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Original Research

Views of Conventional Medicine and Integrative Medicine among Informal Dementia Caregivers and Healthcare Professionals in NW England

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Abstract

The urgent need for innovative approaches to dementia treatment that are acceptable, effective and affordable underlies this research. Growing evidence supports 'integrative medicine' as a potential treatment approach aligned with and including conventional medicine. However, success will depend on addressing barriers, recognising needs of diverse communities and involving people in co-creating desired interventions. The three aims of this study were to, 1) describe conventional allopathic medicine and integrative or functional medicine (I/FM) approaches for dementia treatment in NW England; 2) to explore the views of informal dementia caregivers and service users, compared to healthcare professionals on the benefits and barriers to providing and receiving these two approaches. Thirdly, we engaged caregivers and service users in co-creating a vision for dementia treatment based on their needs and expectations. We conducted semi-structured interviews, focus groups and a deliberative workshop. Data were analysed using framework analysis. A total of 49 participants reported benefits and barriers to providing and receiving treatments. Themes related to inequalities of socioeconomics and access, cultural influences, disempowerment, demotivation and physician pressures. For instance, the NHS conventional medicine

approach provided free nearby access, highly rated post-diagnostic support and good quality web-based information. Barriers included limited discussion of non-pharmaceutical treatment options, low-morale and high rates of stress and burnout among GPs who felt de-motivated as they could not slow or stop the progression. I/FM benefits included time for in-depth investigations to determine the underlying causes of a patient's dementia, and practitioners trained in addressing them. Barriers included limited access to I/FM practitioners, need to pay for services, difficulties of making lifestyle changes such as diet, need for strong support from caregivers (or payment for a health coach) and poor compliance. Participants co-created a vision for dementia treatment including the wider environmental, social and cultural context. Neither conventional NHS medicine nor I/FM provided consistently beneficial treatment outcomes for dementia. Findings support the development of a model of dementia treatment that includes the benefits provided by both existing approaches, but further informed by patient, caregiver and practitioner experience and co-design. Such an approach must consider a complexity of cultural and generational needs, ensuring empowerment, making available current evidence, resources and support.

Keywords
Dementia; treatment; integrative medicine; functional medicine; Gujarati; co-design

1. Introduction

Dementia is understood to be a progressive, irreversible neurodegenerative disease in which the structure and chemistry of the brain becomes increasingly damaged over time. This particular narrative of dementia invites care and support as the dominant responses, supplemented by pharmacological treatments or neuropsychological approaches, which at best delay decline [1]. However, due to the existence of non-pharmacological approaches it is appropriate to review and compare the costs and benefits of different approaches and the extent to which a more integrative approach might be beneficial. Recently, a multiple case study report provides preliminary support for a multi-component approach to slowing cognitive decline [2], adding to the growing evidence base for this approach improving cognitive function for persons with mild cognitive impairment or dementia [3, 4]. The current study explores the potential for integration of a multimodal approach within dementia treatment in the UK.

Integrative medicine (IM) is an umbrella term that covers a broad array of modern and traditional approaches to health. Rakel (2017) describes IM as healing-oriented medicine that takes into account the whole person [5], including all aspects of lifestyle and therapies from various cultures, while focusing on the least invasive, least toxic and least costly [6]. Current interest in IM as well as the rationale for choosing to investigate it in this study is largely driven by conventional medicine's limited ability to reduce the prevalence of chronic long-term conditions (LTCs), coupled with IM's recent effectiveness in neurological conditions [7], diabetes [8] and obesity [9]. The typology in Table 1, based on Ring and Mahadevan [10] expresses the full range of modalities that might be included in what is called an integrative medicine approach.

Table 1 Integrative Medicine (IM) modalities.

