

Giving and receiving a diagnosis of a progressive neurological condition: a scoping review of  
doctors' and patients' perspectives

Eleftherios Anestis<sup>1\*</sup>

Fiona Eccles<sup>1</sup>

Ian Fletcher<sup>1</sup>

Maddy French<sup>1</sup>

Jane Simpson<sup>1</sup>

1. Division of Health Research, Lancaster University, Lancaster UK LA1

\*Corresponding author [e.anestis@lancaster.ac.uk](mailto:e.anestis@lancaster.ac.uk)

Abstract:

**Objective:** Delivering a life changing diagnosis can be a distressing experience for patients and a challenging task for professionals. Diagnosis delivery can be especially difficult for individuals with neurodegenerative diseases such as motor neurone disease (MND), multiple sclerosis (MS) and Parkinson's disease (PD). This review aims to scope the literature on doctors' and patients' perspectives on diagnosis delivery for these conditions in order to enhance our understanding in this area and identify potential research gaps.

**Methods:** A scoping review methodology was used, and data were summarised using content analysis.

**Results:** 47 studies fulfilled the inclusion criteria. Studies showed that although patients were generally satisfied with diagnosis delivery, a considerable proportion was still dissatisfied with aspects of the consultation, especially the information and time provided and the doctor's approach. Only six studies addressed doctors' perspectives, which focused more on doctors' practice.

**Conclusion:** There was a significant research gap in professionals' perspectives. The review also found that although basic standards of good practice were being met, a significant proportion of patients were dissatisfied with diagnosis communication.

**Practice Implications:** Professionals delivering such diagnoses need to assess and respond to patients' information needs, provide time for questions and maintain an empathic attitude.

**Keywords:** breaking bad news, diagnosis communication, neurodegenerative conditions, motor neurone disease, multiple sclerosis, Parkinson's disease, scoping review

## 1. Introduction

Diagnosis delivery for a significant health condition is a particularly challenging aspect of doctor-patient communication and most commonly described as ‘breaking bad news’ [1]. Bad news is usually described as ‘any information likely to drastically alter a patient’s view of his or her future’ [p.1597] [2]. How such news is delivered can have a long-term impact on the patient’s satisfaction with care [3], understanding of the disease [4], involvement in decision-making, psychological adjustment [5], prolonged distress, confusion and treatment adherence [6]. At the same time, delivering a serious diagnosis can also be an emotionally challenging task for healthcare professionals. This aspect of their clinical work can induce moderate but lasting stress reactions [7] and emotions of anger and guilt, and distressing thoughts around their powerlessness to make a positive difference and their own personal fear of death [8].

Studies in this area have been conducted predominantly within fields such as oncology, obstetrics and emergency medicine [6], however bad news delivery can be a critical issue in other medical specialties such as neurology. Progressive neurological conditions such as Parkinson’s disease (PD), multiple sclerosis (MS) and motor neurone disease (MND) are incurable and result in a gradual decline in physical and cognitive functioning, restricting individuals’ daily activities and affecting their quality of life and psychological functioning [9]. Before receiving their diagnosis, patients often experience a stressful pre-diagnostic period [10], are often misdiagnosed and may experience significant diagnostic delay [11-13]. Reaching a diagnosis for such motor neurodegenerative diseases (MNDDs) can be a demanding task for health professionals due to the similarities in and overlap between symptoms of different conditions [14,15] and the need for specialised testing. Communicating the diagnosis can also be challenging for doctors since such ‘bad news’ might elicit reactions of different types of distress from the patients [16].

Given the progressive, often life-threatening nature of these conditions and the likely stressful pre-diagnostic experience, receiving the diagnosis will be a critical time for patients. A PD patient survey reported that ‘satisfaction with the explanation of the condition at diagnosis’ had a significant effect on future quality of life [17]. This review will focus on three neurological conditions which all include forms of neurodegeneration<sup>(i)</sup>. Neurologists commonly deliver these diagnoses which primarily affect movement and have a high ‘burden of illness’ i.e. impact on both human and economic dimensions [18]. A scoping review was undertaken to identify and summarise existing empirical studies which addressed doctors’ current practice and perspectives on breaking bad news, and patients’ experiences and perspectives on the process of diagnosis delivery. Other reviews in this area have not focused solely on receiving the diagnosis but more on the experience of services [19-21] or doctor-patient interactions in general [22] and have excluded studies on professionals’ perspectives. Including both patient and doctor perspectives will achieve a better understanding on the neurologist-patient interaction at this critical timepoint, to identify areas of miscommunication, and gaps in the literature.

