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### **Clinicians' attitudes towards cognitive and behavioural screening in motor neurone disease**

**Citation for published version:**

Crockford, C, Stockton, C & Abrahams, S 2017, 'Clinicians' attitudes towards cognitive and behavioural screening in motor neurone disease', *British Journal of Neuroscience Nursing*, vol. 13, no. 3, pp. 116-123.  
<https://doi.org/10.12968/bjnn.2017.13.3.116>

**Digital Object Identifier (DOI):**

[10.12968/bjnn.2017.13.3.116](https://doi.org/10.12968/bjnn.2017.13.3.116)

**Link:**

[Link to publication record in Edinburgh Research Explorer](#)

**Document Version:**

Peer reviewed version

**Published In:**

British Journal of Neuroscience Nursing

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**Accepted:** British Journal of Neuroscience Nursing, January 3<sup>rd</sup> 2017

**Title:** Clinicians' attitudes towards cognitive and behavioural screening in motor neurone disease.

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**Acknowledgments:**

The authors gratefully thank the participants in this study. CC was supported by a studentship from the Euan MacDonald Centre for Motor Neurone Disease Research.

## **Abstract**

Amyotrophic Lateral Sclerosis (ALS), the most common variant of Motor Neurone Disease, is a fatal neurodegenerative condition marked by progressive motor disability. Cognitive and behavioural changes occur in approximately 50% of patients, which may impact caregiver burden, adherence to life-prolonging interventions, and care planning. The aim of this study was to explore the attitudes and practices of Health Care Professionals working with ALS patients in Scotland towards cognitive and behavioural screening. Structured interviews with ALS Healthcare Professionals were conducted and subjected to thematic analysis. While 93% of clinicians in this study believed that cognitive and behavioural screening should be routinely applied for all patients, it is not currently common practice, nor are formalised screening tools widely used. Participants noted that barriers to screening include other members of staff, limited resources, and issues concerning patients and their families. Participants suggested that increased education and training, making screening a standardised protocol to all patients and increased psychology input may help overcome these barriers.

## **Key points**

1. Cognitive and behavioural screening in MND is important in the management and care of patients and their families, as highlighted by recently updated guidelines from the National Institute for Health and Care Excellence (NICE).
2. While the majority of Health Care Professionals in this study recognise its importance, cognitive and behavioural assessment is at present not provided to all patients and methods of evaluation are often informal.
3. Barriers exist to implementing screening programmes including a lack of resources, perceived attitudes of other staff members, and of patients and their families.

4. Increased resources, education, and psychology input may assist in overcoming these barriers and providing modern holistic care to patients and their families.

## **1. Introduction:**

Motor neurone diseases (MND) is an umbrella term for neurodegenerative syndromes marked by degeneration of the upper and/or lower motor neurons of the brain and spinal cord. Half of patients with MND die within 30 months of symptom onset, most commonly due to failure of the respiratory system. Amyotrophic Lateral Sclerosis (ALS), the most common form of MND, is classified by involvement of both the upper and lower motor neurons, presenting as muscle rigidity, wasting, and weakness (Strong et al., 2009).

However, in addition to the physical symptoms, it is now recognised that impairments in cognition and behaviour are common in patients with ALS. Difficulties in executive functions (e.g., problem solving, decision making, social perception), language (e.g., word finding, comprehension), and behaviours such as apathy are commonly reported (Raaphorst et al., 2012; Beeldman et al. 2015). It is estimated that approximately 50% of ALS patients experience some changes in cognition and behaviour, of which approximately 15% meet diagnostic criteria for frontotemporal dementia (Goldstein and Abrahams, 2013). A clinical, pathological, and genetic overlap has been established between and frontotemporal dementia confirming that the two conditions constitute a spectrum disease (Turner et al., 2013).

Changes in cognition and behaviour have important implications for patient management (Abrahams, 2013) and have been associated with significantly shorter survival time in patients with ALS (Elamin et al., 2013; Caga et al., 2016). People with ALS and cognitive change have shown less compliance with life-prolonging interventions (Olney et al., 2005; Martin et al., 2014), and have a reduced ability to plan and organise medications (Štukovnik et al., 2010). Furthermore, behavioural symptoms are one of the greatest contributors to caregiver burden, perhaps over and above physical symptoms (Lillo et al., 2012). Thus, the accurate and timely understanding of patients' cognitive and behavioural profile

is of vital importance. Recently updated guidelines from the National Institute for Health and Care Excellence have incorporated recommendations for cognitive and behavioural assessment in patients with MND (NICE, 2016). These guidelines note that a patients' cognitive and behavioural status has implications for end of life planning, the type of medications that should be prescribed, the use of gastronomy, and the use of respiratory interventions. Additionally, discussions around care should be tailored to each person's needs, communication ability, cognitive status, and mental capacity (NICE, 2016).