Integrative Medicine (IM) Modalities www.ncim.org.uk www.collegeofmedicine.org.uk www.imconsortium.org www.oshercollaborative.org	
Lifestyle Medicine	Non-pharmacological and non-surgical management of chronic disease with a focus on nutrition, physical activity, stress management and sleep.
Preventive Medicine	Protect, promote and maintain health and wellbeing; prevent disease, disability and death through education, research, service and partnerships. www.acpm.org
Mind-body Medicine	Biofeedback, yoga, various forms of meditation, mindfulness-based stress reduction (MBSR), prayer, hypnosis, guided imagery
Energy Medicine	Therapeutic touch, healing touch, Reiki, Qigong, acupuncture, acupressure, Shiatsu, biofield tuning
Manual Therapies	Chiropractic medicine, osteopathic manipulative treatment, massage therapy, bodywork, reflexology
Whole Systems	Naturopathic Medicine, Functional Medicine, www.ichnfm.org www.ifm.org Homeopathy, Traditional Chinese Medicine, Ayurvedic Medicine, Anthroposophy

As one example of IM (see Table 1), whole systems approaches purport to activate the body's inherent healing mechanisms and can thereby treat the root cause of illnesses [11]. Whole systems modalities offer multimodal interventions logically suited to address the multidomain causes of chronic LTCs [12]. Functional medicine (FM) is one such modality which trains practitioners in a root cause analysis approach to treating chronic disease [13, 14]. An FM prescription may include acupuncture, Ayurveda, chiropractic manipulation, detoxification programs, herbal and homeopathic supplements, specialized diets, massage, meditation and mindfulness practices, neuro-biofeedback, nutritional supplements, Tai chi or yoga. One study looking at the FM model recently demonstrated beneficial and sustainable associations with health-related quality of life [15].

Regarding dementia, a multiple case study report by James et al. has shown preliminary support for the feasibility of using a multicomponent FM approach to slow cognitive decline [2], providing imaging evidence of improved brain connectivity and efficiency. Prior studies have demonstrated reversal of cognitive decline, improved memory and quality of life with a personalised multimodal approach (Bredesen et al. 2016; Bredesen et al. 2018) [16, 17]. While the above studies occurred in the Netherlands and North America, the current study builds upon recent case reports in the UK demonstrating improvements in symptoms of memory decline from a personalised multimodal approach [18].

In the UK, conventional medicine is offered free of charge to all National Health Service (NHS) patients. However, if a patient chooses to attend an IM practitioner for treatment, it is an adjunct to their routine NHS care, for which they need to pay privately. The reasons why patients and caregivers choose to look beyond the standard NHS provision may be cultural preference and language spoken, religious or community beliefs about health and disease, distrust of pharmacology, recommendations from friends and community, health literacy and so on. It is therefore necessary to hear a diversity of voices in order to design interventions relevant to people, places and situations [19].

IM practitioners are medically qualified and able to integrate their treatment with what the patient is also receiving from their own general practitioner (GP). IM practitioners are often GPs who have undertaken further training in an IM modality. It was these rare GPs with IM training whom we sought in our study as they could share insight into the benefits and barriers of both worlds from lived experience. We sought further insight from NHS GPs and healthcare professionals not trained in the IM approach and working only in the NHS conventional medicine paradigm, either in a GP surgery or the memory assessment service (MAS).

Based on this accumulating evidence, our study had the following aims:

1) Describe conventional medicine (NHS and MAS) and integrative or functional medicine (I/FM) treatment approaches for dementia in NW England
2) Explore the views of informal dementia caregivers and service users, compared to healthcare professionals on the benefits and barriers to providing and receiving these two approaches
3) Investigate views on needs, expectations and a vision moving forward

2. Methods

2.1 Design

The study design consisted of 32 semi-structured interviews, 3 focus groups and a deliberative workshop with dementia caregivers, service users and healthcare professionals (see Table 2) conducted over a 13-month period in England. As we aimed to understand attitudes, beliefs and views, we chose to gather qualitative data which permitted the in-depth exploration and understanding of the perspectives of the population of study as they encounter, engage and live through situations [20]. An interview schedule was developed to explore the perceptions of family carers and healthcare providers on the challenges and needs in providing and receiving such treatments for dementia. Interview topics for caregivers included their experience, support needs, expectations and outcomes accessing NHS services for dementia or memory problems; their awareness or experience of holistic lifestyle treatments for memory problems and dementia; their views about the benefits or disadvantages to such treatment programmes; expectations or willingness to pay in money, time or effort; support anticipated or required; interest, willingness and ability to use online resources, technology and so on. Interview topics for GPs or healthcare professionals included their role and involvement in providing services for dementia or memory problems; awareness and experience with holistic lifestyle treatments; what constitutes their treatment approach; successes and challenges in delivering it; benefits or disadvantages; extra services or support required (e.g. testing, coaching, supplements); costs to the patient involved; internet and technology use, etc.

