

Support for practitioners working with people with neurodegenerative disorders

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Psychological difficulties experienced by people living with neurodegenerative disorders are often unrecognised and poorly managed. A lack of specialist services means that people may not always be seen by practitioners who are experienced in these conditions and who therefore may lack confidence when supporting these individuals. The current study has been conducted on behalf of the Faculty for the Psychology of Older People (FPOP). Practitioners working in a psychological setting who work with people with neurodegenerative disorders were surveyed to find out what type of support or training they would like to have, and with what psychological difficulties they needed this support. Data were analysed descriptively and then some exploratory hypotheses tested using a series of Spearman's rank correlation coefficients to explore the relationships between the amount of experience practitioners had and their confidence levels, as well as the support they needed. All four 'experience' items and all three 'support' items were found to have a significant positive correlation with the 'confidence' subscale. In addition, medium or large effect sizes were found in five of the correlations. Respondents reported wanting the most support with working with depression, apathy and cognitive difficulties; the most popular ways to receive support was via in-person training courses and supervision.

Some people living with NDDs experience psychological difficulties including issues relating to the complexities regarding diagnosis and testing, disease progression and the varied and distressing physical symptoms that people experience, which require comprehensive professional help. It follows therefore that addressing the disabling psychological and cognitive difficulties that many people with NDDs experience can increase quality of life (QOL), reduce physical symptoms and reduce financial spending within the healthcare system. Given this, it is surprising that there is so little provision for psychological issues in this field. For instance, it is estimated that around two-thirds of people with MS who are depressed receive no support for this depression (Mohr, Hart, Fonareva, & Tasch, 2006).

There appear to be several barriers for receiving psychological help. Firstly, the individual is unlikely to be referred for help with adjustment to the condition and psychological factors associated with quality of life (QOL), for example, and are more likely to be referred for medical treatment to deal with the physical symptoms of the condition. Secondly, it would seem that some practitioner psychologists may therefore be insufficiently equipped to support clients with NDDs who are referred for psychological assistance. A further barrier is the fact that non-physical, mental health related problems are insufficiently recognised, and in turn referred. The lack of clear guidelines, as well as this lack of experience leads to some psychologists and other clinicians having minimal knowledge of NDDs and the common issues that affect people with NDDs, and thus the confidence to support their clients effectively when they are referred into their services.

Aim of this research

The motor neurodegenerative disorders workstream within FPOP is currently seeking to urgently address this gap in support for and knowledge regarding working with this client

group. The aim of this study, therefore, was to conduct a scoping survey aimed at practitioner psychologists and other professionals who work with people with motor NDDs. The survey aimed to find out what training they have received or would like to receive in future. However, NDDs with a typically earlier age of onset will also be discussed within this paper; this is due to the similarity across many areas, such as physical and emotional problems, as well as the lack of psychological support available. The effective management of people with dementia tends to be addressed using specific memory services and thus was not included in this survey.

A number of provisional hypotheses have been made to guide the analysis of the data. These include the hypothesis that confidence in working with people with NDD would correlate with years of experience and that practitioners who felt the least able to support people with a NDD would have more training needs. **Method**

Participants

Respondents were practitioner psychologists (e.g. from the fields of clinical psychology, counselling, or clinical health psychology etc.), as well as other practitioners involved in the psychological care of people with NDDs, such as counsellors, CBT therapists, nurses, who had expressed an interest in FPOP or were FPOP members. The survey was also forwarded on to other members of the BPS, including the Division of Neuropsychology.

Design

The study was a 36 item survey of a primarily quantitative nature. There was also a short open question at the end designed to give respondents the opportunity to provide any comments regarding support or training, that they felt had not been addressed in the main body of the questionnaire. In order to test the two hypotheses, respondents were asked three

questions relating to their confidence in working with people with NDDs, as well as four questions related to their experience and three questions related to the amount of support they felt they needed in working with people with NDDs (Table 1).