Unfortunately, measuring cognition in patients with ALS has been historically difficult. Standardised cognitive screening, and neuropsychological assessment more generally, rely on a person's ability to either speak or write their responses, often under timed constraints. Additionally, evidence suggests that clinicians are poor at detecting cognitive impairment using clinical judgement when compared to formal cognitive screening (Cohen et al., 1993; Crawford et al., 2001; Burleigh et al., 2002; Bouwmans and Weber, 2011; Mitchell et al., 2011), particularly in cases of mild cognitive deficits (Dungen et al., 2011). While no identifiable research is available on the practices of clinician's caring for patients with ALS, within elderly primary care settings some research suggests that cognition appears to be evaluated principally using clinical judgement. For example, Bush et al. (1997) found that 72.8% of primary care physicians evaluated cognitive status using clinical judgement while only 27.2% used a formal test. More recently, Galvin, Meuser and Morris (2012) found that formal screening tools, such as the Mini Mental State Examination, are used widely by healthcare professionals.

For patients with MND, tools such as the Mini Mental State Examination are not appropriate due to the requirement for intact motor skills. Fortunately, in recent years, a number of ALS-specific screening tools have been developed, most notably the ECAS (Edinburgh Cognitive and Behavioural ALS Screen; Abrahams et al., 2014) which has been validated on Scottish, German and Italian populations (Lulé et al., 2015; Niven et al., 2015; Loose et al., 2016; Poletti et al., 2016). The ECAS has been shown to be sensitive to cognitive impairment against extensive neuropsychological investigation (Niven et al., 2016) and is possible to administer in patients with even severe motor

disability (Lulé et al., 2015). The ECAS is designed for use by non-neuropsychologist staff, such as doctors, clinical care specialists, and other medical professionals.

While the importance of understanding the cognitive and behavioural profile of neurological patients is clear, a number of barriers have been identified in the implementation of cognitive screening in primary care settings; for example, Bush et al. (1997) found that a lack of time, patients becoming offended or resisting, lack of proven benefit, and inadequacy of available tests all posed problems. Similarly, Boustani et al. (2005) identified increased time burden, no referral access to neuropsychology, patient refusal, and that physicians do not fully understand the operating characteristics of screening tests. Yet, more recently, Fowler et al. (2012) found that patient refusal of cognitive screening is low, and more unlikely in patients who perceive there to be benefits.

However, there exists a dearth of knowledge as to the attitudes and practices of Health Care Professionals (HCPs) in ALS services with regards to cognitive and behavioural screening.

The aim of this study was to explore HCPs' attitudes to screening, and more specifically, views on the importance of screening, practices around screening, and what barriers exist to the implementation of screening for cognitive and behaviour change in ALS in Scotland

## **2. Methodology:**

Structured interviews consisting of both open-ended and forced-choice questions were undertaken with participants. Thematic analysis was used to analyse the data. This study received ethical approval from the Psychology Research Ethics Committee of University of Edinburgh.

### **2.1. Participants**

Participants were HCPs working with patients with ALS and recruited from 6 NHS health boards in Scotland. Fourteen HCPs took part in this study, including 5 ALS clinical care specialists, 5 neurologists (3 consultant neurologists and 2 specialist registrars in neurology), and 4 psychologists (2 clinical psychologists and 2 clinical neuropsychologists).

Participants, on average, had spent 10.04 years in their current role, and an average of 11.64 working with patients with ALS. Clinical care specialists were recruited through MND Scotland, while neurologists and psychologists were recruited via chain-referral sampling methods.

## **2.2. Procedure**

Participants were contacted by email and invited to take part in this study. Participants were given the option to complete the interview by telephone, in person, or to complete an online form. In all cases, questions posed to participants were identical. Twelve participants were interviewed by telephone, while two completed the online form. Those who chose the online form stated that this was due to time restrictions. Responses of participants who completed the online form did not thematically differ from those who completed an interview. Interviews were conducted between February and May 2015 and lasted approximately 20-30 minutes. Interviews were audio-recorded, transcribed verbatim (transcripts were anonymised to protect confidentiality), and subjected to thematic analysis. Thematic codes emerged post-hoc based on participant responses.