To further elucidate needs and views going forward, a deliberative workshop and feedback interviews were held to present preliminary findings of the earlier interviews and focus groups to participants, and to hear their reflections and further thoughts on framing a future vision for dementia treatment. Within this workshop preliminary findings were also presented from recently completed case reports mentioned above [18].

Table 2 Participants – location, attendance and demographics.

Family Carers & Service Users	Focus Grp L1 Mar '18	Focus Grp L2 Mar '18	Focus Grp T1 Apr '18	Interviews June 2018	Deliberative Workshop DL Nov '18	Feedback interviews Nov '18	**Total**
Lancaster	9	6	-	-	8	-	23
Tameside	-	-	7	9 (Dyadic)	-	3	19
Total informal caregivers & service users							42
Practitioners Interviews - Jan 2018 through Feb 2019							
2 GPs in the NHS *and* practising I/FM privately (total 15 interviews over 13 months)							2
4 GPs practising *only* in the NHS; 1 clinician in the MAS							5
Total healthcare professionals							7
Total Interviews (9 dyadic; 3 feedback; 20 practitioner interviews [15 + 5])							32
Total Participants (42 informal caregivers & service users; 7 healthcare professionals)							49
Total Data Collections (32 interviews, 3 focus groups and 1 deliberative workshop)							36

Demographics	Focus groups				Interviews				
Ethnicity	Age Range	M	F	n =	Age Range	M	F	n =	
white British	52 - 78	5	17	22	42 - 66	3	2	5	27 (55%)
Gujarati Asian (Hindu)	58 - 80	0	7	7	65 – 90	2	12	14	21 (43%)
Japanese	52	0	1	1	-	-	-	-	1 (2%)
Service users / caregivers	52 - 80	5	25	30	43 – 90	0	12	12	42
Practitioners	-	-	-	-	42 - 66	5	2	7	7

2.1.1 Participants

We involved a purposive sample of 49 participants (Table 2) in 32 interviews, 3 focus groups and a deliberative workshop. The non-random technique of purposive sampling was used to enable the deliberate choice of participants due to the qualities they possessed as discussed below [21].

2.1.1.1 Group 1 included informal dementia caregivers and service users from the communities of Lancaster and Tameside (an area in Greater Manchester). These two areas were chosen for their comparatively different sociocultural and ethnic demographics in an effort to recruit people of diverse backgrounds and experiences. Group 1 was recruited through organisations including the University of the Third Age, the Centre for Ageing Research Continuing Learners Group and Dipak Dristi (an Asian day-support organisation for elders). Participants were aged between 42-90 years and identified as white British, Japanese or Gujarati Asian Hindu with heterogeneous socioeconomics, education, occupation, mobility and English fluency. The Tameside focus group, whose participants were older Hindu women in the Asian community, was co-led by a Gujarati-speaking translator who was known to them as she assisted with their weekly activity group at the community centre. We conducted and recorded dyadic interviews which were transcribed and

translated by this fluent English-Gujarati translator. Participants in Group 1 received travel reimbursement and gift cards.

2.1.1.2 Group 2 included healthcare professionals identified through practitioner organisations, a local health collaborative, a national healthcare conference and clinical practices. Four GPs practised NHS conventional medicine only and one healthcare professional worked in the MAS. Two IM practitioners worked both in GP practices as well as in private clinics, having pursued further training in an integrative medicine modality, including FM. Both GPs were committed to regular interviews, giving a total of 15 over 13 months, for which they were remunerated. Group 2 ranged in age (42-66 years) and in gender (5 men, 2 women). Five practitioners identified as white British and two as Gujarati Asian Hindu. All were based in NW England although some of their patients came from outside this area. These 5 practitioners received gift cards. All practitioners self-identified as being involved in treating people with cognitive decline or dementia, identifying as IM or FM (I/FM).