Table 1

Questions in survey related to confidence, experience and support

| <i>Question Category</i> | <i>Question</i> |
|--------------------------|--|
| Confidence 1 | Do you feel you are adequately prepared to deal with the psychological difficulties experienced by people with NDDs? |
| Confidence 2 | How confident do you feel about working with people with NDDs? |
| Confidence 3 | How adequately do you feel able to support people with NDDs? |
| Experience 1 | Time in years since qualified. |
| Experience 2 | Percentage of workload relating to NDDs |
| Experience 3 | Amount of CPR relating to NDDs in last 12 months |
| Experience 4 | Amount of training received during training relating to NDDs in hours |
| Support 1 | How much additional support do you need in working with people with NDDs? |
| Support 2 | How much CPD do you feel you need in a 12 months period to assist you in working with people with NDDs? |
| Support 3 | Do you feel that the amount of CPD that you currently receive relating to NDD is satisfactory? |

The study was granted ethical approval by the Research Ethics Committee of the researchers' host institution. Data were collected between the months of October 2014 and January 2015.

Results

Sample Characteristics

A total of 185 respondents completed the survey. The majority of the sample self-identified as clinical psychologists ($n = 119$), followed by neuropsychologists ($n = 30$) and trainee psychologists ($n = 19$). The remainder were counselling psychologists ($n = 4$), assistant psychologists ($n = 3$) and clinical neuropsychologists ($n = 3$). Eleven respondents reported being in another role to those listed in the survey (other, $n = 11$). A total of 159 respondents

were qualified (85.9%), with the remainder either not qualified or currently in training. Of the qualified respondents, the mean length of time qualified was 13.4 years ($SD = 9.39$). A total of 114 of all respondents classed themselves as full time (61.6%), with the mean full time equivalent (FTE) being 0.87 ($SD = 0.2$).

Service and therapeutic modality characteristics

Respondents reported a total of 243 posts held, with places of work being reported as older adult setting ($n = 59$), neuropsychology ($n = 53$), clinical health psychology ($n = 34$), other ($n = 31$), community adult mental health ($n = 19$), learning disability ($n = 12$), memory clinic ($n = 12$), primary care adult mental health ($n = 10$), health psychology ($n = 5$), substance misuse ($n = 4$), and forensic psychology ($n = 4$).

The mean number of contact with clients was 35.4 per month ($SD = 24.2$). A total of 128 respondents had worked with people with NDDs in the last 12 months (69.2%), and this work represented 34.5% of these practitioners' caseload ($SD = 31.08$). Most respondents reported multiple avenues of referral into their service, meaning a total of 351 avenues of referral were reported, the most frequent being through medical settings (including consultants in hospitals, outpatients clinics, etc.) but excluding GPs ($n = 115$), GPs ($n = 105$), mental health services ($n = 84$), voluntary services and charities ($n = 18$), and other settings including social and legal services ($n = 12$). Some participants did not report any referrals for people with NDDs into their service ($n = 30$). Respondents reported a variety of difficulties for referrals (Table 2). The most common difficulties seen by respondents were depression ($n = 125$), anxiety ($n = 122$), memory ($n = 113$) and adjustment issues ($n = 101$). For those respondents who had worked with people with NDDs, approximately 57.3% ($SD = 35.4$) of those people were referred for psychological difficulties that were considered relating to their diagnosis, rather than unrelated issues (such as phobias or bereavement).

Table 2

Description of difficulties experienced by people with NDDs who have been referred to practitioners or their service

| | Seen by respondents in past or currently | Referred into service in last 12 months |
|---|---|--|
| Mood: anxiety | 122 | 119 |
| Mood: depression | 125 | 122 |
| Mood: stress | 74 | 62 |
| Mood: other | 11 | 23 |
| Cognitive: memory | 113 | 120 |
| Cognitive: capacity | 60 | 70 |
| Cognitive: other | 35 | 38 |
| Specific difficulties: interpersonal | 75 | 68 |
| Specific difficulties: challenging behaviour | 74 | 79 |
| Specific difficulties: apathy | 55 | 45 |
| Specific difficulties: impulse control | 54 | 46 |
| Specific difficulties: adjustment | 103 | 94 |
| Specific difficulties: other | 20 | 21 |
| None / none known | 122 | 37 |

The most common therapeutic modality used by respondents in working with NDDs was CBT ($n = 115$), followed by mindfulness ($n = 60$), systemic therapy ($n = 58$), integrative techniques ($n = 56$), acceptance and commitment therapy (ACT; $n = 45$), compassion focussed therapy (CFT; $n = 38$), motivational interviewing (MI; $n = 33$), solution focused therapy (SFT; $n = 31$), other techniques ($n = 29$), and counselling ($n = 28$). Most work carried out with people living with NDDs was individual therapeutic work ($n = 138$), followed by neuropsychological assessment ($n = 112$), family work ($n = 89$), group work ($n = 34$), consultation ($n = 7$), couple and sex therapy ($n = 4$) and other ($n = 6$).

