developed, using the ACM as a framework on which to inform the questions. The questions were developed

collaboratively with a client living with YOD, who gave input into how to word the questions and which questions to prioritise (Appendix G).

Staff members

Staff members attended a focus group in December 2021. All members of staff were told about the aims of the research and gave full informed consent before participating. Participants discussed what services are currently provided for people with YOD using the different elements of the ACM, and also discussed which services they perceived to be most helpful for people with YOD, and the challenges and barriers faced by those who do not engage in services.

People with YOD

Interviews took place with nine people with YOD between March-August 2022. All participants were told about the nature of the research and gave written informed consent before taking part. Family members were not required to give informed consent as they were not directly participating in the research, although they were allowed to participate in the interviews with the person with YOD's consent. Some adaptations were made to the interview structure to account for the individual needs for people with YOD, for example more closed questions such as "would you consider having one-to-one therapy to help you adjust to your diagnosis" and taking breaks if needed.

Analysis

In order to gather a deeper understanding of the similarities and differences between the views of the staff team and clients, the focus group and interviews were analysed separately. Both sets of data were analysed using inductive thematic analysis (Braun & Clarke, 2012). The interviews and focus group were transcribed verbatim (with all identifiable information anonymised) and then initial codes were developed using words and phrases in each transcript. The codes were then grouped into relevant categories, and

overarching themes and sub-themes were developed. A second author (RV) also examined a sample of the transcripts and coding, and both authors were in agreement with the codes and resulting themes. A reflexive log of all decisions was kept throughout the research process.

Results

Five healthcare professionals supporting the care of people with YOD took part in the focus group, resulting in a 100% response rate. These were three community psychiatric nurses (one of whom was also the team manager), one occupational therapist and one support worker. The focus group lasted 54 minutes.

Of fourteen eligible people with YOD, nine took part in the research (response rate=64.2%). Participants were aged between 55-65 (M=61.4) were all White British, and lived with a range of dementia subtypes including Alzheimer's, vascular, Lewy-Body and frontotemporal dementias, and primary progressive aphasia. All participants were married, and opted for their spouse to join them in the interviews. The time since diagnosis ranged from 3-11 months (M=6.2), and the interviews lasted 34-74 minutes (M=49).

Focus group results

Table 2.1: Themes from focus group

Themes	**Subthemes**
How people are currently supported	"You can go to this group"
	Practical support
	Recent changes
	"There's not an awful lot out there"
People with dementia	"People don't just fit in boxes"
	"Different things for younger people"
	Needs of people with YOD
Barriers to help	Supporting carers ("It's not just about our patients")
	Privacy ("We're not going there")
	"They're just overwhelmed"
	"Well I don't know, but I don't feel I'm supported"

Theme 1: How people are currently supported

“You can go to this group”.

The team explained that *“everybody is given an invitation”* to a post-diagnostic Next Steps group, and then move onto a Living Well With Dementia group, where people are supported with aspects such as *“how can I still live well”*. The team offered Cognitive Stimulation Therapy, although considered streamlining this depending on ability, which was *“something…we need to iron out”*. The team also run an ongoing peer-support group. The team felt there were advantages to groups being both face-to-face and online.

Practical support.

Practical support included handing out leaflets including *“the dementia guide and… individual booklets on the specific diagnoses”*, and providing support with paperwork, such as benefit applications, lasting power of attorney and the Herbert protocol[1], however the team reflected that *“quite a lot of the time [the forms don’t] get completed”* without support from the team. The team provided practical support for physical health, supporting people with *“doing some voluntary work or cultivation work”* and providing assistive technology when needed.

Recent changes.

The team felt the support was *“a bit more formalised now”* compared to previously, as they now had *“set days for groups”* which made the post-diagnostic support *“more accessible”*. The team also reported that a Clinical Psychologist had provided *“brilliant”* support for clients and relatives, but they have since left the team.

“There’s not an awful lot out there”.

The team have referred people to organisations such as Mind, Alzheimer’s Society, Rare Dementia Support Group and Singing for the Brain. However they reported a gap in the

[1] The Herbert protocol is a list of information about the person with dementia that can be given to the police to aid their searches if the person with dementia goes missing.

third-sector for specific YOD support, and felt they were filling this gap with their peer-support group.

Theme 2: People with dementia

"People don't just fit in boxes".

The team explained the importance of *"[being] flexible to the individual needs."* Examples of this include the stage in their dementia journey, meaning it can sometimes be "*too late to be doing things like the groups"*; the age range of people diagnosed with YOD; that some people may not want to access groups because they were *"quite reserved in their live pre- a dementia diagnosis";* and they may want face-to-face or online support.

"Different things for younger people".

The team reported that people with YOD have different needs compared to older people, such as *"[having] children and there's different things for benefits"*, the shock of diagnosis and typically not receiving social care.

Needs of people with YOD.

The team felt that their clients wanted to *"feel they're still being fulfilled and using the skills that they have"*, and gave examples of their clients providing feedback to shape the service. The team also reflected that people with YOD aren't always ready to receive post-diagnostic support, but they were able to access support later if they needed – "*it's…just a different route they can go… but there's always support"*.

Theme 3: Barriers to help

Supporting carers ("It's not just about our patients").

The team explained that the carer was sometimes adjusting to a role-reversal, for example *"if someone's been dealing with the finances all their married life and all of a sudden their partner has to take it on…it puts this barrier up between them"*. They reported that carers can experience difficulties with being both a carer and the main breadwinner

because *"they've used up a lot of their work time as a relative"* so may be limited in the support they can provide.

Privacy ("We're not going there").

The team explained that some people did not want financial support because this process can be *"intrusive into their financial histories"*.

"They're just overwhelmed".

The team noted that it could be difficult to engage with support because *"people feel they're given a lot of information and…it's just overwhelming"*. They also felt clients could become overwhelmed with the idea of mixing with others with YOD because *"they're worried about what they might or might not see"*.

"Well I don't know, but I don't feel I'm supported".

The team noted that some clients reported being unsupported despite being invited to groups and given the information – *"they're getting the invitations and then they still haven't joined"* and *"we still end up doing most of the things for them"*.

A table of all relevant quotations for each theme is displayed in Appendix H.

Interview results

Table 2.2: Themes from interviews.

Themes	**Subthemes**
Receiving the diagnosis	Reaction to diagnosis
	Responses later in the journey
	Therapy? Or something you learn to live with?
	Initial group meeting unhelpful
Practical support	Knowing what paperwork to complete
	Driving assessments
	Day-to-day support
Relationship with the team	Expertise within the team
	Role of the carer
	"It's good to know that she's there"
Group support	Being around others with YOD
	Light-hearted vs serious nature

	Practicalities of the groups
	Frequency of the groups
The future	Maintaining independence
	Planning for the future
	Uncertainty regarding the future
Support for the family	How much input should the team have in supporting families?
	Support for the family
Physical health problems	Greater focus on dementia diagnosis
	Joined-up care

Theme 1: Receiving the diagnosis

Reaction to diagnosis.

Some people felt they had *"known there was a problem for some time"*, meaning it was a *"relief"*. However, some were surprised by the diagnosis and found it *"quite difficult to come to terms with…at such a young age"*. Some people did not agree with their diagnosis as they *"didn't feel as though there was anything wrong"*.

Responses later in the journey.

Some participants reported negative emotions about their diagnosis, and reported that *"sadness…is the driving emotion"*. However, some felt they were adjusting to the diagnosis, and were *"accepting of the situation and trying to make the best of it"*.

Therapy? Or something you learn to live with?.

Some participants felt as though therapy would not help them adjust to the diagnosis because *"it's just going to be there at the end of the day"*. The cognitive difficulties associated with dementia resulted in some participants not being able to access therapy *"because of retaining of the information"*. However, some felt therapy would be useful to help them adjust to the *"bereavement"* of being diagnosed with YOD and to provide strategies to support with mood swings.

Initial group meeting unhelpful.

Participants described the Next Steps group as *"a long process"*, *"a little bit depressing"* and *"death by PowerPoint"*.

Theme 2: Practical support

Knowing what paperwork to complete.

Generally, participants felt supported by the team with form-filling as they *"didn't know what [they were] supposed to be entitled to"*, and that it was useful to have *"somebody fighting [their] corner"*. Those with physical health problems had received less input around benefits, as they were already claiming benefits due to other health conditions. However, some people did not want to pursue financial support, but reported that *"[the team] really pushed us to do it"*, which they found *"stressful"*.

Driving assessments.

Participants reported that the team had helped with the paperwork for driving assessments. Many people reported strong negative emotions with the idea of having their licence revoked, saying it would be *"rotten" "because I rely on my car a lot"*. Participants with a rarer dementia subtype reported that they felt the team were *"trying to take [driving] away from us"* despite being told that the type of dementia they had would not affect their driving ability.

Day-to-day support.

Participants described the Occupational Therapist to be *"very up-to-date with [practical support]"*. Whilst memory aids were discussed in all interviews, this did not appear to be the priority for clients. Participants described that the team tailored their practical support for their individual situations.

Theme 3: Relationship with the team

Expertise within the team

Participants reported that they felt the team had *"always got time to sit down and talk"* and that the team were *"thorough"* and *"helpful"*. Most people said they could not think of anything the team could improve on, however some with rarer dementias felt the team did not understand rare dementias well enough.

Role of the carer.

All participants' carers were heavily involved with the team, however some reported an over-reliance on carers, and that *"there's no one to take any of it away from me"*. Some felt the team could better support the person with YOD to be more independent so the carer was relied on less. Some participants also reported that it would be useful for the team to meet with the person with YOD and carer separately to give each party *"a chance to open up"*.

"It's good to know that she's there."

Most people felt that it was useful to know that the team was in the background, and that the team was engaging in *"emotional holding"*. However, some people described feeling like *"it's intruding on your life"*, but acknowledged that they *"[needed] that connection with someone because you do need advice and help at times"*. They also reported that *"it's nice to have…the continuity of the same lady"*. Participants reported that they could contact the team in between their visits in needed, and that they appreciated that *"they keep in regular contact with us"*.

Theme 4: Group support

Being around others with YOD.

Participants were positive about meeting others with YOD, and that YOD-specific groups were useful as it was *"nice meeting people in similar circumstances"*. People reported that within the groups they were *"not judged, you don't have to explain yourself"*. Whilst some found it helpful to see those further along in their journey as it made them feel

reassured that *"[they're] not doing too bad"*, others found this a more distressing aspect of taking part in the groups.

Light-hearted vs serious nature

The majority of people wanted the groups to primarily be light-hearted and *"better to chit-chat"* and did not want to reflect on the more pessimistic elements of YOD. However, some felt as though there should be space in the groups to reflect on the difficulties of YOD, and felt there was *"an elephant in the room"*, and that *"there can be a tendency to leave out the grief…when actually it's bloody awful"*.

Practicalities of the groups.

There was a strong preference for participants to meet face-to-face *"because you can talk to each other a bit easier"*, and no participant reported transport to be a barrier. It was reported that it was useful that the groups took place on weekdays, as participants were more likely to see friends on weekends than in the week.

Frequency of the groups.

Some people requested *"more get-togethers…with people in similar circumstances"*, and that they wanted *"something ongoing"*. However, not all participants wanted to participate in groups as *"we're not great socialites"*. Others worried about the stigma of other group members thinking *"that bloke's a bit mad"*, and that they *"didn't need to go into a special unit"* to socialise.

Theme 5: The future

Maintaining independence.

Participants reported that the team supported people to *"not let the illness define [them]"*. However they also reported that they would like further support to *"get back into something"* to *"keep [their] independence for as long as possible"*.

Planning for the future.

Some participants reported that they did not want to think about the future, as they wanted to *"just take each day as it comes"*. However, others reported that they wanted more opportunity to address the future, as *"[they had] so many questions about what's gonna happen"*.

Uncertainty regarding the future.

Many people reported that they were uncertain about the future, as they *"don't know what's coming five years down"*. Some also reported that they were not aware whether they could continue to receive support when they turn 65, and reported that to change teams would be *"terrible [because they]…can't identify with older people"*.

Theme 6: Support for the family

How much input should the team have with supporting families?.

The majority of participants felt as though liaising with the wider family was *"more of a personal thing"*. Some participants' family members had been offered therapy, which was *"very helpful"*. However, some participants felt they could be better supported in explaining rarer dementias to their families.

Support for the family.

Generally, the sample felt their families had been *"very good"* and *"they've all started accepting it"*. Whilst some reported that family members had distanced themselves, they did not want input from the team as they felt *"you can't force people"*.

Theme 7: Physical health problems

Greater focus on dementia diagnosis.

Participants with physical health problems reported more input and support from the dementia team than other teams – *"it's only the dementia team that have been…proactive in finding something for him to do"*.

Joined-up care.

Some participants felt as though the team could consult more with the physical health teams to provide a more joined-up approach. It was also suggested if the carer had physical health problems, it would be useful for the team to also liaise with the carer's specialists to provide more holistic care. However, others did not wish for joined-up care, with some expressing anxiety that this would result in them being less central in decision-making, and that they *"like to know what everybody's doing"*.

A table of all relevant quotations for each theme is displayed in Appendix I.

Recommendations

After considering the themes from the individual interviews alongside the focus group, a set of recommendations was fed back to clients in written form, and clients were invited to comment on these (Table 2.3).

