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Distress, Not Symptoms: Reframing Psychological Difficulties in Neurodegenerative Diseases of the Motor System

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Abstract

Psychological distress is common among people living with neurodegenerative diseases of the motor system (NDMS) such as Parkinson's disease, motor neurone disease/amyotrophic lateral sclerosis, and Huntington's disease. Yet the way psychological difficulties are conceptualised in these populations is heavily shaped by medicalised language. Terms such as 'non-motor symptoms' and 'neuropsychiatric manifestations' were originally introduced to draw attention to difficulties beyond movement changes but they now risk positioning mood, anxiety, apathy and related experiences solely as direct manifestations of neurological degeneration. This framing can obscure the rich psychosocial contexts in which distress arises, blur distinctions between emotional responses and disease processes, and reinforce deficit-based and disease-focused understandings that privilege biological explanations over person-centred ones. It may also influence clinical communication, treatment decisions, help-seeking behaviour, and access to psychological therapy and psychosocial interventions, contributing to inequities in care. This article argues that linguistic choices are not neutral: they construct the boundaries of what counts as legitimate knowledge, shape expectations about causality, and delimit the interventions considered appropriate. Without critical attention to these assumptions, individuals may experience distress as biologically inevitable and clinicians may overlook psychosocial contributors that are amenable to change. We propose that greater awareness of the power of language, coupled with empirical investigation into its effects, is essential for developing a linguistic reformulation of psychological distress in NDMS and more holistic, contextually grounded approaches to supporting psychological wellbeing.

Introduction

Signs of psychological distress – e.g., low mood, anxiety, irritability, obsessive thoughts – are common in individuals with neurodegenerative diseases of the motor system (NDMS) such as Parkinson’s disease, motor neurone disease/amyotrophic lateral sclerosis and Huntington’s disease (Dale & van Duijn, 2015; Evans & Norman, 2009; McLeod & Clarke, 2007; Simpson et al., 2019). NDMS are characterised by a progressive decline initially in movement quality although other functions, such as cognition, can then also be affected. Unlike other types of neurodegenerative diseases such as dementia, where difficulties in cognition are the primary sign of the condition, cognitive challenges may not appear – if at all – until many years after disease onset. Individuals with NDMS are therefore often very conscious of any changes to their mental health and social life and seek out solutions (Dobkin et al., 2013; Theed et al., 2018; Zarotti, Simpson, et al., 2019).

While not everyone with such a condition will experience psychological distress and may experience generally high levels of wellbeing, current research indicates that psychological difficulties are experienced more frequently than in those without such conditions and to a larger degree than in many other chronic illnesses (Burchill et al., 2024; Clark et al., 2023; Patel et al., 2023). Moreover, such distress is often reported by individuals to be equally, if not more, debilitating as the motor symptoms they experience (Dale et al., 2022; Eccles et al., 2023; Simpson, Eccles, et al., 2021; Zarotti, D’Alessio, et al., 2024; Zarotti et al., 2022). These psychological difficulties also have a profound effect on family members and in some conditions are prime drivers for significant changes in care, such as nutritional management or admissions to nursing homes, as well increased caregiving burden and burnout (Coates et al., 2021; Essat et al., 2020; Hergert & Cimino, 2021; Ipek & Güneş Gencer, 2024; Okoh et al., 2025; Rabkin et al., 2009; Williamson et al., 2008; Zarotti, Coates, et al., 2019). Consequently, the issue of psychological distress is a lived reality for many already experiencing significant physical and sometimes cognitive impairment.

Until relatively recently, however, the recognition of psychological distress was not prioritised in clinical assessments or included as part of more holistic approaches to providing care and support for people with such life-changing conditions. Where psychological distress was discussed, it was often assumed to be another ‘symptom’ of the neurodegenerative process. Psychological explanations appeared to have limited appeal, possibly because they were interpreted as suggesting a straightforward causal pathway from impairment to distress, rather than reflecting a more complex and often non-linear relationship, often mediated by

psychological processes such as coping, appraisal and adaptation (Brown & Jahanshahi, 1995; Ciriegio et al., 2022; Kjoelaas, Feragen, et al., 2022; Verity et al., 2020; Zarotti, Deane, et al., 2024a).

