Integrated care for intellectual disability and multiple sclerosis
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Chapter 8
Discussion

Introduction

The aim of this thesis has been to explore the relevance and effects of integrated care on patients with costly, low incidence chronic disorders such as intellectual disability (ID) and multiple sclerosis (MS). In order to reach this objective, the following research questions were formulated:

- what is the potential value of integrated care for people with costly, low incidence chronic disorders (in this case ID and MS)?
- compared to usual care, does integrated care result in a higher continuity of care, a reduction of health care needs, a higher quality of life and adequate use of health care professionals?

In the next section the main findings of this thesis will be presented and discussed according to the research questions. After presenting the main findings, the methodological considerations will be discussed. Subsequently, a discussion of the main findings will be presented. Finally, the last part of this chapter pursues the theme integrated care in perspective.

Main findings

Based on the results of the several studies presented in this thesis, the answers on the research questions are discussed per disorder.

Research question 1: what is the potential value of integrated care for people with costly, low incidence chronic disorders (in this case ID and MS)?

Intellectual disability
To explore the potential value of integrated care for people with ID, a literature search is conducted to identify relevant literature on this particular topic. In reviewing the literature it appears that – in theory – integrated care offers potentials for eliminating the fragmentation and discontinuity in health care of community living people with ID. In the care for people with ID, many problems such as a high amount of unmet needs and the failing of health professionals to identify and treat certain medical conditions, may be attributed to the delivery of fragmented care. Cooperation between GPs and other health care professionals may therefore be particularly important to correct the inadequacies in primary health care for this vulnerable population. In this respect, an integrated care approach may have advantages. However, literature on the effects of integrated care for people with ID is
lacking. As a result, the potential value of integrated care for people with ID – based on the existing literature – is still unknown.

Multiple Sclerosis
In order to discover the potential value of integrated care for people with MS, also a literature search is performed. Literature shows that health care for MS patients leaves room for improvement. The presence of unmet needs in MS patients, the major impact from MS on quality of life and the high costs associated with the disease are important driving forces for changing the provision of health care. Since integrated care aims to deliver continuous and effective health care, it possibly may be a way to improve care for MS patients. Literature about the possible advantages of integrated care for MS patients, just as it is in case of people with ID, is largely missing. The results of the few presented studies did reveal a higher level of satisfaction, a saving in health care cost and an improvement of some health dimensions including bodily pain, general health, social functioning and role-emotional, the latter representing the patient's perception of limitations they experience in their daily routine attributed to emotional problems. However, since the quality of the evaluations is arguable, it is not possible to draw strong conclusions about the actual value of integrated care for MS patients.

Research question 2: compared to usual care, does integrated care result in higher continuity of care, a reduction of health care needs, a higher quality of life and adequate use of health care professionals?

Intellectual Disability
An experts’ network was established in order to assess the effects of integrated care on the continuity of care, the amount of health care needs and use of health care professionals. Contrary to the MS study, quality of life was not measured in people with ID since the study on people with ID primarily focused on the other outcomes. In addition, we decided that if an instrument measuring quality of life should be administered, the overall questionnaire in order to collect data among primary carers of people with ID would be too extensive and would take too much time for the primary carers to fill out.

The referrals to and the results of treatment by the experts’ network have been monitored for eight months. Within that time span only six patients were referred to the experts’ network. Unfortunately, due to the small sample size we were not able to measure the effect of integrated care on the outcomes. A number of reasons have been attributed to the low referral rate and it is unlikely that the referral rate is an accurate representation of the actual number of people with ID who are in need of specialist care. Taking this into account, the establishment and the development of the experts’ network – which implies a joint effort in optimizing the care for people with ID – can be seen as an ongoing process.
However, more efforts need to be pursued to obtain full development of the experts’ network.

*Multiple Sclerosis*

In case of MS the effects of integrated care on the continuity of care, the amount of health care needs and the use of health care services was assessed by delivering care on the basis of a Transmural Care Model Multiple Sclerosis (TCMMS). During the pilot study (chapter 6) no improvement in continuity of care after the implementation of the TCMMS could be demonstrated. MS patients were already rather positive about the continuity of care before the implementation of the TCMMS. The results of the second study (chapter 7) demonstrated as well that MS patients in both the study group and the comparison group were already satisfied at baseline with the continuity of the care delivered. The positive judgment mainly concerned the cooperation between health care professionals and the equilibrium between health care needs and the supply of health care services. MS patients were less content with the continuity of care in case of transition to or replacement by another health care professional. However, neither this aspect nor other aspects of continuity of care did improve after implementation of the adjusted TCMMS. Health related quality of life in MS-patients as well was – in both the pilot and the second study – not evidently improved by delivering an alternative form of integrated care.