Table 2.3: Recommendations for the team

TEAM AND SERVICE CONSIDERATIONS
• The team to bear in mind that generally, clients were positive about the support they were receiving, and the team are doing a good job. • Most people felt very 'held' by the team even when they did not engage as much in the visits. It is useful for the team to hold this in mind – even if a client does not seem to engage they are likely to be getting a lot of value just by the team checking in. • People were not clear whether they could stay in the service once they turn 65 – ensure this is clarified with every client.
TYPES OF SUPPORT
• There was a lot of variety in the type of support people wanted and at different times – for example, financial support, practical support, emotional support etc. so it is important for the team to be flexible with the type and timing of support they provide. • It may be useful for another staff member to call clients a few months after diagnosis to check whether they feel they are getting the right type of support. They could use a structured feedback form to ensure that each type of support is addressed. • Generally, handing out leaflets and providing practical support (such as memory aids) were not seen to be as useful as other types of support, so this should not be prioritised over other types of support. • The team could have a larger focus on supporting people to keep busy and maintain independence, for example by working with people to find a way that they can still have a structure to their day, or by helping them find volunteering opportunities or ways clients can feel like they are helping.

- It will be useful to offer one-to-one therapy (although not everyone will want this), to support people to come to terms with their diagnosis and provide strategies to support with emotional difficulties.

GROUPS

- The groups are very successful and should continue.
- Most people felt strongly that they wanted ongoing groups. If this is not possible for the team, the team could try to work with charities to ensure there are specific support groups for people with young onset dementia.
- Most people wanted the groups to be light-hearted, and fun, but others wanted a space to talk about areas that felt more difficult to manage
    - It may be useful to agree on the focus of the group at the start so that participants can agree whether the group will be more light-hearted or more serious.
    - It may be beneficial for participants to be told about the focus of each session in advance, so that they can choose not to attend certain sessions if they feel as though this will be too emotional
- Groups should be held face-to-face where possible.
- The Next Steps group is perceived as unhelpful, and therefore people may benefit from having the information from the Next Steps group in email format.

TYPES OF DEMENTIA

- The team was perceived to be very good at supporting the most common dementias, but the team could take more steps to understand how rare dementias are different.
- Teams could work with networks such as the rare dementia network to ensure the staff are able to provide the same level of support for people with rare dementias.

CARERS

- Participants who tended to report feeling supported by the team were noted to generally have a good relationship with their partner, and their partner was able and willing to provide a lot of support. However, some carers felt the team relied on them too much particularly if the carer had their own difficulties. It is important for the team to hold carers in mind, as well as the client themselves.
- It would be helpful for the team to meet with the carers and determine how much responsibility they were able to take on (it's important to note that a lot of carers want to take the majority of caring responsibilities), and to work out what the team could do to make things easier for carers.
- It would be useful to offer to meet with the person with dementia and carer separately.

DRIVING

- Driving is a very large area of concern with most people in the service.
- The team are generally perceived to be very good at the practical support around driving – i.e. the paperwork, but more work could be done around the team supporting the emotional impact of someone having their licence revoked. The team could potentially have some training around helping someone sit with their distress, perhaps taking a more Acceptance and Commitment approach to support.
- We understand community transport options in Northamptonshire are limited, so it may be useful to work with the third sector to explore alternative transport options.

PHYSICAL HEALTH

- If people are having support from other teams due to physical health, ensure to check whether they would like the care to be joined-up or not.

The themes and subsequent recommendations were reported in a feedback session attended by six team members, two clients and three carers, where they were discussed in detail. The group requested some changes to the feedback form which was incorporated into the final form (Appendix J).

Discussion

This project aimed to determine the current level of post-diagnostic support within the YOD service, which aspects were perceived as useful and accessible by clients, and also aimed to determine what further post-diagnostic support would be useful to people with YOD. The study found that the majority of participants were satisfied with the support that they were receiving, and found this both useful and accessible, however there were a number of additional elements that the team could put in place to further support their clients, such as by supporting people to maintain their independence, the team to rely less on carers and widen their knowledge around rarer dementias. Putting these additional changes into place would be likely to allow clients to better cope with the challenges outlined in the ACM (Brooker et al., 2017), leading to more positive cognitive appraisals and reduced psychological distress.

It is imperative to involve people with YOD in shaping service provision (Mayrhofer et al., 2021) to ensure clients are getting the right type of support. Previous research has demonstrated that people with YOD require a number of factors such as age-appropriate support, opportunities for social participation, opportunities to articulate their views and support around finances (Stamou et al., 2021). Our findings mirrored previous research, although emphasised the importance of not using a ‘one size fits all’ approach, and working collaboratively with clients and carers to ensure that they are receiving the right type of

support at the right time. The use of both focus groups and interviews allowed for a thorough understanding of where the views of the team and clients differed, and for this to be accounted for within the recommendations. Both the participants and the team reported a lack of YOD services within the third sector, and this may be useful for commissioners of third sector services to consider so that people with YOD can receive support outside of the NHS.

Data collection for this study took place 12-17 months after the first lockdown in the UK, and many participants reported a delay in their diagnosis due to the COVID-19 pandemic. It is therefore possible that this cohort of participants were further along their dementia journey than is typical for people who have been diagnosed for 3-15 months, which may influence the type of support they require. Additionally, a large proportion of participants expressed a preference for a more practical approach to their support that did not overly focus on their emotional experiences. It is important to note that 89% participants were males aged 55-65, who traditionally experience more stigma around help-seeking for mental health difficulties, (Farina, 1981) and therefore may find it more difficult to engage in therapeutic support. It is possible that repeating this study with a predominantly female sample could result in more participants requesting psychological and emotional support with their diagnosis.

Limitations

This study has a number of limitations that must be acknowledged. Firstly, participants were all White British – whilst this reflects the wider demographics of Northamptonshire, where only 8.5% people are non-White, (Northamptonshire Health & Wellbeing Board, 2019), it would be useful for future YOD research to include clients from ethnic minority backgrounds to ensure that the recommendations are culturally sensitive and reflect a more diverse range of clients. Additionally, all participants taking part in the interviews were married, with partners being heavily involved in their care and with the team.

It is possible that people without a spouse may have different support needs to those who are married, and these differences would not have been captured within this study. All spouses were present for the interviews, and took part in the interviews at the participant's request. Whilst the interviewer regularly checked in with the people with YOD, who all confirmed that their partner was accurately portraying their views, validity may have been improved with interviewing the participants alone. However, due to the language impairments associated with dementia, this may have reduced the quality and richness of the data.

Additionally, whilst the focus group with a wide range of staff was useful for enabling discussion and capturing a range of views, it may have led to some bias in participants' responses. The manager of the team participated in the focus group, and it is possible that some other members of the team may have felt they could not be as honest in reflecting on what support they provide for fear of repercussions.

Despite the limitations, this study provides useful insights into the support needs of people with YOD, so that services can ensure that they are meeting the needs of their clients and providing the best possible support that they are able to.

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Theory Driven Research Project

Can Loneliness Predict Substance Use Among People in Treatment for Opiate Addiction?

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Proposed Journal

Addiction is a high-impact journal that welcomes papers researching the origins of all types of addiction. The journal publishes research that explores factors that could link to addiction in clinical settings. The journal has previously published research exploring how loneliness can relate to addiction, but within the context of nicotine addiction.

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Abstract

Background and Aims

Opiate misuse is a serious problem within the UK, with the relapse rate reported as over 90%. It is important that clinicians have an understanding of psychosocial factors associated with substance use so that these can be incorporated into interventions. Previous research has demonstrated the importance of social network in recovery and interventions, but loneliness is often not taken into account within social network research with opiate users. The study aimed to understand whether loneliness could predict opiate use at baseline and six months, when controlling for social network size, depression, anxiety, engagement and baseline substance misuse.

Design

The study used both a cross-sectional and longitudinal questionnaire design.

Setting

Recruitment took place in a Tier 3 NHS Substance Misuse Service.

Participants

Participants were 178 service users who were receiving opiate substitution treatment from the service. 122 participants completed the follow-up questionnaires after six months.

Measurements

Participants filled out the following questionnaires: University of California Los Angeles Loneliness Scale; an adapted Treatment Outcomes Profile; Social Network Index; Patient Health Questionnaire; Generalised Anxiety Disorder Scale. Participants also indicated the three most important contacts in their social network from a pre-determined list. The amount of times participants visited the service over a six month period was also measured.

Findings

The results demonstrated that only baseline substance use predicted substance use after six months, and that loneliness did not predict substance use at either timepoint.

Conclusions

The findings suggest that simply focusing on loneliness or social network size may not be beneficial for opiate users, and service users may benefit from an approach tailored to their individual circumstances. It may also be possible that reducing substance use may also impact levels of loneliness, which may not have been captured by only measuring baseline levels of loneliness.

INTRODUCTION

Substance use disorders are a serious problem within the UK, and are associated with poor physical health (1,2), poor mental health (2,3) and poor social outcomes such as homelessness (4) and unemployment (5). According to the most recent data, death from substance misuse is the highest on record (6).

Of those people who use substances in the UK, opiate addiction is particularly common, with substances such as heroin and morphine being the most frequently mentioned substances on death certificates (7). There has been an increase in opioid-based painkiller prescribing in the UK (8), leading to an increase in opioid addiction, with many people transitioning to opiates, such as heroin, to satisfy their cravings. Although substance misuse levels are high, data suggest that 60% of opiate users access treatment (9), meaning there is the opportunity to support a large number of people to reduce their substance use. However, relapse rates in opiate addiction are especially high, with some research reporting relapse rates as high as 80% in the first month, and 91% overall (10). Whilst methadone treatment can reduce the physical effects of opiate withdrawal, there is a need for ongoing holistic support for people to have the best chance of recovery from opiate use (11).

It is essential that services also address the factors that may predict relapse from substance misuse recovery, to ensure that these factors are addressed during treatment to promote the best possible chance of recovery. This research adds to the understanding of how people in treatment can be best supported by exploring whether social networks and loneliness are factors influence recovery.

Substance use and social networks

It is widely understood that having a supportive social network can be an important factor in successfully recovering from substance misuse (12–14). Research has demonstrated that belonging to social groups is linked with higher chances of recovery regardless of the

makeup of those groups (11), and that people with larger social networks and more frequent social contacts are more likely to recover from substance misuse difficulties (15). Furthermore, people residing in areas with lower social capital are more likely to misuse substances (16)

The above evidence can be explained by the Social Identity Model of Recovery (SIMOR) (17). This model suggests that for successful recovery, someone's identity and values must shift from someone who is an addict/substance user to someone who is in recovery and enjoying a healthy, substance-free lifestyle. SIMOR emphasises the importance of social networks in facilitating this change. The model is based on Social Identity Theory, which states that someone's sense of self is derived from their group memberships, and Self-Categorisation Theory, which states that group status is achieved over time as people become more representative of the group, embodying similarities with other members and becoming aware of their differences from other groups.

There are interventions that are based on the principles of SIMOR that are designed to support people in their recovery. Social Network Behaviour Therapy (18) is a technique used with those recovering from alcohol use disorders. It involves working collaboratively with the service-user to identify social network members who can support positive change, and members who will inhibit change, so that the service-user can form stronger connections with the former. There is evidence for social network interventions being successful in supporting people to recover from substance use (18–20), however other studies have shown that social network interventions do not have a significant effect on recovery (21). It is therefore possible that there are other factors that may influence the success of social network interventions for people recovering from substance use. These factors need to be explored to inform interventions so that those accessing treatment are offered the highest possible standard of support and chance of recovery.

Social network, loneliness and recovery

It is important to distinguish between the concepts of social network and loneliness. Whilst social network can be defined as “the set of people with whom an individual is directly involved” (22), loneliness can be defined as “the unpleasant experience that occurs when a person’s network of social relationships is deficient in some important way” (23). Research has demonstrated that subjective loneliness is a different concept to objectively being alone (24), and is not predicted by the number of social contacts (25). Thus, it is important to note the distinction between loneliness and social network – it is possible to have a large social network but feel lonely, and it is also possible to have a small social network but not experience loneliness.

Within substance misuse research, it is important to explore the link with loneliness as a separate construct to social network size. There is a clear link between loneliness and substance misuse (26–28), and loneliness can also predict relapse from substance misuse recovery (29–31). Additionally, loneliness is associated with common mental health problems such as depression and anxiety (32–34), which are also associated with substance misuse, (35,36) further highlighting the potential importance of loneliness as a factor in substance misuse.

It is possible that loneliness is also a factor in SIMOR. Whilst SIMOR emphasises the importance of social networks in supporting recovery from substance misuse, the model does not explore how loneliness may impact this process (37). Service users may be particularly vulnerable to feelings of loneliness, as they are experiencing a period of transition into recovery, where their social relationships may also be changing. It is therefore important to explore loneliness independently from social network among people in treatment for substance misuse to determine whether loneliness is a factor that could influence the likelihood of a successful recovery.

Current study

To our knowledge, no study to date has explored the relationship between loneliness and social network size in relation to substance misuse; it is therefore currently unknown whether distinctions need to be made between these two constructs when supporting people in treatment. Previous research has highlighted the need for more longitudinal designs when looking at the link with loneliness and substance misuse (26), and therefore the current study explores the link between loneliness and substance misuse, both longitudinally and cross-sectionally. As well as controlling for social network size, the study controls for depression, anxiety and treatment engagement within a UK National Health Service substance misuse service. Depression and anxiety are related to both loneliness (32–34) and substance use (35,36), and it is therefore important to ensure that loneliness is measured as a separate construct by controlling for these variables. Treatment engagement was included to determine whether service users were fulfilling some of their social needs by interacting with staff at the service, which may lead to negative implications upon discharge. The study adds to our understanding of whether baseline loneliness can predict changes in substance misuse over a six month period, which will contribute to better understanding of the factors that predict treatment outcomes. Due to the heterogeneity of an individual's social network, the study also explored the types of people in participants' social networks who are viewed as most important for their recovery. This adds to our understanding of the elements of someone's social network that may be the most fundamental in alleviating loneliness and promoting recovery, so that this can be taken into account in future interventions.