However, while positive developments have certainly taken place in terms of recognising that NDMS are not merely motor conditions and accepting that psychological distress is real and impactful for affected individuals (Pandya et al., 2008; Shojaie et al., 2023; Ventura et al., 2015), newer linguistic barriers have emerged which simply provide a different set of obstacles and oversimplifications. We also argue that while such linguistic barriers exist, people with these conditions who would benefit from psychological therapy will still struggle to access timely, person-focused and appropriate care and will experience disadvantaged access to mental health services. In short, as we will evidence below, we conclude that people with NDMS are experiencing health inequalities, partly due to the current conceptualisation of psychological distress and its prominence and power within current health care discourses.

The Biomedical Framing of Psychological Distress

In an attempt to focus attention on difficulties other than the movement problems experienced by people with Parkinson's, the term "non-motor symptoms" was coined in the 1990s and has gained increased traction (Kuhn & Müller, 1997; Lyons et al., 1997; Muller et al., 1997). In a revised version of an earlier scale, the clinician-rated Non-Motor Symptoms Scale (NMSS) for Parkinson's Disease (Chaudhuri et al., 2007) includes 13 'non-motor' domains, with five relating to psychological challenges: depression, anxiety, apathy, psychosis and impulse control disorders. Superficially, this might seem positive – the presence of psychological difficulties is an accepted part of assessment in a scale endorsed by neurologists and recommended to be administered according to individual circumstances. However, this conceptualisation clearly posits the listed psychological challenges as 'symptoms' - in other words, manifestations caused by PD-related brain changes and not a more multifactorial, biopsychosocial response to coping and living with the illness.

While originating in Parkinson's, the catch-all term 'non-motor' has also now spread to the description of psychological problems in other motor neurodegenerative conditions such as Huntington's disease and motor neurone disease (Aldaz et al., 2019). Similarly, the term 'neuropsychiatric', which is an extremely common description of similar psychological difficulties, frames the main cause as biological (brain-based). This framing is, of course,

unsurprising given the medical background of the majority of researchers and clinicians in this field but carries several important implications, as outlined below.

It Limits Theoretical Flexibility and Reinforces Disease-Based Models

Terms such as ‘symptom’ or ‘neuropsychiatric’ assume that psychological distress is mechanistically rooted in neurological change and imply that it is a direct manifestation of underlying brain pathology. This can obscure the person’s subjective experience including their emotional reactions, social context and identity changes following neurological illness (Simpson et al., 2019; Zarotti et al., 2022). It may lead clinicians and researchers to view distress as a defect to be treated, rather than, at least in part, as a meaningful or understandable response to difficult circumstances, shaped by, for example, past experiences, current circumstances and societal pressures. It also emphasises a focus on psychological deficits as opposed to living well, given the assumption that psychological difficulties are an inevitable consequence of the disease process (Barak & Achiron, 2009).

At times, the biological foundation of psychological difficulties ceases to be a mere implication, with claims in basal ganglia disorders (e.g., Huntington’s, Parkinson’s) that “much of this [depression] is the direct result of pathological changes in the brain, presumably activating some final common pathway, that result in the clinical syndrome of major depression” (Rosenblatt & Leroi, 2000; p. 25), or that “anxiety is intrinsic to PD [Parkinson’s] and may serve as a risk factor for PD development” (Heim & Djamshidian, 2025; p. 2). In fact, in one review article Parkinson’s was even defined as the ‘quintessential neuropsychiatric disorder’ (Weintraub & Burn, 2011).

It should be noted that our present argument is not against *all* biological explanations of psychological distress in NDMS. Indeed, we recognise that adopting the axiomatic claim that *any* explanation of psychological distress based on neurobiological changes alone fails to explain its contributing factors would make us victim of the same mechanistic way of thinking which we are critiquing (Soofi, 2025).

However, while neurobiology certainly matters, the biomedical model can close off integrative perspectives – such as psychosocial or constructivist approaches that recognise meaning-making and narrative as central to recovery (Kendler & Parnas, 2008). In fact, by de-emphasising the considerable contribution of both social and psychological factors to understanding psychological distress, biomedical framings in NDMS appear to go against the very “challenge to biomedicine” issued by George Engel (1977), which deeply revolutionised the field of psychiatry

in the second half of the 20th century by introducing the biopsychosocial model of recovery (Jacob, 2015; Salmoiraghi & Zarotti, 2024; Smith, 2002).

