Working with Older I

Building an initial understanding of UK Recovery College dementia courses: A national survey of Recovery College and memory services staff.

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Abstract

Purpose: Recovery Colleges were developed to support the recovery of people with mental health difficulties through courses co-produced by professionals and people with lived experience. This study examines the use of Recovery Colleges to support people with dementia.

Design/methodology/approach: A survey was circulated to UK Recovery College and memory service staff, exploring provision, delivery and attendance of dementia courses. Open responses provided insight into participant views about recovery in post-diagnostic support and the practicalities of running dementia courses.

Findings: 51 Recovery College staff and 210 memory service staff completed the survey. Twelve Recovery College dementia courses were identified across the UK. Three categories emerged from the qualitative data: post-diagnostic support, recovery in the context of dementia, challenges and areas of innovation.

Originality: This study highlights the benefits and practicalities of running Recovery College courses with people with dementia. Peer-to-peer learning was seen as valuable in post-diagnostic support but opinions were divided about the term recovery in dementia.

Key words: dementia, post-diagnostic support, recovery college, memory services, co-production, peer support

Introduction

A Recovery College provides educational courses that aim to support the personal recovery of people living with mental health difficulties. There are many definitions of 'recovery' in mental illness, but for the purpose of this paper, 'recovery' refers to managing symptoms whilst living a meaningful life (Perkins *et al.,* 2012). Recovery Colleges emerged in America in 2000, and now exist in over 20 countries (including Canada, Hong Kong, Israel, Italy, Japan, the Netherlands, and Sri Lanka) and an international community of practice has been established to promote knowledge exchange (Whittley *et al.,* 2019).

Recovery Colleges have an ethos of empowerment and inclusivity (Whish *et al.,* 2022) realised through co-production and co-facilitation, with experts by experience collaborating with healthcare professionals to co-produce and co-deliver courses (Whittley *et al.,* 2019). Recognising that the consequences of an illness such as discrimination (Anthony, 1993) may be more detrimental than the illness itself, courses cover a range of topics to support people through the recovery journey, including self-management, employment advice and understanding and exploring identity.

UK Recovery Colleges are typically embedded within the National Health Service (NHS), with some run by voluntary organisations. They have been shown to have a positive long-term impact for individuals experiencing mental health difficulties (Thompson *et al.,* 2021); where attendance is associated with improved quality of life, self-management skills, and goal achievement (Thériault *et al.,* 2020). Ongoing research examines how Recovery Colleges can benefit people who use mental health services (Recovery Colleges Characterisation and Testing (RECOLLECT) programme (Henderson *et al.,* 2020), as currently little is known about who benefits from them and why. Some groups, including people with dementia, appear to be underrepresented in Recovery Colleges (Bowness *et al.,*

2022). A scoping survey of UK Recovery Colleges (2019) found that 11 (39.3%) of the 28 that responded, offered dementia courses (Lowen *et al.,* 2019).

A recovery-based approach could enable people to live a meaningful life alongside dementia (Gavan, 2011). A key definition of recovery within mental health, aligns closely with definitions of living 'well' with dementia (Department of Health (DH), 2009) and calls to focus on strengths rather than deficits (Wolverson *et al.,* 2016). The importance of education to support living positively with dementia is well recognised (van Horik *et al.,* 2022), as is the value of peer support as highlighted in the UK's national dementia strategy 'Living Well with Dementia' (DH, 2009).

Recovery Colleges could potentially drive culture change within mental health services by challenging power dynamics between clinician and patient (Hopkins *et al.,* 2022) and increasing inclusivity and equitability, which is urgently needed within post-diagnostic services provided to people with dementia. According to people with dementia and their families, post-diagnostic support does not meet their needs and access to support can be difficult depending on where people live, resulting in inequalities (Frost *et al.,* 2021; Robinson & Arblaster, 2020) and feelings of abandonment by the health system (Kelly & Innes, 2014). This has been further impacted by the COVID-19 pandemic, with people left to self-manage due to reduced healthcare service provision (Giebel *et al.,* 2021). Recovery Colleges, therefore, could provide an innovative and empowering approach to post-diagnostic support for people with dementia and their families while bridging a critical gap in healthcare provision. However, there is little currently known about current provision to support dementia within the Recovery College model.