Primary hypothesis

- Loneliness will predict substance use after six months, controlling for possible confounds of social network size, baseline substance use, depression, anxiety and treatment engagement

Secondary hypothesis

- Higher baseline loneliness will be associated with higher baseline substance misuse, controlling for possible confounds of social network size, depression and anxiety

As well as the above hypotheses, we will also explore which types of social relationships participants consider most important in promoting substance misuse recovery.

METHOD

Participants

G* power indicated 89 participants were needed for a significant effect size (effect size f^2=0.15, alpha error probability=0.05, loneliness as the predictor variable & social network, depression, anxiety, engagement & baseline substance misuse as control variables). Due to the longitudinal nature of the research, we over-recruited at Time 1 in order to account for participants dropping out of the research. A longitudinal research study centred around opiate use reported a 40% drop-out rate after 6 months (38), however after consultation with the team about the amount of opiate users who tended to drop out of the specific service, we decided to account for a 50% drop-out rate, and therefore recruited 178 participants at baseline. Our sample was recruited from a Tier 3 setting within an NHS Trust in London (ethics approval reference=22/NS/0023; Appendix K). Tier 3 services are “structured community-based drug treatment services” (39). Inclusion criteria were: receiving an opioid substitute prescription for opiate addiction, being aged 18 years and over, being able to understand English and being willing and able to give informed consent. Exclusion criteria was: not receiving a script for opioid substitute treatment, (although polysubstance users were included). Eligible participants were approached by their key worker or another member of the team and given information about the research. All participants gave informed consent by

signing a consent form or recording their consent onto an encrypted device, and completed the questionnaires either on paper, over the phone or using an online link.

Measures

Outcome measure

*Substance misuse***.** Our outcome measure was adapted from the Treatment Outcome Profile (TOP), and was completed by the participants at 6 months (Appendix M). This was the total number of days on which participants used any substance in the last four weeks. This is the national tool for monitoring substance use in the UK, with proven reliability and validity (40).

Important contacts: Participants indicated the three most important people in their social network (Appendix N). The participants were able to choose from a pre-determined list of social contacts, which included an "other (please specify)" option.

Exposure measure

Loneliness. Loneliness was measured using the University of California Los Angeles Loneliness Scale (UCLA) (25). Participants rated 20 statements on a 4-point Likert Scale, such as "I am unhappy doing so many things alone". Participants could score between 20-80, with higher scores reflecting more loneliness. The UCLA has been demonstrated to have high reliability and validity (25).

Potential confounding variables

Social Network. Social Network size was measured using the Social Network Index (SNI) (41). Participants were asked about whether they had a relationship with a number of different types of people, for example parents, children, friends or colleagues, and then rated how many of these people they contacted at least once every 2 weeks. Participants' SNI score was based on the amount of people they spoke to every 2 weeks.

Depression. Depression was measured using the Patient Health Questionnaire (PHQ-9) (42). Participants rated 9 statements on a 4-point Likert scale. Participants could score between 0-27, with higher scores indicating higher depression.

Anxiety. Anxiety was measured using the Generalised Anxiety Disorder scale (GAD-7) (43). Participants rated 7 statements on a 4-point Likert scale. Participants could score between 0-21, with higher scores indicating higher anxiety.

Engagement. Engagement with the service was taken as total number of contacts with the service from baseline to 6 months, established from electronic patient records. Due to an incident with the electronic patient record system, nine participants had two weeks' worth of data missing from their electronic patient record. The number of contacts with the service within these two weeks was prorated for each participant from the number of contacts they had within the rest of the six month period.

Procedure

Recruitment took place between April 2022 and March 2023. Participants were able to fill out the questionnaires online, or with a researcher either over the phone or in person. At baseline, participants completed the adapted TOP, UCLA, SNI, PHQ-9 and GAD-7. Participants were then contacted 22-30 weeks after they filled out baseline questionnaires, and asked to complete the adapted TOP. Participant engagement with the service was recorded between baseline and 6-month follow-up. If participants were not able to be contacted after 6 months for the research, but had filled out the TOP with their key worker during the 22-30 week timeframe for other reasons related to their care, this was recorded as 6-month follow-up data.

Data analysis

Descriptive statistics

All data analysis was conducted using SPSS v29 (44). Descriptive statistics for all questionnaires were reported, and results were compared for participants who completed questionnaires at both timepoints compared to participants who dropped out after baseline (Tables 3.1 & 3.2). All characteristics for participants who completed all questionnaires were compared with participants who dropped out, using a Chi^2 test for categorical variables, and a t-test or Mann Whitney test for continuous variable depending on the distribution of each variable.

Loneliness and substance misuse

To understand the cross-sectional relationship between loneliness and substance misuse, a hierarchical regression was conducted with the baseline TOP score as the outcome variable. SNI, PHQ-9 and GAD-7 were included as predictor variables in the first block, with UCLA being added to the second block.

To understand the longitudinal relationship between loneliness and substance misuse, hierarchical regression was also used with the six month TOP score as the outcome variable. Baseline TOP score, PHQ-9, GAD-7, engagement and SNI were included as predictor variables in the first block, and UCLA was added to the second block

Key members of social network

The frequency counts for each type of relationship selected as being the most important to aid substance misuse recovery were reported.

RESULTS

A total of 178 participants completed the baseline phase of the study, and 122 participants completed the 6 month follow-up (retention rate 65.8%).

Participant characteristics

The demographic characteristics reported for participants who completed and dropped out of the research are presented in Table 3.1. 56 participants (31.5%) did not complete the 6-

month follow up data. The reason for non-completion was participants being lost to follow up (94.6%, N=53), or death of the participant between baseline and follow-up phases (5.4%, N=3) (deaths of participants were due to factors external to the study, & not due to any factor related to study participation). Sample characteristics are reported for both complete and incomplete cases (Tables 3.1). Participants who dropped out of the study were significantly younger than participants who completed the study (45 years vs 50 years).

Table 3.1: Demographic characteristics of the sample

	Complete Cases	**Incomplete cases**	**Statistics**[1]
Age	Mean=50.1 SD=10.6 Range=20-72	Mean=45.0 SD=9.2 Range=28-67	t=-3.04 df=176 95% CI=-8.31—1.78 p<.01
Gender	65.6% male 33.6% female 0.8% non-binary	78.6% male 21.4% female 0% non-binary	X2=3.07[2] df=1 p=.08
Ethnicity	76.2% White 10.7% Black 6.6% Mixed 3.3% Asian 2.5% Other 0.8% Prefer not to say	69.6% White 5.4% Black 7.1% Mixed 10.7% Asian 3.6% Other 3.6% Prefer not to say	X=.87[3] df=1 p=.35
Marital Status	49.2% divorced 22.1% single 11.5% married 9.8% separated 7.4% widowed	27.3% divorced 36.7% single 14.5% married 14.5% separated 7.3% widowed	X2=.28[4] df=1 p=.60
Employment	87.6% unemployed 12.4% employed	7.3% employed 92.7% unemployed	X2=1.03 df=1 p=.31

[1]Chi-square test used for age, gender, ethnicity, marital status and employment; t-test used for age
[2]Compared male and non-male participants
[3]Compared White and non-White participants
[4]Compared married and non-married participants

Table 3.2 demonstrates the results of all variables included in the regression for complete and incomplete cases. Participants who dropped out of the study used significantly more substances at baseline compared to those who completed both stages. (TOP score 71.2 vs 44.8).

Table 3.2: Characteristics of the sample for variables included in the regression

	Complete Cases	**Incomplete cases**	**Statistics[1]**
Loneliness	Mean=54.6 SD=17.4 Range=20-80	Mean=58.7 SD=15.1 Range=20-80	U=3030.5 Z=-1.21 p=.23
Substance misuse (baseline)	Mean=44.8 SD=31.0 Range=0-169	Mean=71.2 SD=43.5 Range=0-196	U=2154.0 Z=-3.96 p<.01
Substance misuse (follow-up)	Mean=36.3 SD=29.1 Range=0-133	N/A	N/A
Social network	Mean=7.7 SD=8.1 Range=0-39	Mean=6.0 SD=6.1 Range=0-32	U=2927.5 Z=-1.28 p=.20
PHQ9	Mean=15.3 SD=7.1 Range=0-27	Mean=16.4 SD=7.7 Range=0-27	U=2956.0 Z=-1.01 p=.32
GAD7	Mean=11.7 SD=6.6 Range=0-21	Mean=12.8 SD=6.5 Range=0-21	U=2915.5 Z=-1.1 p=.26
Engagement	Mean=6.6 SD=4.4 Range=0-25	N/A	N/A

[1]Mann-Whitney test used for all variables due to non-normal distribution

Descriptive statistics for all demographic and questionnaire information for all participants collectively are reported in Appendix O.

Longitudinal relationship between loneliness and substance misuse

After log-transforming the six-month follow-up data, the residuals were shown to have a normal distribution (Komolgorov-Smirnov=.10). A hierarchical regression analysis was performed to analyse the effect of loneliness on substance misuse after six months. The first block of the regression included social network, depression, anxiety, engagement with the service and baseline substance misuse, and then loneliness was added in the second block. The overall regression model predicted 32.2% of the variance, (R^2=.32, F(6,114)=9.02, p<.01). Social network, depression, anxiety, engagement and baseline substance use predicted approximately 31.5% of the variance, although only baseline substance use was a significant

predictor in the model. Loneliness only accounted for an extra 0.7% variance in the model, and was not a significant predictor (Table 3.3).

Table 3.3: Regression analysis showing loneliness, social network, depression, anxiety, engagement and baseline substance use as predictors of substance use after six months

Variable	Cumulative		Simultaneous	
	R^2 change	F change	β	p
Block 1				
Social network	.32	F(5,115)=10.56*	-.07	.41
Depression			.08	.47
Anxiety			-.18	.11
Engagement			-.05	.52
Baseline substance use			.55	<.01
Block 2				
Loneliness	.01	F(1,114)=1.23**	.12	.27

*p<.01
**p=.27

A Pearson correlation was also run to check for collinearity, and loneliness was found to be highly correlated with social network (r=-.33, p<.01), depression (r=.58, p<.01) and anxiety (r=.60, p<.01). The hierarchical regression was therefore rerun without social network, depression and anxiety to account for multicollinearity. The overall model predicted 30.1% of the variance (R^2=.30, F(3, 118)=16.97, p<.01). Baseline substance use and engagement predicted 29.6% of the variance, but only baseline substance use was a predictor of substance use at six months. Loneliness accounted for 0.6% of the variance, and was not a significant predictor in the model (Table 3.4).

Table 3.4: Regression analysis showing loneliness, engagement and baseline substance misuse as predictors of substance misuse after six months

Variable	Cumulative		Simultaneous	
	R^2 change	F change	β	p
Block 1				
Engagement	.30	F(2,119)=24.99*	-.05	.54

Baseline substance misuse			.55	<.01
Block 2				
Loneliness	.01	F(1,118)=0.95**	.08	.33

*p=<.01
**p=.33

Cross-sectional relationship between loneliness and substance misuse

The residuals of the cross-sectional data were shown to have a normal distribution (Komolgorov Smirnov=.054). A hierarchical regression analysis was performed to analyse the cross-sectional relationship between loneliness and substance misuse. The first block of the regression included social network, depression and anxiety, and then loneliness was added in the second block. The overall model predicted 5.3% of the variance (R^2=.05, F(4,170)=2.38, p=.03). Social network, depression and anxiety predicted approximately 5.2% of the variance, although none of the variables individually were significant predictors in the model. Loneliness predicted an extra 0.1% of the variance, and was not a significant predictor (Table 3.5).

Table 3.5: Regression analysis showing loneliness, social network, depression and anxiety as predictors of baseline substance misuse

Variable	Cumulative		Simultaneous	
	R^2 change	F change	β	p
Block 1				
Social network	.05	F(3,171)=3.11*	.03	.67
Depression			.10	.38
Anxiety			.17	.11
Block 2				
Loneliness	.00	F(1,170)=0.22**	-.05	.64

*p=.03
**p=.64

A Pearson correlation was also run to check for collinearity, and loneliness was again found to be correlated with social network (r=-.36, p<.01), depression (r=.52, p<.01) and

anxiety (r=.59, p<.01). The hierarchical regression was therefore rerun with no other confounders to account for multicollinearity.

The overall model predicted 1% of the variance (R^2=.01, F(1,176)=1.73, p=.19), and showed that loneliness was not a significant predictor of baseline substance use.

Important relationships

Of the 178 participants taking part in the research, 175 participants answered the question about the most important contacts in their life. Figure 1.1 demonstrates the distribution of the most important relationships for participants. The most common types of important relationships were with immediate family (i.e. parents, children and siblings), with 65.7% (115/175) participants citing at least one immediate family member as important in their social network. Whilst the majority of participants had a key worker that they saw regularly, only 14.9% (26/175) participants cited their key worker as important in their social network. 9.7% participants (17/175) indicated that they did not have an important relationship with anyone in their life.