## **2. Method**

A scoping review was adopted to incorporate patients’ and doctors’ perspectives that have been reported in qualitative and quantitative studies. Scoping reviews focus on mapping and summarising key concepts from a range of research activities and identifying potential gaps in a broad research topic [23]. They offer similar rigor to reviews using a systematic review methodology, and aim to understand complex topics and not simply summarise the best available evidence. Heterogeneous designs can be included and quality assessments are not

usually conducted [24]. This review followed the 6-step framework developed by Arksey and O'Malley [23] and further recommendations by Levac and colleagues [24]. Five of six steps were completed, while the sixth optional step, consultation, was omitted. These steps are briefly outlined below:

i) Identifying the research question

The research question was: What are patients' and doctors' perspectives on the delivery of the diagnosis for MND, MS and PD? The term 'perspectives' was intentionally broad in order to capture both a priori themes such as patient satisfaction and doctors' practice and to identify and map other key concepts addressed by the literature.

ii) Identifying relevant studies

PubMed, CINAHL, PsycINFO and Scopus were accessed, using subject terms where available. The search strategies were developed with the help of a subject specialist librarian (see Appendix A). The citation lists of all the included papers were hand searched for additional studies, Google Scholar's 'cited by' service was also accessed.

iii) Study selection

Table 1 summarises inclusion and exclusion criteria.

[Insert Table 1 here please]

Empirical studies of any design were included in the review if they were published in a peer-reviewed journal and addressed patients' or doctors' perspectives on the delivery of diagnosis for MNDDs focusing on the consultation when the diagnosis

was delivered. As a first step, titles were screened and all irrelevant papers were excluded. Then abstracts were screened, irrelevant studies were excluded, relevant studies were included and potentially relevant studies were read in full. The main reasons for excluding articles included: no data on diagnosis delivery, a focus on the pre-diagnosis journey, and only addressing patients' emotional reactions to diagnosis. The first author screened all retrieved citations and consulted the rest of the research team to resolve any ambiguity. Additionally, a random 10% of all retrieved citations were reviewed by another author (MF) and any discrepancies were resolved. Figure 1 features a PRISMA diagram which illustrates the study selection process.

[Insert Figure 1 here please]

iv) Charting the data

Study information and results which addressed the research question were extracted (see Table 3).

v) Collating, summarising and reporting the results

Except for a few cases of basic numerical analysis of percentages, data answering our research question were analysed qualitatively through a conventional content analysis approach [25]. The content codes were organised into meaningful categories which summarised available evidence. Results regarding patients' perspectives were analysed and reported independently for each neurological condition, and doctors' perspectives were analysed together due to the limited number of relevant studies.

### 3. Results

#### 3.1 Overview of studies included in the scoping review

In total, 47 studies were included in the review. Table 2 summarises basic study characteristics and Table 3 presents characteristics for every study included in the review.

[Insert table 2 here please]

[Insert table 3 here please]

The majority of studies (n = 22) focused on MS; studies on doctors' perspectives were severely underrepresented in the literature with only six studies included in this review. Qualitative and quantitative methodologies were equally represented in the patient studies and all study designs were retrospective. Studies represented a range of countries, mainly from a western perspective, however the similarity of themes across studies indicated that patients' experience of receiving a diagnosis shared common features.