To address this knowledge gap, we undertook a national survey examining the views and experiences of individual Recovery College and memory service staff regarding recovery-led

approaches for people with dementia. We aimed to establish how many UK Recovery Colleges offer dementia courses and specifically we sought to understand:

- How have dementia courses been designed and delivered?
- Who has attended dementia courses?
- How has COVID-19 impacted course provision?
- What do professionals understand by the term 'recovery' in the context of dementia?

This work was the first step of a research project called DiSCOVERY (NIHR131676, 2022-2024) which aims to provide guidance for co-producing, implementing, delivering, and evaluating Recovery College dementia courses.

Method

A multi-site, cross-sectional, mixed-methods questionnaire study was conducted with UK Recovery Colleges and memory services from April to June 2022.

The survey was created using SurveyMonkey® (Momentive Inc., 2022) and contained 74 questions, across 6 sections exploring: the development and provision of dementia courses in Recovery Colleges and memory services, the practicalities of co-production and the impact of COVID-19 (see supplementary file). Following demographic questions, participants were asked different questions depending on whether they identified as predominately working in a Recovery College or memory service. Recovery College staff were asked about their links with NHS memory services and their understanding of the term 'recovery' in dementia. Memory service staff were asked whether signposting to Recovery College dementia courses was part of routine clinical practice, whether the term 'recovery' was used in relation to dementia and if staff were co-producing dementia courses in their local Recovery College. The survey comprised of multiple-choice questions and open response items. It was based on a previous scoping survey (Lowen *et al.,* 2019) and created

by the research team who are from a range of professions including psychology, psychiatry, and nursing. The draft survey was shared with four memory clinic clinicians and two Recovery College staff, for piloting to ensure questions were answerable, coherent, and specific. Following adjustments in response to feedback, the survey was reviewed by the wider research team. The final survey was user-tested by members of the research team to ensure functionality.

Recruitment

A short film introducing the study was co-produced by study staff and Patient and Public Involvement group members. This, alongside the survey invitation was emailed to 41 NHS mental health trusts. Contact details for Recovery Colleges were found through hand-searching organisational websites. Targeted distribution included the Royal College of Psychiatrists Memory Services National Accreditation Programme; Implementing Recovery through Organisational Change networks; the Faculty for the Psychology of Older People; Facebook Psychology groups and Occupational Therapy networks. The survey was advertised on social media platforms including Facebook and Twitter, and the DiSCOVERY webpage.

All staff working in a Recovery College or memory service were eligible to participate, including those organisations that did not have a dementia course, and multiple responses from each site were allowed. Mental health trusts without a Recovery College or memory service were not eligible. Four NHS trusts declined to participate as it was not relevant to them and two stated they do not have a Recovery College.

The recruitment target was 70 responses based on a response rate of 50% from all UK Recovery Colleges and mental health Trusts.

Data Analysis

Descriptive statistics and tables were used to summarise quantitative data. Qualitative content analysis was used to analyse the open responses (Bengtsson, 2016). Open responses underwent repeated reading by two researchers. Key points were identified, and initial codes were generated then sorted into potential themes which were discussed and reviewed to ensure they were distinguishable and relevant to the research question. Responses provided contextual understanding to the quantitative data.

Ethics

The study was approved by the West Midlands - Coventry & Warwickshire Research Ethics Committee (22/WM/0021) on 9/3/22 and the Health Research Authority on 16/3/22.

Results

Response rates

The survey recorded 261 completed responses. From this, 51 were from staff who identified as predominantly working in Recovery Colleges, 210 from memory services and 38 responses were incomplete. An incomplete response was defined as any response without an organisation name or if it was unknown whether the respondent worked for a Recovery College or memory service. Table I shows the number of responses received from each UK region including the number of Recovery College dementia courses identified.