Training and continuing professional development

Regarding the amount of training in working with people with NDDs the sample had received during their training to be qualified, the mean number of hours of those who reported receiving teaching on this subject ($n = 112$) was 21.4 hours ($SD = 50.3$). Fourteen

participants could not remember; of the remainder who were qualified, 51 reported not receiving any training ($n = 51$). Of those practitioners who have worked with people with NDDs in the past 12 months, 59 practitioners (31.9%) reported not having any continuing professional development (CPD) in NDDs in the past 12 months.

Information and research

The most popular method of obtaining extra information related to NDDs in the previous 12 months was via general internet searching ($n = 135$), followed by academic journals ($n = 127$) and websites of specific charities e.g. Parkinson's UK ($n = 127$) (Table 3).

Table 3

Resources accessed in the previous 12 months on issues relating to NDDs by respondents

| Type of resource | Number of respondents |
|--|-----------------------|
| General internet searching | 135 |
| Academic journal articles | 127 |
| Websites of specific charities / organisations | 127 |
| Leaflets of specific charities | 72 |
| Books | 71 |
| Websites of professional bodies (e.g. BPS) | 68 |
| General media | 42 |
| Magazines of professional bodies (e.g. BPS) | 30 |
| Leaflets from professional bodies (e.g. BPS) | 28 |
| None | 25 |
| Magazines by specific charities | 24 |
| Colleagues/ supervision | 10 |
| Conference/ event | 5 |
| Other | 4 |

Future support

Respondents gave information on how they would prefer to receive support or future training relating to working with people with NDDs, as well as specific difficulties for which they felt that they would like support (Tables 4 and 5).

Table 4

Order (by priority) of difficulties or types of practice related to NDDs with which practitioners would like support

| <i>Difficulty</i> | Mean | Rank |
|-------------------------|------|------|
| Depression | 4.42 | 1 |
| Apathy | 5.10 | 2 |
| Cognitive difficulties | 5.23 | 3 |
| Evidence based practice | 5.30 | 4 |
| Memory | 6.18 | 5 |
| Challenging behaviour | 6.48 | 6 |
| Work with carers | 6.61 | 7 |
| Palliative | 6.69 | 8 |
| Anxiety | 6.84 | 9 |
| Panic | 6.94 | 10 |
| Impulse control | 7.01 | 11 |
| Other (optional) | 7.19 | 12 |

1- most preferred way of receiving support; 6- least preferred way of receiving support.

Table 5

Practitioners' preferred ways to receive support relating to NDDs

| <i>Method of support</i> | Mean | Rank (by mean) |
|---------------------------|------|----------------|
| In person training course | 1.96 | 1 |
| Supervision | 2.82 | 2 |
| Online training course | 3.32 | 3 |
| Web resources | 3.70 | 4 |
| Local mentoring | 3.75 | 5 |
| Leaflets | 5.44 | 6 |

1- most preferred way of receiving support; 6- least preferred way of receiving support

Correlation analyses

To test the first hypothesis (the amount of confidence a practitioner has in working with people with NDDs will be related to the amount of experience they have), the confidence subscale was correlated with the four questions related to experience. The data were analysed using the non-parametric test Spearman's rank correlation coefficient. To test the second hypothesis (those who feel least able to support people with NDDs will want the

most training in this area), the confidence subscale was correlated with three questions related to support again using Spearman’s rank correlation coefficient. All four ‘experience’ items and all three ‘support’ items were found to have a significant positive correlation with the ‘confidence’ subscale (all $p < .001$). In addition, medium or large effect sizes were found in five of the correlations (Table 6). Given that all items were found to be statistically significant, it can be assumed that both hypotheses were supported.