#### 3.1 Receiving the diagnosis of MND

##### *Satisfaction with diagnosis delivery*

In general, patients with MND were satisfied with the way neurologists delivered the diagnosis, but this was not always the case. Patients in an Italian survey gave high ratings of satisfaction with bad news communication and felt that the doctors were encouraging and

understood their feelings during the diagnosis [26]. Other quantitative studies [27,28] reported mixed results; although the majority of patients were satisfied with how the diagnosis was delivered, 32% to 35% of patients felt dissatisfied. In particular, patients were mostly satisfied with the privacy provided and the absence of interruptions during the consultation, with only a few exceptions reported. Satisfaction was also positively associated with patients' perceived ability of their neurologist, although it is unclear whether the term ability specifically referred to their communication skills or their general medical competence [28]. However, 36% to 56% of patients rated their doctor's ability as average or below average [28,29]. Similarly, qualitative studies also revealed mixed results with patients sharing both positive and negative experiences [30,31] although a study of a single centre which was following international guidelines for MND care received only positive feedback [32].

### *Information provision*

Given the rarity and life-threatening nature of MND, patients often required detailed information about their diagnosis. Patients wanted to know about current research on MND, disease-modifying therapies, their prognosis [26], their entitlements to services [32], the treatment plan and information sources [28,30]. However, it was sometimes felt that the doctor shared insufficient information about these topics [29,30]. Patients also reported their dissatisfaction with doctors, indicating that the information given was not always adequate and that the doctors did not always check they had clearly understood the information [34] or provide the opportunity for questions [35]. This elicited a 'feeling of abandonment' with patients feeling responsible for seeking information about their condition themselves. However, some patients felt that there was limited potential for further information due to the



poor prognosis [36] and a qualitative study highlighted that patients' receptivity to information differed dramatically [37].

### *Consultation duration*

Survey studies reported a mean consultation of approximately half an hour [28,29]. Patients who had received longer consultations were more satisfied and considered their doctor more skilled [28]. On the contrary, doctors who were judged to possess poor skills only spent an average of 13.4 minutes on the consultation [29]. Patients were often frustrated with a very short consultation as they did not have the opportunity for discussion [31]. At the same time, they knew the clinicians were in high demand and it could take months for the next appointment [34]. Receiving such a complex diagnosis required time for them to digest the information provided, express their feelings and ask questions. The evaluation of a fast-track diagnostic service based on principles of good practice in breaking bad news showed positive patient satisfaction regarding the communication of the diagnosis and the time taken [37]. Similarly, a qualitative study which assessed patients' perspectives on diagnosis delivery in a 2-tiered approach reported positive outcomes. Patients viewed the second appointment - which they received only 10-14 days after the first - as an opportunity to prepare questions, clear misunderstandings and make informed decisions regarding their treatment [36].

### *Doctors' empathy*

Qualitative studies and qualitative comments in quantitative studies sometimes highlighted the need for doctors to show more empathy. Patients often felt that their doctors did not approach such a serious diagnosis in a caring and sensitive way and were described as '*detached*', '*very*

*clinical*’ and *‘insensitive*’ [31,38]. Similarly, Pavey et al. [34] described that patients considered that doctors were unwilling to be personally involved and offer emotional support; a participant in the Hughes et al. [33] study also reported feeling *‘dehumanised*’. However, most studies that addressed the issue reported mixed experiences [30,31,33,35,39] or even exclusively positive experiences [37]. Patients valued being listened to when they expressed their anxieties and fears regarding the future [36] and those who were satisfied with their doctor’s approach [31] described them as a *‘fantastic, caring person*’ and *‘kind and empathetic*’. Interestingly, the older study reported that patients often found a straightforward and even blunt disclosure style acceptable [40].

### 3.2 Receiving the diagnosis of MS

#### *Satisfaction with diagnosis delivery*

Regarding general satisfaction with the way doctors broke the bad news for a MS diagnosis, studies presented mixed results. A quantitative survey showed that 67% of patients were completely and 24% were partially satisfied with the diagnosis delivery, 64% thought the medical staff were kind, 30% thought they were attentive and only 6% thought they were unfriendly or hasty [41]. It is noteworthy though, that this survey was conducted in a single MS centre. Additionally, two studies from Norway which used the same questionnaire found that there was definitely room for improvement as only 33% - 55% of patients were satisfied with the circumstances in which their diagnosis was communicated [42,43]. Qualitative studies, on the other hand, indicated that although some positive experiences were reported by patients, these were the exceptions [44,45].