TABLE I

Recovery College support for people with dementia

Responses related to current, historic, and future dementia courses are shown in table II. There were 12 current courses relating to dementia support across the UK which were identified in the survey. Fourteen (6.7%) memory service respondents reported routinely guiding people to Recovery College dementia courses for post-diagnostic support, 124 (59%) stated they did not, and nineteen (9%) had recommended non-dementia-specific courses. It should be noted that multiple responses could represent the same service.

TABLE II

Course delivery

Five (26.3%) of the 19 Recovery College respondents that stated they currently or previously ran a dementia course, reported their course was co-produced with people with dementia, compared to three (13%) memory service responses. Table III shows who courses were delivered by.

TABLE III

Who attends Recovery College dementia courses?

Recovery College respondents provided demographic information/estimates about attendees of their dementia courses, which are displayed in table IV.

TABLE IV

The impact of COVID-19

Of those that responded to questions about the impact of COVID-19, three (25%) said their dementia courses stopped running. Three Recovery Colleges attempted to adapt to difficulties brought on by lockdown restrictions by moving online.

Qualitative Results

Content analysis derived three categories and six sub-categories from the data (see table V).

TABLE V

Post-diagnostic support

This theme encompasses the value of post-diagnostic support and the importance of co-production.

The value of post-diagnostic support

All respondents valued post-diagnostic support for people with dementia and their families. Memory services often had their own bespoke support:

> *We provide in house "Understanding Dementia" courses and have a post-diagnostic clinic. – Memory service participant #043*

> *We have a Carers Support group and are exploring a Living Well with Dementia intervention. – Memory service participant #177*

Recovery colleges that developed dementia support recognised an unmet need following diagnosis;

> *We recognised that our older adults services did not have coproduced education available for their service user and carer group. – Recovery College participant #025*

> *The courses were started to ensure support, including peer support and choice was given to both those people living with dementia and those supporting them. – Recovery College participant #014*

All respondents viewed 'education' as central to post-diagnostic support. Ensuring people understand dementia and learn practical approaches to manage, was seen as essential to living well with dementia;

> *Also to provide education to [people with dementia] and their carers regarding maintaining a safe home environment and understanding about their condition. – Recovery College participant #024*

The importance of co-production

The best-practice in delivering education was including people with dementia as experts by experience. Recovery Colleges and memory services with dementia courses recognised that co-production was essential to their success.

> *Person living with dementia is absolutely key to this course and I don't think it would be valid without her. – Recovery College participant #002*

This is the most essential part of the course - they provide first-hand experience of positive role models of people living well with dementia. Their experience and voice is far more powerful than what clinicians are able to bring as they live and breathe it with first hand lived experience. – Memory service participant #073

Recovery in the context of dementia

Whilst agreeing on the value of post-diagnostic support particularly when co-delivered alongside people with dementia, the notion of dementia 'recovery' resulted in strongly divided opinion. For some, the idea of recovery echoed their understanding of living well and related to having a 'life worth living'. Key to recovery was maintaining independence and autonomy, a sense of self and social support, living well 'despite', 'regardless', 'within limits' of dementia;

Supporting people to take control of their lives and live a meaningful, safe quality of life. – Recovery College participant #024

It's about supporting people to keep their identity and a sense of self – living with dementia without it defining them. – Recovery College participant #027

In contrast, some participants expressed that the word 'recovery' did not apply to dementia given its progressive nature and the lack of a cure;

There is a fundamental problem with the term "recovery" with respect to dementia, not least that living well with dementia is a lot about acceptance of and adjustment to

the fact that you are not going to "recover" in the commonly accepted sense. – Memory service participant #099

"Recovery" is a challenging concept to apply to dementia, given it is degenerative in nature. – Recovery College participant #025

Some memory service participants expressed concerns that the term recovery could engender false hope in dementia specifically, due to the lack of current cure for the condition;

It is a rather unusual word recovery, when discussing dementia as there is no cure or recovery involved. The word recovery could give our clients false hope. – Memory Service participant #105

Challenges and areas of innovation

This category includes reasons courses have stopped, difficulties with staffing and partnership working.