Although no effects could be demonstrated regarding continuity of care and quality of life, effects for the amount of health care needs and the use of health care professionals by MS patients could be confirmed. After delivery of care on the basis of the TCMMS, the expressed needs of MS patients declined from 57 (before implementation) to 19 at the end of the study period. These 19 health care needs were partly newly defined needs and partly needs that could not be met due to the unsolvable nature of the underlying problem. The second study (chapter 7) shows that – despite the large number of existing health care needs in the field of motion, movement, personal care, pattern of urination and sexuality – only limited reduction of the health care needs occurred during the provision of integrated care. A reduction of health care needs was only reached when it came to personal care, defecation and vision.

By providing care on the basis of an alternative form of integrated care, both MS patients of the pilot study and patients of the effect study did consult the nurse specialist more frequently. Besides an increase in the use of a rehabilitation team during the pilot study, the use of other health care professionals did not change by the delivery of integrated care.
Methodological shortcomings

Because of dissimilarities in the design and research sample of the two studies, also the methodological shortcomings are separately discussed per disorder.

**Intellectual disability**

As mentioned before, the small sample size of the study provided a limited dataset. Consequently, an estimation of the intervention effect could not be presented. In chapter 4 several reasons are presented with respect to the inclusion of only a few respondents. The most plausible explanation of only a few referrals to the experts’ network may be the fact that GPs were convinced that they already provided adequate care. When a person with ID consults a GP for a certain health care problem, the GP generally is competent enough to diagnose and treat the patient adequately. In some cases however, an area of health care may be unrecognized, neglected or overlooked, for example when the individual is assumed to be under care of another health care professional or when clinical signs are less obvious. Health screening and health promotion for people with ID in general practice in particular have been demonstrated to occur less frequently than in the general population. As a result certain health problems commonly remain unrecognized or poorly managed.¹ As the main providers of primary health care for people with ID, GPs need to be acquainted with the specific health problems of people with ID in order to be able to identify those.² When unfamiliar with the specific health problems, GPs will be unable to recognise or detect certain existing, potential or latent health problems and will not feel the need to refer the patient for example to a specialized physician for people with ID (AVG).

Another less plausible explanation is the increased experience of GPs due to the ongoing community integration of people with ID since the nineties. As a result GPs may feel accustomed to this heterogeneous patient population with its complex health care needs and – in the course of time – have gradually gained experience necessary to deliver high-quality medical care. Also the unfamiliarity of the GP with the rather new specialism AVG may have influenced the extent to which GPs referred their ID patients to the experts’ network.

**Multiple Sclerosis**

The first methodological shortcoming is related to the representativeness and comparability of the population under study and the comparison group involved. Since the demographic data of respondents was limited, it was not possible to control for type and stage of disease and relapses experienced. The lack of certain demographic data may have resulted in potential confounders because in this study this tendency may mask an effect that does exist.³ The recruitment procedure of both groups was different as well. The study group proved to comprise mainly MS patients with complex health care needs whereas the comparison group comprised a more representative sample. As a result, the comparability of both groups is restricted. Another concern could be the selective loss of respondents:
due to the absence of information about decliners and drop-outs it is not clear how self-selected the two groups were. This also may have distorted the measure of effect (non-response bias).

The second methodological issue concerns the study design. The study concerns a quasi-experimental design in which random assignment of the participants is not performed. Randomization was not feasible since the intervention – in this case the TCMMS – was targeted at the meso level in health care, in this case at health care professionals. As a result patients could not be randomly assigned to an experimental or a control group. Consequently, the groups were probably not equivalent and so there is a reasonable chance that the results obtained can be interpreted alternatively. For this reason, firm conclusions cannot be drawn.

The third methodological limitation is represented by the duration of the study. For practical reasons the study period was limited to ten months. Improvement of health outcome within this limited time frame may prove difficult. Conversely, the variability of MS in individual patients over time, makes it hard to monitor and judge long term effects of interventions.