Lancaster focus groups (L1 & L2) occurred in March 2018. In Tameside a focus group (T1) occurred in April. Upon returning in June, the research was conducted following guidance from the group gatekeeper advising that the participants (who were people with dementia and their family caregivers) preferred to meet with the researcher dyadically instead of collectively in a group. They felt more comfortable to talk about their dementia experience privately, rather than in front of their peers. Feedback was also given and discussed in interviews in November.

2.1.2 Dementia-Specific Research Processes

These productive research collaborations were enabled by building relationships [22] with local groups and organisers for 2 years prior to the research commencing. The gatekeepers were aware, sensitive and shared their thoughts and concerns prior to and throughout the research and the data collection processes. Also, in some circumstances the term ‘memory problems’ was found to be more culturally appropriate. Hence ‘situational sensitivity’ was required and cues were taken from the family carer in such situations [23].

Research ethics approval was granted by the researchers’ host institution.

2.2 Data Analysis

Data from interviews and focus groups were analysed using framework analysis (FA), a systematic and flexible approach to analysing qualitative data [24]. FA is an emerging method of qualitative thematic data analysis that is increasingly used in healthcare studies [25]. Originally developed for applied social policy research this approach is increasingly used in health care research [26, 27]. FA involves a 5-step process: 1) familiarisation through data immersion; 2) developing a theoretical framework by identifying recurrent and important themes; 3) indexing and pilot charting; 4) summarising data in analytical framework; and 5) synthesising data by mapping and interpreting [25]. The researcher [GC] undertook the initial framework development which was then shared and refined through discussion with the wider team.

3. Results

3.1 Research Question One

Describe conventional medicine (NHS and MAS) and integrative or functional medicine (I/FM) treatment approaches for dementia in NW England.

Descriptions of both approaches are compared in Table 3. During the research we found practitioners identified with the title of either IM or FM, depending on their training. We therefore include both in the data analysis below and designate this as I/FM.

Table 3 Dementia treatment approaches – the NHS and the MAS compared to integrative medicine or functional medicine.

	Conventional Medicine - National Health Service (NHS) and Memory Assessment Service (MAS)	**Integrative Medicine or Functional Medicine (I/FM)**
Current Aim and Approach	Conventional allopathic medical care starts with the patient's general practitioner (GP); preliminary diagnosis is performed by the GP and non-dementia causes if present are treated and ruled out (B12 deficiency, depression, etc); patient is referred to the MAS where diagnosis is confirmed and medication is prescribed if appropriate; patient followed up until medication is stabilized and then patient is discharged back to their own GP.	I/FM is individualised and empowers the patient and practitioner to work together to address the underlying cause of disease rather than symptoms, to treat chronic LTCs and promote optimal wellness. This requires a detailed understanding of each patient's genetic, biochemical, and lifestyle factors which are modified or impacted through direct personalised treatment plans. These may include mental, emotional, functional, spiritual, social and community aspects. Practitioners prefer to treat the whole person rather than just one organ system.
Assessment and Investigation	The GP and the MAS used blood tests, medical history, neuropsychological testing and sometimes CT or MRI scans to diagnose and reach a dementia diagnosis. The GP also treated the patient if they found a medical issue (thyroid problem, B12 or folic acid deficiency) diagnosed in a blood test, thereby ruling out other causes of memory problems. Further testing at the MAS included neuropsychological testing, patient history questionnaire and an assessment of the social and emotional situation indicating care or	Practitioners took a history, used in-depth surveys, investigated with blood and tissue panels and developed a treatment plan. Testing for hypothyroidism and T4 to T3 conversion disorder; B12 and folate deficiencies / metabolism disorders; Vit B & D deficiencies; iron deficiency / overload; high ammonia / nitrogen overload; miscellaneous metabolic disorders (with organic acids); possible contributing medications / supplements; risk factors for toxicity / heavy metals exposure (all screened for dental amalgam) and yeast and bacterial overgrowth (in organic acids testing).

