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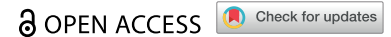


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RESEARCH PAPER



# Healthcare professionals' involvement in breaking bad news to newly diagnosed patients with motor neurodegenerative conditions: a qualitative study

Eleftherios Anestis<sup>a</sup> , Fiona J. R. Eccles<sup>a</sup> , Ian Fletcher<sup>a</sup>, Sofia Triliva<sup>b</sup>  and Jane Simpson<sup>a</sup> 

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## ABSTRACT

**Purpose:** Research on breaking bad news (BBN) in healthcare has mostly focused on the doctor-patient interaction during a single consultation. However, it has been increasingly recognised that BBN is a wider process that also involves other healthcare professionals. This qualitative study explored non-medical<sup>1</sup> healthcare professionals' involvement in BBN to newly diagnosed patients with motor neurodegenerative conditions in the UK.

**Materials and methods:** 19 healthcare professionals working with people with motor neurone disease, multiple sclerosis, Parkinson's disease or Huntington's disease took part in individual, semi-structured interviews which were analysed using thematic analysis.

**Results:** Four themes were constructed: dealing with the diagnostic aftermath, unpacking the diagnosis, breaking bad news as a balancing act and empowering patients to regain control over their health and lives. Participants reported being broadly involved in BBN by supporting patients with negative diagnostic experiences, re-iterating diagnostic information and helping patients understand the impact of their condition. The challenges of effectively breaking bad news and how these difficult conversations could help empower patients were also emphasised.

**Conclusions:** BBN was a critical and challenging aspect of healthcare professionals' clinical work with newly diagnosed patients with motor neurodegenerative conditions. Besides providing information, BBN was perceived as a way to educate patients, encourage them to make decisions and prepare for the future.

## ARTICLE HISTORY

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## KEYWORDS

Breaking bad news; neurodegenerative conditions; neurorehabilitation; motor neurone disease; multiple sclerosis; Parkinson's disease; Huntington's disease; communication

## ► IMPLICATIONS FOR REHABILITATION


- Breaking bad news is a potentially under-recognised but significant aspect in the neurorehabilitation of neurodegenerative conditions.
- Listening to patients' stories about a long and occasionally unsatisfactory diagnostic journey and allowing them to express their frustration can be critical in regaining patients' trust and building a relationship with them.
- Newly diagnosed patients have not always received adequate information about their condition at diagnosis or they might have not understood or retained that information. It is, therefore, essential that patients' understanding of their condition is assessed, misconceptions are cleared and appropriate information about the nature and impact of the diagnosis is provided.
- Irrespective of the length of experience, breaking bad news was perceived as a multi-faceted, challenging, stressful and emotionally demanding task.
- Formal support and specialised training on breaking the bad news that addresses the incurable, unpredictable and progressive nature of motor neurodegenerative conditions could help professionals with this challenging task.

## Introduction

In healthcare, bad news is defined as "any information that adversely and negatively affects the patient's view of the future" [1]. The process of delivering this news is usually called "breaking bad news" (BBN) and is considered a critical aspect of patient-provider communication with a long-term impact on patients' satisfaction with care [2,3]. Most of the research on this topic has focused on the consultation when a clinician delivers the

diagnosis; however, this depiction of BBN as an isolated event between the patient and the clinician has been criticised [4]. Studies on patients' experiences have indicated that receiving bad news is more of an ongoing process than a single event [5,6]. In addition, viewing the process of BBN as a broader aspect of care [7] (and not confined to a single episode) might also better reflect both medical staff's [8] and other healthcare professionals' (HCPs') clinical reality [9].

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It has been increasingly recognised that HCPs other than doctors are also involved in the process of BBN. Most of the research on non-medical HCPs' involvement in BBN has been conducted within oncology [10,11] and has focussed on nurses. Besides sometimes being present at the diagnosis delivery consultations, nurses are often also responsible for supporting patients post-diagnosis [4]. This can include providing clarifications and clearing misunderstandings, explaining the impact of the diagnosis, sharing information on treatment options and prognosis, encouraging decision-making, and offering emotional support [10,12,13]. Despite the stress and the emotional toll of BBN, nurses have reported finding that involvement in such conversations strengthens their relationship with patients and helps them become better professionals through self-reflection [4,10]. BBN has also been recognised as a common aspect of speech and language therapists' and audiologists' practice, mostly in the form of delivering bad news to parents of a child. A recent qualitative study highlighted the challenges that these professionals face both in terms of phrasing their message but also dealing with the emotional impact of BBN [14].

The communication of bad news can be a critical issue for other specialties as well, such as neurology. A review of qualitative studies on HCPs' experiences in delivering information about recovery in acquired neurological conditions showed that professionals were mostly challenged by the uncertainty in predicting recovery potential, assessing patients' readiness to receive information and being honest without taking away hope [15]. Professionals were concerned that BBN could undermine patients' hope, which was considered vital for neurorehabilitation, helping patients remain motivated and engaged in therapy. However, findings from a qualitative study that explored the meaning of hope in neurological physiotherapy practice suggested that there were different types of hope beyond the hope for physical recovery and that hope was a dynamic concept embedded in interaction and cultivated through communication [16]. In another qualitative study, neurological occupational therapists reported being routinely involved in difficult bad news conversations without having received adequate formal training on how to break bad news effectively [17]. Participants in that study reported being usually involved in such conversations when discussing plans for discharge and the end of active treatment, however, the authors suggested that future research should address therapists' experiences in BBN for specific conditions, such as progressive neurodegenerative conditions.

Progressive motor neurodegenerative conditions (MNDDs), such as motor neurone disease (MND), Huntington's disease (HD), multiple sclerosis (MS) and Parkinson's disease (PD), are at present considered incurable and can result in a gradual physical and often cognitive decline [18]. Besides their similarity in terms of their neurodegenerative nature and impact on motor and cognitive functions, there are major differences among these MNDDs, for example in terms of their prognosis and how they are diagnosed. Among these conditions, MND is the most directly life-threatening and has the shortest life expectancy with 50% of patients dying within 30 months from symptom onset [19]. On the other hand, HD is different from other MNDDs in that it is inherited and can be confirmed through genetic testing years before disease onset, which is often characterised by the manifestation of motor symptoms around the age of 40 [20]. Therefore, BBN for these conditions can be a challenging task for professionals [21] especially since patients with MNDDs have often experienced a long and stressful pre-diagnostic journey [22–25]. In addition, due to the growing recognition of the

potential positive outcomes of introducing palliative care in the early stages of these conditions (especially MND), professionals are often required to have early conversations around disease progression and advance care planning [26,27]. A scoping review of patients' and doctors' perspectives on diagnosis delivery for these conditions showed that although best-practice standards in BBN were reported as being met by doctors, patients were often dissatisfied with the manner the diagnosis was delivered, the time invested, and the information provided at that point [28]. However, there are currently no studies that focus on the involvement of non-medical HCPs in BBN specifically for these progressive conditions.