## **3. RESULTS:**

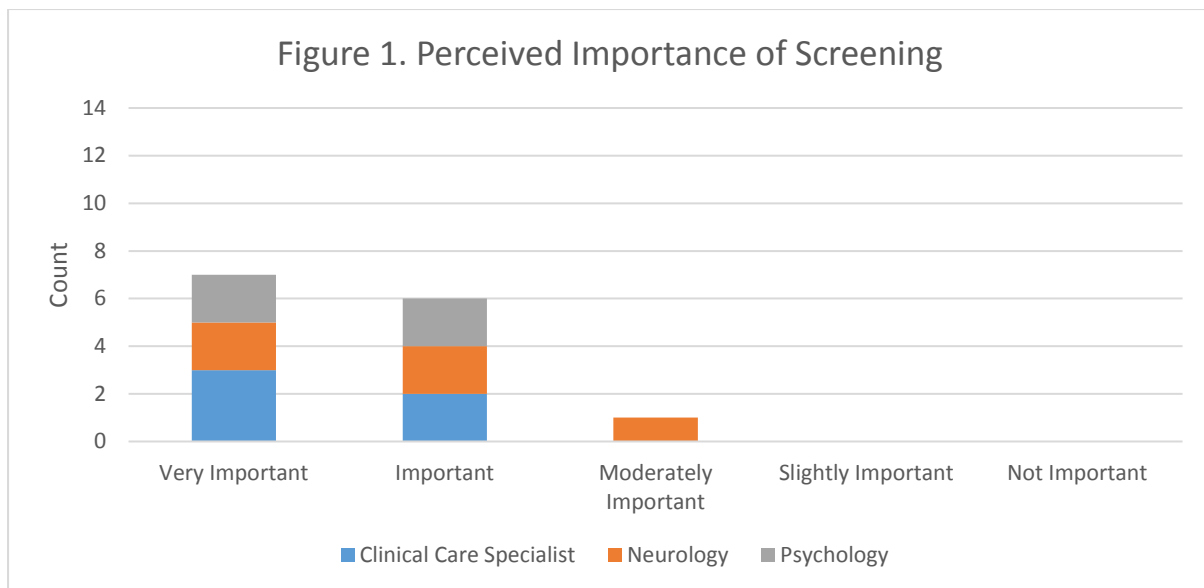
3.1. Attitudes and practices to screening: Participants were asked how important they viewed screening for cognition and behaviour on a five-point Likert-type scale. Figure 1 shows that all but one participant believed screening to be either important or very important.

**Table 1. Overview of analysis themes**

Topic	Themes	Subthemes	Disciplines
<i>Importance of screening</i>	Care provision & planning	Person-centred care	All
		how staff communicate	All
	Capacity	Consent to interventions	All
		Power of attorney	CCS, Psychology
<i>Barriers to screening</i>	Staff barriers	Perceived unimportance	All
		Negative patient outcomes	All
		Lack of awareness	All
		Lack of confidence	All
		Who should administer?	Psychology
	Resources	Time	All
		Staff	CCS, Neurology
		Training/Education	CCS, Neurology
		ALS-Specific tools	Psychology
<i>Solutions to barriers</i>	Increased resources	Refusal	CCS, Psychology
		Patient impairment	CCS, Neurology
	Increased resources	Increased education/training	All
		Increased psychology input	All
		Increased CCS staff	CCS, Neurology
	Standardisation	Screening as standard protocol	CCS, Psychology
	Other	Technology	CCS
		ALS-Specific Tools	Psychology

Note: CCS = Clinical Care Specialists, All = Clinical Care Specialists, Neurology, Psychology.





Participants were asked to qualify their judgement of perceived importance, and additionally, asked whether they perceived there to be benefits to screening. For participants who reported screening to be important or very important, two categories emerged for the importance of screening: a) care provision and planning, and b) decision making and mental capacity.

a) Care provision and planning: The majority of participants noted that screening allows HCPs to provide holistic, person-centred, and individualised treatment, as opposed to addressing ALS as solely a physical condition. Participants additionally reported that screening allows clinical staff to tailor the way in which they communicate with patients and with their families.

