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What next? Experiences of social support and signposting after a diagnosis of dementia

Abstract

The experience of being diagnosed with dementia can be shocking. This may be compounded if individuals feel that there is a lack of signposting onto further avenues of support following diagnosis. This study, then, examines how social support is promoted in the diagnostic process. Using purposive sampling and a grounded theory approach, semi-structured interviews were conducted with 13 members of a dementia empowerment group in Northern Ireland, discussing both their experience of diagnosis and also their subsequent group membership. Respondents reported both positive and negative experiences of diagnosis. Feelings of shock and bewilderment accompanied this process. Only one was able to identify a direct link between a medical professional and referral to the empowerment group, others being referred by other health professionals or dementia navigators. The study indicates that, due to disorienting feelings, one diagnostic consultation is insufficient to explain both the diagnosis and offer follow-up support. Therefore, more explicit links to navigators or other services need to be made at the point of diagnosis to prioritise information regarding opportunities for social engagement for those being diagnosed.

Keywords

Dementia diagnosis, service user experience, social support, empowerment groups, dementia navigators

What is known about this topic

- Both individuals being diagnosed with dementia and the professional giving the diagnosis find this experience difficult

What this paper adds

- Those diagnosed would like more information at diagnosis about what social support exists to address their own needs
- However, one diagnostic event may be insufficient in terms of giving information to individuals both about diagnosis and avenues for social support
- More explicit pathways could be developed to ensure connections are made to workers, such as dementia navigators, who will manage the post-diagnostic support for those diagnosed.

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Introduction

Being diagnosed with dementia is life changing. Diagnosed individuals report conflicting emotions such as shock, relief and affirmation (Bronner, Pernecky, McCabe, Kurz & Hamann, 2016), embarrassment and distress (Aminzadeh, Byzsewski, Molnar & Eisner, 2007), and shame, aggression and denial (Low, McGrath, Swaffer & Brodaty, 2016). Longer-term side effects include depression, isolation and decreased self-esteem (Rahman & Howard, 2018). As such, opportunities to offer support are especially valuable upon diagnosis. Whilst social support is recognised within the United Kingdom's (UK) local and national policies (Department of Health, 2016; DHSSPSNI, 2011), there is sometimes a fragmented approach to dealing with diagnosed individuals' social, with informal carers, rather than professionals, feeling they take the lead (Bieber et al., 2018). This article's purpose, then, is to investigate experiences of individuals recently diagnosed with dementia in Northern Ireland (NI) regarding how they were signposted on to social support.

Context

There has been a notable rise in UK dementia diagnoses since the launch of a National Dementia Strategy in 2009 (Donegan et al., 2017), increasing by 50% since 2012 (Department of Health, 2016). There were estimated to be 850,000 people with dementia in the UK by 2015 (Prince et al., 2014) including over 40,000 individuals under 65 (Roach, Keedy, Bee & Williams, 2014). NI has the highest per capita percentage of dementia diagnoses (Donegan et al., 2017), with there being at least 23,000 diagnosed (Dementia Together NI, 2016) and approximately 7,000 undiagnosed (Mynes & Byrne McCullough, 2015).

Experiencing an early or timely diagnosis

Early diagnoses of dementia occur when the first signs of neurological and cognitive changes are observed but where clinical symptoms may be less apparent (Brayne & Kelly, 2019; Watson, Bryant, Samson-Fisher, Mansfield & Evans, 2018). Those with early stage dementia contradict stereotypes

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about incompetence and incapacity (Murphy, Jordan, Hunter, Cooney & Casey, 2015) as those diagnosed largely retain capacity and usually clearly understand the implications of diagnosis (Milne, 2010). An early diagnosis occurs when individuals retain autonomy to self-manage their health (Read, Toye & Wynaden., 2017; Mountain & Craig, 2010) and, post-diagnosis, most continue to reside in the community, leading active lives (Briggs, McHale, Fitzhenry, O'Neill & Kennedy, 2018) and making their own decisions (Watson et al., 2018; Read et al., 2017). An early diagnosis provides a concrete answer for enquirer uncertainty over distressing symptomology (Wilcock et al., 2016) and pharmacological treatments are at their most effective during early stages (Milne, 2010).