	support needs. For instance, the history taking may hold clues to industrial jobs, head injury, depression, bereavement and loss.	Quantitative memory testing was generally not done but subjective reports of patient and carers were taken as part of the initial assessment of overall health. Genetic testing was sometimes done, depending on patient age and history.
Prescribed treatments	If the memory loss cannot be treated medically by the GP, a cholinesterase inhibitor such as donepezil or rivastigmine was prescribed if the investigation deemed it appropriate. The dosage was monitored and adjusted if needed and the patient was discharged back to their GP for follow-up.	Treatment depended on questionnaires and blood tests and included dietary advice (e.g. ketogenic diet, elimination diet), supplements (B12 injections), detoxification protocol (e.g. removal of dental amalgams), medications, lifestyle changes such as exercise and movement, brain training, stress reduction (meditation) and improving sleep.

3.2 Research Question Two

Explore the views of informal dementia caregivers and service users, compared to healthcare professionals on the benefits and barriers to providing and receiving conventional NHS medicine alone or alongside I/FM (Table 4).

Table 4 Benefits and barriers - conventional medicine (NHS and MAS) compared to integrative medicine or functional medicine.

Benefits and Barriers		
Caregivers & Service users	**Conventional Medicine - National Health Service (NHS) and Memory Assessment Service (MAS)**	**Integrative Medicine or Functional Medicine (I/FM)**
Socioeconomics & health equity	Provides free access to care for all	Services are private pay; health coaching if offered is an additional expense
Access	Nearby local surgery and MAS in local area	Sparse, distant, at times online
Waiting time to be seen	Varies depending on backlog and demand, sometimes weeks	Varies depending on backlog and demand, sometimes months
Consultation time	Generally 10 minutes; longer in the MAS	Generally 60-90 minute sessions
Investigation with the patient	Routine with a standard set of blood tests; *"Doctors don't ask anything … just give you medicine"* (FT1) One carer felt her mother-in-law's complaints about lack of sleep and appetite were dismissed as *'normal'* (CT1)	Patient questionnaire and interview; use of web-based online or email data collection and information dissemination; direct contact with patient either in-person or via video calling
Support	Offered through MAS; highly rated; offers	Improvement takes much

	signposting; *"extraordinarily wonderful… utterly exemplary… stunningly good in terms of supporting people."* (FL1)	consistent effort with support from family, friends and/or the caregiver. Online support and health coaching may be available.
Media & marketing	The NHS "*has some very good sites"* (FL2) Conversely, media undermine health efforts, *"They will eat rubbish meals, cheap food… buy an expensive outfit, it's just what the media portray..."* (CT7), also, *"you can be quite frightened about what you find online."*	Carers find out about symptom reversal online and follow-up with a practitioner, but their expectations overshadow the amount of time and effort that must be involved if they are to achieve a similar amount of success.
Sociocultural	Patients may mistrust pharmaceuticals; have witnessed the side effects of polypharmacy.	Patients feel unable to discuss their use of I/FM with their regular GP.
Empowerment	Patients can lack personal responsibility, *"they want the prescription, that's a general problem with medicine, some people actually want to bury their head in the sand."* (FL1)	Patients may remain disempowered even when seeing an I/FM practitioner, especially if they were *'brought in'* by their carer.
Participant codes	**FT1** – Focus Group Tameside **CT** – Caregiver Tameside **FL1 & FL2** – Focus Groups Lancaster	
Healthcare professionals	**Conventional Medicine** - **National Health Service (NHS) and Memory Assessment Service (MAS)**	**Integrative Medicine or Functional Medicine (I/FM)**
Socioeconomics, compliance and health equity	All patients regardless of socioeconomic status or healthcare needs have equal access and levels of service available in the area close to where they live	Compliance is *"absolutely a massive problem, because I can't force patients to come back and see me because they have to pay every time they come back."* (IP2)
Sociocultural	Wealth inequalities equal health inequalities, *"unhealthy food is the cheapest food"* (CP4)	Elderly, confused… "*don't like taking pills, don't want to eat funny food"* (IP1)
Motivation	GPs felt demotivated as they could not address the underlying causes of dementia, and so are not slowing or stopping the progression, "*drug therapy's clearly not going to make a difference really".* (CP2)	The families of patients *"are often desperate for them to get better".* They begin energetically but "*you need a motivated carer"* (IP2) to maintain the constant effort to modify and change.
Support	*"You can't just give somebody a handful of supplements… their diet could be all over the place… bad diet, good supplement*	*"It took nine months of working with the health coach to change her attitude towards self-care…*