Awareness of recovery orientated services

Despite Recovery Colleges offering a range of courses that may be useful for people with dementia, some memory service respondents had never heard of Recovery Colleges;

I've been running our memory clinics services since 2005 and have never heard of Recovery College" – Memory service participant #063

Other memory service participants were unaware that Recovery Colleges could offer support to people with dementia;

> *I was not aware this was available. Recovery college has seemed to be primarily aimed at working age adults. – Memory service participant #010*

> *I'm ashamed to admit that, as a clinician working in memory services for 6 years, I was unaware that the recovery college applied to those with dementia. – Memory service participant #059*

However, many respondents expressed interest in finding out more:

> *It would be good to link up with the Recovery College as it has not been so much on our radar. It is a valuable resource. – Memory service participant #136*

Participants raised concerns about support for people with dementia being offered outside older peoples services;

> *We do not run dementia courses as they are best run by the specialist older people's teams. We do however support specialist teams to coproduce recovery college style courses that they can then run. – Recovery College participant #009*

Difficulties in running courses

Respondents who offered recovery courses in dementia described practical difficulties in maintaining the courses.

We haven't run it for some time due to the nature of dementia meaning people involved in coproducing or delivering the workshops were no longer available due to changes in their wellbeing. – Recovery College participant #025

It was frequently highlighted that the relationship and integration between Recovery Colleges and memory services could be improved;

Don't think we have any connection with the memory service. – Recovery College participant #040

It would mean a culture shift in management to start engaging with recovery college. – Memory service participant #127

Services also shared examples of innovation and joint working. One memory service was *'in the process of recording podcasts for people with dementia to be available within the recovery college' (Memory service participant #016).*

Challenges of COVID-19

The COVID-19 pandemic was a significant difficulty in continuing to deliver Recovery College dementia courses. Some colleges suspended courses and one respondent said that co-production had *'stopped altogether' (Recovery College participant #027).*

Some courses continued running online, however this meant the benefits of face-to-face contact were lost:

Personable feel you get form a face to face session was lost due to lockdowns. – Recovery College participant #004

Online delivery limited who could attend due to aspects of digital exclusion in people living with dementia:

It prevented people who are not computer literate from receiving group support. – Recovery College participant #014

It was suggested that '*the people attending the virtual workshops are possibly more affluent' (Recovery college participant #014)*, thus '*risks excluding some people who have no or limited access to technology. (Recovery College participant #002).*

Several respondents identified benefits of online courses including allowing individuals to attend from their homes, removing the difficulties of travelling;

People from a wider geographical area can now potentially register as no travel to venue involved. – Recovery College participant #002

Positive was the move online as it helped more people access the course who couldn't travel due to long distances or disability. – Recovery College participant #004

Discussion

This study highlights the divisiveness of the term recovery in the context of dementia. For some, the idea of recovery fits well with understandings of living well with dementia and advocacy and empowerment approaches. However others felt the term recovery in the context of dementia could engender false hope, reflecting previous research suggesting the word 'recovery' may offer an unrealistic impression of a cure for dementia (Adams, 2010). It highlights the power of words and the need for consideration of the terminology used in the context of dementia (Swaffer, 2014).

Twelve UK Recovery College dementia courses were located. According to survey respondents, more women than men attend Recovery College dementia courses, reflecting the 2:1 ratio of women to men diagnosed with dementia (Mielke, 2018). Consistent with the age relationship with dementia, Recovery College attendees are reported to be older than the general population, with two-thirds aged 56-75 years. Respondents reported that nearly 80% of attendees were White British, under 15% from Asian ethnic groups and few from Black/Black British ethnicities. Some courses may be specifically attracting people of Asian ethnic origin, but not those from Black ethnic groups for whom the incidence of dementia is thought to be higher (Pham *et al.,* 2018). These differences may reflect the service user or community profiles of the specific respondent organisations offering dementia courses or may suggest there are potential barriers to access for individuals from Black ethnic groups. These dynamics will need to be investigated further as the number of people from ethnic minority backgrounds living with dementia is estimated to increase seven-fold by 2060 (Tsamakis *et al.,* 2021).