An early diagnosis is not necessarily timely as some feel unprepared for the diagnostic burden when memory problems first arise (Brayne & Kelly, 2019), timeliness relating to when the enquirer wants to seek help (DuBois, Padovani, Sheitens, Rossi & Dell'Agnello, 2016). Diagnosing early may exert undue pressure on already stretched resources (Brayne & Kelly, 2019), so an appropriate time for diagnosis may align with perceived eligibility for services (Dhedi, Swinglehurst & Russell, 2014). Nevertheless, timeliness equated to 'as soon as possible' for 92% of respondents in Watson et al's (2018) study. Timeliness is dependent not just on practitioner expertise but also on the duration individuals and families take to identify cognitive problems, commonly two to three years from the onset of symptoms (Lian et al., 2017), by which time significant deteriorations may have occurred. Diagnosis at a younger age may take substantially longer (Draper et al., 2016), as there may be greater reluctance to prescribe dementia as the source of symptoms (van Vilet et al., 2013).

Individuals may fear diagnosis due to uncertainties about the condition (Mahieux, Herr & Ankri, 2018) and perceptions that nothing can be done to help (Minghella & Schneider, 2012). Whilst being diagnosed can be stigmatising, intrusive and accompanied by significant losses, such as employment (Milne, 2010), in the NI context, policy makers recommend an early diagnosis to allow individuals the best opportunity to direct their own care planning (DHSSPSNI, 2011). As such, timeliness and

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earliness should converge to facilitate access to appropriate treatment and support, giving individuals and families time to understand what is happening and make future plans (Bonner et al., 2016; DuBois et al., 2016). As early diagnoses occur when individuals retain control and capacity, opportunities for meaningful social engagement should be encouraged (Campbell et al., 2016).

Individuals with dementia 'secondary' in diagnosis?

Person-centred care for people with dementia should respect individual preferences and include flexible programmes of support following diagnosis (Martin, O'Connor & Jackson, 2018). However, the diagnostic process may prioritise the needs of carers over those being diagnosed (Tanner, 2012; Manthorpe et al., 2011). Research focuses on diagnosing medical professionals (DMP) being more likely to relay a diagnosis to carers (Low, McGrath, Swaffer & Brodaty, 2018) to help them understand the condition (Phillips et al., 2012) as they may feel ill equipped (Bronner et al., 2016). However, the majority of individuals with memory problems both have a right to be informed (Campbell et al., 2016), and also want to be told whether they have dementia (Mahieux et al., 2018; Robinson et al., 2011). Post-diagnostic support services, such as day care and respite, may meet carer needs (Low et al., 2018; Bunn et al., 2012) but are inappropriate for independent individuals with early stages dementia.

Professional communication of diagnosis

Previously, studies have found DMP to express uncertainty around diagnosis (Bamford et al., 2004). However, increasing rates of dementia diagnosis more recently perhaps reveals growing confidence (Donegan et al., 2017; Wilcock et al., 2016). Nevertheless, there remains hesitancy. DMP may be reluctant to communicate diagnoses due to concerns that it may be stigmatising (Low et al., 2018; Koch & Iliffe, 2010). Some practitioners use euphemisms such as 'memory loss' to minimise distress (Phillips et al., 2012). Others diagnose mild cognitive impairment (MCI), which formally recognises cognitive declines, though there remains inconsistency as to how this condition is conceptualised

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and constructed (Klekociuk, Saunders & Summers, 2016) and whether this is a precursor to dementia or a discrete condition itself (Beard & Neary, 2013).

The development of memory clinics has also improved and hastened dementia diagnosis, especially in younger enquirers (Draper et al., 2016), though those being diagnosed may not wish to be referred by a trusted GP to an unknown specialist or service (Lian et al., 2017). One English study reported that two thirds of those diagnosed were referred to a specialist service for the diagnostic event (Wilcock et al., 2016). Whilst GPs may be reluctant or find it challenging to diagnose dementia, some feel responsibility but also constrained by time limitations to give the attention required (Phillips et al., 2012).

DMP are sometimes perceived as poor communicators lacking empathy (Koehn, Badger, Cohen, McCleary & Drummond, 2016). Diagnosed individuals have expressed “feelings of abandonment or ‘being sent away’ by professionals on receipt of diagnosis” (Kelly & Innes, 2016: 167). One area that could improve relates to how those diagnosed access support services (Manthorpe et al., 2011).

