Integrated care for intellectual disability and multiple sclerosis
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Chapter 1

Introduction

Background

Continuity of care is an important element of the delivery and organization of health care. Especially with reference to chronically ill patients it is an essential aspect of health care delivery since these patients are seen by an array of providers in a wide variety of organizations and places. Continuity of care can be seen as the delivery of services by different health care providers in a coherent, logical, and timely manner and is often referred to as a continuum of care.\(^1\)

Since the adoption of the Structuumnota Gezondheidszorg\(^2\) (Policy paper Structuring health care) in the Netherlands in 1974, concerns are raising about continuity of care. From that time the general practitioner (GP) and primary health care centres are pushed forward with a gatekeeper role in prescribing drugs and referring patients to hospital and specialist care. The objective of this health care reform was to reduce the use of specialist care and, with that, to control the increasing health care costs. About ten years after the reorganization of health care, several questions raised about the efficiency of the strict separation between primary care and specialist care and the effects on quality of care, especially for the chronically ill. As a result of the compartmentalization of health care, the responsibility among the various health care professionals remained unclear because professionals restricted themselves to their own area of competence. Consequently, patients as well as health care professionals experienced a lack of continuity of care, caused by this deficient coordination between primary and specialist care. In order to deal with the consequences of service gaps or overlaps due to separation between primary care and specialist care, time and resources were wasted. Also the expected positive effect of the reform on cost containment remained forthcoming. The Dutch pattern of health care expenditures stayed in line with other Western European countries even though the access to services in the second-line medical care in other countries was easier.\(^3\) Not surprisingly, this development was unwanted.

Nowadays, especially continuity of care is of great importance, since the ageing population often suffering from multiple and complex health problems is considerably growing. Also the population having a chronic illness still increases, among other things as a result of advances in medicine that have enabled people with chronic illnesses to live longer.\(^4\) Both health care providers and policy makers more and more faced that they had to work in multidisciplinary teams in order to deliver adequate care.\(^5\) They increasingly became aware of the usefulness of the insight of different bodies of knowledge, and a wider range of skills in order to deliver the required services.\(^6\) By bridging the gap between different healthcare providers, the efficiency, quality and effectiveness of health care could
be improved. Also the advise of the Commission Biesheuvel (1994) – who was ordered to advise the government about the modernization of curative medicine – was mainly directed towards the need to come to a coherent working continuum of care. For this purpose, partition between the cure and the care sector had to be broke down in order to facilitate cooperation between health care professionals.\(^5\)

The negative results of the reform and the new insights into the delivery of adequate care gave occasion to experiment with other forms of health care delivery; among them integrated care. Integrated care is an approach that refers to a coherent and coordinated set of services which are planned, managed and delivered to individual service users across a range of organizations and by a range of cooperating professionals and informal carers.\(^6\) The concept of integrated care, the relation with other concepts and research on integrated care will be further discussed in the continuation of this chapter.

### Integrated care: definition, related concepts and research

#### Definition of integrated care

Integrated care emerged in the United States in the 1990s and is defined as ‘inter-sectoral cooperation (coordination/networking) between care providers from both the health (medical) and social care sector in order to deliver seamless/continuous care to people with multiple needs, as a remedy to fragmentation and discontinuity’. It is required when the services of separate agencies and individual professionals do not cover all the demands of the multiple problem service users.\(^7\) Although uniform features of integrated care are lacking, the definition provides some key direction about the components of integrated care.\(^8\) The following elements are described in the literature:

1. **Coordination of care.**\(^8-10\) Coordination of care is an important component of integrated care to achieving quality health care outcomes.\(^11\) It is defined by Donabedian as the ‘process by which the elements and relationships of medical care during any one sequence of care are fitted together in an overall design’.\(^12\)

2. **Organisational structuring.**\(^8-10,13\) Examples are multidisciplinary teams, tailor-made care and agreements on collaboration. It is essential that professionals have mutual confidence, that they are aware of the expertise of other health care professionals and that they understand the perspectives of other professionals’ approach to patients.

3. **Specially assigned staff.**\(^8,9,13\) In order to deliver integrated care, a sufficient number of well-trained professionals with specific expertise in integrated care is necessary, in particular the case manager. The case manager has to collaborate, provide support, and ensure appropriate care throughout the continuum. Therefore the case manager has to be a professional who is experienced in working with a collaborative team. The case manager has to serve as an overseer and director of a patient’s care ensuring that efforts of the health care workers involved are integrated and coordinated.

4. **Use of protocols.**\(^8,9,13\) Protocols are standardised, written guidelines for coordination between professionals in general or for the transfer of service users in particular.\(^9\)
protocols and a shared view of care are crucially important in the provision of integrated care.

5. **Self-management support and patient education.** In integrated care it is essential to involve patients as partners in their own care process. To encourage self-management, more and more patients with chronic conditions are empowered through education.

