Situation Review of Care Deficits and Management Programs for Multiple Sclerosis in Germany

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Background:

- Provision of chronic care in Germany is regarded as deficient
- Introduction of care management programs to the statutory health insurance (SHI) since the beginning of the 1990s to improve quality of care and to cut costs of chronic care
- 120,000 to 180,000 multiple sclerosis (MS) sufferers in Germany
- MS causes a significant economic burden: about one out of three patients is affected by early retirement in consequence of MS
- Due to its broad range of neurologic symptoms MS is characterized by a strong need for interdisciplinary and cross-sectoral care programs

Objectives:

- To identify existing deficits in MS care
- To analyze whether care management programs for MS exist and how they are designed
Methods

In order to identify existing care deficits:

- Systematic literature review (Embase and Scopus)
- Complementary internet research
- Expert interviews with representatives from associations of healthcare professionals, SHI funds, patient organizations and policy decision makers

In order to identify existing care management programs:

- Questionnaire survey for the 40 largest SHI funds in Germany (according to the number of insured); coverage rate of SHI insured > 90%
- Development of a standardized questionnaire, content:
  - Existence of care management programs for MS
  - Reasons for and against the implementation of care management programs for MS
  - Description of program content
- Initial date of distribution: Nov. 2012, written reminder: Jan. 2013
- Verification and finalization via phone call: Feb. to June 2013
Results I

Structural Deficits:
- Insufficient coordination between different sectors and between different (medical) disciplines involved in MS care
- Insufficient care structures, e.g. no comprehensive provision of programs for coping with MS
- Insufficient information about medical specialists experienced in the diagnosis and therapy of MS-symptoms

Deficits in the diagnostic area:
- On average 3.5 years pass by until the diagnosis MS is made, although new diagnostic tests and criteria allow a diagnosis within a few months after the onset of the disease

Deficits in the area of therapy:
- Many patients (17-34%) still do not get basic disease modifying treatment (DMT) although they are suitable for DMT
- Dropout rate for basic DMT is 35% in the first year; experience with well supervised patient groups shows that even for 2-year periods significant lower rates are possible
- Insufficient use of symptomatic therapy: especially fatigue (79%), cognitive disorders (83%) and ataxia (62%) remain untreated
Results II

Care management programs:
- Response rate of the questionnaire: 67.5% (27/40 SHIs)
- Coverage rate of SHI insured: approx. 77%

6 care management programs for MS:
- Mostly contracts according to §§140a et seq. Social Code Book V (SGB V), but also §73a, §73b and 73c SGB V

Reasons for care management programs:
- High demand for care, counseling and coordination
- High cost of disease
- Conclusive concepts presented by health care providers

Reasons against care management programs:
- Other priorities
- Lack of convincing concepts
Discussion and Conclusion

- The review revealed several deficits in MS care; they are of structural nature as well as in the diagnostic and therapeutic area.
- SHI funds recognize the necessity to provide care management programs for MS, yet many set other priorities.
- Established care management programs often address many of the identified care deficits (e.g. guideline-oriented treatment; coordination of interdisciplinary treatments, rational pharmacotherapy).
- Frequent reason for the absence of MS care management programs: other priorities and the lack of convincing and conclusive concepts.