This more limited conceptualisation in turn limits the availability of approaches which are not biological or medication based. This can be through the lack of grants awarded in the non-biological space and the lack of regard given to them within the wider health and social care landscape (British Psychological Society, 2021; Clare et al., 2026).

It Blurs Distinctions Between Emotional Responses and Disease Processes

The road to diagnosis can be long and frustrating, with changes in function, at least initially, often subtle and perhaps still within the normal range or easily confused with other common-age-related difficulties, such as muscle aches and lack of dexterity (Anestis et al., 2020; Mistry & Simpson, 2013) . For some conditions, a formal diagnosis might come years after perceived changes. In Huntington's disease, given its genetic autosomal dominant transmission, children are often brought up in challenging circumstances, with issues such as attachment difficulties, emotional abuse and lack of communication commonly reported (Keenan et al., 2007; Kjoelaas, Jensen, et al., 2022; Maffi et al., 2025; van der Meer et al., 2006; van der Meer et al., 2015). For example, Gunn et al. (2023) found that psychological difficulties including depression, anxiety and irritability were present across individuals with Huntington's disease, non-gene carriers and family members, suggesting that these experiences are not solely attributable to neurodegenerative processes but may also reflect broader familial and psychosocial contexts. It is therefore not surprising that 'pre-diagnostic' levels of psychological distress occur. However, such reports are often seen as early signs of the disease (Martinez-Horta et al., 2016) – contributing to a narrative of a disease process which also affects psychological wellbeing.

Even describing these as 'symptoms' carries the risk of pathologising normal human reactions to perceived and anticipated losses, childhood trauma, changes in functional abilities or uncertainty in the face of global issues such as the recent COVID-19 pandemic (Garner et al., 2023; Simpson, Zarotti, et al., 2021). This can result in over-medicalisation and under-recognition of psychosocial factors that could be addressed through therapy, social support or other practical adaptations (British Psychological Society, 2021; Zarotti, Eccles, et al., 2021; Zarotti et al., 2020; Zarotti, Mayberry, et al., 2021).

It Undermines Person-Centred and Contextual Understanding

A purely medicalised vocabulary focuses attention on the *brain* rather than the *person*. It neglects how distress and disability are shaped by identity, relationships, stigma, employment or cultural meaning (Burchardt, 2004; Goering, 2015). Moving from ‘neuropsychiatric symptoms’, ‘psychiatric manifestations’, or ‘symptoms’ to more person-centred language allows for richer, holistic conceptualisations for people with NDMS. As overarching terms, we would suggest ‘psychological difficulties’, ‘emotional adjustment difficulties’, ‘coping difficulties’ or ‘mental health difficulties’. For specific mental health presentations, we would simply name the difficulty – low mood, anxiety etc. However, we would also suggest that all mental health problems are accompanied by a co-produced formulation – see Dale et al. (2022) for an example – which explains the cause of the difficulty and its maintaining and precipitating factors.

It is recognised that some individuals may be comfortable with the use of biomedical labels, as biomedical framing of psychological distress might help reduce some of the felt or enacted stigma associated with mental health or improve access to medical treatment and benefits (Pereira & Skovdal, 2022; Stone et al., 2020). Clinicians also sometimes believe it helps counteract stigma (Corrigan & Watson, 2004). However, this framing may also reduce individuals’ perceptions of their ability to seek or adhere to forms of support that are not primarily pharmacological, including psychological and behavioural interventions, even though such approaches can themselves involve meaningful biological processes (Li et al., 2024; Van der Zwaan et al., 2025; Zarotti, D’Alessio, et al., 2024). For clinicians it can continue the limited emphasis on structured psychological therapies, reflecting the continued dominance of medically oriented management frameworks (Anderson et al., 2018).

It Affects Care, Communication, and Stigma

Stigma is known to affect outcomes for people with neurological disease (Elliot et al., 2019), and in some conditions a “double stigma” associated with both diagnosis and mental health difficulties has been described (Mula & Kaufman, 2020). Within NDMS, emerging evidence suggests that stigma is shaped not only by a NDMS diagnosis but also by how psychological experiences are interpreted, with one HD participant noting that “you’re blaming everything on that [HD] now” (Theed et al., 2018; p. 216). Another HD study has shown that the emotional and behavioural aspects of HD are central domains through which stigma is experienced, rather than being separate from it (Boileau et al., 2020). In Parkinson’s disease, stigma is influenced by the interpretation of both visible and less visible features, contributing to concealment and social

withdrawal (Crooks et al., 2025), and is associated with poorer psychological wellbeing (Eccles et al., 2023). While research has not directly examined the effects of specific terminology, these findings suggest that the meanings ascribed to psychological experiences may constitute an additional, interacting layer of stigma.