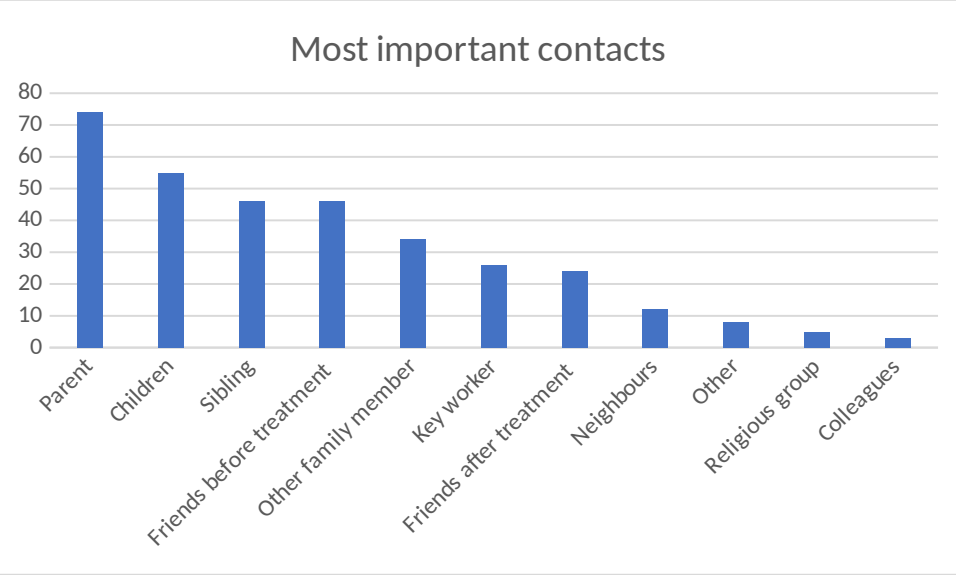

Figure 1.1: Most important relationships for participants

DISCUSSION

The current study aimed to determine whether loneliness was associated with opiate use, and also whether loneliness predicted opiate use over a six month period. This is important because the relapse rate for substance use is high (10), and exploring psychosocial predictors of substance use will allow interventions to take these factors into account to ensure that substance users have a higher chance of recovery. Contrary to expectation, the main study finding was that loneliness was not cross-sectionally associated with substance misuse, or predictive of later substance misuse. Furthermore, substance use also could not be predicted by social network size, depression, anxiety or engagement with a UK community drug treatment service. Only higher baseline substance use predicted higher substance use after six months

The findings also demonstrated that the majority of participants had at least one social contact in their life. The majority of people cited family members as the most important contacts in their social network. It may be useful to explore further perceptions of relationships with family members in order to better understand how such relationships may be harnessed to aid recovery. The study also found that the majority of participants did not include their key worker as an important social contact; this suggests that most people had sustainable relationships and were not dependent on the service for social support.

Clinical Implications

This study demonstrated that loneliness did not predict substance use at baseline or after six months. Whilst social network size, depression and anxiety together were associated with baseline substance misuse, this finding must be interpreted with caution as none of the variables individually predicted substance misuse, and the overall model predicted only 5% of the variance. Baseline substance misuse predicted substance misuse at six months, which is unsurprising considering that recovery can be a long and gradual process. Whilst SIMOR suggests that social network size is a key factor in substance misuse recovery, and previous

research suggests that loneliness would also be predictive of substance use, the current findings suggest that neither loneliness nor social network predict substance misuse over a 6-month period.

The findings may reflect the diversity within populations misusing substances - a large amount of the research surrounding SIMOR is centred around social interventions for alcohol use, such as Alcoholics Anonymous (37), and there are some differences in the recovery trajectories and presentations between alcohol and opiate users (45). It is therefore possible that there are other factors that are more present in populations using opiates compared to using alcohol, which may be more predictive of recovery. It would be beneficial for this study to be repeated with participants from populations using different substances in order to better understand whether loneliness and social network size vary depending on the substance used.

There are also some alternative explanations for our findings that there were no variables associated with substance use. It is possible that as a person recovers, loneliness and social network size also change over time, and it is even possible that reducing substance use may increase loneliness in the short-term, if someone is reducing their interactions with others who misuse substances. Future research could include a longitudinal measure of loneliness and social network size to capture this change and determine how this relates to substance use over a longer timeframe. It may also be helpful to complete qualitative interviews with participants to achieve a better understanding of how they feel loneliness relates to their substance use recovery. The interviews would also be able to better capture the makeup of people's social networks, and the extent to which individuals are interacting with other substance users, which was not included in the current study.

The research also demonstrated that people who used more substances were more likely to drop out of the research, and it is likely that this is because they dropped out of

treatment altogether. This demonstrates the importance of being able to deliver short and meaningful interventions to participants whilst they are engaged in treatment, and making each contact count. Whilst longitudinal approaches are of course important, it cannot be assumed that service users with high levels of substance use will stay in treatment long enough to start benefiting from the effects of more longitudinal approaches.

Additionally, whilst previous literature has also noted the distinction between loneliness and social network, our findings demonstrated that loneliness and social network were highly correlated. This could suggest that for service users who would benefit from social network interventions, these interventions could also alleviate loneliness, improving the overall wellbeing of people in treatment even if this does not directly affect substance use. The findings also demonstrate that there is no association between any individual variable and substance use, therefore highlighting the importance of a person-centred approach to treatment. It is therefore imperative that clinicians still take the time to understand service users' individualised needs and strengths in order to build a tailored treatment plan.

Strengths and limitations

The current study has several strengths of note. The retention rate of participants was high and therefore the study is well-powered at both baseline and follow-up. The study is also well-balanced in respect to the gender, age and ethnicity of the participants. The researchers recruited many of the participants opportunistically when they dropped into the service, which means that recruitment did not rely on participants having access to a phone or Internet, which led to a more representative sample of opiate users.

However, the study's limitations are also acknowledged. The study demonstrated that those who dropped out of the research used significantly more substances. Whilst this finding was unsurprising, the fact that it was not possible to follow up participants with higher levels of substance use means that the findings may not be representative of the most vulnerable

people within the service. The study also took place across only one Trust in inner London. Research has demonstrated that those living in urban areas tend to be more lonely than those living in rural areas (46), and therefore results may vary slightly across settings nationally. Finally, the measure of engagement was taken from totalling the number of contacts with the service from each participant's electronic patient record. This study took place during a major software outage that lasted several months, and whilst the data were migrated onto new software, it is possible that some of these data might have been lost during this process, compromising the engagement measure.

CONCLUSIONS

This research explored whether loneliness predicted substance misuse at baseline and over a six month period. The results demonstrated that substance misuse was not associated with loneliness or any other confounding variables. The majority of participants had at least one person that they felt was key in their recovery. This negative finding suggests the need for future research to explore differences between groups using substances and also the need to explore in a more qualitative way the relationship between social network, loneliness and substance use for opiate users. The research also suggests the importance of a person-centred, tailored approach to enable recovery.

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Executive Summary

Can Loneliness Predict Substance Use for People in Treatment for Opiate Addiction?

Opiate use is a serious problem in the UK, and is associated with a number of negative outcomes. It is important to understand what factors predict substance misuse, so that these can be addressed in treatment. Research has demonstrated that people with larger social networks and more frequent social contacts are more likely to recover from substance misuse difficulties. However, whilst some substance users benefit from social network interventions, such as Alcoholics Anonymous, other studies have shown that social network interventions do not have a significant effect on recovery for opiate users. It is important to distinguish between social network, which is the social contacts in one's life, and loneliness, which is the feeling that one's social network is deficient in some way. It is possible to have a large social network but still feel lonely, and vice versa. It is possible that opiate users may be particularly vulnerable to feelings of loneliness when they are in recovery, as they are experience a period of change where their social networks are changing. The study therefore aims to understand whether there is a link between loneliness and substance misuse in a sample of opiate users, whilst also accounting for social network and other variables that influence substance use.

178 people who were receiving treatment for opiate addiction in an NHS substance misuse service took part in the research. Participants completed questionnaires about their substance use, loneliness, social network size, depression and anxiety. 122 participants also completed the same questionnaire about their substance use six months later. We also measured the number of times participants visited the service over a six month period, to determine whether this influenced substance use. Participants also indicated what social

relationships were most important in their recovery from a list of common social relationships.

Results demonstrated that loneliness did not predict substance use at baseline or at six months, and the only other factor that predicted substance use at six months was baseline substance use. There was a significant relationship between loneliness and social network size within this sample. Immediate family members, such as parents, children and siblings, were the most common relationships that were important in service users' recovery, although 9.7% participants did not have an important relationship with anyone in their life.

There are a number of possible explanations for our findings that neither loneliness or social network size predicted substance use. Our findings may reflect the differences in presentation in opiate users compared to other types of substance users, such as people who primarily misuse alcohol, and it may therefore be that opiate users have different treatment needs. It is also possible that loneliness and social network size also change over time as people recover from substance use, which would not have been captured in this study as loneliness and social network size were only measured at one time point.

There were also 35% participants that dropped out of the research, and many of these participants had also dropped out of treatment. These participants used higher amounts of substances at baseline. This finding demonstrates the importance of short and meaningful interventions to participants whilst they are engaged in treatment, and making each contact count. Finally, whilst social network and loneliness have different definitions, our findings demonstrated a strong link between social network and loneliness. This could suggest that for service users who would benefit from social network interventions, these interventions may also alleviate loneliness, improving the overall wellbeing of participants.

Our findings that there is no individual variable that predicts substance use highlights the importance of a person-centred approach to treatment. It is imperative that clinicians take

the time to build a tailored, individualised treatment plan for each service user so that they have the best possible chance of recovery.

Connecting Narrative

When formulating ideas for my thesis, I was keen to have a combination of topics that I knew I enjoyed and had more experience with, combined with topics that I was less familiar with. I have worked with dementia and older adults in a number of roles, and have always known that I wanted to continue research in this field. In contrast, whilst I have always been interested in substance use due to both professional and personal experiences, I had never worked directly with the client group and was keen to learn more. I also felt as though my research projects would tie in well with my third year placement, where I am split across working with older adults and people experiencing homelessness. I wanted to complete both qualitative and quantitative projects in order to broaden my experience in both methodologies.

Whilst people with rare dementia and people suffering from substance misuse ostensibly have relatively little overlap, they are not always mutually exclusive, and I was struck by some of the similarities within my projects. Whilst I explicitly explored loneliness within my sample of opiate users, this is also a common experience for older adults and people with dementia. Another common theme across the client groups was that of stigma, with both client groups reporting to have experienced high amounts of stigma due to their difficulties. The client groups also appeared to be somewhat under-represented within mental health research, with many of their difficulties ‘hidden’ from mainstream society.

I have included a reflective account of each of my projects below.

Systematic Review of the Literature

I first began to consider the differences in carer burden when working on my older adult placement in my first year of the doctorate. I completed a piece of work with a spouse

of someone with frontotemporal dementia, who described some of the difficulties they were experiencing, which appeared very different to the more common difficulties associated with caring for people with Alzheimer's Disease. This sparked my interest in exploring the caregiver burden literature, and I was keen to bring this together in a systematic review.

I found the most challenging aspect of this project to be formulating a research question that appropriately lent itself to a systematic review. It was tempting to 'rush in' and start my searches as soon as possible, but I have learnt the importance of taking the time to ensure that the research question and the search terms are as clear and robust as possible before beginning to filter out papers. Completing the quality appraisals for each paper was also a useful learning experience for me, as I noticed my confidence grow in being able to critically evaluate papers and make recommendations for future research. This process has also allowed me to better reflect on the strengths and weaknesses of all my projects, and take steps to ensure that my research is of a high quality.

Service Improvement Project

I was most looking forward to starting this project, as I have always been interested in young-onset dementia, and was keen to contribute to the research base. I found coproducing the topic guides, recommendations and feedback questionnaires particularly rewarding, as the clients had some very interesting insights that I would never have thought of, and this project has taught me the importance of coproduction in research.

This project has also taught me the importance of adapting research for the specific client group. Most people taking part in this research would have found it challenging to complete a one-to-one qualitative interview, with open-ended questions. However, by taking the time to speak with the participants about their communication needs, I was able to tailor my interviews to ensure that they felt comfortable and able to give their views, for example

by asking more closed questions, giving them more time to answer when they struggled to find the right words, and taking regular breaks.

Before this project, I had never completed a qualitative research study, so this has been invaluable in improving my qualitative research skills. I found it difficult to strike the balance between ensuring that participants' views are fully represented, whilst also generating clear and concise take-home messages for the reader. I found it very useful to discuss this dilemma with my supervisors, one of whom had also seen some of the transcripts, and this has taught me the importance of inter-coder reliability within qualitative research.

Theory Driven Research Project

I first started to reflect on the link between loneliness and substance use when working for a social prescribing charity. I worked with a number of clients who were recovering from substance misuse, and cited a lack of social support as a barrier to recovery. As I read more about this, I started to notice the current gaps in the literature and began to formulate my research question.

I initially found this project the most daunting, due to having to complete the lengthy process of NHS Ethics, combined with my large recruitment target. However, whilst recruiting the participants was of course hard work, I was extremely surprised and humbled by the amount of service users that were willing to help in the research. In conversation with the participants, many of them felt that loneliness was a key factor in using substances, and this was one of their main motivations for helping with the research. This meant that my finding that loneliness was not linked with substance misuse came as a surprise, and I initially found it difficult to explore reasons for non-significant findings in the paper's discussion. This project has taught me the importance of standing by non-significant findings, as these inform our knowledge just as much as statistically significant results.

Future Research

This experience has been both extremely challenging and extremely rewarding, and has contributed to my understanding of how to conduct scientifically robust and high-quality research, balanced against the feasibility of conducting research with challenging client groups. I look forward to continuing my research within my qualified post.

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I would like to thank all of my thesis supervisors – Kathryn, Reena, Lorna, Dominic and Louise – for all of their support, direction and guidance, particularly Kathryn who has also been my course tutor over the last three years. I'd like to give an additional thanks to Dominic for all of your patience and perseverance during my period of TDRP recruitment – knowing that I was just able to pop into your office or drop you a quick WhatsApp if needed was invaluable in keeping me calm during the more stressful periods. I will always think of you whenever I see a psychology meme!

I would also like to thank all of my placement supervisors for their flexibility, meaning I have been able to successfully complete my thesis alongside my clinical work. I would like to especially thank Jon, who was supervising me on placement whilst I was completing my main recruitment for my TDRP. Your regular checks on my wellbeing, and listening to my many, many monologues about whether or not I might hit my recruitment target, was very much appreciated. Thank you also to Becci for continuing to support and grow my passion for older adult, and particularly dementia, work – which has shaped my thesis and I am sure will continue to shape my future work.