*“Informing clinicians who are working with patients about what their needs actually are as opposed to just simply addressing this as a physical condition.”*

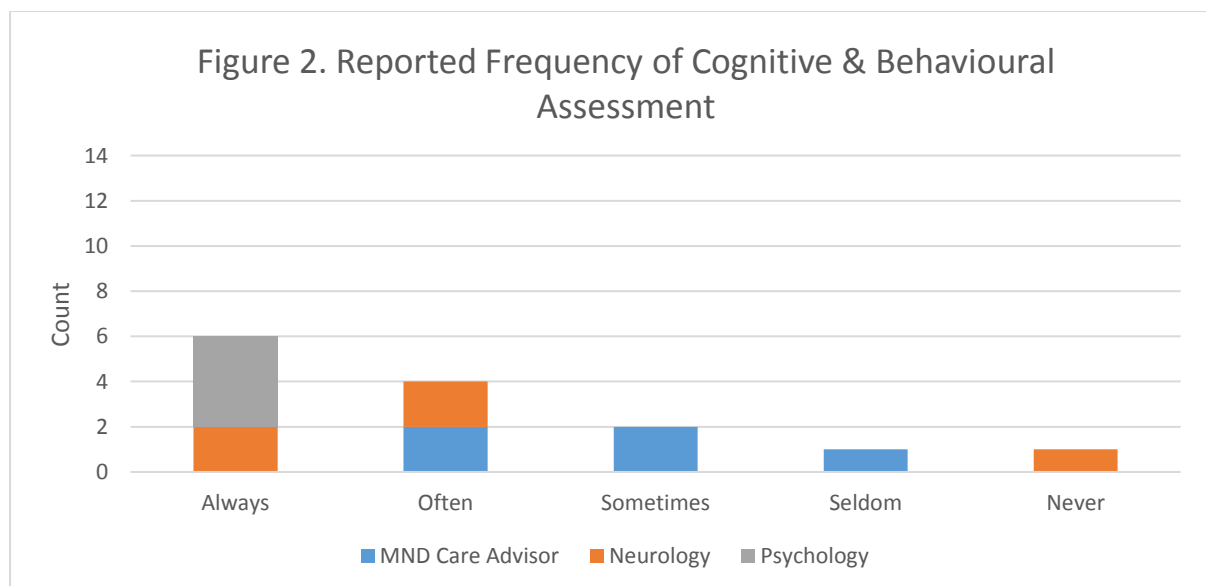
-Psychologist

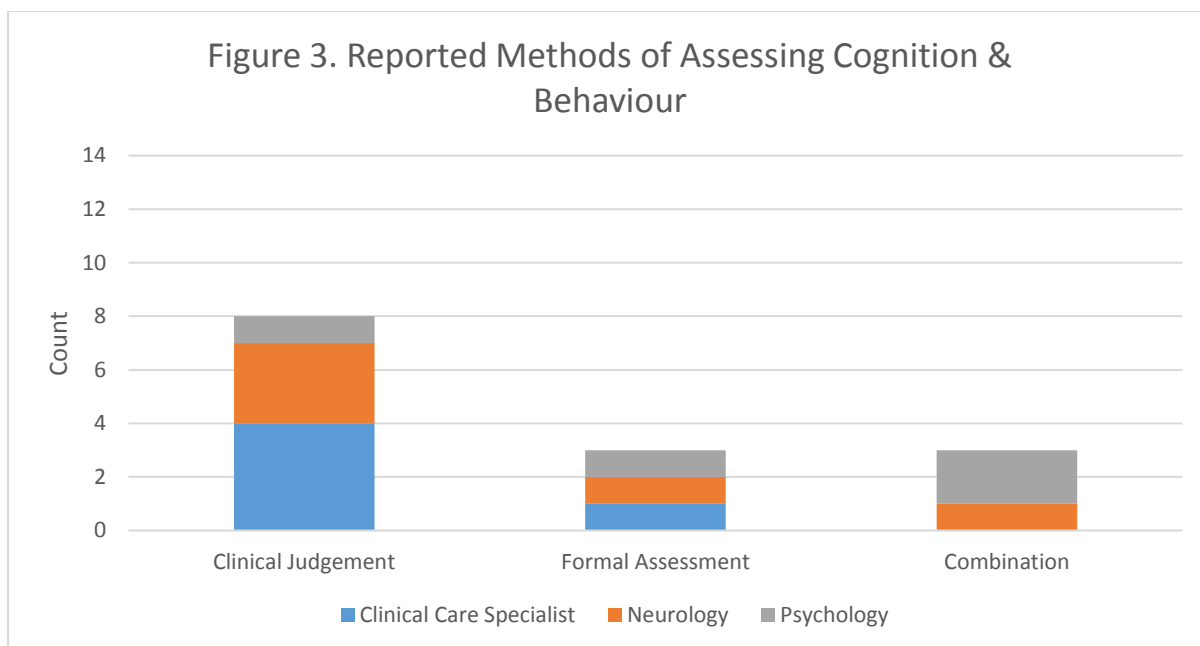
b) Decision making and mental capacity: Participants noted that screening assists in the determination of mental capacity and decision making abilities, which is important as there are end-of-life decisions to make, such as power of attorney, and that medical interventions can be invasive (for example, percutaneous endoscopic gastrostomy). As such, it is important that patients’ capacity to consent is established.