### *Information Provision*

Beyond sharing their preference to be told their diagnosis in an honest and clear way, patients in most studies also shared their views on the amount and nature of the information they received during the diagnostic consultation. A survey showed that although 90% of MS diagnoses were given by neurologists, only 50% of patients considered them their major support regarding the meaning of the diagnosis [46]. In general, data from both quantitative and qualitative studies showed that patients felt they were not provided with adequate information about their condition [44-53] or they had to push to receive the information they wanted [53].

At the time of diagnosis patients seemed to need general information about MS, information on treatment options and managing their symptoms [46,48,52], information on counselling services [51,54] and lifestyle changes [44,53]. A survey [46] showed that 52% of patients were not informed about MS therapies when the diagnosis was made, however in a more recent study [41], 79% of patients considered their doctor's information on treatment choices to be exhaustive. Patients preferred information to be communicated in a simple and direct way [48,50], without the use of medical jargon [50] and reference to worst case scenarios [48]. However, a few studies made it clear that the type of information provided at diagnosis should be tailored to the individual [50] and some patients might not want any additional information at that point when the diagnosis itself is '*enough to handle*' [52]. In addition, patients often felt that accessing reliable information sources was not facilitated by healthcare professionals [45] who sometimes failed to signpost patients to organisations or specialised MS centres which could have been useful [44,49,55].

Patients explained that effective information provision at the time of the diagnosis would help mitigate the fear elicited by the diagnosis it [44,48]. Moreover, in a study in which

43.2% of patients were dissatisfied or very dissatisfied with the information they received at diagnosis, satisfaction with information was associated with more adaptive coping with the condition [55]. Nonetheless, some patients expressed the view that even though the doctor might have provided them with information about their diagnosis, their state of shock might have not allowed them to assimilate it [49,56].

### *Consultation duration*

Time dedicated to the consultation was an important variable which shaped patients' experiences of diagnosis delivery. A survey showed that 50% of patients thought that time taken by the doctor to deliver the diagnosis was too short [49] and patients in qualitative studies [50,53,57] also reported that their appointment felt '*rushed*'. Doctors were perceived to be in a hurry to see the next patient, with not enough time to ask questions and receive answers.

### *Doctors' empathy*

Patients in several studies reported that sometimes their doctors did not show any empathy, did not provide emotional support and delivered the diagnosis in a casual and overly medical way [44,56,49,51,53,57]. In a UK study with focus groups, out of 103 patients with MS, only 8 reported being happy with the communication of their diagnosis [51]. Some qualitative studies captured some extreme scenarios, for example, patients who were told their diagnosis over the telephone [49,58], on Christmas Eve [49] or via mail [50]. Neurologists were sometimes viewed as '*diagnosers*' with little or no interest in the patients [45,59], unable to understand fully the patients' perspective [44]. Patients who had negative experiences reported anger, disappointment and bitterness towards the medical profession [49,59].

Furthermore, a quantitative study associated discussion of patients' emotional well-being with the professional at the time of diagnosis with positive post-diagnostic outcomes [60]. In this study, 44% of patients reported having such a discussion with their doctor which was associated with significantly higher levels of acceptance of their condition as well as other benefits.

### 3.3 Receiving the diagnosis of PD

#### *Satisfaction with diagnosis delivery*

Data on overall satisfaction with the delivery of PD diagnosis indicated that there was room for improvement with 49% of patients being satisfied with their consultation, 29% being neutral and 22% being dissatisfied [61]. A more negative image was drawn in another study where 52.5% of patients rated their experience with the diagnosis delivery as good or very good and 45.3% as poor or very poor [62]. However, this difference can potentially be explained by differences in culture and healthcare systems since, although both were European surveys, the second study gathered data from 35 countries whereas the first one did so from 11.