Due to the complex and progressive nature of MNDDs, patients have constantly to adapt to their declining physical, cognitive and psychological functioning and deal with a series of 'losses', depending on the condition, such as the loss of speech [29], the ability to drive [30] or walk and the loss of independence [31,32]. Guidelines acknowledge the need for healthcare support across the trajectory of the condition and recommend that MNDDs are managed by multidisciplinary teams (MDTs) which can include medical professionals, clinical nurse specialists, physiotherapists, occupational therapists, speech and language therapists, nutritionists and psychologists [33–36]. Beyond pharmacological treatment and symptom management, MDT approaches are patient-centered; they aim to minimise the disease's impact in all aspects of patients' lives and increase their participation in activities while also actively involving and addressing carers' needs [37,38]. Despite having varying methodological rigour, studies have reported evidence that MDT approaches to the management of different MNDDs can have a positive impact on patient outcomes, such as quality of life, physical and psychological symptoms, reduced hospital admissions, reduced activity limitation and even increased survival for the case of MND [39–42].

Given the considerable MDT involvement in MNDDs, many HCPs other than doctors are involved in BBN conversations with patients. In this study, viewing BBN as a wider episode of care, we use a qualitative research approach to explore healthcare professionals' involvement in BBN to newly diagnosed patients with MNDDs.

## Methods

### *Study design and ethical approval*

A qualitative design using individual, semi-structured interviews was adopted in order to answer the research question; what is non-medical HCPs' involvement in BBN to newly diagnosed patients with MNDDs? The interview guide (see [Table A1](#)) was designed based on previous research on BBN [2,4] and followed an exploratory approach to establish healthcare professionals' range of involvement in this task. A PD specialist nurse provided feedback on the interview schedule's relevancy and the overall study design before study initiation. The study received ethical approval by the authors' host institution's research ethics committee (FHMREC18) and research governance approval by the Health Research Authority (Project ID 266719), a unified system for health research governance in the UK.

### *Participants and recruitment*

UK-based, non-medical HCPs working clinically with newly diagnosed patients with at least one of the MNDD diagnoses were eligible for participation. We maintained an open approach

Table 1. Participant profile.

No.	Role	Age	Sex	Years of experience
1	PD nurse specialist	59	Female	23
2	PD nurse specialist	61	Female	43
3	Speech and language therapist	41	Female	19
4	Community matron (supportive and palliative care)	61	Female	40
5	MS nurse specialist	55	Female	34
6	PD nurse specialist	50	Female	26
7	PD nurse specialist	28	Female	6
8	Clinical psychologist	35	Female	9
9	HD nurse specialist	46	Male	25
10	MND nurse specialist	53	Male	32
11	Occupational therapist	58	Female	36
12	Occupational therapist	54	Female	33
13	Clinical psychologist	37	Female	14
14	MS nurse specialist	31	Female	10
15	Physiotherapist	32	Female	10
16	Physiotherapist	30	Female	9
17	Physiotherapist	34	Female	12
18	Clinical psychologist	64	Female	41
19	MND nurse specialist	59	Female	37

Mean age:  $M = 47$  (28–64),  $SD = 12.5$ .

Mean years of experience:  $M = 24$  (6–43),  $SD = 12.7$ .

regarding the range of HCPs we would include in the study (specialist nurses, allied health professionals, psychologists), and we were also guided by the first interviews with specialist nurses who reported on the different HCPs patients consulted soon after being diagnosed. Participants have recruited through collaborations with NHS (National Health Service) Trusts, snowball sampling and advertisement of the study in social media. A participant information sheet and an online consent form to be completed prior to participation were sent to potential participants before an interview was arranged. In total, 19 HCPs were recruited in this study. Participants' characteristics can be found in Table 1. The sample size for this study was mostly based on pragmatic considerations [43]. We aimed to recruit participants who represented most of the different MDT members involved in the care of newly diagnosed patients with MNDDs and we also made sure to recruit specialists who worked with individuals with all four conditions. At 19 interviews, we felt that these goals had been met.

### Data collection and analysis

Data were collected through individual, face-to-face ( $n = 3$ ) and phone ( $n = 13$ ) or video call ( $n = 3$ ) interviews whose length ranged from 35 to 70 min ( $M = 46$  min). Interviews were audio-recorded and transcribed verbatim. The research was conducted within a critical realist (CR) paradigm [44]. This assumes a realist ontology, i.e., a belief that much of reality (stratified into three domains) exists and operates independently of our awareness or knowledge of it. Epistemologically, CR is often described as relativist, meaning that it accepts that our knowledge of reality is gathered in a specific context and therefore our attempts to capture the knowledge of that reality are potentially fallible. Data were analysed both inductively and deductively using thematic analysis and specifically the steps described by Braun and Clarke [45,46]. An inductive approach was mostly followed in terms of exploring professionals' range of involvement in BBN, whereas deductive analysis was more prominent when the coding was influenced by factors which have been identified as critical by previous studies on patient and doctor perspectives, e.g., assessing information preferences [28]. Familiarisation with the data was achieved through listening and transcribing the interviews and re-reading the transcripts before proceeding to the coding phase. The entire data set was coded semantically by EA and ST

(focusing on the explicit rather than the latent meaning of the data) before codes were collated into potential themes. Themes were generated by going back and forth from data to codes and considering different potential themes in relation to the research question and the clinical reality described in the participants' accounts. The four final themes were reviewed and defined by the entire research team before naming them and proceeding to writing-up. A coding example and a list of the codes that constitute each theme can be found in Table A2.

Throughout the process of designing and conducting the study, Yardley's [47] criteria of validity in qualitative research were used to ensure quality. *Sensitivity to context* was ensured through gaining an in-depth knowledge of relevant literature before conducting and analysing the interviews, through developing an understanding of the patient pathways and clinical reality of professionals working with patients with MNDDs and through building an environment of trust and rapport during the interviews. Prolonged engagement with the topic, conducting an adequate number of in-depth interviews with different HCPs and achieving immersion in the data contributed to achieving *commitment* and *rigour*. These were also ensured through having two authors code all transcripts and by involving all authors in the process of theme development. The use of an established approach to thematic analysis [45,46] and detailing all the steps from designing the study to collecting and analysing data contributed to the study's *transparency*. Apart from producing compelling themes, *coherence* was ensured through the choice of thematic analysis as a theoretically flexible, pattern-based method used to highlight similarities and differences which was appropriate for the exploratory aim of this study. Due to this study's exploratory nature, special attention was also given to *reflexivity*, reflecting on how the researchers' perspectives and motivations could influence the interviews and the subsequent analysis and interpretation of data. Although every attempt was made to avoid directing participants and for the results to be grounded in the data, we acknowledged how our subjectivity [38] and prior knowledge of the relevant scientific literature might have influenced coding and theme development. Finally, we believe that this study also fulfilled the criteria of *importance* and *impact*. Exploring non-medical HCPs' perspectives on BBN has been a relatively understudied topic, especially within the care of MNDDs, despite the potential implications of such research on improving professional training and patients'

experiences. Off-the-record feedback from research participants commended the study for its focus on a topic that was clinically critical but an aspect of their practice on which they had not always had the chance to reflect on.

## Results

Four themes were constructed from the data: 1) Dealing with the diagnostic aftermath, 2) Unpacking the diagnosis, 3) Breaking bad news as a balancing act, and 4) Empowering patients to regain control over their health and lives. Participant quotations were used to further illustrate the findings presented in this section and additional quotations for each theme are provided as [Supplemental material](#).