Thank you to the DClinPsy cohort – in particular Ellie, Eimear, Stacey and Lawson for helping me get through the course with my sanity intact. For all the emergency peer supervisions, the waffly panicked voice notes, stats meetings in pubs and the rants on the way to teaching on the Oxford Tube. We started the course as colleagues, but I can firmly now say that you are some of my best friends, and I look forward to many more segways in Spain, drag brunches and Taylor Swift nights in years to come.

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I'd also like to thank Community Connections for igniting my interest in working in both loneliness and dementia. I have such fond memories of this role, and still constantly refer to the Courageous Five as the best team I have ever worked with!

To my mum and my dad, so much of what I have accomplished is down to your unwavering care and support. From school runs, checking homework, 11+ practice papers, parents' evenings, and so much more, I am so grateful for you in giving me such a good start in my education. Thank you both for making the many trips up to Birmingham to support me in completing my undergraduate degree. And more recently, whether you've been sitting in stationary traffic on the North Circular because I'm too busy to meet centrally, or getting locked in Kias when going car shopping, your unconditional love and support has meant the world to me, and I wouldn't be where I am today without you both.

To Sam. It's hard to know where to start. Thank you for all the proof-reading, the evenings spent hashing out ideas and plans, and listening to my stream of consciousness about what is going well and not so well, which has been pretty much constant over the last three years. Thank you for all the times you have cooked dinner, or done the washing up or the laundry without me even noticing because you could sense that I was stressed that day. Thank you for moving from a place you loved without a second thought for the course just so that I could have the career I wanted. I genuinely do not think I would have got through this course without you, and I cannot wait to move to our new home together with our many, many cats.

Finally, I would like to dedicate this thesis to all of the participants who took part in my research. It was a pleasure and a privilege talking to each and every one of you and hearing your stories. I hope my thesis does your stories justice, and I am so grateful for you all taking the time to support me.

Appendices

Appendix A: SRL/SIP: Author guidelines for 'Dementia'

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Dementia, please ensure you have read the Aims & Scope.

1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia. Biomedical and overly clinical research articles will not be accepted.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

The journal also publishes book reviews. We send out a list of books to review twice a year in September and March.

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2. Editorial policies

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As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

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2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged

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Any acknowledgements should be placed on the title page. Your main text should include a Declaration of Conflicting Interests (if applicable), any notes and your References but should be completely anonymized.

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Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

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- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

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Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that

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Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record. The confirmatory letter may be uploaded with your submission as a separate file.

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- include a data availability statement linking to your data. If it is not possible to share your data, we encourage you to consider using the statement to explain why it cannot be shared.
- cite this data in your research

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3. Publishing Policies

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Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have

common usage, please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

Useful websites to refer to for guidance

We recommend that authors refer to the Dementia Engagement and Empowerment Project (DEEP) guidance which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information.

Alternatively, Alzheimer's Australia sets out guidelines for dementia-friendly language, as do the Alzheimer Society of Canada, both of which are useful for guidance.

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6. On acceptance and publication

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7. Further information

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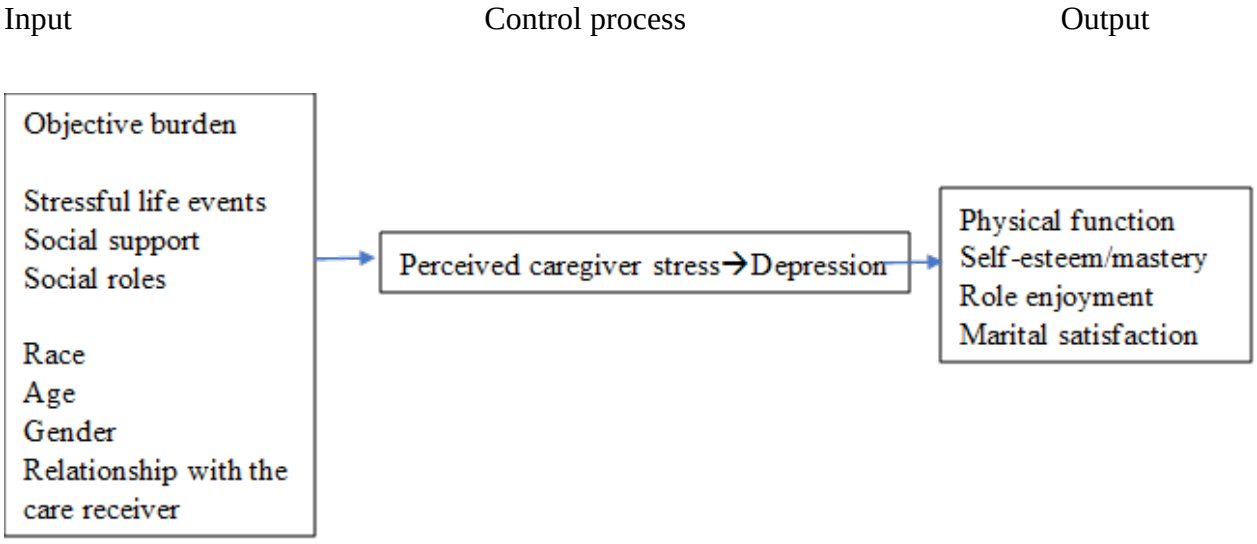
dem.pra@sagepub.com

Appendix B: SRL: Caregiver Stress Theory (Tsai, 2003)



Appendix C: SRL: Query String of Search Terms

(((("caregiver burden"[Title/Abstract]) OR ("carer burden"[Title/Abstract])) OR ("caregiver stress"[Title/Abstract])) OR ("carer stress"[Title/Abstract]) AND (((((("frontotemporal dementia"[Title/Abstract]) OR ("fronto-temporal dementia"[Title/Abstract])) OR ("Pick's disease"[Title/Abstract])) OR ("Picks disease"[Title/Abstract])) OR ("semantic dementia"[Title/Abstract])) OR ("progressive non fluent aphasia"[Title/Abstract])) OR ("progressive nonfluent aphasia"[Title/Abstract])) OR ("progressive non-fluent aphasia"[Title/Abstract]) AND ("Alzheimer's"[Title/Abstract]) OR ("Alzheimers"[Title/Abstract])

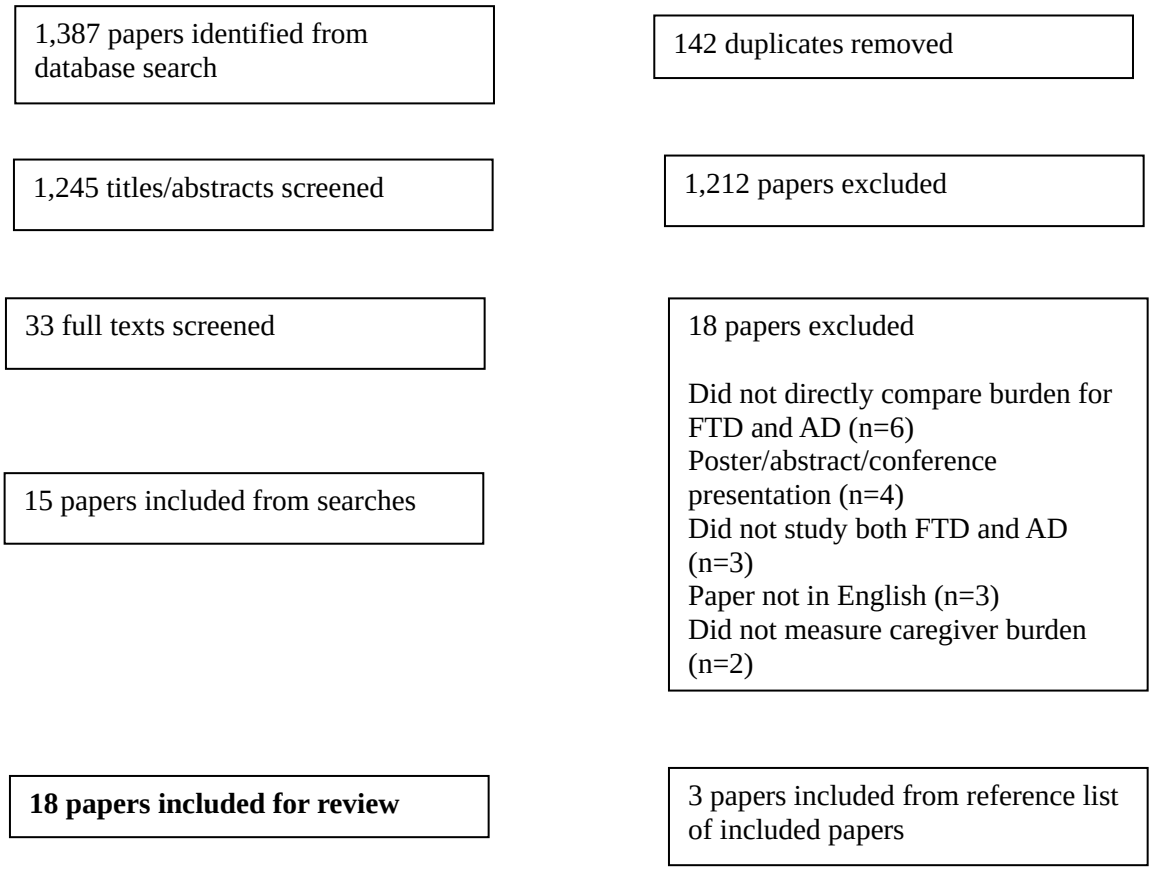
Appendix D: SRL: Standard Quality Assessment Criteria Checklist (Kmet et al., 2004)

Criteria		Yes	Partial	No	N/A
1	Question/objective sufficiently described?				
2	Study design evident and appropriate?				
3	Method of subject/comparison group selection or source of information/input variables described and appropriate?				
4	Subject (and comparison group, if applicable) characteristics sufficiently described?				
5	If interventional and random allocation was possible, was it described?				
6	If interventional and blinding of investigators was possible, was it reported?				
7	If interventional and blinding of subjects was possible, was it reported?				
8	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?				
9	Sample size appropriate?				
10	Analytic methods described/justified and appropriate?				
11	Some estimate of variance is reported for the main results?				
12	Controlled for confounding?				
13	Results reported in sufficient detail?				
14	Conclusions supported by the results?				

Checklist for assessing the quality of qualitative studies

Criteria		Yes	Partial	No	N/A
1	Question / objective sufficiently described?				
2	Study design evident and appropriate?				
3	Context for the study clear?				
4	Connection to a theoretical framework / wider body of knowledge?				
5	Sampling strategy described, relevant and justified?				
6	Data collection methods clearly described and systematic?				
7	Data analysis clearly described and systematic?				
8	Use of verification procedure(s) to establish credibility?				
9	Conclusions supported by the results?				
10	Reflexivity of the account?				

Appendix E: SRL: Flowchart of Included Studies



Appendix F: SRL: Completed Standard Quality Assessment Criteria for Each Study

Quantitative Studies

Paper	1	2	3	4	5	6	7	8	9	10	11	12	13	14	Total
(47)	2	2	2	1	N/A	N/A	N/A	2	2	2	1	1	0	2	0.77
(48)	1	1	2	2	N/A	N/A	N/A	2	2	2	2	2	2	2	0.91
(49)	2	1	1	2	N/A	N/A	N/A	1	1	1	2	2	2	2	0.77
(50)	1	2	2	2	N/A	N/A	N/A	2	0	1	1	0	2	0	0.59
(51)	1	1	2	2	N/A	N/A	N/A	2	2	1	2	2	1	1	0.77
(52)	1	2	1	2	N/A	N/A	N/A	2	2	2	2	1	1	2	0.81
(53)	1	2	1	1	N/A	N/A	N/A	2	1	2	0	0	2	1	0.68
(54)	2	2	1	2	N/A	N/A	N/A	2	2	2	1	1	2	2	0.86
(55)	2	2	1	2	N/A	N/A	N/A	2	2	2	1	2	2	2	0.91
(56)	2	2	1	2	N/A	N/A	N/A	2	1	2	0	2	1	2	0.77
(57)	2	2	1	2	N/A	N/A	N/A	2	1	2	1	2	2	2	0.86
(58)	2	2	1	2	N/A	N/A	N/A	2	1	1	0	1	1	1	0.64
(Riedijk et al., 2006)	1	2	2	2	N/A	N/A	N/A	1	2	1	0	0	1	2	0.64
(60)	2	2	2	1	N/A	N/A	N/A	2	1	2	1	1	2	2	0.81
(61)	1	2	1	1	N/A	N/A	N/A	2	2	2	2	0	1	2	0.73

(Velilla et al., 2022)	2	2	1	2	N/A	N/A	N/A	2	2	2	2	2	2	2	0.95
(63)	0	2	0	1	N/A	N/A	N/A	2	1	1	0	0	1	1	0.36

Qualitative Studies

Paper	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Total**
(64)	0	0	2	0	0	0	0	0	0	0	0.1

Appendix G: SIP: Focus Group and Interview Topic Guides

Focus Group Topic Guide

- Group to describe what current post-diagnostic support is in place for people with YOD
- Group to describe how many of their patients go on to access this – what is helpful/unhelpful/what are the barriers to stopping them access it
- Group to go through each part of the adaptation coping model and discuss what is available, and whether people access this:
    - Support to cope with the challenges of dementia
    - Support with preserving an emotional balance
    - Support with preserving a positive self-image
    - Support with preparing for an uncertain future
    - Support with developing and maintaining social relations
    - Support with developing an adequate care relationship with staff
    - Support with the daycare/care home/nursing environment and procedures [group to ascertain if this is relevant for people diagnosed with dementia within the timeframe].
- Time for group to mention anything else that may be relevant for the research.

Participant Interview Topic Guide

Could you tell us briefly about your experience of being diagnosed with dementia at the memory clinic?