From the definition and descriptions of elements of integrated care one can conclude that integrated care is not an aim in itself, but that it should rather be understood as a process to improve quality of care (access, user satisfaction, effectiveness and efficiency) with the overall aim to improving equitably distributed population health (Figure 1).

According to the WHO health is a state of complete physical, mental and social well-being (quality of life) and not just the absence of disease. Health services contribute significantly to health and the quality of life of people. When the integration of primary, secondary and tertiary care is weak, it will result in poor quality and inefficiency and often causing high costs and unnecessary inconvenience to patients.

Integrated care often involves professionals of different health care settings – for example primary and specialist care – or professionals allied to multiple organisations, such as a general practice and a community agency. Tasks and services also have to be integrated within organisations, but that type of integration is a more common management task, while integration across organisations and services is a relatively new issue for the long-term care sector. Most integrated care initiatives take the form of modifications to what already exists. Examples of modifications are the implementation of protocols for referring patients to the integrated care initiative and making linkages across the boundaries that are inherent in the system. Only few integrated care initiatives do involve significant changes to the structure or process of existing services. These initiatives are mainly directed at integration across the whole continuum of care, such as integration across health, social care, housing and transport.

**Related concepts**

In practice, integrated care appears in a variety of forms like ‘transmural care’, ‘shared care’, or ‘disease management’. Several authors have already expounded the meaning of and the relation between the different concepts. Summarizing, it can be stated that integrated care can be seen as an umbrella term covering a wide range of activities provided over the full continuum of care (from prevention to supportive services for...
Activities of Daily Living (ADL) and assisted-living facilities). By several authors the concepts 'transmural care' and 'shared care' are considered equivalent. Like shared care, also transmural care is directed towards the cooperation and coordination between generalists and specialists on the basis of agreements about shared responsibilities and specification of delegated responsibilities. Home-based and hospital-based care providers join their activities in order to improve the efficiency, the quality and the effectiveness of health care. In comparison with transmural care and shared care, disease management is more robust, has greater impact and is applied on a larger scale. It is characterised by the focus on one disease, client orientation and a broad scope of activities like prevention, diagnostics, treatment, counselling and rehabilitation. These aspects are often less explicit in transmural or shared care.

Although all strategies have in common the aim to improve coordination and integration of services, the lack of common terminology complicates conversation and application.

Research
In the past decade there has been an increase of 'integrated care' initiatives by different health care organizations. In general, most target groups of integrated care suffer from chronic illness or handicaps with multiple care demands and are associated with:
- involvement of several providers in a wide variety of organizations and places;
- a high incidence and prevalence of the disease; and
- high direct and indirect costs (among other things due to long periods of work loss).
As a result, diabetes mellitus and asthma are the classic examples of conditions suitable for (alternative forms of) integrated care.

It is generally assumed that integrated care – by reducing fragmentation and discontinuities – results in increased quality of care and improved patient satisfaction and outcomes, while being cost-effective or even cost-saving at the same time. However, evidence supporting the effectiveness of integrated care is sparse. The major shortcoming in research studies is that integration or continuity is frequently not defined or conceptualized. Consequently, it is difficult to review systematically the findings in this area. Furthermore, not many studies provide quantitative outcome measures and experimental study designs. Another difficulty in evaluating integrated care initiatives is the complexity of such programmes and the time necessary to establish results.

Present studies

Main aim and research questions
The main aim of this thesis is to explore the relevance and effects of integrated care across different health care settings on patients with costly, low incidence chronic disorders. To achieve this goal we performed two different studies in order to evaluate (alternative forms of) integrated care for people with intellectual disability (ID) and people with multiple sclerosis (MS). The selection of the two disorders mentioned is based on practical
reasons on the one hand, namely requests from the field and the availability of funding. On the other hand the choice is based on the lack of evidence on the effect of integrated care in case of low incidence chronic disorders. Therefore, it is interesting to assess whether integrated care is valuable for this populations.

As to the purpose of this study, the following research questions are formulated.

1. What is the potential value of integrated care for people with costly, low incidence chronic disorders (in this case ID and MS)?
2. Compared to usual care, does (an alternative form of) integrated care result in a higher continuity of care, a reduction of health care needs, a higher quality of life and an adequate use of health care services?

All data – except for ‘quality of life’ – is collected regarding both disorders. Data with reference to ‘quality of life’ is only collected in MS-patients since the study on people with ID primarily focused on the other outcomes: continuity of care, number of health care needs and use of health care services.

The results of this thesis may be helpful for (primary carers of) persons with ID or MS. Low incidence disorders are not only costly, but also greatly impact the quality of life of these people. Secondly, this information may enable policy makers, managers and health care providers to improve the delivery of adequate health care to people with ID and MS.

**Intellectual Disability**
People with Intellectual Disability (ID) have a wide range of health problems. Compared to the general population, there is a higher prevalence rate of both mental disorders and (untreated) physical disorders and disability.