The final methodological shortcoming pertains to the questionnaires used. Of the instruments administered only one (RAND-36) was psychometrically evaluated; the internal consistency of the RAND-36 was satisfactory. However, the validity and reliability of the other questionnaires, i.e. health care use, health status, health perception, health care needs and continuity of care was rather low or not evaluated at all. Therefore, the results obtained should be interpreted with caution.

**Discussion of the main findings**

Literature suggests that optimal collaboration with and coordination between health care professionals in the delivery of integrated care have become essential requirements for the provision of high-quality care. Although in this thesis it was only partially possible to confirm justification of this assumption, this does not necessarily imply that integrated care has no or only limited value for people with ID and MS. The fact that the integrated care initiatives presented in this thesis did not have the expected effect may have several causes.

A first explanation may be an improvement of health care shortly after the general introduction of integrated care initiatives. After the actual implementation and evaluation of the initiatives described in this thesis, no additional effect could be demonstrated. Since the introduction of integrated care in the Netherlands, several developments occurred and a number of initiatives were arranged in order to optimize medical care for, among others, people with ID and MS. Regarding people with ID living outside an institution, the introduction of multidisciplinary teams for certain sub-populations such as persons with Down Syndrome or persons with visual handicaps and the introduction and availability of a physician specialized in the care of people with ID were the two most notable
developments. The specialized physician (AVG) acting as a case manager is experienced in working with a collaborative team and, above all, has knowledge and skills of working with people with ID and the ability to relate and interpret the symptoms of the patient. The AVG serves as an overseer and director of a patient’s care ensuring that efforts of the health care workers involved are integrated and co-ordinated. With the arrival of the AVG, the first step in the direction of integrated care was made.

Also in case of MS the time factor is expected to play a role in the disappointing effects of the integrated care initiative, the Transmural Care Model Multiple Sclerosis (TCMMS). Whereas the results of the pilot study did present a substantial reduction of health care needs, the second study in MS patients demonstrated only few limited benefits for MS patients. With reference to the implementation of the adjusted TCMMS, most elements of the protocol, such as case management and co-operation between health care professionals, may have had already full attention in hospitals in the Netherlands. As a consequence of the increase of integrated care initiatives, the opportunity to reveal additional effects based on other, new integrated care initiatives may therefore be limited.

Besides the time factor, the comprehensiveness of the intervention may also have played a role in the disappointing effects. As stated in Chapter 1, integrated care comprises several components, namely coordination of care, organisational structuring, specially assigned staff, protocol use, self-management support and patient education. As stated in literature chronically ill do not often benefit from clinical and behavioural interventions, among other things mainly because the interventions are not comprehensive. Interventions that result in positive changes tend to be complex and involve four areas: activities directed at changing clinician behaviour, changes to the organisation of practice, information systems enhancements, and educational or supportive patient programmes. The most successful interventions addressed all four areas at the same time. No specific intervention, if used alone, led to major improvements in the quality of care for the chronically ill people. Especially patient educational and supportive interventions are crucial in order to achieve improved patient outcomes. Implementation of both initiatives for people with ID and MS is mainly directed to the second area, i.e. changes to the organisation of practice, and therefore should be regarded as only one step in the improvement of care.

A third explanation why results remained forthcoming may be the fact that an extensive assessment of care-as-usual in both people with ID and MS was lacking. Although the voice of all those concerned has lead to the development of the integrated care initiatives, scientific evaluation of care-as-usual was mainly missing. However, a thorough update of care-as-usual is desirable to determine the actions necessary to be taken in order to improve care. Assessments have to be made to evaluate if care-as-usual for persons with ID and MS differs from the optimal situation and if so, what the impeding and facilitating factors are in order to reach this optimal situation. If care-as-usual is accessible and provided at an adequate level, of course it is not obvious to change the provision of health
care. Patients as well as health care professionals and policy makers have to acknowledge the necessity for changing the provision of health care.8

Integrated care in perspective

It is expected that in the nearby future health care will increasingly be provided according to the integrated care principles and that the circumstances for delivering integrated care will improve. Reasons for these expectations are trends in policy, demographic and epidemiological trends and increasing patient empowerment.9