Could you tell me what support you have received from professionals since your diagnosis, if any?
Prompts: what was helpful/not helpful. Did you want more/less? What would you have wanted to be different? Anything you haven't been offered that you think could be helpful? Anything from NHS vs 3rd sector.

What has helped so far with helping you feel more positive about yourself since your diagnosis?
What else may be helpful to make you feel positive about yourself since your diagnosis?
Prompts: Would it be helpful to see examples of people living well with young-onset dementia? Would it be helpful to think about how you can continue work/volunteering?

What has helped you so far in coping with the day-to-day challenges that dementia brings?
What would be helpful to support you with coping with the day-to-day challenges that dementia brings?
Prompts: What type of support? Provided by who? How often? What would it look like. If participant is struggling, examples could be someone coming to the house to support them with the practical challenges/being given practical aids like calendars etc/being taught explicit memory strategies. Also mention targeted apps, mobile devices and peer-to-peer support.

Do you sometimes become upset when thinking about your diagnosis? If so, what helps you with this? What other support would be helpful in coping with this?
Prompts: What type of support? Provided by who? How often? What would it look like. If participant is struggling, examples could be individual/group/online therapy

What have you done so far to help you prepare for the future?
What would be helpful support to help you prepare for the future?
Prompts: What type of support? Provided by who? How often? What would it look like. If participant is struggling, examples could be things like helping with financial support/LPA/PIP process/will writing, support in helping ppt (and family) adjust to the idea that the dementia is going to progress.

How do you find that dementia affects your relationships with family and friends?
What would be helpful to support you to develop and maintain your relationships with family and friends?
Prompts: What type of support? Provided by who? How often? What would it look like. Would you like to meet other people with YOD? If so in what context? Would it be helpful for us to speak to your family friends, perhaps providing some psychoed? Would it be helpful for you to know that there is support out there for your family/friends?

Do you have any relationships with healthcare staff at the moment (either for your dementia or for another physical condition?). What could staff members do to make sure that you have a good relationship with them?
Prompts: Anything they specifically that you would/would not like to hear from them, how often should they contact you?

Are you going to any sort of day centre/care home/nursing home (either for your dementia or for another physical condition?). How could the support you receive in your [day centre, care home, nursing home] be improved?
What are the current routines/procedures – what do you like/not like about that. Anything you would like to be added/removed/anything you would like to be different? Adapt this question to the care that each patient is receiving (if no care, then omit this question).

Is there anything else that you think it would be helpful for us to know when thinking about how to support people who have been diagnosed with young onset dementia, that hasn't already been covered?

Appendix H: SIP: Relevant quotations from focus group

Subtheme	Description	Quotes
THEME 1: How people are currently supported		
"You can go to this group"	Next steps group offered to people who have been diagnosed Living Well With Dementia Group offered after Next Steps group	"So I think the idea is that everybody is given an invitation to a postdiagnostic next-steps group… then they will have a bit of an introduction to all the things that we said, sort of the legal things to consider, what diagnosis means, them just knowing who's in our team, what we offer. And there's a bit in there around other groups that are available as well … the idea is that they would do that and then if somebody is cognitively able the next group to offer is something called Living Well With Dementia, which is 8 weeks, and that is helping, again have a point of discussion about diagnosis and acceptance about diagnosis. Some of the things that have come along with that, things like having to stop driving, which is very often a key thing. And then 8 weeks include sort of moving from that more to 'what can I do, how can I still live well, what do I want to do'" *(Occupational Therapist)*
	Cognitive Stimulation group needs to be streamlined depending on ability	"I think some cognitive assessments were done to measure whether people could benefit but that's quite tricky when somebody might still really value the other elements of going to a group. I think that's something as a service we need to iron out really." *(Occupational Therapist)*
	Groups both online and face-to-face	"Yeah, so we have a peer, an online [group]. Which is quite tricky to do because of quite mixed needs and it doesn't always work but people do come and join that and then, face-to-face ones that meeting out and about." *(Occupational Therapist)*
Practical support	Information sharing through leaflets	"There's the dementia guide and also there's individual booklets on the specific diagnoses that the Alzheimer's society provide, so mostly the nurses would have given those out quite regularly and I think we still do that" *(Nurse)*
	Legal advice	"One of the things, like the Herbert protocol, we can give that out but quite a lot of the time it doesn't get completed and then there is a need for it to be completed, so we make sure that's in place." *(Support worker)*

	Supporting people to go out and keep busy	"But we might get them into doing some voluntary work or cultivation work or other things, just connecting with and having a new focus" *(Occupational Therapist)*
Recent changes	Support has been more formalised	"We've always done an element of [the groups], it's just that I think it's a bit more formalised now". *(Nurse).* "We have sort of set days for groups, and you can go to this group or you can go to that group, rather than us doing, I suppose what we could". *(Nurse)* "With this format we're trying to make it more accessible so I suppose it has kind of developed in lots of ways over the years hasn't it, in how we've tried to get the post-diagnostic support information across". *(Nurse)*
	Changes within Psychology	"A Clinical Psychologist and she's left now, but what she used to do, her support was brilliant, so what she would go and do work with a relative. So if it was really difficult, or they were struggling to come to terms with it or they've got their own issues and that, she would do a piece of work with them and that was really helpful." *(Nurse)*
"There's not an awful lot out there"	Lack of ongoing support in third sector	"They [Alzheimer's Society] were going to start their own young people with dementia… but nothing's ever come from that. Not sure why actually" *(Nurse)*
THEME 2: PEOPLE WITH DEMENTIA		
"People don't just fit in boxes"	People are at different stages when they are diagnosed	"[For] some people, it's too late to be doing some of the things like the groups, so although we have that framework, I think we still need to be flexible to the individual needs, because people with younger diagnosis are a bit more complex" *(Occupational Therapist)*
	Large age range	"When we did the Living Well group and we got feedback, one lady said I don't want to do it with those older people, because even in an older population, somebody's 65 and somebody's 51." *(Occupational Therapist)*

	Different personalities outside of diagnosis	"We do come across people sometimes that don't want, their personalities are that they've never been involved in any groups, and they don't want the involvement, so we do have to respect that, even knowing that you know, that would help, but if they don't engage or if they're quite quiet people, quite reserved in their life pre a dementia diagnosis, we respect that as well." *(Support worker)*
	Different relationships with staff	"I suppose it's, we will see them, I mean, you know we can go and see people every other week if there's a problem. It depends, you know" *(Nurse)* "Sometimes you get people that are quite open and they'll work really well with us. We can get a lot of hostility, get sworn at, all sorts of things really" *(Nurse)*
	Face-to-face vs online support	"Sometimes we've had to put a lot in to get them online and they've really put a lot of effort in themselves. But like one poor lady had to be told to leave because her computer was making a funny noise, and you know, we don't want those negative experiences. So the people involved in that did a follow-up face-to-face and that lady got so much more out of going for a walk with some people. But I think the idea is that both are still ongoing, because we've always said we cover such a wide geographical area, that trying to find somewhere that a lot of people who have been told to stop driving can get to and their partners and families are working. It is at least another way to, even if they just see faces on a screen and don't say a lot, they can just sometimes feel not so alone." *(Occupational Therapist)*
"Different things for younger people"	People with YOD are in a different stage of life	"Obviously younger people may be working, they're working age, so they're going to have children and there's different things for benefits and that isn't there" *(Nurse)* "I find that with younger people …you know in your 50's and that you're not expecting that. That's a huge blow. I mean if you're in your 80's you sort of… but when you're in your 50's, so that whole relationship, because I've got somebody now, and the sexual part of it, everything, has changed from how it was before to how it is now. So from going on holiday together, planning everything together, you end up dealing with incontinence and all sort of things. It's really difficult for people" *(Nurse)*

		"Outside of our team I mean not everyone would meet social services soon after diagnosis, majority wouldn't" *(Occupational Therapist)*
Needs of people with YOD	People want to feel useful	"It's sort of great to have those sort of opportunities really, for people to feel they're still being fulfilled and using the skills that they have" *(Occupational Therapist)* "That's [service user feedback] such a key thing to get them involved" *(Occupational Therapist)*
	People need different support at different times	"It's a learning curve" *(Support Worker)* "So any time, any sort of support and anything they need, it's there all the time really. It's obviously just a different route they can go or whatever but there's always support." *(Nurse)*
THEME 3: BARRIERS TO HELP		
Supporting carers ("It's not just about our patients")	Role-reversal within caring role	"In some families you've got one person that'll do one thing and one person will do another. So if someone's been dealing with the finances all their married life and all of a sudden their partner has to take it on, 'well I don't know', you know and then they ask them and then they're sort of saying 'well no, they don't', obviously because they've lost the insight, it puts this barrier up between them so they just don't daren't do it sometimes I think." *(Nurse)* "They don't realise you know that they have to be the voice, they have to take on this information because the person that's diagnosed can't do it." *(Support Worker)*
	Not having time to support people whilst being the main breadwinner	"Relatives can't always stop working to take their person to a group or help them to access a group because they're the main breadwinner" *(Nurse)* "What I've come across is that people have gone through a lot before they've been given that diagnosis in attending medical appointments and assessments. So they've

		used up a lot of their work time as a relative, to be able to give that further time to support with post-diagnostic or further information" *(Support worker)*
Privacy "We're not going there"	Not wanting to talk about finances	"I think I had a few that it seems to be around finances… as soon as we mention the finances… it was like 'we're shutting the door on that sort of thing, we're not going there'." *(Nurse)* "I think because of the social care side of things how that can be intrusive into their financial histories and savings and things like that. People are quite guarded, so they don't want to have that support." *(Support Worker)*
"They're just overwhelmed"	Feeling overwhelmed with information	"I think one of the things, I know I've heard people say and in the articles I've read in the past, a lot of the feedback is that people feel they're given a lot of information and they don't know what to do with it all or it's just overwhelming, and particularly for families where we're saying you know, you should get on and register for LPA, you should be doing this and that, advance decision making" *(Occupational Therapist)*
	Fear of seeing people further along the journey	"They won't access it even though it would probably be beneficial for them because they're worried about what they might or might not see." *(Nurse)*
"Well I don't know, but I don't feel I'm supported"	People not feeling as though they are supported	"Because we've had a lot of people that just say 'oh I haven't been given any support'. And we've invited them, made sure they're getting the invitations and then they still haven't joined." *(Occupational Therapist)*
	People not engaging with support	"I was going to say going on that, what we do sometimes, we give so much information out all the time, and people still don't take anything up and we still end up doing most of the things for them." *(Nurse)*

Appendix I: SIP: Relevant quotations from interviews

Subtheme	Description	Quotes
THEME 1: RECEIVING THE DIAGNOSIS		
Reaction to diagnosis	Knowing the diagnosis was coming	"I think we'd known there was a problem for some time" *(Carer 7)*
		"I think a relief because it meant there was something wrong" *(Carer 1)*
	Relief at the diagnosis	"Once the diagnosis came in… it was as if for the first time we could just sort of look at it face to face." *(Client 1)*
		"It's quite difficult to come to terms with it, especially at such a young age. Normally, you associate… well I used to associate dementia with 70's, 80's, and you know, you only turned 60 earlier this year didn't you. So that's the hard bit". *(Carer 7)*
	Surprise by the diagnosis	"I don't think for [person with dementia], because [he's] been so poorly for such a long while, I don't think he specifically noticed the symptoms of the dementia creeping up on him" *(Carer 5)*
		"Bit of a bloody kick in the knackers basically, it's hit me in, dunno which way to turn." *(Client 5)*
	Not agreeing with diagnosis	"Well it's difficult really because I didn't feel as though anything was wrong with me" *(Client 2)*
		"I think that the people that have diagnosed me with dementia need to go back to college and learn how to diagnose people because I don't think there's nothing wrong with me" *(Client 4)*
Responses later in the journey	Negative emotions	"Sadness really, is the driving emotion" *(Carer 7)*

		"It's quite a pessimistic diagnosis really" *(Carer 5)* "It's not an easy diagnosis to get your head round. As much as before we got it we were pretty certain this is what we were dealing with but even so, once we got it it took me about 3 weeks to get my head around it, I really… because it was final. All of a sudden it was this is what you've got, and as much as it opens up lots of opportunities for us and lots of support and lots of groups to go to and people to be able to ask and this type of stuff, which was great, it's still you've got it in black and white." *(Carer 5)* "We're mourning in a way the life that we can't have that we thought we would have" *(Carer 5)*
	Adjusting to diagnosis	"You know we're dealing with a whole new set of problems that we've not had before, and that's, you know, it's trying to navigate your way down this path that's being a bit brambly." *(Carer 5)* "I was probably not for it but I'm not accepting it now, accepting of the situation and trying to make the best of it, you know." *(Client 3)*
Therapy? Or something you learn to live with?	Therapy not useful	"Well I think it's just something you've got to learn to live with really, it's… you can talk about it all you want but it's just going to be there at the end of the day anyway, so I'm not one for naval gazing really." *(Carer 7)* "Well I'll end up in a box whichever way it goes." *(Client 5)* "My Dad always told me when I was kid, son, silence is golden, that's it. Got to be quiet." *(Client 4)* "It's just, I feel that, if there is something wrong with me it's my business and nobody else's so it's up to me. And if I've got a problem that I can't get over, I can do what you and everybody else does, phone up the GP, go and see the doctor, go and explain to the doctor what I feel the problem is, and he can say this that. I don't have to tell members

		of the family or members of the public what's wrong with me." *(Client 4)*
	Cognitive issues making therapy inaccessible	"It was in the pipeline for him to maybe speak to a psychologist… and it was sort of determined that because of [person with dementia's] diagnosis… if he saw a psychologist say on a weekly basis, because of his retaining of the information …they didn't think be that beneficial for him." *(Carer 3)*
	Therapy would be useful	"I'm surprised there isn't any art therapy or drama therapy because I think that would be much more helpful" *(Carer 1)*
		"I think that this is the thing is this area of work where it is long-term, you know, it's a bereavement, and nobody tells you how you can do that." *(Client 1)*
Initial group meeting unhelpful	This meeting could be improved	"We didn't really like that meeting because it sort of, it was a bit mixed up in the fact that there was various people there but with different conditions and it just, it was a little bit depressing to be honest with you, a little bit depressing for me and [person with dementia], and but it wasn't really a meeting for people to say things, but people tended to go on a little bit, and it does sort of, it was, it was a bit boring you know, and we didn't get on with that meeting" *(Carer 9)*
		"[It was] death by PowerPoint" *(Carer 6)*
		"It was a long, it was a long process, a long process to sort of say I'm the occupational therapist, I'm the doctor" *(Carer 6)*
		"I had to take time off work, which I didn't think was necessary" *(Carer 6)*
THEME 2: PRACTICAL SUPPORT		
Knowing what paperwork to complete	Positive about help with form-filling	"You've got your bus pass now, you've got a blue badge for the car. They've, we've just in the past few days got the OK for the lasting power of attorney which they helped us with" *(Carer 7)*

