

Thesis summary

Integrated care for intellectual disability and multiple sclerosis

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The results presented in this review are based on my thesis presented at the University of Groningen on 22 March 2006. The main aim of the project was to study the relevance and effects on integrated care on patients with costly, low incidence chronic disorders.

The research was based on two independent studies. Study one focused on intellectual disability (ID) and included a literature review and a pilot study. Whereas the literature review concentrated on the potential value of integrated care for people with ID, the focus of the pilot study was to determine the actual value of integrated care for this population. For this purpose, an experts' network consisting of a variety of disciplines including medical specialists, special education-ists and paramedics, was designed, available for people with ID living outside an institution. By implementing this network it was expected that the delivery of integrated care resulted in higher quality of care, adequate treatment of health care problems, detection of unrecognized and untreated health problems and appropriate use of health care services. The activities of the experts' network have been monitored for eight months. Within that time span only six patients were referred to the experts' network. Consequently, the treatment of only one patient was completed by the experts' network.

Study two concentrated on multiple sclerosis (MS) and included a literature review, a pilot study and an experiment with a pretest–posttest comparison group design. The literature review also was directed towards exploring the possible value of integrated care for people with MS. While the aim of the pilot study was to assess the applicability and the preliminary effects of a Transmural Care Model Multiple Sclerosis (TCMMS), the aim of the second effect study was above all to identify the effects of the structural implementation of the slightly adjusted TCMMS.

The TCMMS was developed in order to stimulate cooperation between health care professionals working in different settings. The main aim of the TCMMS was to reduce the number of health care needs of people with MS. In the pilot study and in the following study, respectively 40 and 77 people with MS were monitored by means of a questionnaire prior to and several months after implementation of the TCMMS. In the second study, 96 people with MS received care-as-usual (comparison group).

The results of Study one (ID) are too limited to draw any conclusion and to make clear whether integrated care contributes to a higher quality of care.

The results of Study two (MS) reveal that in the pilot study the number of health care needs of people with MS was reduced from 57 to 15. However, no differences were found in quality of life, continuity of care and burden of disease. Equal to the results of the pilot study, no improvement of continuity of care could be demonstrated after the structural implementation of the TCMMS. A reduction of health care needs, quality of life and the use of health care professionals hardly changed by delivering integrated care.

On the basis of the studies presented in this thesis a common agreed statement regarding the effect of integrated care for people with costly, low incidence chronic disorders cannot be addressed. Nevertheless, the results do not automatically imply that integrated care has no or limited value for people with ID and MS. It is expected that health care will increasingly be provided according to the integrated care principles. Consequently, integrated care experiments for these populations are needed in order to further refine the integrated care approach and to highlight areas for improvements.

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