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Support for practitioners working with people with neurodegenerative disorders

2013 Cohort
Lancaster University Doctorate in Clinical Psychology
What are Neurodegenerative Disorders?

- Incurable and debilitating conditions that result in progressive degeneration and death of nerve cells (neurons). Hundreds of NDDs.
- Wide range of difficulties including:
  - Movement difficulties – MND, Parkinson’s, Huntington’s
  - Fatigue- e.g. MS and Parkinson’s
  - Speech and swallowing problems – MND and MS
  - Cognitive difficulties- Parkinson’s, Huntington’s, MS
Psychological difficulties

- Anxiety, depression, adjustment difficulties, memory, apathy etc.
- Many reasons e.g.
- Lengthy and stressful diagnosis
- Adjustment to complicated medication regimes
- Side-effects from medication
- Unpredictability of future
- Biological – association between lesions in brain and depression
Management of Neurodegenerative Disorders

- Focus has been on managing the physical aspect of NDDs through drug therapy. However...
- Reducing depression has been found to improve quality of life (QOL) and decrease risk of suicidal ideation
- Level of psychological adjustment has a greater impact on health related QOL than the objective degree of severity of PD
- Stress in people with MS has been found to exacerbate disease progression
Management of psychological difficulties

• Anxiety and depression commonly managed through pharmacological interventions
• Disadvantages: side effects such as fatigue, insomnia and constipation. Also been linked to heart problems
• People who are experiencing depression can find it difficult to adhere to drug treatment
• People don’t want to take more drugs
Psychological support

- Practitioners in psychological settings may not have many referrals for people with NDDs into their service - due to lack of specialist services, rarity of some conditions and emphasis on drug treatments.
- They may lack experience and confidence in assisting people living with NDDs.
Aim of study

• To survey practitioners employed in a psychological setting who work with people with neurodegenerative disorders (NDDs)
• How much training in this area had they received?
• How confident do practitioners feel when working with people with NDDs?
• What type of support or training do they want?
• Confidence levels will be linked to experience
• Those who feel least able to support will want the most training
Design

• 36 item survey – mostly mix of Likert and categorical data
• Delivered via email using email distribution lists to potential participants
• Online – Qualtrics – minimised missing data
• Easier to analyse, and more accurate
• Collected data between October and January
Results

185 respondents – 85.9% qualified
Mean time qualified – 13.4 years
114 (61.6%) full time
Most common psychological difficulties seen in people with NDDs

Referred into service in last 12 months
Training and continuing professional development

- Mean number of hours of those who reported receiving teaching on NDDs during training was 21.4 hours ($SD = 50.3$)
- 51 reported not receiving any teaching
- 59 practitioners (31.9%) of those who worked with people with NDDs in the last 12 months reported not having any CPD on NDDs in the past 12 months
How do practitioners access support?

- General internet searching
- Academic journal articles
- Websites of specific charities
- Leaflets of specific charities
- Websites of professional bodies
- Magazines of professional bodies
- Leaflets from professional bodies
- General media
- Magazines by specific charities
- None
- Colleagues / supervision
- Conference / event
- Other
How would practitioners like to receive support?

• Practitioners prioritised in person training courses, followed by supervision as the most preferable ways to receive support.

• This is in contrast to how frequently they are accessed now - these ranked amongst the lowest.
Possible Explanations

• Research on intention-behaviour consistency has found that the longer the time between measuring intention and behaviour, the less predictable performing that behaviour will be.
• Events and conferences that are currently organised may not match the training needs of the practitioners and thus they access information via different means.
• May not be the budget for practitioners to access training courses
• Services may not release practitioners for training due to work load and service demands
• May receive supervision from supervisors who similarly lacked confidence in this area
Testing hypotheses

• Three items related to confidence were classed as a subscale
• Cronbach’s alpha (α) was .922 – high internal consistency
• Correlated with three items relating to amount of support and four relating to experience
Results

• All four ‘experience’ items and all three ‘support’ items were found to have a significant positive correlation with the ‘confidence’ subscale ($p<.001$).

• Medium or large effect sizes were found in five of the correlations

• The least confident practitioners want the most support

• Those who have the least experience would like the most training
Conclusions

• Some practitioners who have worked with NDDs have not had any teaching or training in this area

• Practitioners are not accessing support via their preferred routes

• Some practitioners lack confidence and experience in working with NDDs and report needing a lot of assistance
Limitations of study

- Does not establish cause- cannot say whether practitioners lack confidence because they do not see many people with NDDS, or because they do not receive enough training/support.
- No volunteers participated in research- valuable sector of practitioners
- Some geographical areas under represented
- Self- report
Dissemination

• Will be submitted to relevant journal for publication
• Submitted for publication in newsletter of organisation that commissioned survey
• Fed back to members of Parkinson’s UK in February 2015
Thank you!

Questions?