### *Dealing with the diagnostic aftermath*

This theme illustrates the challenges healthcare professionals faced concerning patients' experiences of the diagnostic pathway up to their contact point and how their diagnosis was communicated.

Participants reported usually seeing patients with MNDDs one week to several months post-diagnosis, depending on the severity of their condition, the symptoms they were presenting and the referring medical consultant. Some professionals indicated that they were frequently the first HCP patients saw post-diagnosis and they often found themselves bearing the brunt of the patients' annoyance and irritation after the long pre-diagnostic journey and negative diagnostic experiences. Participants described how they often had to manage patients who wanted to "let off steam" (Participant 6) and were "angry" (P1, P5, P13), "frustrated" (P13), "mistrustful" (P5) and "dissatisfied" (P6, P19) due to diagnostic delays and misdiagnoses or feeling that their symptoms had not been taken seriously for a long time.

"I had one young woman who's been saying for years there's been something radically wrong and she was then transferred to, erm, psychology, for health anxiety [...] and then there was a significant incident and she was rushed into hospital and it turned out that she had MS and that she was right, there was something far wrong. And, so therefore, she was very mistrustful then." (P5)

Besides diagnostic delay, participants also explained that patients were angry and frustrated or even scared and withdrawn because of how they had received their diagnosis. In particular, professionals mentioned cases when patients had received their diagnosis over the phone or *via* a letter but mostly reported doctors' "blunt" (P14, P18) approach and inadequate information provision at diagnosis as the two most common patient complaints.

"One particular bad sort of... was a patient that felt as though, erm, the consultant (in private practice) gave her diagnosis and she said, 'all I remember them saying is', 'well, how are you going to pay?'" (P7)

HCPs, in these cases, felt they had to deal with the "aftermath" (P5, P7) of a sub-optimal diagnostic experience. They highlighted the importance of allowing patients to express their anger and dissatisfaction, empathise with them, and de-escalate the situation, hold a 'neutral ground', and reassure them that they were going to support patients for the entire illness journey in order to gain back patients' trust. A few specialist nurses also mentioned that specific doctors, usually general neurologists working in the NHS or privately, often did not refer newly diagnosed patients. As a result, patients were left to cope independently for several months, and nurses had to deal with that 'mess' or even misinformation that patients had received at diagnosis.

"Some of our patients see a neurologist privately because perhaps it's taken them a longer time to get to their actual appointment, this is just an example. It may be that particular person hasn't had the knowledge of who to refer them onto afterwards. So, it could be that I get to then go and see that patient six months down the line opposed to six weeks, and by that point they've lost faith in the system a bit, they've not known who to contact, they may have been on their medication and not known whether it was working or not. So, you have to kind of then, erm, you do have a bit more of a mess, if you like, rather than it being straight-forward." (P7)

However, most participants emphasised that, in general, neurologists were competent in communicating the diagnosis, but did not always have the time needed to provide enough information and some patients might have just been angry towards the bad news, not necessarily the way it was broken. When patients had a positive diagnostic experience, this made HCPs' first appointment with patients easier. A positive experience was exemplified when patients had received the information they needed at diagnosis, were prepared to ask questions and were generally adjusting better to their condition.

"I think anecdotally, the better the delivery of diagnosis, the better the support at the beginning, the better- the more involved the patient is, the better the prognosis and how they're managing, how they cope." (P6)

### *Unpacking the diagnosis*

This theme describes how HCPs helped newly diagnosed patients understand their diagnosis through often difficult conversations. These conversations were often distressing for both HCPs and patients but were acknowledged as vital to the participants' role. The nature of information communicated during these conversations was often different depending on the professional's expertise. However, it was generally related to the incurable nature of MNDDs, the impact of the condition on patients' daily lives and issues related to prognosis.

Participants reported that when they first saw patients, not all of them had fully understood their diagnosis. Despite short diagnostic consultations, which hampered adequate information provision, they believed patients' state of shock when receiving the diagnosis did not allow for information to be absorbed, and some patients were reluctant to look for further information post-diagnosis. In contrast, HCPs felt "lucky" (P3) and "privileged" (P11) to be able to dedicate enough time for their appointment and even offer double-slot appointments to meet the needs of newly diagnosed patients.

"We're fortunate that we have a lot more time with patients, than certainly the consultants do. Our appointments can be 45, routinely they are 45 minutes, but I have been with some patients an hour and a half, 2 hours, because they had that many questions and they just wanted to know and wanted to share information." (P3)

Patients' limited understanding of their diagnosis as described above, and sometimes due to cognitive changes as a result of the condition, meant HCPs often had to re-iterate what was said to them at diagnosis, explain the nature of their condition and clarify what could be done for them in terms of medication. An MS specialist nurse (P5) reported that she had even seen newly diagnosed patients who did not know what type of MS they had, and she sometimes had to break the bad news to people with progressive MS regarding their ineligibility for disease-modifying treatments<sup>2</sup>. In general, HCPs were often responsible for managing patients' expectations regarding medication or therapy's scope and explaining the incurable and progressive nature of

MNDDs. These conversations were often believed to be “*the hardest thing to say*” (P4) and “*the final blow*” (P5) for patients.

“Sometimes patients go from one doctor to another, one neurologist to another, they, they travel far away for this magic pill ... that doesn’t exist and I’ve also been in that position, where I’ve been the one who said, there isn’t a magic pill and, you know, I think, it’s important that we are transparent with patients and not give them false hope.” (P6)

Besides reiterating information given at diagnosis, HCPs’ primary role in the first appointments with patients was to help them understand the implications of their diagnosis and its impact on different aspects of their lives. One participant used a metaphor to illustrate this by comparing the diagnosis to a seed that was given to the patient, and the HCPs’ role was to “*unpack the news*” and assist patients to explore what would grow out of that “*seed*” (P9). Sharing information about the impact of an MNDD diagnosis and responding to patients’ questions and concerns often inevitably led to BBN conversations. These conversations’ content was often different depending on the participants’ role and patients’ circumstances and the questions patients asked. Patients often wanted information about their prognosis and the impact of their diagnosis on their family life and work. Discussing how the diagnosis might disrupt patients’ life plans and decisions was particularly difficult for participants.

“You know, there is a lot of discussion around prognosis, around ‘How long will I be able to do this? And what happens if I’m no longer to do that?’ [...] ‘Will I be able to stay in work?’, ‘Will I be able to see my family grow up? I have quite young children; will I be able to see them grown up?’” (P11)

“I saw them for a first consultation and his speech was already quite dysarthric and he was talking about getting a new job in a call centre and then he was gonna be starting that the next week. And that was a difficult conversation to have, cause obviously I can’t, I couldn’t say, ‘well, you can’t possibly do that’ ... but also to give some advice around ‘oh that might be tricky, would they have any more sort of admin type work rather than on the phone? People are going to struggle to understand you.’ That you, know, that’s difficult.” (P3)

Participants whose professional focus was patients’ movement and physical function were often involved in difficult conversations when they had to clarify patients’ misconceptions or validate their concerns, often related to the loss of independence. Because of the progressive nature of MNDDs, physiotherapists, for example, had to explain that, most of the time, therapy would not improve their movement, but it would help them maintain as much mobility as possible, prevent falls and aid everyday mobility problems. HCPs would also perform assessments and share information about disease progression and the potential future need for home adjustments and the use of equipment such as a hoist or a wheelchair. This information was not always welcomed by patients and could trigger more detailed difficult conversations about future losses.