#### *Information provision*

In Bloem's and Stocchi's [62] European survey, 62.2% of patients reported having received general information about their condition and although less than 1% reported not having received any information, only 22.1% said they received detailed information. Around 14% received information about medication at diagnosis and less than 2.8% received information regarding PD support organisations. In the same study, the information provided

at diagnosis was considered helpful or very helpful by 64% of respondents, with a more recent European survey reporting the same percentage (64%) [61]. In this survey, although respondents reported having received general information about the causes, symptoms and medication, nearly half stated they had not received any information on non-drug treatments at diagnosis. Qualitative studies often reported patients' negative experiences with information provision at diagnosis. Patients often felt that they left the consulting room with very little information about their condition [63-65]. There were instances when patients' questions were not answered in a satisfactory manner [65] or patients reported receiving no information at all from their doctors but were encouraged to buy a book about PD or search information on the internet instead [63].

#### *Consultation duration*

Inadequate information provision could be associated with limited consultation duration since only 38% of patients in the most recent European patient survey reported being given enough time to ask questions, while 17% would have liked more than the time they were given and 12% were not given any time at all [61]. Other studies also reported short consultation times (even 5-10 minutes in extreme cases [65]) which did not allow time for a detailed explanation of the diagnosis [63,64,66]. On the other hand, some patients were satisfied with the information they were provided [65] and it should be noted that being given too much information was also at times considered problematic [67].

#### *Doctors' empathy*

European surveys presented mixed patient experiences regarding the doctor's approach to delivering the diagnosis. Bloem and Stocchi [62] used a 10-point Likert scale to measure clinicians' attitude, ranging from abrupt to kind, in which 58.9% of patients gave positive scores (6 to 10) and 36.4% gave negative scores (1 to 5) with 16.9% choosing the best possible and 11.3% the worst possible score. Percentages differed in a more recent survey where 50% of patients reported that their PD diagnosis was communicated quite or very sensitively and 50% felt it was given not very or not at all sensitively [61]. Qualitative studies were consistent with these findings and provided vivid accounts of patients who felt that receiving the diagnosis was an important moment for them which was not always handled appropriately by the doctors. The diagnosis was often communicated abruptly, in a casual way, without any sensitivity or compassion [63,66,67].

Patients often shared similar stories in which their diagnosis was handled '*routinely*' in a '*business-like*' way, in an appointment so '*swift*' that they did not have space to consider their reaction [63]. On the contrary, an account from a patient who had a positive experience with her doctor indicated that patients value doctors who show an understanding of the emotional impact of the diagnosis, adopt a positive attitude and provide reassurance that their condition can be managed with professional help. Indeed, a more sensitive delivery of the diagnosis was associated with higher patient satisfaction, having a stronger relationship with satisfaction than the helpfulness of the information provided, and the time provided to ask questions [61].

### 3.4 Doctors' perspectives on communicating the diagnosis for MNDDs

Studies on doctors' perspectives on communicating a diagnosis for MNDDs were limited and reported little data on the actual consultation. Instead, these studies focused on

other issues such as when the diagnosis should be disclosed. Data relevant to our review question were mostly associated with neurologists' practice.

For the case of MS, doctors often [46,68] (28%-58.3%) avoided using the term 'multiple sclerosis' when communicating the diagnosis or did so only at the end of the consultation or in subsequent visits (57%) [69]. Instead, other terms such as '*demyelination*' or '*nervous system infection*' were used [68], possibly because they were considered less 'negatively charged' and less associated with the stigma associated with the term MS. Overall, neurologists in these surveys seemed to be sensitive to the emotional impact of the diagnostic process and reported being willing to support patients through information provision. The vast majority reported delivering the diagnosis of MS in a private setting [68], involving patients' relatives [68,69] and approximately 50% took more than half an hour (and sometimes more than an hour) for the consultation [46,69]. Most neurologists felt emotionally involved in the relationship with the patient (64%) and used the shared decision-making model (87%). They aimed to initiate bidirectional communication, answered patients' questions (61%) and tried to 'offer comfort and support suggesting a disease-modifying therapy' [69]. Around 77% believed the way they communicated the diagnosis assisted the patient in understanding the meaning of the diagnosis [68] and although 79% considered their communication practice as competent, only 14% believed they had managed all patient needs and expectations [69].