*“There’s a lot of invasive medical procedures involved sometimes in ALS and you have to ask the question of whether the person’s got capacity to make these decisions”*

-Psychologist

The methods by which HCPs screen for cognitive and behaviour change, and the frequency of such screening, were explored. Participants were asked a forced choice question as to whether all patients diagnosed with ALS should be screened for cognitive and behaviour change as standard. Of the 14 participants, 13 (92.86%) responded ‘yes’ and one participant responded ‘no’. When asked how often participants in this study evaluated patients’ cognitive and behavioural status, 71.43% stated always or often, 21.43% stated sometimes or seldom, with one participant never evaluating cognition and/or behaviour. However, of the participants who did evaluate cognition and behaviour, 61.54% reported using their clinical judgement solely, with 38.46% using a formal screening tool, or a combination of a screening tool and clinical judgment. Neurologists, clinical care specialists, and psychologists all reported that cognitive and behaviour assessments was currently conducted within their discipline, suggesting no clear pattern as to who tends to perform such assessments.





### 3.2. Perceived barriers to screening

Participants were asked what, if any, barriers existed to the implementation of screening. From participants' responses, three categories of barriers were identified: a) staff-specific barriers, b) resource barriers, and c) patient/family barriers.

a) Staff-specific barriers: These concern other members of staff or disciplines reported by participants of this study. All of the participants in this study (i.e., all HCP disciplines) reported at least one barrier relating to other members of staff, in particular, that staff held negative attitudes toward screening. These attitudes include a perceived unimportance of screening, the perceived negative psychological impact that identifying a cognitive or behavioural deficit might cause to patients, a lack of clinician awareness of cognitive or behavioural change, a lack of confidence in administering screening, and concern around who should administer screening. One participant reported that clinical staff feel *"that it's not an important exercise to put patients through [...] a sense that the physical wellbeing is sometimes more important than the emotional and cognitive wellbeing."* -Psychologist

However, one of the most commonly cited staff-specific barriers was in reference to Neurology specialists, as opposed to other professions. For example, that Neurologists miss the subtleties of cognitive and behavioural change, and the effects that this can have.

*“I mean even ten years ago people were told that well don’t you worry because ALS doesn’t affect the mind in any way. And in fact there are some consultants that still say that”*

b) Limited Resources: In addition to other staff, resources were commonly noted as a barrier to screening, in particular time, staffing levels, access to training, and appropriate assessment tools. Despite the desire to implement screening, the length of each consultation was deemed insufficient to administer formal screening. Moreover, staff viewed screening as a sensitive issue and that HCPs needed to build a rapport with the patient first, adding additional time requirements. Further to this, participants reported that insufficient training was provided in the administration of screening tools and that services were understaffed.

c) Patients and families: A number of participants, particularly psychologists, noted that patients themselves may be a barrier to screening, such that, patients and carers may refuse. Additionally, the presence of cognitive or behavioural symptoms was suggested to pose a challenge in and of itself. However, participants expressed that this is a rare occurrence and that, in all cases, that this was only a perceived barrier, rather than from experience with patients.

*“I think some of the barriers can be patients themselves not wanting to engage in it because it’s another assessment tool that’s highlighting weaknesses in their profiles.... for me, in my experience on the whole, I have not really found a lot of barriers in patients themselves.”*

-Psychologist

3.3. Suggested solutions: In addition to identifying barriers to screening, participants were asked if they had views on how barriers may be overcome. Three common solutions were offered by participants: a) increased education, b) increased psychology input, and c) screening all patients as standard practice. Three other solutions were also offered: increased number of ALS clinical care specialists, use of technology, and development of ALS-specific screening tools.