[Participant quoting how they would introduce the possibility of home adjustments to newly diagnosed patients.] “Well, I know you don’t need it right now, but and that’s absolutely fine, but thinking ahead, you know, that could be a challenge.” And it depends on how and where the person is in terms of their sort of acceptance and adjustments because they might say ‘I don’t want to go there; I don’t even want that conversation’. And you’re like, ‘Okay, that’s fine.’ And there are other people who might say, ‘Well, do you think, I’m going to get worse?’ or ‘Do you think that’s going to happen?’” (P11)

Similarly, when seeing newly diagnosed patients with MND, speech and language therapists discussed the difficulty of introducing patients to sensitive but critical topics such as the potential loss of speech and the changes and dangers around swallowing. Participants mentioned that there was no easy way to

deliver this information and even discussing ways to manage these, such as augmentative and alternative communication aids and Percutaneous Endoscopic Gastrostomy [a surgical insertion of a feeding tube into the stomach through the abdominal wall], could be very emotional for patients.

“We have to break the bad news, of... ‘yes, actually, eating and drinking can kill you’ and ‘yes, you will most likely lose your ability to communicate verbally as well.’” (P3)

Another sensitive topic that participants usually discussed with newly diagnosed patients was driving and the need to inform the UK Driver and Vehicle Licensing Agency about their diagnosis. Even when patients were still fit to drive, HCPs believed it was their professional obligation to discuss this even though it could often trigger patients’ fears about future loss of independence.

“Talking about driving can be very difficult, it’s a sensitive issue for many patients, but I think, you know, it fits into the same sort of category as offering pieces of equipment to the patient for the first time, you know, it’s a very emotive subject for many patients, you know, it’s a real symbol of, you know, things are moving on.” (P10)

Psychologists referred to the difficult discussions they often had with newly diagnosed patients about the cognitive changes associated with MNDDs. Patients were often referred to their service for cognitive screening, so part of their role was to explain the rationale behind neuropsychological assessments – which sometimes included a mental capacity assessment – and then share the results. Professionals acknowledged the stress surrounding these discussions, especially with patients who had just received their diagnosis, who were experiencing physical symptoms and were now discovering cognitive symptoms as well.

“Sharing the cognitive results after the neuropsychological assessments, sometimes these conversations can be difficult, for example some people with MND they have also got cognitive impairment, and this can be a difficult conversation for people to have. You know, they worry that this means they are going to develop dementia and you can’t necessarily reassure them that it won’t, we can’t guarantee that the cognitive side won’t get worse.” (P11)

Some participants also mentioned that it had become increasingly common to have end of life and advance care planning conversations early on, especially with MND patients and other newly diagnosed patients whose condition had significantly progressed. Such discussions could include do-not-resuscitate orders, gastrostomy, non-invasive ventilation and palliative care referral. Participants acknowledged the importance and benefits of having these discussions but also detailed the difficulty of initiating them. Some participants felt this would always be a challenging task for them, while others believed experience had increased their confidence in initiating these conversations.

“I’m having conversations about advanced care planning, end of life, decisions and alternatives ... I’m triggering the conversation and I am doing it early. That’s relatively new, I think, in health, because one thing you didn’t do, is talk about, you know, death and dying and so on, but certainly over the last couple of years and it is, it is difficult when you first start talking about it and raising it, but once you’ve done it several times you get a feel for it.” (P1)

Nevertheless, all participants agreed that BBN was emotionally difficult, an unavoidable but significant part of their role. During and after BBN, HCPs reported sometimes feeling “*drained*” (P5, P19), “*exhausted*” (P5), “*sad*” (P1, P7, P8) and “*anxious*” (P8) and had sympathy for the patients, especially knowing how these conditions would progress and that they would have to give more bad news as the condition deteriorated.

### Breaking bad news as a balancing act

This theme details the shared experience among all participants regarding the challenges of sensitively and effectively BBN. Providing critical information to newly diagnosed patients was described by HCPs as a balancing act that required good communication skills, experience and empathy. In particular, when BBN, participants reported having to find a balance in terms of their approach and language they used and the amount of information they shared and during the process by effectively assessing patients' information needs.

Being pragmatic and accurate when explaining the progressive and incurable nature of MNDDs, the uncertainties around progression rate and the potential impact was perceived as professional duty and responsibility that helped patients '*know where they stand*' and '*make plans for their life*' (P1). In their experience, conversations around bad news had to be carefully worded to reflect the unpredictable nature of MNDDs.

"They're hanging on your every word really, 'cause they see you as the expert so you have to be careful exactly what you're saying and try not to say things too... you know, in too much of a concrete way, black and white way, when the issue is a bit more grey than that." (P9)

Giving honest and straightforward information about such critical topics was believed to be appreciated by patients and helped HCPs build a long-term relationship with them based on trust. However, participants also acknowledged the distressing nature of the information they often provided and underlined the need to adopt a sensitive approach, mostly because patients "*will never forget the way they were told the news*" (P19).

"Actually, it's nice if you can do it in a way that you'd want to be told or you'd want to be cared for, if it was for your family members. I think it's all you can do, human nature, really. I don't think there's ever a one-stop-shop for that." (P17)

Moreover, participants often discussed the need to balance BBN by also providing some positive information to instil hope. They described the challenge of achieving a "*fine line*" of being pragmatic and motivating at the same time so that people could focus on the present but also plan for the future:

'I try to encourage them to have a realistic mindset and practically plan for the future, but at the same you don't want to absolutely destroy somebody's hope as well. So, again, I think that's quite a fine line of, you know, being practical and planning ahead, but at the same time keeping somebody's motivation up to keep doing, you know, not just give up basically, 'cause you want them to focus on the here and now and what I can do right now but then also with an eye ahead to the future.' (P16)

Hope in this context was not associated with curative treatments, but it was conceptualised by HCPs as focussing on what realistic goals patients could achieve and what could be done to improve their quality of life. This information could include what support was available from the services, how symptoms could be managed, how the disease progression rate could be different for different people, the positive effects of lifestyle changes and information about ongoing research. Participants reported trying to "*give a balanced view of the future which is truthful but hopeful*" (P9). However, this was not always an easy task, especially when patients presented with rapid progression or severe symptoms. In these cases, participants discussed the challenge of getting the balance right in terms of providing hope, but not "*unrealistic*" (P1, P11) or "*false*" (P6, P16) hope.

"I think being able to give people hope is really, really important in rehabilitation. And sometimes it is hard to be hopeful when people are seeing all manners of aspects of their life changing It's how you

balance that hope giving within the context of not being unrealistic either." (P11)

Deciding the nature and the amount of information they provided when BBN was another challenge that professionals faced in these initial appointments. This could depend on how each patient's condition had progressed and the symptoms they were experiencing, but participants were mostly challenged by how much patients' communication preferences could vary. HCPs agreed that it was essential to adopt a flexible approach and establish patients' communication preferences and information needs before BBN.