Table 6

Confidence subscale as correlated with experience and amount of support required

| <i>Question</i> | Confidence Subscale |
|---|---------------------|
| Time in years since qualified | .193* |
| Percentage of workload relating to NDDs | .457* |
| Amount of CPR relating to NDDs in last 12 months | .577* |
| Amount of training received during training relating to NDDs in hours | .213* |
| How much additional support do you need in working with people with NDDs? | .414* |
| How much CPD do you feel you need in a 12 months period to assist you in working with people with NDDs? | .404* |
| Do you feel that the amount of CPD that you currently receive relating to NDD is satisfactory? | .549* |

* $p < .01$

Discussion

The present study sought to investigate what type of support practitioners working in a psychological setting would like in regards to working with people living with NDDs. Respondents reported wanting the most support with working with depression, apathy and cognitive difficulties, and the most popular ways to receive support was via in-person training courses and supervision. As expected, respondents who reported the most experience in working with people with NDDs felt the most confident when it came to working with clients in this area. A second hypothesis, that those who feel least able to support people with NDDs would require the most training in this area, was also supported via a number of correlations.

Preferred methods of support

The study found that the most popular way that practitioners would like to receive training on working with people with NDDs would be in-person training courses, followed by supervision, however this was at odds with the most common way that this information is currently accessed (i.e. using the internet, accessing academic journal articles, and using the websites of specific charities or organisations). Training courses ranked 13 out of 14 of methods currently being accessed, and a significant proportion of people who worked with NDDs had not had any CPD on this subject in the previous 12 months. One explanation for the discrepancy between desire for in-person training events and how many are currently accessed by the practitioners who took part in the study could be that courses, events and conferences that are currently organised do not match the training needs of the practitioners and thus they access information via different means.

An alternative to costly training events would be the development and accessibility of courses or programmes specifically designed for people living with NDDs. For example a CBT based course focussing on adjusting to living with MS has been developed by researchers (Moss-Morris, Dennison, Landau, Yardley, Silber & Chalder, 2013) in conjunction with the MS Society. If similar courses were adapted for use with people affected by other NDDs and rolled out in a similar way via relevant national organisations, this would reduce the need for in-person training sessions which may not be well attended

Supervision was the second most preferred way to receive support regarding NDDs, however is currently stated as being accessed 12th out of 14. This may be because those who do receive psychological supervision may not view the supervision that they receive as being specific to NDDs. An alternative explanation would be that those giving supervision in this area maybe amongst those practitioners who feel unconfident in this area and therefore their

supervision may lack specialist guidance relating to the difficulties experienced by people living with NDDs. This is especially likely given the lack of specialist services in the UK.

Future Research

A shortcoming of the study is that it does not establish any causes regarding why not enough people with NDDs access psychological help- from the findings presented within this study, it is not possible to state whether practitioners lack confidence because they do not see many people with NDDs, or whether it is because they do not receive enough training or support. Future research should seek to answer these questions, in order to better inform any future service development, so that the lack of specialist psychological support for people living with NDDs is addressed. Future research could also focus on those under-represented regional areas to identify what support, if any, is recognised by local practitioners, in order to add this information to the findings so far, particularly as respondents have identified a desire to attend training events relating to NDDs and thus identifying the ideal location of any held in future is especially important. More work should be done to identify the reasons why practitioners want in-person training but do not commonly access it.

References

Mohr, D. C., Hart, S. L., Fonareva, I., & Tasch, E. S. (2006). Treatment of depression for patients with multiple sclerosis in neurology clinics. *Multiple Sclerosis, 12*, 204-208.

doi:10.1191/135248506ms1265oa

Moss-Morris, R., Dennison, L., Landau, S., Yardley, L., Silber, E., & Chalder, T. (2013). A Randomised Controlled Trial of Cognitive Behavioural Therapy (CBT) for Adjusting to Multiple Sclerosis (the saMS Trial): Does CBT Work and for Whom Does It

Work? *Journal of Consulting and Clinical Psychology, 81*(2), 251-262.

Doi:10.1037/a0029132