Community responses and support

DMP lack knowledge regarding appropriate community or support services that may assist those diagnosed (DuBois et al., 2018; Koch & Iliffe, 2010) and, due to feeling accountable for referrals, may mistrust unknown third sector services or feel they are unreliable (White, Cornish & Kerr, 2017).

Some DMP do not prioritise aftercare arrangements (Prince, Comas-Herrera, Knapp, Guerchet & Karagiannidou, 2016; Robinson et al., 2011) and social support may be regarded as discretionary or even a luxury (Minghella & Schneider, 2012). Yet potential social isolation (Herron & Rosenberg, 2017; DuBois et al., 2016) or exclusion (Greenwood & Smith, 2016) is a challenge following diagnosis.

Carers express distress at a perceived lack of group services for loved ones (Herron & Rosenberg, 2017). Moreover, a larger social network involving friendships for diagnosed individuals is

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associated with better cognition (Baloch, Rifaat, Chen & Tabet, 2019) and supportive community connections leads to more effective dementia management (Prince et al., 2016). UK and NI guidance state signposting to supportive community or voluntary services improves the lived experience of those diagnosed (Department of Health, 2016; DHSSPSNI, 2011) yet the establishing of support groups for people with dementia is discouraged or seen as a lesser priority by statutory agencies (Minghella & Schneider, 2012).

Research identifies specific benefits from social engagement (Manthorpe et al., 2011). Peer support groups help maintain identity (Harman & Clare, 2006), empower members (Boyle, 2014), promote acceptance and engagement with society (Read et al., 2017), and instil hope, facilitate grief, raise awareness of services and provide opportunities for learning (Yale, 1999). Being with diagnosed peers reduces burdens and feelings of isolation, normalises difficulties and adds perspective (Preston, Marshall & Bucks, 2007).

Methods

The article's purpose is to report on how those diagnosed with dementia related the diagnostic event to subsequent involvement in their empowerment groups. Previously, much research has relied on caregivers rather than people with dementia (Murphy, Jordan, Hunter, Cooney & Casey, 2015; Werner, Karnielli-Miller & Eidelman, 2013), though inclusion of the voices of those diagnosed is now increasing. To contribute to this body of knowledge, this study focuses solely on the views of 13 participants who attend dementia empowerment groups in four locations in NI. Two groups were located in cities, the third in a small town and the final in a village serving a broad rural area. These groups are facilitated by an advocacy charity and the groups provide both support and opportunities for consultation and engagement with policy makers and the public.

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Sampling was purposive: only those with dementia and attending groups were included. **Group facilitators asked group members if they wanted to participate and gave interested parties a project information sheet, ensuring individuals were fully aware of the study's aims well in advance.**

Interviewees were aged between 48 and 80, with five under 60 years (See *Table One*). Seven were female. **Whilst eight of 13 interviewees reported a dementia diagnosis prior to 65, often the boundary line for a diagnosis of young onset dementia (Draper et al., 2016), the term early-stage-dementia has been preferred as this clearly delineates that, whatever the respondent's age, participants retained substantial capacity, autonomy, and insight into their condition.**

Insert Table 1 around here

Ethical considerations

Involving people with dementia in research evokes concern around consent and capacity. Following the lead of the Bamford review on mental health and the Mental Capacity Act (2005) in England and Wales, the Mental Capacity (Northern Ireland) Act 2016 advocates for capacity to be presumed, including in research practices, unless otherwise directed (Lynch, Taggart & Campbell, 2017; Harper, Davidson & McClelland, 2016). Participants' capability to take part in the study was observed in a number of ways. Firstly, the researcher was directed by guidance from the professional facilitators. Secondly, group members demonstrated capacity in terms of **independently travelling** to and from the group and involving themselves in the group's decision making processes. Finally, following guidance from the functional test for capacity, group members were able to understand the research task, could retain this information and were able to weigh up the importance of this before making a decision (Lynch et al., 2017). In this study, all those taking part gave written consent. **The researcher read this form with every candidate, checking that all aspects were clear before commencing. This included information on how participants' contribution was voluntary and could be withdrawn at any time, specific information as to how their interviews would be recorded,**

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transcribed and stored, and how responses and direct quotations could be used in potential journal articles. Each participant was given a pseudonym to minimise the chances of their being identified. The research study gained ethical approval through [Ulster University Research Ethics Committee](#) in December 2016 (reference REC/16/0102).