When people with ID move from an institution to private homes and group homes in the community, they will be reliant on a GP rather than an institutional doctor for their primary medical care. The quality of primary health care for people with ID however often seems inadequate due to a shortage of professionals familiar with their needs. As a result, apart from a wide range of health problems, people with ID experience disparities in health, shorter life spans, and poorer access to professional health care than people without ID. In the Netherlands there are an estimated 110.000 persons with ID (prevalence rate of 7 per 1000). In the Netherlands ID is the greatest single cause of health care costs for men (comprising 10.3% of the total costs of health care for men nationally). Moreover, these costs are expected to rise even more in the future because of the ageing population.

**Multiple Sclerosis**
Multiple Sclerosis (MS) is a chronic neurological disease that may cause diverse and often unpredictable symptoms with an uncertain rate of progression like fatigue, bladder- and bowel problems, mobility- and sensory problems. MS primarily affects adults, with an age of onset typically between 20 and 50 years, and is more common in women than in men.
The cause of this disorder is not known, but environmental, viral, and genetic factors are thought to play a role.

The delivery of health care to MS patients is characterized by the involvement of a wide range of services which provide several strategies to help combat many of the health problems of MS patients. However, the coordination and continuity of care delivered by those services often seems seriously deficient; the services are fragmented, communication is poor, goals are often not shared, and there is an unacceptable delay in the onset of these services once they have been recommended. The prevalence rate of MS is 0.55 per 1,000 (male) and 1.13 per 1,000 (female). In case of a constant prevalence, currently 4,300 man and 9,100 women in the Netherlands suffer from MS. Despite its relatively limited prevalence, MS has considerable economic consequences. Costs of MS are dominated by costs outside the health care system (productivity losses due to long periods of work loss), non-medical costs (transformation of the house) and informal care by family or friends resulting in productivity loss of the caretaker. At least half of all patients are significantly dependent upon others for mobility and other activities.

**Similarities**

Although ID and MS in nature are two entirely different disorders, they do have a number of similarities with reference to diagnosis and severity of their disorder and to lacunae in the care process.

**Diagnosis**

- The diagnosis of both ID (particularly in young children) and MS is frequently missed. Diagnosis can be difficult because the symptoms can be very mild and may be similar to a number of other diseases. Diagnosis is highly dependent on a comprehensive personal and family medical history, a complete physical examination and, in case of ID, a careful developmental assessment of the patient.

**Independency**

- People with ID as well as people with MS often have multiple health problems and are most likely dependent on different health care professionals.
- People with ID as well as people with MS rely upon some level of assistance, and/or an informal care network to facilitate them living at home. Several studies have identified higher levels of stress and poorer physical and mental health experienced by life-long, family carers.
- Both people with ID and those with MS experience problems accessing timely and appropriate health care. Lack of timely access to health care services can be particularly problematic for people with chronic and/or disabling conditions, who are often at risk of deteriorating health, secondary conditions, secondary functional losses, and decreased independence.
Knowledge and experience of health care professionals

- Lack of knowledge about the disease due to a rather low incidence rate of both ID and MS.\textsuperscript{57} Lack of knowledge includes knowing the signs and symptoms, as well as screening and treatment options. Until recently in the Netherlands, GPs supported only 1-2 children and five adults with ID and 3-5 people with MS in their practice.\textsuperscript{56,59}
- An additional problem is a lack of awareness of appropriate specialist support services, and their availability. Many providers are not experienced enough to address and coordinate the complex and often unclear care needs of the patients.\textsuperscript{57}

Poor patient outcome

- People with ID as well as people with MS do have a high amount of unmet needs.\textsuperscript{39,42,60-62}
- Misconception that nothing can be done, so-called diagnostic overshadowing, i.e. the tendency to attribute all problems to the person's disorder (in this case ID and MS).\textsuperscript{42,44,63} Much comorbidity like ocular or depressive symptoms remain undetected and untreated because the symptoms are thought to be related to the disorder.\textsuperscript{64} By failing to treat certain health problems, especially in their early stages when clinical signs are least obvious, but intervention is most effective and least expensive.
- Consequences of cost-cutting strategies. Since the health care costs for patients with chronic illnesses are high, also people with ID and MS are targets of cost-cutting strategies. These strategies can include denying coverage for needed tests, treatments and transport or blocking referrals to specialists.\textsuperscript{65}

Outline of this thesis

In the second chapter of this thesis an overview will be given of specific health problems in people with ID. In the third chapter the potential value of integrated care for people with ID is described. Subsequently, in chapter 4 the results of a study on the effectiveness of integrated care for people with ID will be presented. Chapter 5 addresses the possible value of integrated care for MS patients. Chapter 6 and 7 present results of a pilot study and an effect study respectively on the effectiveness of integrated care for MS patients. Finally, in chapter 8, general conclusions of the studies in this thesis are presented, the main findings are discussed, and recommendations for future research are given.
References


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