Trends in policy

Over the past decades the Dutch government is increasingly trying to improve quality of health care while at the same time keeping health care expenditures within limits. As a result, since the eighties several committees in the Netherlands dealt with questions about health care planning and cost containment of health care expenditures, respectively the Dekker committee (1987), the Dunning committee (1991), the Biesheuvel committee (1994) and the Welschen committee (1994).10-13 Considering the activities of the committees, particularly in the advise of the Biesheuvel committee, there was considerable emphasis on streamlining the provision of health care by means of a coherent care delivery system in which the separation between the care and the cure sector had to be replaced by a care continuum. Despite the fact that these recommendations date from 1994, the majority of the present health care reforms in the Netherlands is still based on the advice of the Biesheuvel committee.

Demographic and epidemiological trends

Worldwide, life expectancies are increasing and populations are ageing. Over the last century, life expectancies have increased by 30 to 40 years in developed countries. This is partly due to advances in medical science and technology, but also because of successful public health and development efforts during the past 100 years.14 As people age, clinicians are increasingly confronted with diseases and impairments and with the management challenge of the overall burden of morbidity in their patients.

Due to advances in medicine and technology, the life expectancy of people with ID is also increasing. As a result the prevalence of ID is rising, especially when it comes to individuals with ID over 50 years old. For the same reasons, the prevalence of MS will increase as well. One consequence of these changes in demographics is an additional increase in the incidence and prevalence of chronic health problems. With reference to ID an increasing number of older patients will develop age related co-morbidity, including cardiovascular, musculoskeletal and respiratory conditions, and sensory impairments.15 Comorbid conditions in people with MS, among other things, include urinary tract infections and pneumonia.16 Since patients with chronic conditions require treatment, health promotion and rehabilitation services in multiple settings over a period of time, there is a
growing need for coordination of services, cooperation of service providers and involvement of patients, for example by means of providing integrated care.

With reference to the populations in this thesis, most problems are expected for the ageing population with ID. Older adults, especially with a mild intellectual disability – those who live on their own – are often marginalized and not provided with minimal support. Rehabilitative services, vocational opportunities and quality old age services are not provided or even not available. Management of comorbid disorders, resulting in an improvement of health care, can be made through a variety of strategies, many consisting of a closer liaison between existing services. A closer liaison means maximising communication and cooperation with all those involved and ensuring adequate exchange of information, which make an integrated care approach inevitable.

Patient empowerment
Nowadays, there are social and political trends towards encouraging patients as active agents in managing their disorder, the so-called patient empowerment. Patient empowerment is defined as the enhanced ability of patients to actively understand and influence their health status. Because only patients know about their experience of illness, social circumstances, habits and behaviour, attitudes to risk, values, and preferences, not only the knowledge of the doctor but also the knowledge of the patient is needed to manage illness successfully. In addition, through the availability of the internet and comparable resources patients and carers are better informed, more self-confident and emancipated, acknowledging their rights and demanding high quality services. In the nearby future it may be expected that the provision of primary health care only takes place according to the principles of integrated care, since the patient or the informal carer wants a well informed care network of which all its members are familiar with the most recent state of the art. This holds true even more in situations in which the individual lives on his own, most likely in rather restricted circumstances as a result of intellectual disability or MS. These living conditions will not be a sole reason for admission to an institution or a hospital when healthcare is provided as it should, i.e. in an integrated approach in which case-management and coordination throughout the day are crucial elements. In order to meet the consequences of the ongoing patient empowerment the overall access to and in particular the continuity of services has to be improved. For this purpose, health care services have to take over more responsibility in providing better management, health promotion services and comprehensive rehabilitation.

Conclusion
As stated in chapter 1 of this thesis, diabetes mellitus and asthma are the classic examples of conditions suitable for integrated care. On the other hand, integrated care programmes for less frequently occurring disorders like ID or MS – and as a consequence evidence supporting the effectiveness of these programmes – is mainly lacking. However, on the basis of the demographic and epidemiological trends and the changing expectations of the
patients it is expected that health care will increasingly be provided according to the integrated care principles. Consequently, integrated care experiments for these populations – including detailed and well-considered evaluations – are needed in order to further refine the integrated care approach, to establish how and why integrated care is or is not working, and to highlight areas for improvement. Subsequently, the results of the evaluations can be used to offer patients the best possible treatment, care and support.
References