Procedure

The researcher conducted face-to-face semi-structured interviews between June 2017 and April 2018 at [the four venues](#) where participants usually met in their groups. [The researcher engaged in preliminary conversation to put the interviewee at ease \(Murphy et al., 2015\) and checked, through the consent form process, that each fully understood the process.](#) Interviews, which lasted [between 20 and 55 minutes](#), were recorded digitally. [Given the potential for sensitive topics, the researcher checked on completion how each participant felt and asked for reflections on the process \(Murphy et al., 2015\).](#)

Analysis

Grounded theory was used to learn inductively what participants considered most important about their social lives post-diagnosis, with predetermined knowledge being kept to a minimum (Glaser & Strauss, 1967). Research questions may unintentionally predispose a respondent towards a particular response (Tufford & Newman, 2010). An example of the initial draft of questions is in [Table 2](#). [Questions initially examined the pre-diagnosis life, what changed subsequent to diagnosis, group experiences and views on social lives generally outside the group. Whilst an interview schedule was used to commence conversations, an iterative and flexible approach was adopted, ensuring that responses in early interviews led to changes in latter engagements. For example, the first question always asked participants how they joined the empowerment group. Rather than answering this directly, respondents often used this opportunity to speak about their diagnosis. The opening exchange with Teresa was somewhat typical:](#)

Researcher: The first question I wanted to ask you is how did you come to join [the group]?

Teresa: Do you want me to start from when I was diagnosed...?

Participants outlined, often in depth, challenges with diagnosis and its emotional impact. Reflecting on initial interviews and recognising this was a most important topic for respondents, an inductive response ensured the researcher gave increasing time for participants to explore this matter. This validated participants' own priorities of what was relevant. This article, then, evidences emergent data that relays participants' view of the diagnostic process and its changes to their social lives.

Insert Table 2 around here

Initial coding was undertaken by reading interview transcripts carefully line by line and highlighting meaningful words and sentences in each narrative. These were then categorised, using NVivo 11 software, with a subsequent process of axial coding resulted in various subthemes. After further analysis and the narrowing of focus to matters pertaining only to diagnosis and post-diagnostic support for the purposes of this article, these yielded the three themes highlighted below. The extensive use of quotations in the following section adds weight to how themes are evidenced in participants' own words. These are then analysed in the Discussion.

Findings

Experience of diagnosis

Some participants identified positive practice at diagnostic stage. Teresa conveyed the DMP's compassionate manner and sensitivity.

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“[I] went in to see [DMP] and he’d been talking to me for a long time and he was very good [...], and at one stage he did say to me, Teresa, would you like to know if you [...] have dementia? I says, of course, I would. So he went on for another wee while and then I saw him kind of getting down on his honkers a wee bit [...], and I thought, there’s something coming here [...] He says, you’ve got dementia” (Teresa).

For others the diagnostic process felt lengthy.

“I went through all the period then of memory clinics and all the rest of it which takes a long time and that’s what I find is frustrating with the medical profession because it takes so long to get any solutions” (Lorcan).

“I went to see my doctor and tried to talk to him about it and he didn’t want to know [...I feel they] don’t know very much about dementia [...], they tend to shy away from it” (Nuala).

Unhelpful comments from professionals had a lasting impact.

“I was quite shocked when [the specialist gave the diagnosis], he was [...] very abrupt, just stuck his head out the door and says, you’re not allowed to drive anymore and you’re not allowed to drink anymore” (Oisin).

“I was diagnosed by [consultant] and he was nearly gloating about it [...He was] extremely smug about it. Extremely, it was really off-putting because he was so smug about the whole thing. He [...] was, ‘I diagnosed her and [other consultant] didn’t.’” (Yvonne).

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“Diagnosis was terrible. I think it was handled so badly that day and I want changes there [....] Just the way it’s done, the whole thing’s done [...], he ushers you out and you go home and that’s it [....] He told us to put [...] my affairs in order [....] He opened the door, ushered us out [....] This was about ten to four on a Friday. I learned then he [...] flew home to Manchester, he headed to the airport for half four on the Friday afternoon” (Zachary).

Ursula did not give her permission to her DMP to share information.