Individuals with NDMS may feel alienated or stigmatised by terms that sound clinical or pathological. Professionals may default to pharmacological approaches (Andriessen et al., 2025; Vajda & Solinas, 2005), while not considering or undervaluing psychological or social interventions (Zarotti, D'Alessio, et al., 2024). A less medicalised framing instead promotes collaboration, empathy, and shared understanding of distress (Cunningham et al., 2019; Soofi, 2025; Wolverson et al., 2019).

Historically, a prime example of this has been offered again by the field of dementia. In the mid 1990s, a meeting of the International Psychogeriatric Association began to popularise the term 'behavioural and psychological symptoms of dementia' (BPSD) to describe psychological distress and mental health difficulties in this population (Cunningham et al., 2019). While originally driven by the aim to increase clinicians' understanding of factors affective behaviour in people with dementia (hence the use of 'behavioural' and 'psychological'), the emphasis placed on 'symptoms' arguably produced the opposite effect, with BPSD being perceived as a stigmatising term which perpetuated the medical model, ignored the impact of unmet needs of people with dementia and promoted the use of psychopharmacology as first line of therapeutic approach (Liperoti et al., 2008; Wolverson et al., 2021).

Over the past decade, this perception has led to an advocacy campaign to ban the term altogether (i.e., '#banBPSD') and replace it with less stigmatising and more meaningful language based on the perspectives and experiences of affected individuals (Cunningham et al., 2019; Swaffer, 2019; Swaffer & Country, 2018). In this regard, a recent mixed-methods survey of people with dementia reported that 'distress' was "described as a 'nicer term' and the 'least offensive', while some terms could make people feel 'guilty' or 'daft'" (Wolverson et al., 2021; p. 1997). Similarly, a study involving multidisciplinary professionals and stakeholders highlighted 'distress' as an example of less stigmatising terminology based on shared human experience (Wolverson et al., 2019).

In this regard, it is important to note that research with people with dementia has long been influenced by psychological understandings, particularly spearheaded by Tom Kitwood's social-psychological theory of dementia care (Kitwood & Bredin, 1992), which argued that BPSD could

be better understood as “actually valid responses to inappropriate external circumstances and relational approaches” (Cunningham et al., 2019; p. 109). On the other hand, similar psychological approaches promoting critical, user informed engagement with terminology in NDMS are still very much in their infancy.

It Takes Control Away

Perceptions of control in people with NDMS are also deeply affected by language, since biological deterministic explanations across all difficulties may depict current negative experiences as uncontrollable and unavoidable and leave little to no hope for a future life (Eccles & Simpson, 2011; Verity et al., 2020; Zarotti, 2022). On the other hand, addressing perceived control with psychosocial interventions has proved to yield positive results both in terms of mental health and clinical outcomes in people with neurodegenerative diseases as well as other chronic conditions (Barlow et al., 2015; Marks et al., 2005; Robinson & Lachman, 2016; Tyack & Camic, 2017; Zarotti, Deane, et al., 2024b). Examples of such interventions may include goal-oriented and physical rehabilitation improving feelings of self-efficacy (Hindle et al., 2018; Ritter & Bonsaksen, 2019) as well as mindfulness-based and dance therapy programmes promoting more internal locus of control (Advocat et al., 2016; Prewitt et al., 2017).

However, the development of novel psychosocial interventions is also at risk of being affected by medicalisation, which can implicitly impose biomedical standards of evidence and particularly the prioritisation of randomised controlled trials (RCTs). While RCTs are well suited to evaluating discrete, standardised treatments such as in drug trials, they may be less appropriate for complex, holistic approaches that are context-dependent and involve multiple interacting components. As has been argued, complex interventions often require more pluralistic and context-sensitive forms of evaluation beyond traditional hierarchies of evidence (Greenhalgh et al., 2017). Similarly, rigid adherence to narrowly defined evidence standards risks marginalising valuable forms of knowledge and practice (Chalmers, 2003). Therefore, in this view medicalisation not only carries the risk to take away control from people with NDMS, but also from the wider psychosocial research community by dictating methodological standards which may be inappropriate and could underestimate the potential benefits of non-medical approaches (Westen et al., 2004).