"Rather than bombard someone, it's really important to kind of judge what kind of information they need from you." (P14)

"Yeah, you have to be really flexible around, erm, what information you give and also what information you don't give." (P4)

Assessing newly diagnosed patients' preferences and needs were deemed a difficult task for several reasons. HCPs reported that knowing the person, their personality and having a relationship with them helped with this process. However, this was not the case with newly diagnosed patients. In these first appointments, participants detailed the importance of establishing patients' understanding of their condition and their needs in terms of topics they wanted to discuss. For example, clinical neuropsychologists asked patients why they thought they were referred to them and explored their understanding of the impact of MNDDs on their cognition before they shared information about neuropsychological assessments. In addition, participants reported tailoring their practice concerning patients' emotional state and body language and mostly being guided by patients' questions. At the same time, they understood that patients who seemed calm or asked questions about prognosis might have not necessarily be ready to receive bad news. Before giving such information, HCPs would usually "*double-check*" (P3) if patients wanted this information.

Mis-assessing patients' information needs could have an impact on building a relationship with them. Some HCPs in this study admitted that they had at one point '*got it wrong*' (P3) by sharing more information than the patient was able to process at that time and highlighted the importance of giving the bad news at the right time.

"I went away from this meeting thinking, "I've done the wrong thing really", because it really stifled my relationship with her at the early stages, kind of went away thinking, 'Was that necessary?', it was true but was it necessary, at this point to break bad news to her or could I just left it a bit longer." (P14)

At the same time, other professionals believed it was their duty to share information that could prevent future crises, even though the patient might not have been ready or keen on discussing these topics. For example, occupational therapists felt they sometimes had to share information on mobility equipment and house adaptations early on, despite patients' often negative reactions. Sharing such information could prevent patients from making uninformed decisions in the future, such as buying expensive equipment that would be ineffective for their condition.

"I get people to think quite far ahead when they are quite well, or they don't have that level of ability issues and I think that's quite hard for them to think about it at that time. [...] What I want them to, or what I don't want to happen is for them to get to that point and for them to say 'Well, no one told me that would happen, or no one told me this wouldn't work'. So, I think we need to be honest with them, make sure they are informed, and they can make the right choice for them." (P12)

Moreover, although participants acknowledged the benefits of involving the patient's family in these appointments, they also

detailed the challenges that they could bring to the process of BBN. For example, an HD specialist nurse reported how a patient's mother was clearly against the patient knowing that they had started presenting movements that were signalling the disease onset. On the contrary, family members sometimes could "fire" (P14) questions, which could trigger the delivery of information that patients might not have been ready or wanted to receive at that point. In these cases, HCPs had to balance the conversation by clarifying what information the patient wanted and sometimes also supported the relatives by having a separate discussion with them.

"Their partner might be wanting lots of information about how to practically manage, 'how am I gonna care for the person further down the line?', whereas the patient themselves might be like, 'I don't want to think about that, I don't even want to know, I don't wanna discuss that' and then you can get these two levels of conversations happening, which can be quite difficult to manage." (P12)

Participants agreed that there was no easy way to give bad news. Although some followed relevant guidelines, they avoided following "rigid pathways" (P10) because of the differences in patients' communication preferences and the complexity of MNDDs, and the different disease progression rates. Every newly diagnosed patient appointment required a unique balancing act for the bad news to be delivered effectively for that specific person. Despite this challenge, HCPs believed that achieving this balance could help participants feel supported, accept their diagnosis and move on knowing a plan they could work on together.

"This is gonna sound really strange, I actually feel that... If it's done probably, it can help the patient and I like to think that I've got enough experience and I've got enough understanding and empathy that I do it well and there is no easy way to give bad news [...] but I'd like to think that if done well it can help the patient accept the diagnosis and the journey, but it's hard isn't it?" (P4)

### **Empowering patients to regain control over their health and lives**

This theme describes how conversations around bad news were often interwoven or followed by HCPs providing support and empowering newly diagnosed patients to regain a sense of control over their health and lives. Alongside providing important information, professionals performed holistic baseline assessments, identified areas they could provide support, encouraged patients to make decisions and plans for the future, and provided links to other HCPs and support sources.

As previously mentioned in themes two and three, participants believed that BBN in these initial appointments helped patients make sense of their diagnosis and its impact and develop an understanding of what to expect in the future. Although often distressing for patients, HCPs' rationale behind having some of these difficult conversations was to instill a sense of control. Providing information on communication aids, for example, was viewed positively by participants as a tool to manage the loss of speech for MND patients. Similarly, sharing information on home adjustments and the use of mobility equipment aimed to prepare patients for potential future loss of or difficulty in movements and to reassure them that their independence would be maintained as much as possible. Early discussions about advance directives were also difficult for patients. However, participants believed they gave patients a sense of control through communicating their preferences and making decisions about their end-of-life care.

"It's hard to do (end of life conversations) and it's hard for some patients, but they do not regret doing it and they gain from it. It gives them a sense of control in a condition that is out of their control." (P15)

BBN also helped HCPs educate patients and involve them in decision-making effectively. After explaining the nature and impact of MNDDs and the scope for treatment, participants often had extensive conversations with patients regarding treatment options and their side-effects, and ways they could manage their condition. Following a patient-centred approach, the goal of these conversations was to involve patients actively in the consultations, enabling them to make informed decisions about how they wanted to manage their condition and plan their lives.

"It's obviously supporting people to make the decisions that they feel are in their best interests at the time. There are a lot of people who choose a riskier option because they feel they get more quality of life, more enjoyment from eating and drinking than they would from having it via a tube... so they, they would prefer to take the risk of shortening their life for, for a little bit more quality of that life." (P3)

HCPs in these initial appointments, especially specialist nurses, also reported performing holistic assessments, which included questions about the patients' family, work, hobbies and life in general. Participants emphasised the importance of giving the patients time to talk about their lives and actively listen to their stories, concerns and matters to them. This way, participants could identify areas of the patients' lives to provide support and even act as the patient's advocate. For example, HCPs highlighted the importance of helping patients continue working for as long as possible, getting in touch with occupational health departments and putting in workplace arrangements, or providing practical information about benefits.

"There's also, I mean, there's practical stuff like liaising with... work is a huge thing, people start to need reasonable adjustments in their workplaces so I'm helping them in the benefits, helping them stay at work and liaising with the occupational health department, advocating for them on their behalf, just doing pragmatic [...] supporting them to continue driving..." (P9)

After completing holistic assessments with newly diagnosed patients, professionals were also able to signpost them to other HCPs and support sources such as local groups and disease associations, depending on their specific needs. Participants wanted patients to be well-informed about all the support available to them and enable them to decide how much support to receive and what referrals they wanted to be made for them.