“[The consultant] says, you have Alzheimer’s, he says [...], what is your husband’s number? [...] I told him my number and he phoned him just straight off. He didn’t say to me, I’m going to tell him but he just phoned him straight off. He says, your wife has Alzheimer’s” (Ursula).

Yvonne went on to express concern that consultants did not listen.

“It’s just getting that balance right and people listening to you, which is what I found very difficult with the Trust with the doctors [....] GPs were fine, the consultants all were, they were right [*as in correct*]. They weren’t always right.” (Yvonne)

Reaction to diagnosis

In line with wider findings, interviewees reported shock and a subsequent inability to take in further information during consultation. This led to ruminations about things being left unexplored.

“When I did come out of the doctor’s [...] and my daughter was with me, I was sitting in the car and I sorta, the tears, feeling sorry for myself and when we come up home, we chatted about it” (Maolisa).

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“It didn’t go [...] into my head that I had, you know, so he was talking and talking and talking and [...] I didn’t hear, I did not hear one word he said. Just went over my head” (Teresa).

“So that was it, [the neurologist] said I’m really sorry, there’s nothing we can do [...], the only thing we can do is bring you back once a year for check up and see how it’s all progressing [...] And I says, right, okay, so then I went home and obviously tried to digest all this” (Nuala).

“I’m sorry to say, Phelim [...] that you’ve got Alzheimer’s dementia [...] Look, my mind sort of went blank then [...] I was listening but I wasn’t listening [...] I was scared of [my son] crashing the car or something on the way home, so when I got it, I was in shock like. [...] I don’t know if I was in that office for two minutes or two hours. I don’t know [...], I honestly don’t know” (Phelim).

Referrals to services

DMP were in their comfort zone when it came to medical processes and referrals and interviewees were often happy with how these matters were activated.

“It was quite intense and then, funny, it’s like I was really lucky, two weeks later I had got my MRI scan, you know, within two weeks so that was [...] very quick and two weeks later I was diagnosed” (Teresa).

“When I told [my GP], she already had looked after [other relatives], so she picked up on it right away. She says, Phelim, if I send for a scan, will you go for a scan? I says, I will.... So all this went through [...] brave and quick” (Phelim).

However, when it came to social support, others were more clearly instrumental in referring

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individuals to the empowerment groups. Ten of the 13 participants talked about this (see *Table 3*).

Insert Table 3 around here

It was unusual for participants to reveal a direct link between the DMP and a referral to an empowerment group.

“There was no referral made to them by the consultant [...] One of my biggest fights is to get somebody to be there when you come out the door. Your head might still be spinning but just take you for a cup of tea and a handful of leaflets to give you” (Zachary).

Only one reported being informed of the empowerment group by their GP and none by consultants or specialists more likely making the diagnosis. Other health or social care professionals played a role.

“I was with an occupational therapist for a few weeks and... she was the one who pointed me towards the [empowerment] group” (Oisin).

Three members were referred by dementia navigators, employed by the health and social care trusts in NI, who typically would be alerted to diagnoses by memory clinics (Belfast Health & Social Care Trust, no date).

“Within a few weeks of diagnosis, I had a visit from a dementia navigator and within a week after that [the empowerment group facilitator] had come out to see me... and a week after that I was in the group. So for me it was very positive and very quick” (Quinn).

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There was however a sense that geographical location had an impact on signposting to support services.

“The navigators are brilliant but yet if you are unfortunate to live in [... city], that area, some people there was saying it was about six months [...] between diagnosis and seeing somebody” (Roisin).

Even when the navigator was seen positively, there were concerns about the time-limited nature of certain posts and funding.

“You definitely need a navigator because [...] I think her time’s running out now [...] She is a fantastic person [...] It was her really that got me [...] on the wee courses that really sort of helped me and then getting out here to [the empowerment group]” (Teresa).

Although evidence of direct referrals to social support was scant, DMP did acknowledge its benefits.

“My consultant [...] maintains that, you know, people who meet in a group like this [...] keep at a much more even keel, even slightly improve whereas if people who would sit at home all day every day, [...] there’s a quick decline” (Roisin).

One conduit used by DMP for supplying advice on formal and informal support was through written literature. However, two participants reflected upon how the information distributed was clearly oriented towards carers.