Bespoke dementia courses were based around the 'living well' agenda and covered topics such as adjustment, managing symptoms, and how to live well. These courses aimed to help people understand more about dementia, develop coping skills, and meet others with similar experiences. The coproduction of the courses with people with dementia was viewed

as a strength. These findings resonate with a recent qualitative case study exploring the experiences of people with dementia who undertook a Recovery College dementia course, where co-production and peer-to-peer learning emerged as important aspects of the support received (West *et al.,* 2022). Co-production activities promoted '*breaking down the "them and us" barriers common in traditional healthcare professional-service user relationships'*. Having a person with dementia co-facilitating the course provided attendees with positive role models that bring relatability, and a genuine understanding of living with dementia. Current clinical offers of post-diagnostic dementia support risk contributing to Prescribed Disengagement™ (Swaffer, 2015; Low *et al.,* 2018). Threats to personhood and autonomy can occur where support is professional-led, delivered 'to' rather than 'with' people with dementia.

These findings revealed exciting innovations in Recovery College provision for people with dementia including the co-production of podcasts and the move to a blended or online approach. Online delivery was seen as having some benefits related to improved accessibility but could exclude those who are less computer literate or lack the resources needed to participate, highlighting socioeconomic barriers in accessing courses during the pandemic. Further work is needed to explore what works for whom and when.

There were Recovery College dementia courses that stopped during the COVID-19 pandemic and some had not restarted. People with dementia and their families have been disproportionately affected by COVID-19 (Daley *et al.,* 2022), with many reporting increased loneliness and increased psychological distress (Alzheimer's Society, 2020). Post-diagnostic support is more important than ever to reduce isolation, particularly for people who received their diagnosis remotely with reduced access to subsequent support. With various NHS Trusts looking to review and restart services this would seem a key time to consider a Recovery College approach.

This is perhaps particularly timely given Recovery College are an example of integrated working between mental health services, patient advocates and the voluntary sector, aligning with the NHS drive to integrate services to tackle inequalities in outcomes, experience, and access (NHS, 2022). People with dementia often fall between the cracks in services and feel they have been left to manage their difficulties alone (Arblaster & Brennan, 2022). A significant proportion of memory services respondents were unaware of Recovery Colleges running in their organisation or even that such services were relevant to people with dementia, although it is possible that their local Recovery College did not run a dementia course. This perhaps explains concerns about poor attendance at some dementia courses. Encouragingly, several participants who were unaware that Recovery College dementia courses existed, expressed interest in exploring this further. The need for joint working between services was emphasised in relation to role clarity in Recovery Colleges, the overlap between clinical support or therapy and Recovery Colleges where the latter focus is on empowerment through education and peer support (Whittley *et al.,* 2019). One implication here is the need for buy-in by all services in developing this provision, the need for clear roles and responsibilities to be established in the co-production of Recovery College dementia courses, and discussion to arrive at a palatable name for recovery-orientated courses.

Limitations

The strength of this study is its good response rate with data from across the UK collected in a short time. However, the study has some limitations. Multiple responses from the same trust could have skewed findings related to the number of Recovery College dementia courses currently running. It is possible that some services have not responded to the survey. The survey may also be subject to a response bias. People may be more likely to respond if they feel passionate about Recovery Colleges and may feel the need to positively

represent their service rendering the survey vulnerable to a social desirability effect. Furthermore, the qualitative data obtained is likely to lack detail without the exploratory aspect of qualitative interviews. It should be noted that survey respondents have provided retrospective estimates of Recovery College attendee characteristics, as this information is not collected routinely, so its accuracy cannot be verified. Also, this was collected from a limited number of respondents, so may not be generalisable nationally. Conclusions from this data can only be indicative at this stage. Future work will explore how these courses work for people of diverse backgrounds. Finally, responses given may not reflect the experiences and opinions of all participants as they were completed by one person representing a Recovery College course.