"If a new client comes through this door, what we do is we go through a very robust assessment for them, including all of the symptoms, all of the difficulties, it's not a 10-minute or 15-minute hospital appointment, it is very much a holistic looking at their life as it is now and things that we can do to help, we put in place, so for instance, they might leave with a whole pile of appointments that are gonna take place within the next six months." (P5)

Also, the importance of self-management in appointments with newly diagnosed patients was highlighted. HCPs reassured patient services would support them throughout their "journey", but they also stressed the need for patients to manage their condition. Participants encouraged patients to adhere to medication regimes, lead a healthy lifestyle through physical activity, eat healthily, look after their mental health and seek support and advice when needed.

"I feel [what] we [have] also got to do is give people, empower people to self-manage. [...] I say that with good management that comes from both the healthcare professional and the patient who needs to take some responsibility, we can, we can preserve a good quality of life. They have to take some responsibility in terms of adhering to the

medication regimens and engage in some form of physical activity.” (P6)

Finally, HCPs emphasised that a significant part of their supporting work included motivating and encouraging patients to maintain a positive outlook. Participants discussed that despite the challenging and emotionally-loaded bad news conversations, their initial appointments with patients were not just “*doom and gloom*” (P3). Working with newly diagnosed patients often included helping them accept their diagnosis and focus on maintaining or improving their quality of life. For example, psychologists reported using several models used in rehabilitation to help patients cope with their diagnosis and promote psychosocial adaptation to the condition. HCPs, in general, encouraged patients to keep setting and achieving meaningful goals, engage in activities they enjoyed and not let their diagnosis “*take over their life*” (P14).

“So, I guess it’s about reframing it, isn’t it? So, inevitably, it’s sad, but people will die, but it’s about making sure they were able to go on that last family holiday, it was about making sure they were able to go on that - to go to that wedding, or whatever and what do we need to put in place to allow that to happen? So, it’s about supporting people to make, you know, plans.” (P11)

## Discussion

To our knowledge, this is the first study to address non-medical HCPs’ perspectives on BBN and supporting newly diagnosed patients with MNDDs. Although HCPs’ involvement in BBN in neurorehabilitation has been addressed by other studies, these focused on acute neurological conditions such as stroke and traumatic brain or spine injury and specifically on BBN in relation to rehabilitation potential and recovery [48–51]. The analysis constructed four themes. HCPs working in the care of patients with MNDDs were broadly involved and had a significant role in the process of BBN: from managing patients who had a negative diagnostic experience, to re-iterating diagnostic information, discussing the impact of the condition and further supporting patients to adjust to their diagnosis and regain a sense of control. BBN was not perceived as a straightforward task but as a dynamic process that required empathy, strong communication skills and a unique balancing act, tailored to the specific diagnosis, patient information needs and communication preferences. By having these difficult conversations early, HCPs aimed to help patients regain a sense of control, make decisions regarding their treatment, plan and prepare for the future but also maintain a sense of hope. We believe that the results of this study will help increase awareness of non-medical HCPs’ involvement in BBN for MNDDs, how these difficult conversations can benefit patients and how to support professionals to approach effectively this challenging aspect of their practice.

### *Listening to patients’ stories on diagnosis communication*

Previous qualitative studies on patients’ experiences have shown how receiving an MNDD diagnosis was viewed by patients as the drop of a “*bombshell*” [52,53]. Interestingly, using another war-related metaphor, HCPs in this study discussed their experiences of dealing with the “*aftermath*” of the diagnosis, especially when patients had negative diagnostic experiences. Participants explained how, having moved from the initial shock of the diagnosis [54], patients needed to express their emotions of fear about the future and often anger and dissatisfaction regarding how their diagnosis was communicated. Similarly, in a qualitative

study about the challenges of BBN, HCPs working in a variety of settings (including neurology but with no specific mention of MNDD care) discussed how they sometimes had to “*pick up the pieces*” when information-giving had been mishandled by other professionals [13]. According to participants in the current study, diagnostic delays, inadequate information provision and doctors’ approach to diagnosis delivery were the primary sources of dissatisfaction, which have also been documented in other studies with patients with MNDDs [28]. HCPs highlighted the importance of showing a genuine interest and listening to patients’ stories about their diagnostic experiences and allowing them to express their emotions. This helped them empathise with patients, build the base of a relationship with them and regain their trust, factors which have been found to facilitate bad news conversations between HCPs and patients [55]. Moreover, in the context of chronic conditions, illness narratives can be valuable in assessing patients’ psychological adaptation, hope and mental well-being [56] and therefore help HCPs tailor their communication and address patients’ psychological needs.

### ***Difficult but essential conversations: helping newly diagnosed patients with MNDDs understand their diagnosis, gain a sense of control and prepare for the future***

All HCPs in this study were involved in a range of tasks which could be considered as BBN, such as re-iterating and supplementing information that was given at diagnosis, sharing prognostic information, discussing the impact of the diagnosis, correcting patients’ misconceptions (often regarding the scope of treatments) and validating their concerns. Their accounts supported the concept of BBN as a dynamic process that involved several MDT members and covered various topics related to the diagnosis and the professional’s expertise [13,57]. Besides sharing information about the nature of MNDDs and symptoms, participants adopted a holistic and patient-centred approach to BBN by addressing topics which other studies have also highlighted as necessary for patients such as the impact of the diagnosis on their daily lives, their family, relationships and work, the availability of benefits and help with planning for the future [58]. Unlike doctors [8,59] and other healthcare professionals [13] who have reported lack of time as a factor that affects their practice in BBN, HCPs in this study felt “*lucky*” to be able to invest adequate time for these initial consultations and cover all aspects of the diagnosis that patients wanted to discuss.

Nevertheless, effective and tailored information provision is a crucial component of the neurological rehabilitation process [60] and patient-centred care in general [61]. Despite the often distressing nature of these conversations, participants argued that these were crucial to helping patients understand the current situation, what to expect in the future, and how they could be more actively involved in their care. BBN for HCPs in this study was also considered a part of their patient education role and a prerequisite for supporting self-management and shared-decision making regarding treatments and goals, which are also significant elements of the neurorehabilitation process [60] and the long-term management of chronic conditions [62]. Patients who have developed an understanding of their condition can make informed decisions about their treatments [63], and well-supported patient involvement and shared decision making have been linked to better patient-provider communication and clinical outcomes, increased treatment compliance, and reduced healthcare costs [64]. By having these difficult conversations early on and enabling patients to make decisions, plan their lives and future, consider

the realities of their condition and set goals for their therapy, participants in this study tried to help patients regain a sense of control. Perceived control has been positively associated with well-being in patients with MNDDs [65] and being well-informed about PD has been established as an essential factor for perceived control in PD patients [66]. Several participants in this study also mentioned initiating discussions about advance care planning with newly diagnosed patients as a form of increasing patients' sense of control. Indeed, having advanced care planning conversations around diagnosis when cognitive function is usually preserved is critical for conditions with a relatively short life expectancy such as MND. However, their significance has also been increasingly recognised even for MNDDs which are not immediately life-threatening such as PD [67,68].