“[The consultant had] nothing for me. I’ll never forget and he said he’d send me out something and five weeks later I got a leaflet for [...] communicating with people with dementia and that’s the first information I got. It was a carer’s leaflet” (Zachary).

“I was given the Trust book and the Trust book is, ‘talk softly to them’, ‘don’t shout’, you know, ‘put the mat at the door, so they don’t fall’ and I, my mother had Alzheimer’s and I was sitting going, I thought it was so patronising [...] It wasn’t, that book wasn’t for me. It might have been for a carer but it definitely wasn’t for me” (Yvonne).

Discussion

This article finds that diagnosis raises anxieties for both those diagnosed and the professional diagnosing, hindering a full and frank discussion about post-diagnostic options. Social support may bolster cognitive development and delay the worsening of the condition (Minghella & Schneider, 2012) and policies recommend social support for people with dementia. Despite this, referrals to social support at diagnosis for these interviewees was often overlooked. Despite acknowledgement of the importance of social support for those with dementia, the lion’s share of the NI Executive’s guidance on post-diagnosis care is directed towards health care needs and management, and carers’ roles (DHSSPSNI, 2011). These messages relegate the individual’s social needs and ability to be autonomous behind health care concerns. However, if DMP lack confidence in social support services, the reallocation of signposting to a third party, such as a dementia navigator, is a positive and necessary intermediary approach.

Emotions roused by diagnosis question whether it is appropriate or advisable during the diagnostic event to discuss opportunities for social engagement. In this study, participants talked about shock, feeling tearful, struggling to listen and denial. These feelings compromise the ability to retain subsequent advice during consultation. Participants in Clare, Rowlands & Quin’s (2008) study speak

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of the diagnosis experience as a journey into unfamiliar territory, accompanied by disorientation and anxiety regarding associated losses. Diagnosis then is not an ending but a point where difficult questions and uncomfortable ruminations surface (Campbell et al., 2016). The diagnosis process should appreciate the time and adjustment required to come to terms with this transition (*ibid.*).

The diagnostic process should not be a one-off event (Dhedi et al., 2014; Koch & Iliffe, 2010; Aminzadeh et al., 2007): there should be more than one appointment to discuss diagnosis **and enable effective care planning (Kelly & Innes, 2016)**. This could involve the outlining of appropriate support services that community and voluntary agencies provide. The NI Executive recognise that the diagnostic interview should improve, recommending the allocation of a key worker, and putting a system in place to ensure the provision of practical advice, support and information, including independent sources of advocacy (DHSSPSNI, 2011). In this study, positive contact with dementia navigators, other professionals and informal contacts that helped initiate involvement with empowerment groups, indicate that this sometimes is activated. The use of different services, as advocated by the UK's Department of Health, ensures better opportunities for appropriate and adequate access to multiple supports (Campbell et al., 2016).

Giving those diagnosed written information on social care and voluntary services could be best practice on the part of DMP (Lecouturier et al., 2008) and may be regarded by some GPs as a sufficient response to social need (White et al., 2017). By contrast, in this study, two participants reported being given inappropriate advice pamphlets **aimed at carers, a finding that echoes other research (Kelly & Innes, 2016; Mountain & Craig, 2012), and which reflects** a potential structural oppression whereby people with dementia are underestimated and perceived as lesser or diminished. Potential strengths and capabilities, often intact at early stages (Yale, 1999), are ignored. Yet, living well with dementia is the central theme in the NI Executive's strategy in addressing the needs of diagnosed individuals in the province (Dementia Together NI, 2016). This

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report focuses on emphasising what people with dementia can rather than cannot do and supports the individual “doing the things they enjoy but [with...] some support to do them in a slightly different way” (*ibid.*, p14).