Apart from a survey assessing MND care in Italy, which found that the time taken to explain the diagnosis was around 30 minutes [70], the only survey focusing solely on the communication of MND diagnosis was conducted in Australia and assessed neurologists' current practice and experiences of breaking bad news [71]. Most neurologists (68%) used two consultations to deliver the diagnosis with the mean duration of each consultation being 23 minutes. The duration was double (45 minutes) for neurologists who practised in multidisciplinary MND clinics. Almost all (98%) of neurologists reported having a patient's



relative involved in the consultation, 73% referred to an MND association and 78% gave the diagnosis in a private space but only 41% were always able to avoid interruptions. Regarding the content of the consultation, the degree of certainty, how the diagnosis was reached and the course of the disease were the most discussed aspects, while being honest without taking away hope, dealing with a patient's emotions and spending enough time were the most challenging aspects. About 70% of neurologists reported that delivering the diagnosis was a '*very to somewhat difficult*' task and believed that difficulties were due to the lack of effective treatment for MND, the fear of causing distress or not having all the answers. Moreover, communicating the diagnosis induced '*high to moderate*' stress and anxiety for 65% of neurologists.

Finally, Pinder's study conducted in the UK [72] explored general practitioners' (GPs') perspectives on the diagnosis of PD. This qualitative study focused on professionals' experience of reaching the diagnosis and the beliefs that informed their practice. Diagnosing was often a '*eureka moment*', a moment of theoretical '*coherence*' that gave satisfaction to the doctors. The diagnosis was viewed positively since it did not only validate their role as 'diagnosticians' but also enabled them to initiate treatment, help patients manage their condition and prove their symptoms credible. A PD diagnosis was not viewed as so 'emotionally loaded' by GPs especially when it was diagnosed in older people and it was often compared with other 'more serious' conditions. Doctors tried to incorporate these views into the communication of the diagnosis to help patients come to terms with the disease. In addition, several doctors were more empathetic and tried to deliver the diagnosis in a way which showed consideration for how PD might affect patients' relationship with their bodies and their daily lives.

#### **4. Discussion and Conclusion**

## 4.1 Discussion

Although the topic of breaking bad news has been studied more extensively within other fields of medicine [6], a considerable number of studies were identified that addressed this issue for MNDDs. This scoping review revealed a significant research gap in doctors' perspectives of delivering a MNDD diagnosis. Moreover, the small number of doctor-studies included in this review made it difficult to compare and contrast patients' and professionals' views on the delivery of the diagnosis of an MNDD. Overall, patients across conditions were fairly satisfied with the way they were told their diagnosis and more recent papers drew a more positive image than older ones, potentially due to the growing emphasis on the importance of communication in healthcare and the patient-centred care 'movement'[73, 74]. Most doctors also reported relatively high standards of practice in delivering this task. However, survey studies reported considerable percentages of patients who were dissatisfied with the process and, with the qualitative studies, illustrated several aspects of the diagnosis delivery consultation which could be improved.

Effective information provision and patient education are considered two of the pillars of patient-centred care, a model of care considered appropriate for individuals with chronic conditions and complex health care needs such as MND [75], MS [76] and PD [77]. However, patients in the studies included in this review often expressed their dissatisfaction with both the amount and nature of information they received (or did not receive) during the delivery of their diagnosis. Studies with newly diagnosed cancer patients have shown that information provision can lead to several positive outcomes such as gaining a sense of control, reducing anxiety, promoting compliance, realistic expectations, self-care and feelings of safety [78]. Increasing patients' knowledge of their condition can tackle stereotypical disease

representations that do not apply for all cases (e.g., equating having MS with being wheelchair-bound and dependent). Providing adequate and timely information at diagnosis is also vital for shared-decision making, especially for conditions such as multiple sclerosis when long-term treatment decisions have to be taken early on [79,80]. Additionally, some patients reported that their doctor did not signpost them to relevant organisations or reliable information sources which raised feelings of abandonment. This was a missed opportunity to connect with community-based organisations which have been shown to generate a feeling of relief while offering a holistic approach to supporting patients and their carers [81]. Being left alone to seek information for their condition themselves, patients often turned to the internet, where information sources varied in reliability and could be misleading, especially regarding treatment options [82,83].