Most commonly, participants suggested that education may overcome barriers to screening. Education referred to patient/caregiver and staff. The majority of participants felt that it is important to increase awareness, highlight the benefits of screening, and increase the opportunities for formal training. Commonly reported, was that participants felt psychology should have a larger input into patient assessment, specifically, that dedicated psychologists should be part of the multidisciplinary team. However, some disagreement emerged as to who should administer screening. While neurologists felt that both clinical care specialists and psychologists should be responsible, psychologists were sceptical of non-specialists administering cognitive/behavioural screening due to a lack of formal training and experience. Currently, participants in this study noted that screening was not specific to any one discipline.

An additional recommendation to increase screening in ALS was to make it standard practice for all patients and in so doing, patients may not feel singled out or at risk. Finally, other less-reported solutions include the increased staffing of clinical care specialists in Scotland, and the utilization of technology in interpreting formal screening tools.

## **4. Discussion:**

The aim of this study was to explore HCPs' attitudes to cognitive and behavioural screening in ALS. Fourteen HCPs were interviewed and asked their opinion as to the importance of screening, their practices around screening, and what barriers they perceive to exist. This study found that the majority of HCPs deemed screening to be important or very important due to its implications for care

provision and end of life planning, and for issues surrounding decision making and mental capacity. Specifically, participants noted that assessment of cognition and behaviour allowed for the provision of person-centred, holistic and individualised treatment that sees MND as more than a physical disease. Given the rapid rate of disease progression, important decisions are necessary with regards to end of life planning and treatment. Thus it is seen as crucial to understand the ability of a patient to make such decisions, and what additional supports may be required to do so. These findings suggest that HCPs are largely in agreement with the recently updated NICE guidelines on assessment and management of ALS (NICE, 2016).

Ninety-three percent of participants stated that screening for cognition and behaviour in ALS should be standard practice for all participants, but only 71.43% stated that they evaluate always or often. Of the HCPs who evaluated cognition and behaviour seldom or more frequently, only 38.46% reported formally evaluating cognitive and behavioural status of ALS patients using a screening tool.

The discord between attitudes and practice may be that in reality, HCPs are only formally screening patients when cognitive and behavioural symptoms are severe or overt, such as cases of comorbid dementia. Yet, the majority of patients with ALS will present with mild cognitive and behavioural changes that may not be explicitly evident on observation. Research has demonstrated that even mild changes can have significant impact on caregivers (Lillo et al. 2012), affect the patients' ability to manage their medications (Stukovnik et al. 2010), and reduce engagement with life prolonging interventions (Olney et al. 2005; Martin et al. 2014). Therefore, it is important to offer screening to all patients, regardless of whether overt symptoms are present, closing the gap between attitudes and practice.

Even in those cases where cognition and behaviour is evaluated, clinical judgement is the most common method employed. Based on previous research citing the poor accuracy of clinical judgement to detect cognitive and behavioural impairment (e.g., Mitchel et al. 2011), and the frequency by which this method was employed by participants in this study, it is highly likely that patients with cognitive and behavioural changes are not being identified. With the development of short ALS-specific tools such

as the Edinburgh Cognitive and Behavioural ALS Screen, and the growth of multidisciplinary care systems, it should be possible for HCPs to include screening as standard practice for all patients. Given this, clinicians should be moving away from informal assessment and toward a standard screening procedure using a validated formal test.

### **Barriers to Cognitive and Behavioural Screening**

When HCPs were questioned as to what barriers existed in implementing cognitive and behavioural screening, three themes were identified: a) staff-specific barriers, b) resource barriers, and c) patient/family barriers.

While the majority of HCPs in this study believed screening to be important, all participants also noted that a significant barrier was other staff. Perceived unimportance, lack of awareness, and potential negative consequences to patients were cited as possible obstacles to the implementation of screening. In particular, participants reported that neurologists' attitudes posed a significant barrier. This perception may be a by-product from the current care structure of neurology-led clinics in which medical or palliative facets of care are prioritised. Moreover, as noted by participants, appointment times between patients and neurologists are short, and there may not be sufficient time for cognitive/behavioural symptoms to be evident. As such, the barrier may be the clinical context.