The use of specialist services such as memory clinics is regarded as being more effective in providing effective post-diagnostic support (Kelly & Innes, 2016; Prince et al., 2016; Robinson, Tang & Taylor, 2015). Diagnosed individuals view services as valuable if they are able to signpost on to community support initiatives (Mayrhofer, Mathie, McKeown, Bunn & Goodman, 2018). DMP do not need to fulfil this role: diagnosed individuals appreciate dedicated and sensitive project workers who facilitate referrals to social support (Kelly & Innes, 2016). What is important is ensuring there is a clear system in place where the referral agent is identified early and appropriate processes activated. DMP increasingly recognise the benefits non-traditional outlets offer through the concept of social prescribing. This involves linking service users with non-clinical activities often facilitated by third sector organisations to enhance community well-being and social inclusion (Moffatt, Steer, Lawson, Penn & O’Brien, 2017; Baker & Irving, 2016; South et al., 2008), and includes signposting to relevant agencies that offer social support (Chatterjee, Camic, Lockyer & Thomson, 2018). DMP are already comfortable using social prescribing to tackle mental health conditions and social isolation (Mossabir, Morris, Kennedy, Blickem & Rogers, 2015) but may not respect the roles, knowledge and expertise of non-medical third sector service providers (White et al., 2017; Aveling & Jovchelovitch, 2014). If DMP feel less confident about social prescribing, this emphasises the importance of maintaining the role of dementia navigators. As one community organiser notes:

‘I think it’s still incredibly rare for there to be health referrals. I have never been involved in anything like that before . . . to have a doctor saying “I think this would be a good idea”’
(Baker & Irving, 2016, p387)

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Although DMP recognise the value of social concerns, they prioritise physical care needs and lack insight beyond their own individual expertise and institutional logic (Vince, Clarke & Wolverson, 2017; Baker & Irving, 2016). As a result, DMP are not always well informed about social support opportunities and links with third sector and community services are weakened. Dementia navigators help negotiate these uncertain waters, networking between boundaries, gaining knowledge of local services and being sensitive to the value of connections between different groups (South et al., 2008). Navigators take an holistic view of an individual's situation.

However, **in line with the UK Government's 2016 joint declaration, high quality post-diagnostic care and support is required at the point of diagnosis (Department of Health & Social Care, 2016)** so DMP should aim to be better informed about local social opportunities. Strategic collaborations that complement services help diagnosed individuals, build mutual understanding and respect, and promote social prescribing at grass roots level (White et al., 2017). A confident referral from a DMP can be especially valuable as this could help legitimise, in the diagnosed person's eyes, the service to which they are being referred (Mossabir et al., 2015).

Limitations

The study has used participants from empowerment groups in four locations in NI and findings may be difficult to generalise to wider populations elsewhere. Nevertheless, the study is validated by the wider literature's reporting experiences of difficult diagnoses, lack of practitioner confidence and uncertainty about social support.

Conclusion

This paper finds that, whilst the social needs of people with dementia are recognised as important, direct referrals to services from DMP appear rare. However, this is not entirely bad. Firstly, this study highlights that the diagnostic consultation is often overwhelming for those receiving a diagnosis and

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therefore taking in information about potential avenues of social support is compromised. Secondly, and linked to this, DMP expertise is mediated if there are other roles, such as dementia navigators, who can follow up and make referrals to appropriate services. DMP do not need to provide insight into areas outside their institutional logic, but there should be explicit procedures in place to ensure that people with dementia's social needs are recognised and respected, and appropriate referrals forwarded. There appears to be some good practice in this respect but this is not universal. As such, the importance and value of social support for those diagnosed should not be neglected in the medical process of dementia diagnosis.

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Table 1: Profile of Interviewees

<i>Name (Pseudonym)</i>	<i>Age</i>
Lorcan	74
Maolisa	74
Nuala	48
Oisin	55
Phelim	66
Quinn	74
Roisin	58
Stephen	80
Teresa	69
Ursula	78
Wilson	69
Yvonne	54
Zachary	55

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Table 2: Draft interview schedule

Main question	Suggested follow up
How did you come to join the empowerment group?	What was life like for you prior to joining?
What do you like/dislike about the group?	How does the group assist in maintaining social relationships?
What has changed since becoming diagnosed...?	In terms of (i) employment; (ii) social lives; (iii) any other changes?
What is your experience of loneliness?	Have you noticed changes in experiences of loneliness since becoming diagnosed?
Generally how would you describe your social life/social network now?	

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Table 3: How participants became aware of voluntary agency support group

Name	Route
Maolisa	Dementia Navigator
Nuala	Internet search
Oisin	Occupational Therapist
Phelim	Age NI workers
Quinn	GP
Roisin	Dementia Navigator
Teresa	Cousin/Dementia Navigator
Ursula	Friend (existing group member)
Yvonne	Sister-in-law
Zachary	Community Psychiatric Nurse