		"Initially it was form-filling central here" *(Carer 7)* "You know, the amount of forms to fill in is… when it comes to form filling it's… it's nice to have help put it that way. And to know what forms to fill in in the first place." *(Carer 7)* "We have got somebody fighting our corner" [in relation to difficulties in claiming PIP] *(Carer 4)*
	Not needed for people with physical health	"I didn't know a lot of what you were supposed to be entitled to." *(Carer 4)* "I haven't particularly needed any help because we were doing it anyway." *(Carer 5)*
	Pressure to pursue PIP	"They seemed very much pressure, or biased or whatever, onto benefits, so they really wanted us to go down the PIP route, and we don't feel like we actually need it. We don't need it financially, and we don't, we feel that we don't need it. And they're very much a case of well it's there… So we don't really want to do it, but they really pushed us to do it I would say." *(Carer 6)*
Driving assessments	Frustration and worry about driving	**"**[It]upset me a bit because I rely on my car a lot like" *(Client 3)* "I just am a bit frustrated with it all" *(Client 3)* "It'd be rotten to see that I can't drive" *(Client 2)*
	Pressure from team to stop driving	"We found this process really stressful and I think this is probably one of the most stressful things that we've had to go through." *(Carer 6)* "The driving is his key to his independence, and we kind of felt like they were trying to

		take that away from us." *(Carer 6)*
Day-to-day support	Support with physical health	"She's very up-to-date isn't she, with things" *(Client 3)*
	Memory aids not priority	"I guess it would but I'm not quite sure how it would fit in" *(Client 1)* "He doesn't need that. I'm here, I'm here with him all the time" *(Carer 4)*
THEME 3: RELATIONSHIP WITH THE TEAM		
Expertise within the team	Strong relationship with the team	"She always, she'd always got time to sit down and talk and, you know like, we'd talk to her, and you know, everything okay and all that sort of thing" *(Carer 9)* "You're confident about having a laugh and a joke with her." *(Client 9)* "They've been, they've been really good, they're very understanding, and you know as you say it's all a bit overwhelming isn't it, when you first get the diagnosis and you get all this information coming at you and you're like wooahh, but once you figure out what you need and what you don't need, and just knowing that they're there, just knowing that they're on the end of the phone and if you do get in a pickle that you could pick the phone up and they'll answer. That's more than I could, you know I could answer, because it just makes it so much easier." *(Carer 5)* "They're very good at guiding us in the sense of like, I've never done this because I'm not the type anyway, but Google, you get a diagnosis and you Google it, and preparing for the future to answer you from my perspective is they've guided us towards the formal websites where we can get the formal information. They've been very good like that. When [person with dementia] got his initial Alzheimer's diagnosis, of course it encompasses a shock to hear the word, but he was very much, they're much that you're an individual in this situation, and they've never given comparisons, they've said you know we'll work with you at each stage of dual diagnosis, you know, it's taking each day as it comes and that's really what I feel they've instilled in us. Don't overthink it,

		don't overlook it, just go with it but we're here for you whenever you want us really." *(Carer 3)* "And she's really thorough isn't she. Really helpful. Doesn't matter how long she's on the phone for, she explains it and when you have your thick moment and say I don't get that bit, she goes over it again. I can't fault them from my perspective, I just can't, it sounds like we're just really lucky." *(Carer 3)*
	Nothing for team to improve on	"I can't think of anything that's not been helpful, really." *(Carer 7)* "All I can do is give some positive feedback" *(Client 3)*
	Not understanding rarer dementia	"I think the real issue is that they actually don't understand what PPA is" *(Carer 6)*
Role of the carer	Team over-relied on carer	"They're very reliant on me" *(Client 6)* "I'm literally like trying to juggle it on top of my own" *(Carer 8)* "I feel some of the time so much is on top of me. I feel like and there's no one to take any of it away from me, it is down to me, there's no choice, I've got to get on with it." *(Carer 8)* "For [person with dementia] it's very difficult for him to pick up the phone. It's difficult for him to write emails. So… you've alienated him already." *(Carer 6)*
	Wanting time to speak alone	"I think a massive thing would be that each person could have an opportunity to speak on their own. Because it gives that person a chance to go, do you know what, he's doing this to me, or he could go, she's doing this to me, at least that way someone's got a chance to open up and be able to just get off their chest... It would be a chance to put something there and, is that normal, should he be doing that, you know, without making that person feel stupid or like a child" *(Carer 8)*

"It's good to know that she's there"	Helpful to be able to contact team	"I'm sure if we needed, if we needed help we could get in touch and they'd come round." *(Carer 7)*
		"I wonder whether both [named 2 nurses within the team] did this emotional holding, they were very good, you know how they kind of helped you think about this new reality alongside practical help" *(Carer 1)*
	Keeping in contact with the team	"But what's really nice is that they keep, you know they keep in regular contact with us" *(Carer 5)*
		"I think it's just nice to have… the continuity of the same lady, face." *(Carer 4)*
	Feels intrusive	"It's sometimes you can feel it's intruding on your life, but you know sensibly that you need that connection with someone because you do need advice and help at times particularly going forward." *(Carer 2)*
		"We want to sort of live our lives fairly normally at the moment." *(Carer 2)*
		"I think you want to feel like you're sort of still in control of your own life and that you're making your own decision and that" *(Carer 2)*
THEME 4: GROUP SUPPORT		
Being around others with young-onset dementia	Meeting others with YOD	"Nice meeting people who are in similar circumstances" *(Carer 7)*
		"It helps with other people of your age and you can actually communicate with them and they're in the same situation as you aren't they" *(Carer 9)*
	Not having to explain YOD	"You go somewhere where you're not judged, you don't have to explain yourself, you just turn up" *(Carer 5)*

		"You can kind of talk to each other and you don't feel so isolated or the odd one out because everyone has similar experiences" *(Carer 1)*
		"They basically know that I've got a, got a problem, so they adapt themselves to suit me." *(Client 5)*
		"With the dementia I think he feels that he's treated more like normal." *(Carer 9)*
	Seeing others in a worse position	"I think that I'm not doing too bad compared to what they are." *(Client 2)*
Light-hearted vs serious nature	Wanted light-hearted and fun group	"Well when the meeting's finishing and anything like that, we talk about football … we don't think how's your dementia getting on." *(Client 9)*
		"I think it would be better to chit chat" *(Client 6)*
		"We were talking about the Russia invasion, just about the politics, just current information." *(Client 6)*
	Space to talk about negatives	"There can be a tendency that it can leave out the grief, the bereavement, the losses people have felt, and there is no space for that because people get jollied along, let's all be jolly and happy when actually it's bloody awful." *(Carer 1)*
		"It's really interesting, you know, kind of thinking about the elephant in the room, because we can have this manic defence you know, 'let's cheer up, have a cup of tea,' but actually if we learn to understand it then I think as we go further down the line hopefully you understand yourself better and you won't have to be as anxious." *(Client 1)*
Practicalities of groups	Meeting face-to-face	"Because you can talk to each other a bit easier." *(Client 7)*
	Driving not a barrier	"If it's local it wouldn't be a problem." *(Carer 7)*

		"That would be absolutely fine for me to drive" *(Carer 9)* "They offered taxi, they offered, I don't think they offered car share because I don't think you can covid-wise, but they were very, very positive in actually getting him there, there really wasn't any barriers or any excuses really." *(Carer 6)*
Frequency of groups	Wanting more groups	"More get togethers probably with people in similar circumstances" [when asked how the team could improve] *(Carer 7)*
	Anxiety around groups ending	"In an ideal world… there'd be something ongoing." *(Carer 2)* "You've kind of formed a little bond with people there and obviously it's going to be quite sad when that comes to an end" *(Carer 1)* "It's a shame because I think, what is it another 3 weeks time, that's the end of it and I don't know what will happen after that." *(Client 2)*
	Open to occasional groups	"Even pre his diagnosis, like the groups and things, he would never really have wanted to have been a joiner even pre-diagnosis. Together we're not great socialites and things like that." *(Carer 3)*
	Wanting to keep social life separate	"We used to go to care homes and do the manual repairs… I actually look at some of these people and think Christ what's wrong with that person… I wouldn't want somebody coming in here and saying, even if they're only just saying it to themselves, oh you know that bloke's a bit mad, such and such, you know." *(Client 4)* "I'm happy playing my pool on a Wednesday, I don't need to go into a special unit to go and play it" *(Client 4)*
THEME 5: THE FUTURE		

Maintaining independence	Support in maintaining independence	"You want to stay independent or keep your independence for as long as possible don't you" *(Carer 7)* "It's difficult to know what else we can do to, you know, sort of keep you engaged in things isn't it? That is my worry" *(Carer 2)* "You don't need to be put out to grass" *(Client 1)* "She encourages you to, not to let the illness define you, keep living and doing the things you enjoy really, doesn't she." *(Carer 3)* "I know I've got problems but I want to get back into something" *(Client 8)* "[Person with dementia] doesn't go anywhere or do anything really do you, unless I force him" *(Carer 8)*
Planning for the future	Not ready to think about the future	"I don't wanna know, I just take each day as it comes" *(Carer 9)* "I know perhaps it's a bit irrational but you just hope that you'll go on like this for as long as you possibly can" *(Carer 2)* "If you let yourself dwell on things too much then it can get too much. You know, sometimes if you, I don't know I just feel that I'm coping better by just doing what we're doing, living our lives as best we can, but know that if suddenly we need help then it'll be there" *(Carer 2)*
	Wanting a plan for the future	"How do I deal with the future? You know that's another thing, neither of us knows, I've got so many questions about what's gonna happen" *(Carer 8)*
Uncertainty regarding the future	Not knowing what future will look like	"Especially when you're younger, we don't know what's coming 5 years down… you know we don't know how, we don't know what you're prognosis it, we're none the wiser." *(Carer 5)*

		"One of the things that we often comment upon, and we've spoken in the group about is, is you just don't know" *(Client 1)*
	Future of support from the team	"Here we will leave the young dementia team at 65, so that is quite significant." *(Carer 6)*
		"Something actually I'm not clear about, whether we're now on their books forever, or whether if [PWD] changing his age, is he going to move into another service. And that would be terrible because [PWD] so you know can't identify with older people because they're in a different stage of life if that makes sense." *(Carer 1)*
THEME 6: SUPPORT FOR THE FAMILY		
How much input should the team have with supporting families?	Not prioritising family support	**"**I think most of the people we know are intelligent enough to know… and probably have other people, relations and that who've been affected by dementia as well" *(Carer 7)*
		"I don't personally, I don't think the team could have helped us much in that area. I think that is sort of a bit more of a personal thing, I think, I think generally we've been given a good overview of what it is, the symptoms, where to go, where to research, so I think probably of us both either one would share updates with the family, and they've taught me a lot really about the condition and whatever, so I think we've been primed with enough information to share with the family without any involvement" *(Carer 3)*
		"We'll deal with it as a family you know" *(Carer 9)*
		"I knew that I had to do it and I knew the words I had to say and I knew how I had to approach it." *(Carer 5)*
	Wanting support to explain rarer dementia	"We did ask them how to tell people that you've got dementia as such, and we got given

		an Alzheimer's card. He doesn't have Alzheimer's." *(Client 6)*
	Therapy for family members useful	"Well [daughter], she's had psychology sessions hasn't she… and I think that's been very helpful." *(Carer 1)*
Support from the family	Diagnosis not impacted family relationships	"Well family, they've been very good" *(Carer 7)*
		"They've all started accepting it" *(Client 3)*
	Occasionally people distance themselves	"You can't force people" *(Carer 7)*
THEME 7: PHYSICAL HEALTH PROBLEMS		
Greater focus on dementia diagnosis	More support from dementia team	"We've had more support from that team than we have really from the Parkinson's Team, you know like, we don't sort of, we haven't had any, sort of, interaction with them or we haven't had any suggestions from them to do different things. It's only the dementia team that have been, you know, proactive in finding something for him to do." *(Carer 9)*
Joined-up care	Wanting more joined-up care	"They should all be conversing together" *(Carer 9)*
	Not wanting more joined-up care	"I think they're good enough" *(Client 3)*
		"I like to know what's going on. I like to know what everybody's doing" *(Carer 5)*

Appendix J: SIP: Feedback questionnaire for participants

Are you satisfied with the practical support the team is providing you? *(Prompts: memory aids, adaptations to the house, support for your physical health problem)*

- Yes
- No
- I do not need any practical support

Please give any more information below:

……
……

Are you satisfied with the emotional support the team is providing you? *(Prompts: therapy, emotional support within groups, providing emotional support during home visits)*

- Yes
- No
- I do not need any emotional support

Please give any more information below:

……
……

Are you satisfied with the financial support the team is providing you? *(Prompts: benefits, Blue badge etc.)*

- Yes
- No
- I do not need any financial support

Please give any more information below:

……
……

Are you satisfied with the social support the team is providing you? If you don't feel you need any social support, please tick "not applicable" *(Prompts: groups, signposting to services)*

- Yes
- No
- I do not need any social support

Please give any more information below:

……
……

Are you satisfied with how the team is helping you consider the future? *(Prompts: practical support such as LPA, emotional support such as coming to terms with diagnosis)*

- Yes
- No
- I do not want to consider the future

Please give any more information below:

……
……

Are you satisfied with how the team is supporting your family/friends? *(Prompts: working collaboratively with carer, providing therapy for family if appropriate, providing information about dementia for families/friends)*

- Yes
- No
- I do not need the team to support my family or friends

Please give any more information below:

……
……

Are you satisfied with the teams' knowledge and expertise about dementia?

