9

Discussion

9.1 Introduction

This thesis describes a type of care that tries to give a substantive, demand-orientated answer to the care requirements of patients with a need for care that is either persistent or permanent. This care model is known in Dutch as Passiviteiten van het Dagelijks Leven (PDL) and given in English here as Care of people who are Powerless in Daily Living (PDL care).

As mentioned in the introduction, the aging of the population in coming years will only increase the demand for care. Consequently, more care will be required for patients with complex problems and there will be greater demand for the services of the care sector. In addition, individualisation, normalisation and the growing role of the media will require changes in the sector. In actual working practice, these changes have already begun. To help develop and underpin the quality of care in relation to the quality of life of the patient, it is important to couple practice to theory.

So far PDL care has been developed in working practice to so called ‘recipe knowledge’. After this working practice created ‘procedure knowledge’: PDL care was described in procedures, developed by care providers themselves, influenced by experiences of patients and themselves in care giving. To help develop and underpin the quality of care in relation to the quality of life of the patient, it is important to couple practice to theory. This thesis provides the follow up to the procedure knowledge of practice with practice-orientated research. In this thesis scientific theory is formatted to PDL care. The research described in this thesis studied PDL care in order to provide scientific support for it and create a basis for further research. Although positive effects of PDL care on the patients’ quality of life have been experienced by care providers, the effects have not been scientifically studied yet. In the study of this thesis research is done how PDL care should be implemented and which preconditions need to be met in order to do this correctly. Research is done for which patients PDL care is indicated, how this could be measured and set out the first steps to guidelines for decision-making and implementation. These elements: how, with which preconditions for use, and for whom, will support a basis for further research. After the study of this thesis, further studies e.g. for the effects of PDL care can be done.

PDL care is intended for people with a high degree of total care dependency from which no cure or recovery is possible. The starting point of PDL care is that such people should let go of the idea of cure or recovery and learn to deal with the loss in order to focus on quality of life. The acceptance of loss can be difficult task – not only for the patient but also for the health care providers. In some cultures, such as that of the United States, it is not acceptable talk openly about ‘not getting better’. However,
continuing to aim for rehabilitation or recovery when there is no prospect for this cannot be the right way to go. The Dutch saying ‘It can’t do any harm and may do some good’ doesn’t apply here because there definitely is harm involved – training for recovery that will never happen leads to frustration and wastes the energy of both patient and health care provider. It is then better for people to direct their efforts at an improved quality of life, maximum use of residual capabilities and stress-free care giving. The discussions about whether to aim for rehabilitation confirms the importance of a good prognosis and if a patient has any prospect of cure or recovery, the care and treatment will be directed at rehabilitation and recovery.

The Dutch word passiviteit – the central concept in PDL care – is taken from physiotherapy where it means ‘no active muscle strength’. In this sense, it cannot be translated as ‘passivity’, so the preferred translation is ‘powerlessness’, which native English-speaking professors and colleagues confirm is better suited to describe the inability of the patient to act. Consequently, ‘Care of people who are Powerless in Daily Living (PDL care) was selected as the English term for PDL care.

PDL care was chosen as the subject of this thesis because it is being increasingly used in the care of the elderly in Flanders and the Netherlands, where positive effects on the patients’ quality of life have been seen. It also conforms to current thinking about care and with developments in the care sector. In this summary, Section 9.2 gives the most important results in the form of answers to the research questions (9.2.1 – 9.2.9) and recommendations for the use of PDL care (9.2.10). During the research of this thesis items came forward related to the care of the elderly. These items do not specifically concern PDL care but do place PDL care in the wider context of care. Therefore, not being part of the research questions, section 9.3 is added to give the items a place in this thesis.

9.2 Summary

9.2.1 Research questions

Chapter 1 provides the background to this study and the research questions it is based on. The following research questions were formulated for the research on Care of people who are Powerless in Daily Living:

1. What type of care is PDL care?
2. What is the current application of PDL care?
3. What are the defining characteristics of PDL care and what is an accurate definition of PDL care?
4. What are the preconditions for the successful application of PDL care?
5. What is the relation between PDL care and palliative care?
6. What are the characteristics of patients that determine the choice of PDL care and which measuring instrument can be used for this purpose?
7. How is the decision for applying PDL care taken and how is it initiated for an individual patient? Can a guideline be drafted for this process?
PDL care can be used in nursing homes, in care homes, by home help and in the care of the mentally handicapped. Information on actual practice was collected from nursing homes in the Netherlands and larger institutes for care of the elderly in Flanders since these are the places that PDL care is currently most used.

9.2.2 What type of care is PDL care?

In Chapter 2, PDL care is examined from different perspectives with the help of a work model – the health care perspective, the treatment perspective and the stage of support by the health care providers. With respect to the patient’s level of functioning and health condition, PDL care is intended for patients with a major or complete care dependency. Seen from a care perspective, the patient has little or no capacity for self-care. In such a case, the care is provided by professional health care providers with specific expertise and skills. The care is supplemented where necessary by volunteer care. The treatment perspective shows the need to stabilise the patient’s situation and their need to learn to deal with handicaps that will be permanent. This involves acceptance of the lowered capabilities of the patient from handicaps from which no cure or recovery is possible and, instead, to make the best of the patient’s residual capabilities. Looked at from the perspective of the support stage, the carers take over, partly or wholly, the patient’s self-care activities, namely a correct lying position, being able to sit well, washing, changing, clothes, getting around and eating. In PDL care, these care activities are described as lying down, sitting, washing, dressing, changing, turning and feeding. PDL care is based on the biopsychosocial model, which is an approach in which physical, psychological and social problems are approached as part of an integral whole and is also a form of emotion-orientated care. It assumes the patient’s wishes and perception. PDL care is suited to people with serious chronic disorders, which can be either somatic or psychogeriatric such as dementia. PDL care is also used in palliative care.