On the other hand, studies on neurologists' practice illustrated a willingness to support patients via information provision. Although, as stated above, the limited volume of data on doctors' perspectives does not allow for robust comparisons, this discrepancy between patients' experiences and doctors' reported practice could be attributed to doctors' often not assessing accurately patients' information needs [79]. The preferred amount of information differed significantly among patients, but in general it seemed that doctors tended to underestimate patients' information needs [84].

Whether health care professionals showed compassion while delivering the diagnosis was another major topic addressed. Patient studies across conditions reported mixed results regarding the doctor's manner of managing the consultation. While this was not the case for everyone, it was often felt that they did not receive emotional support at the time of diagnosis and described unsympathetic, detached, insensitive professionals with an overly medical and casual approach. In other words, as Habermann [64] noted: 'The human significance was passed over and objectified by what is known about the disease and treatment'. [p.404].

Patients' negative experiences highlighted a contrast between their strong emotional reaction to the news of the diagnosis and the often-emotionless practice of their doctors, which left them feeling angry, disappointed, bitter or even dehumanised.

A factor that could partially explain why individuals felt they did not receive adequate information and emotional support from their doctors were time constraints. Individuals across conditions often reported receiving short consultations, which caused frustration and a sense of being 'rushed' [65].

#### 4.2 Practice and research implications

This scoping review showed that several aspects of the diagnosis delivery process could be improved. Although the difficulties inherent in effective doctor-patient communication are significant, efforts must be made to promote a culture of continuous professional development and learning in this important area [85]. Adopting a truly patient-centred approach to communication needs to be the overarching framework for development and improvement. As part of this, healthcare professionals delivering such diagnoses need to assess patients' information needs by being sensitive to patient cues, checking their understanding of the information provided and providing time for questions. However, given that many professionals are restricted by time, it is suggested that they at least provide basic information about the condition, an overview of treatment options and effects of the condition on daily life and then signpost patients to reliable information sources such as specialist nurses and disease associations which will further support them. Delivering the diagnosis in two consultations has also been found to be beneficial to patients. Moreover, professionals need to maintain a caring and empathic attitude, avoid an overly medical and detached approach and provide support especially to patients who show the need to share their concerns and emotions.

Beyond practice implications, future research should incorporate doctors' views, encourage experiential and emotional explorations and, therefore, create a deeper and more holistic understanding of the doctor-patient communication at the time of diagnosis. The aim of this would be to shed light on the challenges and facilitators of effective communication at this time, inform best practice guidelines and appropriately support professionals.

#### 4.3 Limitations

This scoping review's main limitations are the inclusion of only studies written in English due to funding and time constraints, and the potential inclusion of low-quality studies due to the absence of a quality appraisal tool. However, this is usual practice in scoping reviews [86]. In addition, the screening of the titles/abstracts and the eligibility assessment of the papers were made by only one person and only 10% of the citations were reviewed by a second person.

#### 4.4 Conclusion

This scoping review found that diagnosis communication is a crucial moment for patients with MNDDs which requires a careful approach from doctors. Although some basic standards of good practice were being met and patients were generally satisfied, a significant proportion of patients were dissatisfied with the way they were given their diagnosis, reported issues related to inadequate information provision, lack of empathy and insufficient consultation duration. The review also found an important research gap on professionals' perspectives of giving bad news to individuals with these conditions. More research involving

both the bearer and the receiver of bad news for MNDDs is needed for the development of evidence-based training programmes and guidelines for diagnosis communication, all informed by a patient-centred approach.

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**Footnote:** (i): MS's neurological nature has been a matter of controversy in medicine. We signpost to this review of data that supports neurodegeneration as the major cause of irreversible neurological damage: Trapp, B. D., & Nave, K. A. (2008). Multiple sclerosis: an immune or neurodegenerative disorder?. *Annu. Rev. Neurosci.*, 31, 247-269.

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