	doesn't necessarily give you good results." (CP2)	*nutritional therapist, telephonic support, health coaching"* (IP1)
Empowerment	Some patients are disempowered, *"People just want to have a quick fix. Practically no patients are willing to put in effort for themselves, they are used to having everything for free; they don't want to take responsibility for doing anything."* (CP4)	Likewise, an I/FM patient *"got a lot better in terms of their energy…brain fog lifted, memory's getting a bit better, just taking the supplements, and then 'I did my diet for two months and now I'm just going to eat normally again'."* (IP2)
Conflicts between conventional and I/FM approaches	NHS colleagues if untrained about whole systems approaches can be dismissive. This creates a sense of isolation, disregard for the GP aware of or learning the I/FM approach.	NHS use of statins and dental amalgams, effects on cognition are highly contested; metabolic problems "never going to be picked up in the NHS… (but are) entirely treatable."
GP pressures	Low morale and high rates of stress and burnout. *"Doctors are scared and tired, they see 50-60 patients a day."* (CP4) Pressure from patients, *"Doctors are afraid they will get a complaint. Patients bully you, you have to give them what they want."* (CP1)	Practitioners may feel stressed without adequate staff to manage communications *"emails are crazy"*, provide dietary guidance & support, spend hours on data evaluation, while constantly upgrading their professional training and expertise.
Participant codes	**CP** – Conventional Medicine General Practitioner **IP** – Integrative/Functional Medicine Practitioner	

These tables summarised the views of informal dementia caregivers and service users, compared to healthcare professionals on the benefits and barriers to providing and receiving conventional NHS medicine alone or alongside I/FM. Themes included inequalities of socioeconomics and access, diversity of cultural needs, disempowerment, demotivation and physician pressures. For instance, the NHS conventional medicine approach provided free nearby access, highly rated MAS support and good quality web-based information. Barriers included limited discussion of non-pharmaceutical treatment options, low-morale and high rates of stress and burnout among GPs who felt de-motivated as they could not slow or stop the progression. Treatments needed to be much more complex and individualised, a lot of time is needed which GPs do not have. Whereas simple, straightforward interventions, were much easier to make. I/FM benefits included in-depth investigations to determine the underlying causes of a patient's dementia, practitioners trained in addressing them, and some memory impaired patients who were able to improve. Barriers included limited access to I/FM practitioners, the need to pay for service, difficulties of making lifestyle changes such as diet, need for strong caregiver support and/or hiring a health coach – all contributing to poor patient compliance.

3.3 Research Question Three

Investigate views on needs, expectations and a vision for dementia treatment. This includes data from feedback interviews and the deliberative workshop. Participants included dementia caregivers and service users (Table 5).

Table 5 Needs, expectations and a vision for dementia treatment.