It Becomes Part of the ‘Accepted Science’ of the Condition

Since NDMS are primarily neurological conditions, there has been - rightly - an emphasis on using scientific approaches to help understand and provide curative or symptomatic treatments. In

this regard, the language of science plays a pivotal role in conferring an ‘objective’ context and shaping and reinforcing scientific methodology (Argamon et al., 2008), to the point of being considered as an essential tool within the field of medicine (Cassell & Skopek, 1977; Fleischman, 2008). However, language can move from being a useful descriptive tool to playing a more constitutive role in defining what is understood as legitimate knowledge.

Within the field of NDMS research, the longer terms such as ‘non-motor symptoms’ or ‘neuropsychiatric symptoms’ are used, the more they become the ‘accepted science’ of the conditions and a sign of an esteemed in-group membership (Ashokkumar & Pennebaker, 2022). These words and phrases then become so ingrained that their use becomes uncontested and to challenge such usage can seem overly pedantic.

A Linguistic Reformulation of Psychological Distress

Language is far more than a means of communication; it is a fundamental medium through which thought and culture are constructed and expressed. While the term ‘non-motor’ might seem purely descriptive, it represents a specific understanding of a construct. Clearly some researchers in this area do see psychological distress – entirely or mainly – as part of the disease process and so for them this description is probably unremarkable and an accurate reflection of their world view. However, we need, regardless of whether we agree with the accuracy of its description or not, to realise that the implications of using such a term on not just its conceptualisation but much wider concerns.

Thus, the first thing we can do is be aware of the power of the language and accept that no phrasing is either neutral, purely descriptive, or free of wider implications.

For many working psychologically with people with NDMS, particularly with neurology colleagues, sharing the same terms can be an easy short-cut. However, the use of particular phrases usually comes from the dominant speciality, which in the case of care for people with motor neurological conditions is represented by neurology, psychiatry, and gerontology – all medical specialties. As indicated earlier, challenging accepted language might be seen as churlish, petty, and non-collegiate. It might also be seen as non-academic, especially given the overwhelming use of overly medical terms in so many academic papers. Sharing common language can be a way of fitting in, but this should not occur to the detriment of obtaining a more comprehensive understanding of individuals’ multifactorial distress.

It is therefore important to draw attention to the use of medicalised language where it appears and encourage the use of less medicalised terminology.

A key challenge in articulating the implications of specific language use is the limited empirical evidence examining its effects within this context. Within the field of clinical psychology, arguably due to the very verbal nature of talking therapies, the various effects of framing language have traditionally received significant attention (Gkotsis et al., 2016; Harper, 2023; Russell, 1989). However, studies in the field of NDMS are non-existent, despite preliminary evidence available from mixed-methods investigations focused on people with other types of neurodegenerative diseases (e.g., dementia) highlighting how the language chosen to refer to psychological distress has significant consequences in terms of shaping not only one's own perception of human experiences and mental health, but also other people's (Wolverson et al., 2019, 2021).

Consequently, we need to provide evidence of the effects of the current discourse and involve people with these conditions in considering alternative, psychologically informed linguistic formulations of psychological distress in NDMS.

It has been argued here that using medicalised language can, unintentionally, pathologise understandable distress, narrow the focus to biology at the expense of psychology and context and undermine person-centred care and more holistic approaches to ensuring wellbeing. A more helpful approach uses language that recognises distress as a human, contextual and meaning-laden experience - one that exists *alongside* neurological change, rather than merely *caused by* it.

We need to recognise that phrases are seldom purely descriptive or value-free.