- Yes
- No

Please give any more information below:

……
……

Is there anything else you think would be useful for the team to know?

……
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**It was agreed in the feedback session that clients should be offered to complete this at 3 months post-diagnosis, and then every 6 months after this. Questionnaires could be filled out by clients and/or carers, and clients could have a choice to fill this out with their care co-ordinator or with someone else in the team.*

Appendix K: TDRP: Author guidelines for 'Addiction'

Author Guidelines

Addiction will be published in online-only format effective with the 2023 volume. This is a proactive move towards reducing the environmental impact caused by the production and distribution of printed journal copies and will allow the journal to invest in further innovation, digital development and sustainability measures. Published articles will continue to be disseminated quickly through the journal's broad network of indexing services, including Web of Science, MEDLINE and Scopus. Articles will also continue to be discoverable through popular search engines such as Google.

Sections

1. Submission and Peer Review Process

Addiction welcomes manuscripts reporting original research on clinical, epidemiological, human experimental, policy-related, and historical aspects of addiction and addictive behaviours including, but not limited to, alcohol, opioids, stimulants, cannabinoids, tobacco, nicotine, and gambling. *Addiction* does not publish single clinical case reports. *Addiction* does not publish animal research – but authors of this research may wish to send their manuscript to *Addiction Biology*.

We strive to give authors a prompt service in terms of the time it takes to complete an initial evaluation of a manuscript, and if taken forward, completion of its peer review. Usually, we complete the former in 1-2 weeks, and the latter within 6-8 weeks. We can also *fast track* manuscripts with highly important findings that will inform practice and policy; here, our aim is to complete the review process within 2–3 weeks. Please contact the **Editor-in-Chief** if you have a manuscript nearing completion and you would like us to consider expedited review.

Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at http://mc.manuscriptcentral.com/addiction

Addiction requires all authors to provide a declaration of interests statement.

We will not normally publish editorials, reviews, and commentaries that refer to a commercial organization, its affiliates, and any product or device, where the author has a

financial connection with the organization or product in any of the following categories of conflict of interest: shares, consultancy, employment, honoraria for providing lectures, and any work on the manuscript that has been funded with support of a commercial organisation.

2. Article Types published in *Addiction*

Research Reports

Research reports are expected to contain a quantitative, qualitative, mixed-methods or narrative analysis. When producing a findings manuscript from these studies, we approve of presentation economy and judicious editing. Placing material in an appendix is often a good means of keeping a manuscript within limits; but we recognize that some manuscripts – especially those describing complex methods and findings – need more space.

As a guide on word length (excluding abstract, tables, figures, and references):

- a quantitative short-report should not exceed 2,000 words (with no more than 15 references);
- a quantitative research report from an observational study should generally not exceed 3,500 words unless the authors provide good reason;
- the editors recognise that certain research designs and analyses - including but not limited to randomised controlled trials and other experiments, complex observational follow-up cohort studies, and qualitative and mixed-methods evaluations - need more space to clearly describe their methods and procedures, but authors are nonetheless strongly encouraged to not exceed 4,500 without a clear justification set out in a covering letter;

Authors wishing to submit longer reports should contact the **Editor-in-Chief** to discuss.

Below is our specific guidance on the various types of research report we publish:

- Reports on randomized controlled trials must concern a registered study. There are several international and regional registries including gov and ISRCTN. The front page of the manuscript should specify the trial registration number, the date of registration and when this was done. This should also be shown in the method section along with a link to the registry location if possible. Usually, the trial is registered before enrolment of the first participant. Any change to the protocol must be described.
- Descriptions or evaluations involving interventions should use the TIDieR checklist. To assist review and for later reproducibility, studies on psychosocial interventions should include a link to a protocol or other materials, or submit supplementary material for the article's on-line appendix.
- **Observational studies** should be reported following the STROBE or TREND guideline.
- **Qualitative studies** should be reported following an appropriate guideline (e.g. COREQ, SRQR, RATS, and CASP). Our guidance on qualitative studies can be found here and here.

- **Economic evaluations** should use the CHEERS guideline.
- **Diagnostic accuracy evaluations** of instruments and measures should use the STARD
- Reports on randomized controlled trials should conform to the CONSORT guideline and use the appropriate extension (e.g. for pilot and feasibility trials; pragmatic trials; non-pharmacologic treatment interventions; multi-arm parallel group randomized trials; cluster randomized controlled trials, and adaptive designs). All items specified on the CONSORT checklist should be included in the main text of the report, even if they have previously been included in a protocol or registration document. It is not sufficient to simply reference such documents on the CONSORT checklist.

Please note that authors must complete the appropriate guideline checklist and submit this alongside the manuscript. Reviewers will use this to check compliance.

Pre-registration of analysis plans

Addiction encourages pre-registration of the analysis plans for the analysis of data and requires that all manuscripts report whether or not pre-registration was conducted.

A pre-registered statistical or health economic analysis plan presents a detailed description of the research aims and hypotheses, along with a detailed description of which measures will be used, and how these will be analyzed (including the level of statistical precision to be used for estimates) and who will be involved. The analysis plans for quantitative study designs will usually describe how missing data will be managed, and which sensitivity analyses are planned, and they may describe command syntax for statistical software. There may be some uncertainty, so the plan may set out some decision rules that will guide the approach taken for the analysis. At present, it is uncommon for qualitative studies to pre-register their analysis plans, but we encourage authors to do so. Note that editors and peer reviewers look favorably on the reports that follow the discipline of pre-registration.

Contributors need to ensure that the description of research questions, hypotheses and how outcomes are described align with the stated (and registered) aims of the study. If there is any deviation, this needs to be justified. Pre-registration of a file setting out the analysis plan can be done straightforwardly using the **Open Science Framework**. A link to a pre-registered analysis plan must be given in the statistical analysis section of the method along with the date of publication. Please note that if the analysis was done without pre-registration, the findings should be described as exploratory. More information is available **here**.

Reviews

Reviews are highly valuable communications for our readers. They draw together a body of literature to summarise what research has been done on a specific topic and are a source of knowledge. Reviews are expected to be registered (**PROSPERO**) and be reporting according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (**PRISMA**). A PRISMA checklist must be submitted as an additional file for review. All reviews will be 'systematic', which means they will set out very clearly the search strategy (including key

words where appropriate), the selection criteria for articles to include, the basis for integrating findings, and procedures used to evaluate quality and bias. Where possible we expect a suitable, bounded body of research to be subject to statistical meta-analysis; but we recognise that this is not always feasible, and a narrative synthesis should be the described approach. Reviews that do not conform fully to PRISMA may be considered if authors can provide a convincing case that the procedures used are not likely to lead to bias in the conclusions. We recognize that reviews often have a lot of material to present, but we ask authors to aim for 4,500 words (excluding abstract, tables, and references). Very long tables may need to be placed in the on-line appendix.

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Articles must be based on original historical research, arising from archival research and/or the analysis of original documents as well as a thorough literature review that sets the article in the context of existing work. We expect the discussion section to offer some commentary on current and future theory, policy, or practice. A length of 3500 words is preferred (excluding notes and references) but we will consider longer articles.

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Monographs should be structured as research reports or reviews as appropriate.

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The **CONSORT statement** checklist on reporting and the companion guidance notes should also be followed to ensure that close alignment with CONSORT is built into the planning of the trial (see references). The word limit is normally 4,500 words. Authors of protocols should note that the journal places no requirement on them to submit subsequent research reports to the journal. Contributors to this section are encouraged to contact the Editor-in-Chief if they are uncertain about the suitability of their protocol for the journal. Protocol submissions will usually be screened before a review decision is taken using the below key methodology features.

(1) A single primary outcome with a clear description of the basic clinical measure and how it translates into an analysed comparison variable (e.g. change from baseline, final value, time to event). If a clinical measure has been recorded at more than one follow-up time point, the primary comparison variable should be specified at a single time or for a single time interval. Outcomes at other time points should be specified as secondary. If supported, a repeated measure analysis model can be used for the primary outcome variable analysis, although the focus on a single key point is essential.

(2) A description of the analysis plan will set out the specific methods to be used, particularly in relation to the primary outcome variable comparison, and should include a clear justification for why the method is most appropriate. The assumptions underpinning the handling of missing data should also be given, preferably in terms of the MCAR, MAR or MNAR framework. Sensitivity analyses around these assumptions are usually warranted.

(3) The statistical power to detect an effect on the primary analysis variable should ideally be 0.95, such that both alpha and beta are 0.05, although in situations where samples are practically restricted, 0.9 power (beta = 0.1) might be considered. A clear justification for the sample size should be given, based on previous work. This should be based on an effect size expressed in the natural clinical units, rather than a generic measure.

References:

1. The SPIRIT statement
2. The CONSORT statement

3. Moher et. al. CONSORT 2010 Explanation and Elaboration: updated guidelines for reporting parallel group randomised trials. BMJ 2010;340:c869 doi: 10.1136/bmj.c869

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- Word count (excluding abstract, references, tables, and figures);
- Declarations of competing interest;
- Primary funding;
- Clinical trial registration details (if applicable).

Structured abstract (see further instructions below);

Six to ten keywords;

Main body;

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Tables (each table complete with title and footnotes);

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Statistical parameters used to estimate an association must be accompanied by a confidence interval (the 95% interval is standard). Exact p-values from statistical tests should be reported. Please avoid use of the term 'trend' for analyses that fall short of the set level of statistical precision used in the study. Care should be taken to avoid the phrase 'no difference' when a tested comparison is not statistically significant since this could well be due to insufficient power. Null findings should be described as 'inconclusive' or lacking clear evidence for an effect. Calculation of a Bayes Factor or Credible Interval is encouraged. More information is available **here**.

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Appendix L: TDRP: Approval letter

North of Scotland Research Ethics Committee (1)
Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Telephone: 01224 558458
Email: gram.nosres@nhs.scot

NHS Grampian

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

25 February 2022

Ms Lorna Hogg
Deputy Director (Clinical and Professional) & Consultant Clinical Psychologist
Isis Education Centre
Warneford Hospital
OXFORD
OX3 7JX

Dear Ms Hogg

Study title:	**The relationship between loneliness and substance misuse recovery: a longitudinal study**
REC reference:	**22/NS/0023**
Protocol number:	**PID15945**
IRAS project ID:	**300494**

The Research Ethics Committee (REC) reviewed the above application at the meeting held on 24 February 2022 via MS Teams. Thank you and Miss Emma Corcoran for attending to discuss the application.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Appendix M: TDRP: Adapted TOP form

SUBSTANCE USE QUESTIONNAIRE

The next few questions will ask you about your substance use over the last 28 days.
If it is difficult for you to work this out, it may be easier for you to calculate how many days you have used substances over the last week, and multiply this by 4. If you have not used a substance in the last 28 days, just put 0.

Over the last 28 days, on how many days have you used?

Alcohol:

……

Opiates/opioids (including street heroin and non-prescribed opioids):

……

Crack:

……

Cocaine:

……

Amphetamines:

……

Cannabis:

……

Tobacco:

……

Other (please specify): ……

Appendix N: TDRP: Important Contact Questionnaire

Important Contacts Questionnaire

Please tick up to three types of people that you feel as though are the most important people in your social network at the moment:

- € Parent(s)
- € Child(ren)
- € Sibling(s)
- € Other family member
- € Partner/spouse
- € Friend(s) (made before you entered treatment)
- € Friend(s) (made after you entered treatment)
- € Care co-ordinator or other key worker in your treatment
- € Neighbours
- € Colleagues/co-workers
- € People from a religious group
- € Other: (please specify)

Appendix O: TDRP: Characteristics of All Participants

	Mean (continuous variables) Percentages (categorical variables)	Standard deviation (range)
Continuous variables		
	Mean	Standard deviation (range)
Age	48.6	10.5 (20-72)
Substance Misuse Score (Baseline)	53.2	37.5 (0-196)
Loneliness	55.9	16.7 (20-80)
Social Network Score	7.2	7.5 (0-39)
PHQ9 Score	15.6	7.3 (0-27)
GAD7 Score	12.0	6.6 (0-21)
Categorical variables		
Gender	69.7% male 29.8% female 0.6% non-binary	
Ethnicity	74.2% White 9.0% Black 6.7% Mixed 5.6% Asian 2.8% Other 1.7% Prefer not to say	
Marital status	42.9% Divorced or formerly living in a marital-like relationship 26.6% Never married or lived in a marital-like relationship 12.4% Married or living in a marital like-relationship 11.3% Separated 7% Widowed	
Employment	89.2% unemployed 10.8% employed	

References for Appendices

Kmet, L., Lee, R., & Cook, L. (2004). Standard quality assessment criteria for evaluating primary research papers from a variety of fields. https://www.crd.york.ac.uk/crdweb/ShowRecord.asp?LinkFrom=OAI&ID=32004000313&LinkFrom=OAI&ID=32004000313

Tsai, P.F. (2003). A middle-range theory of caregiver stress. *Nursing Science Quarterly*, *16*(2), 137–145.