Participants in this study suggested that the perceived unimportance and lack of awareness may be ameliorated by staff educational programmes and awareness campaigns which highlight the importance of cognitive/behavioural screening in line with NICE Guidelines. HCPs in this study suggested that education may alleviate some of the barriers, which may take the form of clinical training workshops, or continuing professional development courses. Galvin, Meuser and Morris (2012) demonstrate that a training programme targeted at HCPs can be effective in improving medical knowledge, confidence in diagnosis and treatment, and enhancing clinical practice. Staff-specific barriers may be partly explained by HCPs have insufficient training in how to practically incorporate a

patient's cognitive and behavioural status into practice. Therefore, such training and educational opportunities for staff may help overcome a number of the barriers cited in this study; for instance, if clinicians were more aware of the benefits to screening, how to administer such a screen, and what to do with that information, the barriers of perceived unimportance, lack of awareness, and lack of confidence may be reduced.

Unfortunately, enhancing and increasing educational and training to staff is constrained by services already identified as under-resourced. HCPs here report having insufficient time, and insufficient staff numbers to implement screening for all patients. To fully adhere to NICE guidelines and provide cognitive and behavioural assessment to patients with MND, increased funding and resources may be unavoidable. However, it is possible that short-term funding solutions may provide initial increased education and training that could be maintained with normal resources thereafter.

However, there was disagreement among participants as to who should administer screening tools. A number of participants suggested that increased screening may be achieved by increased input from psychologists. This may mean psychologists undertaking the assessment themselves, or that psychologists provide supervision to non-specialist HCPs. A dual pathway model where both of these routes are operationalised would maximize the service to capture a larger proportion of ALS patients, including both those who are willing to attend psychology services, in addition to those who do not want to or are unable to attend. Geographical, financial, and staffing restrictions may necessitate that individual health boards or centres operationalise screening programmes according to their unique capabilities.

Interestingly, HCPs expressed that patients and their families might themselves present a barrier to cognitive and behavioural screening. While this is possible, participants herein could not provide examples where this had actually occurred. In a large study of screening in primary care, Fowler et al. (2012) found that patient refusal was low (10.3%), and significantly less likely in those who perceive



there to be benefits to screening. This concern may in fact reflect HCPs desire to avoid causing distress to patients by identifying a cognitive or behavioural symptoms. As such, this barrier may be perceived rather than based on actual practice or experience with patients and families and further research should address this issue.

The barriers which emerged in this study echo some of those previously reported specifically, lack of time and potential negative consequences to patients, clinicians' perceptions of screening instruments, and negative psychological outcomes for patients posed barriers. (Bush et al. 1997; Boustani et al. 2005) Thus, the barriers highlighted herein may not be unique to ALS services, but instead may be common to cognitive and behavioural screening generally and lessons can be learned from other setting in overcoming these barriers in ALS services.

While the results of this study provide the first insights into screening practices and HCP attitudes in Scotland, the sample size for this study was small, and incorporated opinions from different professions working in different health boards. While this provides a diverse range of opinions, it is not possible to determine whether the opinions of one profession or health board will translate to another. Further research is required to better understand whether these results generalise to the larger HCP workforce in ALS services and to explore whether consensus can be agreed. Additionally, the interviews in this study were conducted prior to the release of the NICE guidelines, and as such, it is unclear whether these new guidelines could directly impact on service provision.

## **Conclusions**

Cognitive and behavioural screening should be an integral aspect of care services provided to patients with ALS. While clinicians in this study recognised the importance of cognitive and behavioural assessment, not all patients are being offered this service. Furthermore the use of clinical judgement rather than screening tools may provide a false estimation of patients' abilities. HCPs in this study

identified that barriers exist to cognitive and behavioural screening in the form of other members of staff, a lack of resources, and in patients' themselves and their families. When examining the barriers to screening, increasing education and training to staff, and increased psychology input may, in turn, increase HCP awareness, increase the perceived importance of screening, and increase non-specialists' confidence in the administration of standardised screening. Additionally, making screening standard to all patients, a belief held by 93% of HCPs in this study, may reduce the likelihood of causing distress to patients and their families and ensure that MND patients receive appropriate care provision and planning. While individual health boards may require different approaches to adequately implement screening programmes, a national strategy may be required to ensure consistency and equality of care provision.

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