Qualitative research across Huntington's and Parkinson's disease, as examples, suggests that psychological distress is frequently absorbed into biomedical interpretations of neurodegenerative disease, which may reduce its perceived separability and modifiability. In Huntington's disease, participants often described emotional difficulties as directly attributable to the condition, commenting in one study how "it was just a case of treating the depression as a biological thing" (Theed et al., 2018; p.221). This attributional shift can also be accompanied by reduced perceived agency, with participants describing Huntington's disease as something that "takes over at the end of the day, I can't really do anything about it" (Theed et al., 2018; p.222), alongside understandable uncertainty about psychological intervention ("I haven't a

clue... I'm a little bit confused about... how it can help"; Theed et al., 2018; p.224). A similar pattern is observed in Parkinson's disease qualitative research, where emotional changes are frequently normalised as part of the disease rather than as distinct psychological problems. Participants describe psychological difficulties as "part of Parkinson's disease" and report that these are less likely to be recognised as requiring separate attention or treatment (Crooks et al., 2025; Maffoni et al., 2017). Across both conditions, therefore, psychological distress is commonly framed within the overarching neurodegenerative identity of the disease, which may shape perceptions of controllability, prioritisation, and the perceived relevance of psychological support.

We should provide people with NDMS and caregivers with more space to explore and understand the meaning of their distress.

The view that changes in mood and personality are accepted features of HD is common, including with people with the condition. However, when people with NDMS and their caregivers are allowed to explore more deeply their views, more nuanced understandings can emerge. For example, irritability, which is often seen as one of the three cardinal 'psychiatric' features of HD, can be considered by individuals with HD as more complex than a purely biological symptom, with qualitative accounts emphasising its relational and contextual nature rather than a solely disease-driven phenomenon (Klöppel et al., 2010; Tindall et al., 2025). Similarly, qualitative work in Parkinson's disease challenges purely biological accounts of apathy, suggesting instead that it may reflect a complex interaction between impairment, motivation, and social context rather than being reducible to an endogenous disease process alone (Simpson et al., 2015).

We need to promote a more wide-spread adoption of multidisciplinary work with people with NDMS.

One possible solution to the overuse of medicalised language in NDMS may reside in the more widespread adoption of multidisciplinary team approaches in NDMS, as challenge and discussion from different professional groups have shown to be important ways of improving care and quality of life in people with neurodegenerative conditions (Marchiş et al., 2025). More specifically, by bringing together medical, psychological and social care perspectives, multidisciplinary team approaches can help move beyond narrowly biomedical accounts, think more critically about the impact of language and its nuances, and ultimately diversify the terminology used in conceptualising and understanding distress (Flores-Sandoval et al., 2021).

We need to consider the impact that language has on the way people with NDMS see interventions and their accessibility.

While the use of medicalised language does not always result in approaches to treatment derived from medicine and many users of such language are not aware of the implications of specific phrases and terms, it can nonetheless shape expectations, reinforce particular causal narratives and subtly constrain the options considered legitimate or appropriate for supporting psychological wellbeing. In doing so, it influences not only how clinicians communicate and make referrals, but also how individuals understand their own experiences and whether they view psychological therapy (Zarotti, D'Alessio, et al., 2024; Zarotti, Mayberry, et al., 2021) or other psychosocial interventions such as dance and music therapy (Frisaldi et al., 2021; Roos, 2015; Ulanowski et al., 2025), social support (Coulson et al., 2007; Kjoelaas, Feragen, et al., 2022; Loane & D'Alessandro, 2013), and self-management (Busse et al., 2017; Mulligan et al., 2011; Neville et al., 2025) as relevant or accessible, especially when significant costs and economic inequality may also be involved .

Conclusion

Psychological distress in neurodegenerative diseases of the motor system (NDMS) is real, prevalent and often as disabling as changes in movement, yet the language used to describe it is not a neutral container. Framing mood, anxiety, apathy or irritability as 'non-motor symptoms' or 'neuropsychiatric manifestations' can unintentionally imply that they are biologically inevitable, blur the distinction with normal responses to chronic illness and reinforce deficit-based narratives that privilege biomedical explanations over personal meaning, context and care. Such discourse shapes what clinicians notice, the research agenda, how they communicate risk and prognosis, whether referrals to psychological therapy feel legitimate, and how people understand their own agency and capacity to adapt.

We argue that it is time for a linguistic reformulation of psychological distress in NDMS that recognises distress as a human, socially situated and meaning-laden experience that is influenced by – and not completely reduced to – neuropathology. Attending to language in these conditions offers the opportunity to develop more holistic practice, improve access to psychological support and reduce inequalities in care, as even small shifts in wording can provide room for hope, choice, agency and partnership.

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