### ***The challenge of tailoring bad news conversations to meet individual patients' needs: the potential role of illness uncertainty***

Integral to the participants' accounts were also the challenges they faced in finding the right balance for each patient regarding their approach to having difficult conversations and establishing how much information to give. This has also been highlighted as an important issue for both doctors and clinical nurse specialists working in cancer, palliative care and other fields, especially the challenge of communicating bad news honestly without taking away hope [8,13,55]. Similarly, participants in this study discussed the importance of being transparent and honest when breaking bad news and allowing space for hope. Unlike some neurologists who have expressed some reluctance in conveying hope when delivering the diagnosis of MND and HD specifically in a recent UK survey [69], HCPs in this study stressed the need to instil a sense of hope regardless of diagnosis. Participants reported trying to promote a sense of hope by emphasising what could be done for patients in terms of managing their condition and having a positive outlook regardless of their diagnosis. Their practice aligns with findings from studies that have shown that even patients with life-threatening diagnoses prefer truthful information regarding their prognosis *yet also* want to be given hope [70,71]. However, research on hope in neurorehabilitation has suggested that within a non-directive style of therapy, HCPs should empower and explore patients' own concepts of hope through listening, allowing space for storytelling and offering different perspectives [72]. Besides honesty and hope, HCPs also discussed the challenge of effectively assessing patients' information needs and preferences and deciding how far to go with BBN conversations in these initial consultations. Having a relationship with the patient helped HCPs better assess patients' needs [55] and preparedness for the bad news. However, this was not possible for participants in this study who were meeting patients with MNDDs for the first time. Patients' varied information preferences along with the unpredictability regarding the prognosis, potential impact and rates of progression of MNDDs added to the complexity of this task.

The variation in patients' information preferences and participants' reported challenges of tailoring their approach and finding the perfect balance when BBN can be partially explained by the illness uncertainty (IU) [73] and uncertainty management theory (UMT) [73]. UMT is an interpersonal communication theory which suggests that uncertainty is not inherently negative, and people are not always striving to decrease it [74]. In the context of illness, uncertainty has been mostly associated with negative psychological outcomes [75] and is less commonly perceived as positive (maintaining hope and optimism). During an interaction with HCPs, patients can present different information needs and

information-seeking behaviours depending on whether they want to increase or decrease their uncertainty [76]. Based on our findings, we could argue that for some newly diagnosed patients' uncertainty is not always experienced negatively. Although most patients will feel the need to decrease their uncertainty by developing a better understanding of their condition and their prognosis, other patients might prefer to maintain their levels of uncertainty at that point as part of a slower process of accepting and adjusting to their diagnosis. Patients might also want to decrease their IU in general (by obtaining information about their condition) but maintain their uncertainty about specific aspects of their diagnosis and its impact (e.g., driving), thus using what the IU theory defines as 'buffering coping strategies' [77] such as avoidance, selective ignoring or even shutting down specific BBN discussions. Patients' perception of uncertainty and consequently their information needs and information-seeking behaviour can change over time [76]; it is, therefore, important for HCPs to maintain open communication channels and potentially BBN when patients are prepared to receive it. HCPs in this study mostly respected newly diagnosed patients' readiness for receiving bad news on specific topics but were also faced with moral dilemmas when the ethical values of autonomy, beneficence and non-maleficence seemed conflicting [77,78]. Professionals reported trying to tackle such dilemmas by mostly being led by patients' questions and needs (respecting autonomy) and double-checking before sharing distressing information (non-maleficence). However, there were instances when they felt it was their professional obligation to initiate difficult discussions early on in order to prepare the patient and avoid future crises even when patients were not willing to receive such information (prioritising future beneficence over present autonomy and non-maleficence).

### ***Training and supporting healthcare professionals***

Participants agreed that giving bad news to newly diagnosed patients with MNDDs was a demanding task in terms of communication skills and an emotionally challenging experience. Despite the challenging nature of the task, HCPs have reported being inadequately trained in this domain [4,79,80]. Similarly, participants in this study reported not having received specific training for BBN to patients with MNDDs but had instead learned how to do it effectively through experience or had received training on BBN in general as part of a previous role in palliative or cancer care. Our sample's overrepresentation of experienced HCPs could explain the high standards of practice reported and we are unsure whether these would be the same if less experienced professionals had been recruited. Indeed, a qualitative study of HCPs' perspectives on BBN has indicated that more senior members of the MDT were more able to break the bad news about rehabilitation potential after traumatic brain injury or spinal injury and could manage patients' expectations better [50]. Based on our findings on the broad range of involvement of HCPs in BBN and the participants' reported willingness to receive more training in this domain, we believe HCPs working with patients with MNDDs would benefit from further training. In addition, HCPs would benefit from training and BBN guidance specifically designed to reflect their clinical reality and the specific challenges of MNDDs. The most commonly used guidelines focusing on cancer care seem to mostly represent the traditional view of BBN as a doctor-patient interaction related to diagnosis delivery [81] and have been criticised for not adequately addressing the emotional and supportive aspects of this task [82]. Building upon existing protocols of BBN and using the principles of the interaction adaptation

theory as a basis, the COMFORT model for the communication of bad news proposes a set of core competencies that should be achieved through communication skills training (Communication, Orientation, Mindfulness, Family, Ongoing, Reiterative messages, and Team) [74]. COMFORT adopts a more dynamic view of BBN, addresses the family's and MDT's involvement [83] and has been therefore considered to be appropriate in neurorehabilitation training and practice [84]. Future studies could initially evaluate the feasibility of BBN training for HCPs working with MNDDs and then assess its effectiveness in increasing HCPs' competency in BBN and contributing to positive patient outcomes. Moreover, although exploring HCPs' experiences was not the main focus of the current study, all participants agreed that BBN was an emotionally challenging task. HCPs would often seek informal support from their colleagues after having difficult and emotional conversations with patients and only a few, mostly psychologists mentioned using formal supervision and support. It is possible that BBN is an under-recognised aspect of HCPs' clinical work, we, therefore, argue that besides training, formal forms of support could help professionals deal with the emotional demands of BBN.

### Limitations and implications for further research

This study has several limitations mostly related to possible omissions in terms of topics covered by the interviews and the broad focus of addressing four different MNDDs. Firstly, although cultural factors can be critical in healthcare provider-patient interactions [85], participants in this study did not discuss their influence on BBN. Also, although we focus on newly diagnosed patients, BBN for these conditions is an ongoing process and professionals have to give more bad news as the disease progresses, new difficulties arise, and patients move through the different "stages" of their condition and potentially onto palliative care. Future studies could explore this more dynamic view of BBN in MNDDs. Moreover, all participants in this study worked in the UK, so findings might not be applicable in other countries with different healthcare systems and strategies for the management of MNDDs. Finally, although this study's main aim was to establish HCPs' range of involvement in BBN to newly diagnosed patients with MNDDs, we acknowledge that there are significant differences among these conditions that can impact the nature and the timing of BBN. Future studies could focus on these conditions separately and shed light on the specific topics, challenges and practices around BBN, e.g., in relation to different types of MS or focussing on dementia-related to MNDDs.

