



Needs and experiences of services by individuals with long-term conditions and their carers

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Research team

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Objective

- To carry out a survey of the health needs and experiences of services of individuals with progressive conditions (motor neurone disease, multiple sclerosis, Parkinson's disease) and of their carers
- To assess perceived impact of the NSF for long-term conditions (2005)

Study design

- Literature reviews to update NSF regarding services that might be experienced by respondents
- Qualitative interviews with individuals with one of the conditions and carers
- Development and piloting of a survey for individuals with one of conditions and their carers
- Main survey

Focus of study

- As far as possible on the 11 Quality requirements of the NSF as experienced by respondents

eg

- QR1 Patient-centred care
 - QR5 Community rehabilitation and support
- etc

Research process

- Research Advisory Group (individuals with one of the conditions and carers)
- Met with research team at various points during study and also interacted by phone and email to comment on make recommendations about content of survey

Research process

- Feedback and discussion with (*then*) Health Care Commission and Commission for Social Care Inspection who were planning a parallel, complementary survey
- Main questionnaire went through 11 drafts before piloting
- Then tested on volunteers
- Then piloted
- Modified again prior to main survey

Pilot survey

- Conducted through memberships of MND Association, MS Society and PD Society
- Societies sent questionnaire packs; distributed to members; questionnaires returned in stamped and addressed envelopes to Oxford
- Pack invited individuals with condition to identify and pass on separate questionnaire to their main carer

Pilot survey

- Health status measures (general, SF-36 + condition-specific measure)
- Questionnaire regarding experiences of services
- Similar questionnaire to carers (health status + experience of services)
- 297 (61%) individuals with conditions responded
- 238 (49%) carers responded

Developing main survey: lessons from pilot

- Respondents to pilot asked to comment on questionnaire
- Experience of services section reduced from 75 to 49 items in main survey
- Fewer questions on equipment – difficult to examine via survey
- Shorter generic health status measure – SF36 becomes SF12

Main survey

- Also to be conducted through memberships of three societies
- Involved 35 branches of MSS & 27 branches of PDS
- National membership of MNDA (700 contacted and responding via mail and 190 preferring contact and response via electronic on-line survey)
- Goal to recruit approximately similar numbers across 9 different regions of England
- Survey conducted end of 2008

Responses to main survey

- 2563 individuals with one of the conditions (53% of packs sent out) responded
 - 505 MND
 - 1157 MS
 - 901 PD

Main survey

- 54% female (MS 75% female)

- Mean age 63

MND	67
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MS	55
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PD	71
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2% Black and minority ethnic groups

Main survey: health-related quality of life

- SF-12 Physical component

MND	28.9
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MS	30.8
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PD	31.7
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- SF-12 Mental component

MND	41.8
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MS	42.2
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PD	41.2
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Main survey: receiving a diagnosis

- 18% of sample reported 2 or more years from first seeing GP to receiving a definite diagnosis
- 32% would have liked but did not receive a follow-up appointment with specialist after receiving diagnosis (43% amongst those with MS)

Main survey: receiving a diagnosis

- 42% were given all the information they wanted at the time of diagnosis (30% of individuals with MS)

(41% had not been given and 17% not sure whether been given information they wanted)

Main survey: current medication

- 95% given enough information about how and when to take medication

but

- 39% (only to some extent or not at all) felt that their medication was adequately reviewed

Main survey: treatment by professionals

- 82% felt that specialists in hospital treated them with dignity and respect
- 81% felt that their GP treated them with dignity and respect

Main survey: care planning and coordination of care

- 22% thought they had received a care plan
- 36% reported a single professional who coordinated their care
- 24% felt different health and social services worked well together in planning of care

Main survey: shared decision-making

- 40% felt as much involved in decision-making about their care as they wanted (27% of individuals with MS)
- 40% felt that their wishes and preferences were fully taken into account in the planning of their care (31% of individuals with MS)

Main survey: hospitalisation unrelated to neurological problem

- 500 respondents (20% of the sample) had been in hospital in last year for a problem unrelated to neurological condition
- 54% of this group felt that their needs in relation to their neurological condition were not at all or only to some extent met while in hospital

Main survey: help with housework or personal care

■ Housework

-most did not need help from formal services

-11% of sample did not receive help and wanted it

□ Personal care

-most did not need help from services

-4% of sample did not receive help and wanted it

Main survey: financial help

- 75% reported receiving some financial support from services
- 6% reported needing financial support but not receiving it
- Of those having modifications to home because of condition, 12% needed financial help that they did not receive

Experience with services and health status

- Respondents who reported more problems with services also had significantly poorer health related quality of life
 - Consistent across conditions
 - Consistent across most aspects of services
 - Consistent across generic and condition-specific measures of health-related quality of life

Carers

- 1910 carers responded
- 58% female (but carers for MS 63% male)
- Mean age = 63
- 60% had been carer for more than 5 years (17% among carers fro MND)

Carers: health-related quality of life

■ SF-12 Physical component

MND	48.0
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MS	48.8
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PD	46.2
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□ SF-12 Mental component

MND	43.0
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MS	46.1
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PD	44.0
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Carers: time caring

28% of all carers spent more than 70 hours a week in caring role

MND 37% more than 70 hours a week

MS 24% more than 70 hours a week

Carers: awareness on part of services

- 34% felt GP did not know that they were a carer (or were unsure whether knew)
- 21% had had a carer assessment
- 44% had discussed amount of caring they did with a professional

Carers: Receipt of help from services

- 20% did not receive all the help they needed in relation to **personal caring tasks**
- 24% did not receive all they help they needed with **household tasks**
- 25% did not receive all the help they needed with **physical caring tasks**

Carers: information and training

- 22% would have liked but had not received training in relation to caring tasks
- 56% did not think that information for carers was readily available
- 1% had participated in expert carer programme

Possible weaknesses of survey

- Sampling strategy
- Response rate
- Response biases
- Selectivity of topics
- Limited capacity to explore issues in depth

Lessons from the survey

- Many indications that individuals with progressive neurological conditions access services that are caring and provide resources that help promote quality of life and independence consistent with the goals of the NSF

Lessons from the survey

- Substantial challenges may remain - in relation to individuals with conditions:
 - Follow-up appointments after diagnosis
 - Regular medication review
 - Involvement in decisions about care
 - Care plans

Lessons from the survey

- Substantial challenges may remain - in relation to carers:
 - Awareness and assessment of carers' needs
 - Providing information for carers
 - Involvement of carers in decisions about cared for person's services
 - Accessing help with caring tasks

Lessons from the survey

- There is a broader and more general problem of how to assess quality of services and quality of life of individuals with long term progressive conditions and their carers to ensure progress

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