Conclusions

To our knowledge this is the first study exploring the use of Recovery College dementia courses in post-diagnostic dementia support. The results demonstrate the importance of peer-to-peer support and involving people with dementia in the co-production post-diagnostic services to support living positively. Findings highlight the significance of the language used in the discourse around dementia, issues around accessibility, and the need for improved integration and partnership working between services.

Declaration of Interest Statement

The authors confirm they have no conflicts of interest to disclose.

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Survey Paper Tables

Region	Total Responses	Number of Trusts from each Region (Number of Current Dementia Courses)	Number of Recovery College staff	Number of memory service staff
East Midlands	35 (13.41%)	4 (1)	6 (2.30%)	29 (11.11%)
East of England	55 (21.07%)	4 (2)	9 (3.45%)	46 (17.62%)
London	73 (27.97%)	9 (1)	14 (5.36%)	59 (22.61%)
North East of England	1 (0.38%)	1	0 (0.00%)	1 (0.38%)
North West of England	5 (1.92%)	3 (1)	3 (1.15%)	2 (0.77%)
Northern Ireland	1 (0.38%)	1	0 (0.00%)	1 (0.38%)
Scotland	1 (0.38%)	1	1 (0.38%)	0 (0.00%)
South East of England	17 (6.51%)	8 (1)	5 (1.92%)	12 (4.60%)
South West of England	18 (6.90%)	4	3 (1.15%)	15 (5.75%)
Unknown	1 (0.38%)	1	1 (0.38%)	0 (0.00%)
Wales	5 (1.92%)	3	1 (0.38%)	4 (1.53%)
West Midlands	3 (1.15%)	3 (2)	2 (0.77%)	1 (0.38%)
Yorkshire and the Humber	46 (17.62%)	5 (4)	6 (2.30%)	40 (15.33%)

Table I. Number of responses from UK regions

	Recovery College Responses	**Memory Service Responses**
Does your [service] currently run/facilitate courses about dementia?	Yes: 12 (23.5%) No: 24 (47.1%) Don't know: 1 (2%)	Yes: 14 (6.7%) No: 98 (46.7%) Don't know: 66 (31.4%)
Has your [service] historically run/facilitated courses about dementia?	Yes: 7 (13.7%) No: 13 (25.5%) Don't know: 3 (5.9%)	Yes: 19 (9%) No: 74 (35.2%) Don't know: 70 (33.3%)
Does your [service] plan to start running courses about dementia in the future?	Yes: 4 (7.8%) No: 2 (3.9%) Don't know: 10 (19.6%)	Yes: 11 (5.2%) No: 38 (18.1%) Don't know: 93 (44.3%)

Table II. Provision of dementia courses. *Note: Not all respondents answered this question. Percentages are based on the number of Recovery College (n=51) and memory service (n=210) staff that responded to the survey.*

Who was the Course Delivered by?	Recovery College Responses	Memory Service Responses
People with dementia	3 (25.0%)	3 (13%)
Family or friend supporters	4 (33.3%)	3 (13%)
Staff	11 (91.7%)	5 (21.7%)

Table III. Course delivery. *Note: Respondents could provide multiple responses. Percentages are based on the number of Recovery Colleges (n=12) and memory services (n=14) offering/facilitating dementia courses.*

Age Range	
18-35	1.4%
36-55	17.3%
56-65	35.1%
66-75	31.9%
76+	22.0%
Sex and Gender Identity	
Men	33.4%
Women	66.0%
Ethnicity	
Asian/Asian British	14.7%
Black/Black British	0.29%
White British	79.3%
White Non-British	2.9%
Mixed/Other	1.4%

Table IV. Demographic characteristics of Recovery College dementia course attendees

Post-Diagnostic Support	**Recovery in the Context of Dementia**	**Challenges and Areas of Innovation**
The Value of Post-Diagnostic Support Importance of Co-Production	The Language of Recovery	Awareness of Recovery Orientated Services Difficulties in Running Courses Challenges of COVID-19

Table V. Categories and sub-categories derived from qualitative responses