### Conclusion

This study has been the first to explore the experiences of a range of health professionals in BBN to individuals with MNDDs. Participants' accounts in this exploratory study revealed that HCPs were involved in the process of BBN in a variety of ways and outlined the complexities and challenges they encountered during this clinical task. As well as confirming concepts found in studies of health care professionals working with different patient groups such as the challenges of tailoring information giving and breaking bad news empathically and sensitively, this study has emphasised the positive outcomes of BBN effectively. Participants emphasised that despite the often-distressing nature of the information they provided to newly-diagnosed patients, BBN was a critical aspect of patient education which could also help patients make informed decisions, plan for the future and regain a sense

of control. Thanks to the participants' significant length of professional experience, we believe that other HCPs can learn from our findings, identify challenging aspects of BBN and strategies used to manage these. Finally, we hope that this study will aid in the recognition of BBN as a critical task for non-medical HCPs working with patients with MNDDs and lead to the development of appropriate professional training and support.

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### Data availability statement

The data that support the findings of this study are available from the corresponding author, EA, upon reasonable request.

Footnote 1: Although nurses are sometimes considered medical staff, for definitional clarity we use the term "non-medical" throughout the paper to describe any healthcare professionals other than doctors.

Footnote 2: There are three main types of MS, relapsing-remitting MS, secondary progressive MS and primary progressive MS. Most disease-modifying treatments reduce the number of relapses, therefore only patients with the relapsing type of MS are eligible for treatment. (De Angelis F, John NA, Brownlee WJ. Disease-modifying therapies for multiple sclerosis. *BMJ*. 2018 Nov 27;363.)

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## Appendix

Table A1. Interview guide.

Question	Prompts
Can you tell me how you have come to work in this context and this line of work?	How long are you in practice? How old are you? Where were you trained?
What are your experiences with communicating with patients in this context in general?	How important do you think communication with the patient is?
How long after the patient receives their diagnosis will they usually get an appointment with you?	At this point, how have patients usually dealt with the bad news they received?
At this initial appointment you have with the patient post-diagnosis, are you involved in tasks that could be considered bad news breaking? If yes, can you talk to me about it?	Have patients fully understood their diagnosis and treatment options at this point? If not, do you provide with relevant information? What kind of conversations with patients do you consider to be <i>difficult conversations</i> ?
How do you provide support to newly diagnosed patients with motor neurodegenerative conditions?	How do you feel when you have to provide information that could be perceived as bad news or cause distress? How do you help patients cope with their diagnosis?
How do you feel about this aspect of your clinical work? (I mean breaking bad news and supporting newly diagnosed patients with motor neurodegenerative conditions)	How do you respond to patients' emotional reactions? Are patients willing to receive support at that time?
What are the most challenging aspects of working with newly diagnosed patients with motor neurodegenerative diseases and engaging in breaking bad news tasks?	What are your views on the difficulty of this task? What are some positive aspects of this task? How do you manage your own emotions when conversations are difficult?
What kind of education and training have you received on communication with patients?	Do you always have enough time and a private space for your appointment with these patients? How do organisational factors affect how you provide support at this point? (either helpful or obstructive) What do you do when you feel that you cannot answer some of the patients' questions?
	Have you received training specifically for breaking bad news? Would be interested to receive further training on breaking bad news and supporting newly diagnosed patients?

Table A2. Coding example and breakdown of individual themes and relevant codes.

Transcript excerpt	Codes
I: So, at this initial appointment, you have with the patient, are you involved into tasks that could be considered bad news breaking?	Clarifying patients' misconceptions regarding their eligibility for DMTs Explaining the nature of a diagnosis
P: Well ... yes, sort of, because often, I may be asked, so 'why am I no eligible for a disease-modifying drug?', you know. And it may be because, 'well these disease-modifying drugs tackle relapse and you have a form of MS that doesn't have relapse, therefore, that drug is of no use to you'. And sometimes that is accepted as alright, 'well I understand now, that makes sense' and other times that's taken as, you know, the final blow, 'really, I'm not ever gonna get that drug?', you know. And it takes away that little bit of hope that someone once somewhere along the line had made the mistake and they are going to get this drug, that's difficult.	Explaining ineligibility for DMTs could be accepted by patients or completely shatter their hope Dealing with patients' expectations who have been misinformed Giving patients time for the bad news to 'sink in'
I: How do you react when this happens? When they get devastated by this ...	Providing information on what can be done for the patient to help manage both the physical and psychological impact of MS Explain the importance of self-management despite the incurable nature of MS
P: So, erm what we have to do then is let that sink in and then see, so for the part of the disease that everybody has, the progressive part, here's where we come in, 'whether you've got a relapse and remitting or secondary progressive, primary progressive, what we are looking at here is getting you involved in the strength and balance class, in the mindfulness class, in the fatigue management class, then', you know, 'yoga, pilates'. We explain that whilst there's not a drug, there are other ways to self-manage this disease.	Newly diagnosed patients might lack a basic understanding of their diagnosis Patients might express their anger towards an insensitive diagnostic experience
I: So, you tell me that not all patients, when they come to see you, have fully understood their diagnosis and treatment options?	Although devastated, most patients are not shocked because they knew there was something wrong with their health
P: Oh yeah, that's the case, yeah. And sometimes people come and they don't actually know what type of MS they have.	Listening to patients' illness journeys even before receiving their diagnosis
I: Do they share their experiences of how they received the news with you?	Patient mistrust caused by diagnostic delay and not having her symptoms validated for years
P: Yeah ... I think there are different categories. So, I do come across clients that come to the centre who are very angry with the way that the news has been delivered. And sometimes that's for good reason, for people that were told when they were on their own, people might be upset because a GP has told them over the phone, they've opened up a letter ... I would say by far, the vast majority have had an inkling that there's something significantly wrong and that the news they get is news that they don't want to hear but they're not that surprised, they are devastated but they are not shocked. But there is a lot of anger, a lot of grief, a lot of frustration, particularly if, erm, you know I had one ... I had one young woman who's been saying for years there's been something radically wrong with her and she was then transferred to, erm, psychology, erm, for, health anxiety, and her husband -now bear in mind this is a young couple-, erm, her husband, was saying look, there's nothing wrong, you've had all the tests ... And then there was a significant incident, and she was rushed into hospital and it turned out that she had multiple lesions and that she was right, there was something wrong. And, therefore, she was very mistrustful then.	
Theme	Codes
Dealing with the diagnostic aftermath	Listening to patient stories of bad diagnosis delivery Allowing patients to express their anger or frustration caused by the diagnostic delay Allowing patients to express their anger or frustration caused by sub-optimal diagnostic experiences Empathising with patients who had negative pre-diagnostic/diagnostic experiences De-escalating the situation - holding a middle ground between patients and doctors Acknowledging the time restrictions faced by neurologists
Unpacking the diagnosis	Newly diagnosed patients have not always understood their diagnosis Re-iterating diagnostic information Managing patient expectations regarding the goal of treatment and rehabilitation Clearing misconceptions about the nature of MNDDs Helping patients understand the impact of their diagnosis Discussing prognosis
Breaking bad news as a balancing act	Having enough time to offer long consultations and provide adequate information Being honest and realistic Being sensitive Providing positive information/Promoting a sense of hope Avoid providing false hope Assessing patients' information needs and preferences Providing potentially distressing information regardless of patients' readiness to receive it
Empowering patients to regain control over their health and lives	Breaking bad news to prepare patients for the future Discussing treatment options Supporting patients to make decisions and plan for the future Providing holistic assessments Signposting to other professionals/sources of support Encouraging self-management Providing emotional support