Caregivers & Service users	Needs, expectations and a vision for dementia treatment
Whole systems approach for complexity of human needs	One that addresses the whole person and all aspects relating to health; "*understanding… the whole system is incredibly important."* (CL) Most participants seemed aware of the effects of diet, exercise, emotions and beliefs on the body's ability to heal and wanted a *"prescription that covers the whole range"* (CL) *"It's not drug advances that are going to lead to a reversal of these chronic degenerative diseases… it's diet, lifestyle and supplement I think really."* (CT) They imagined a doctor dealing with the complexity of human needs, *"in sort of packages like your diet, your exercise, pains, emotions, attitude, what we believe and all of that… huge."* Emotional, psychological, spiritual aspects *"have a big impact on your physical health."* (CL) In total, *"If the GP, the memory clinic and the various people can work together to have a plan of action… healthy eating… exercise, and if need be some medication…all worked in conjunction… to be monitored by somebody to make sure it is the right thing."* (ET)
Cultural and generational empowerment and relevance	The Gujarati elders exhibited positivity and eagerness, "*willing to try anything, open to new things… if she thinks it's going to benefit her in any sense or way or form, she will do it." "If something that's going on in society... they would love to know it, anything medical… better way, changing their life."* (ET) People also valued their traditional knowledge, *"Medicine of my own …no side effect, very little cost, good benefit…better than normal I get from the chemist."* (ET) Most Asian people are vegetarian and *"about 9 out of 10"* are vegan. Dietary advice and services need to be culturally relevant, intergenerational & age appropriate.
Availability and sharing of evidence, information & resources	The public needed accurate evidence-informed knowledge in order to make lifestyle changes and to progress towards a personal goal. Trustworthy information was lacking on where to go and what to do. *"Information is prime isn't it. Lack of. I think* (the information gap) *is… a very big issue yeah."* (CL) Caregivers proposed how this could be communicated as a resource, *"…a checklist of things to do, things to pursue, things to explore, things to try...being aware of what's available. Holistic therapies could be introduced* (by the MAS) *as follow up support."* They also proposed, *"a resource tool, a depository."* (CL)
Support to learn, seek and grow	Of concern was the plight of the carer who wants to go beyond conventional medicine. One woman felt unsupported, stepping blindly forward based on

	what she can find out and learn on her own, doubting her decisions, worn out, fearful of consequences, *"Am I doing the right thing? Will it be beneficial?"* (CT)
Activity and environment	Suggestions were multimodal to promote a wholeness of body, mind, spirit and environment: talks on nutrition & supplements; healthy food; dancing class; craft group; cooking group; colouring; singing; outdoors – short walks, gardening, being in nature and being grounded.
Integration	Need for collaboration and information sharing between conventional medicine and I/FM; Need to join with existing services in the city; links to care when needed; a one-stop shop.
Transport	Safe secure transport to and from activity. "*A big issue, even from A to B it's a problem."* (CT)
Support	*"An elderly patient with dementia is not going to be able to do this by themselves, without support."* (CL) Have personnel on hand – health coaches, occupational therapists, volunteers to provide social support for lifestyle changes; *"If she* (my mother-in-law) *was on her own she wouldn't know what to do."* (CT) Support for carers through caregiver trips.
Measurement, technology & evidence	Measurement may be difficult but it is necessary in order to create evidence, both practical and medical. *"You need results."* (CL) Technology: use of online, iPhone, iPad, etc.) "*Skype, online, all of those kinds of things, tremendous potential there"* (CL)
Cost, benefit, willingness to pay and marketing	Cost: *"How much it's going to cost them physically, monetarily, emotionally… not just financially but a lot of these people are time poor."* (CL) Willingness to pay & cost/benefit: *"It depends what the cost will be and (if) they can see some guarantee of benefit… then obviously I think, would be good."* (CT) Marketing: "*What you're looking for is a product, service, package, that's got a brand name which we can then sell to the medicals… an experiment to see if they are prepared to buy, engage with this process, and let's see and measure the implications... (branding) needs to be something… that encourages you."* (CL)
Participant codes	**CT** – Caregiver Tameside **ET** – Elder Tameside **CL** – Caregiver Lancaster

Participants envisioned a broad scope to solving the problem of dementia, seeing it as a wider environmental, social and spiritual concern beyond the biomedical aspects, calling for a more holistic vision moving forward. People saw a whole systems approach as one that addressed a complexity of needs. These included ensuring cultural and generational empowerment and relevance; making evidence available and shared, as well as having information, resources and support available to learn, seek and grow. They proposed a range of activities and environments for use with emphasis on creative endeavours and connection to nature. They argued for true integration of treatment approaches, including the provision of transport and support. They highlighted the need to measure and evaluate technologically in order to build the evidence base and to inform participants about their progress. Participants also offered consideration to issues such as cost, benefit, willingness to pay and marketing.

4. Discussion

Through a qualitative investigation, this study: 1) described conventional medical treatment provided through NHS GPs and the MAS, compared to IM offered privately as an adjunct to this routinely provided treatment; 2) gained the perspectives of informal dementia caregivers, healthcare professionals and older service-users on the benefits and barriers of these two dementia treatment options in NW England; and 3) gathered their views on formulating a dementia treatment intervention moving forward.

Although benefits could be attributed to both approaches, neither were unproblematic for the practitioner, the carer or the patient. Barriers related to socioeconomics, health inequality, sociocultural forces undermining care, patient disempowerment, demotivation, the need for support, conflicts between conventional and I/FM approaches, and physician pressures from colleagues and patients. In supporting the patient and carer, concerns were raised about the need to bridge the gaps in knowledge, resources, confidence and communication, including both strategic and emotional support. In response to the benefits and barriers, caregivers provided an array of needs and expectations, as well as a clear vision to take forward into formulating a whole system integrative intervention.

Results reported poor compliance and good potential for both approaches. This seems to suggest that certain cultural groups, where western conventional medicine is less common and the practice of traditional medicine has a long history, may be more open and accepting of IM approaches. This deserves consideration when developing culturally relevant interventions. There was an unexpected depth of reflection about emotional psycho-spiritual needs and the well-articulated resource needs.

We were able to reach traditionally 'hard to reach' populations as 21 of the participants were from first or second generation South Asian families (originally from the Indian sub-continent or Africa) living in an area of so-called social and economic 'deprivation' in NW England [28]. We experienced none of the language barriers encountered by others discussing cognitive health issues with this population [29]. To avoid possible problems when using an interpreter, we had the audio tapes transcribed verbatim by a bilingual translator.

We acknowledge that the views of a purposively sampled group of people is non-generalisable. This is one of the first qualitative studies to address this topic. It is worth noting that the opinions expressed were not unlike those reflected in the literature, including problems with polypharmacy [30] and patients' needs for informed GPs willing to collaborate with complementary practitioners [31]. Furthermore, this study echoes others showing considerable interest from primary care providers for integration [32], who referred patients because patients requested it (68%) or because conventional medicines failed (58%) [33]. They also found that barriers to integration included NHS staff attitudes or lack of knowledge. Beyond the remit of our study is the issue of cost-effectiveness and cost savings, which have previously been shown across a variety of IM therapies and populations [34].

Further research is needed to provide the views of people formally diagnosed with cognitive impairment or early dementia on the challenges they would face in adopting a more I/FM approach and to help guide any proposed intervention.

4.1 Recommendations

1. Continued implementation and evaluation of integrative medicine treatment approaches for cognitive decline and dementia
2. Further attention to caregiver support, in particular regarding their self-care and motivation towards achieving treatment outcomes
3. Cooperative collaborations between conventional and integrative medicine practitioners
4. Shared decision making in determining personalised treatment plans for individual patients

5. Conclusions

There is an urgent need for innovative approaches to dementia treatment that are acceptable, effective and affordable. Although participants expressed mixed satisfaction with conventional NHS medical treatment, the growing integrative medicine approach described and considered herein is also difficult to achieve, and patient outcomes are less than predictable. When invited to discuss dementia treatment options, caregivers and older service-users envisioned future provision within a broad environmental, social and cultural context, calling for a pragmatic holistic vision moving forward. Findings suggest support for developing an integrative medicine model of dementia treatment informed by patient, caregiver and practitioner experience and co-design.

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Author Contributions

All authors made substantial contribution to the conception and design of the study and the analysis and interpretation of data, have critically revised the paper’s content and approved the final version.

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Competing Interests

The authors have declared that no competing interests exist.

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