In short, the answer to the research question is:

PDL care is a form of emotion-oriented care. PDL care focuses on patients with a major or complete care dependency, and is based on a biopsychosocial model. It assumes the patient’s wishes and perception, with the objective of stabilisation, coping with disabilities with no prospect of recovery and maximum use of residual activity. It is performed by professional health care providers with specific expertise and skills, who partially or fully take over the self-care activities of daily life from the patient.

9.2.3 How widely is PDL care currently used?

In Chapter 3, the current use of PDL care is examined by means of two questionnaires sent to institutes for care of the elderly. One was sent to nursing homes in the Netherlands and to larger institutes for care of the elderly in Flanders, while a second was sent to institutes known to use PDL care. The first questionnaire showed that PDL care was well known to the respondents and used by them – 85% and 72% from the responding groups and 83% and 67% from a sample of the non-responding groups. The results from the second questionnaire show that in practical situations
is used for people with dementia and for people with a chronic somatic disorder. What can be seen is a structured, emotion-orientated approach from different disciplines that work together in a multidisciplinary way. These disciplines are (N=76) doctor (63%), nurse (86%), carer (99%), physiotherapist (93%), ergotherapist (86%), speech therapist (51%), dietician (33%), psychologist (25%), chaplain (13%), social worker (9%) and activity coach (64%). Where the carer is not involved, a nurse always is. Either a physiotherapist or ergotherapist is always involved or, in most cases, both are (N=61, 80%).

A total of 88% of the institutes that use PDL care (N=77) say that the family is involved in its implementation. This involves not only provision of information but also permission to use PDL care, involvement in the care plan, instruction and advice, involvement with the materials used and the layout of the space where the patient lives. The involvement of the patient consists mostly of asking them about their experience, instruction and/or advice, involvement in the care plan, the giving of information about PDL care and permission for its use. The latter is more relevant to chronic somatic patients than to psychogeriatric patients.

In 93% of the institutes (N=74) the agreements regarding PDL care are set out in the care plan of the individual patient. In 84% of the institutes (N=74) the PDL care is used in all of the seven care situations described in which care is provided. Educational programmes have been developed in collaboration with training institutes. The benefits of PDL care experienced by the staff concerns, amongst other things, the patient’s wellbeing, the relation between the family and the staff and, for the staff job satisfaction. The widespread use of PDL care, its manner of implementation and its benefits to the staff all show how important it is to provide it with a scientific description and underpinning.

9.2.4 What are the defining characteristics of PDL care and how can it be defined?

In the care sector itself, there seems to some conceptual confusion about PDL care. The naming of the specific characteristics of PDL care defines its scope while the definition of PDL care states what it is but also at the same time what it is not.

In Chapter 4, PDL care is analysed using the Walker and Avant method. The definition of PDL care found in the literature was tested against the defining characteristics found for PDL care. The defining characteristics of PDL care are worked out in two categories – characteristics relating to emotion-orientated care generally, of which PDL care is one form, and defining characteristics specific to PDL care.

The following defining characteristics of emotion-orientated care were formulated:
- The care is person-oriented: it is focused on the individual.
- The perception and wellbeing of the individual patient form the basis for the care provision.
- The interaction between the carers and the patient is very important: there is eye contact and sudden movements are avoided. The carers explain to the patient what they are going to do and create a calm atmosphere. They carefully enter into a dia-
Dialogue with the patient, taking his/her capabilities and perception into consideration.

- PDL care has a systematic approach to the primary process that serves to monitor and promote continuity in care.
- The care is directed at the psychological, social and physical functioning of the patient.

The following specific features of PDL care were formulated:

- The care is focused on patients with an irreversible self-care deficit.
- The acceptance of the powerlessness with self-care deficiencies of the patient, if these are insurmountable, is essential in PDL care. Residual capabilities are utilised to the optimum and, where necessary, self-care activities are taken over.
- PDL care is concerned with care situations of daily life, that are subdivided into lying down, sitting, washing, dressing, changing, turning and feeding.
- Special skills, aids and provisions are used.
- The working practice is described per patient per care situation and documented in skills, aids and provisions that recur in different care situations, adapted to the specific care situation and the specific patient.
- The aim of PDL care is to make the care situation as pleasant as possible for both patient and carer.
- PDL care uses of an interdisciplinary and multidisciplinary approach. There is close co-operation between care workers, nurses, ergotherapists, physiotherapists, speech therapists, and, sometimes, other disciplines. Nursing and paramedical working practices and expertise are integrated into the care activities performed by care workers. Physiotherapeutic handholds and methods are introduced into care procedures. The ergotherapist provides facilities and/or aids specifically tailored to the particular (partial) powerlessness of the patient or adapts these to the patient. The speech therapist provides advice and aids for to eating, swallowing, mouth hygiene and communication.
- To help with contact with the patient, the care is provided as far as possible on a one-to-one basis. This is referred to as primary nursing.

In looking at the use of PDL care in different care situations, a number of methods, facilities and procedures can, in a general way, be distinguished. These return in different situations, tailored to the specific care situation and to the specific patient. Using the defining characteristics, a comparison was made with other interventions, namely transfer policy (borderline case), sensory therapy (related case) and ADL training (contrary case).

The PDL care-specific characteristics found in the concept analysis are tested in Chapter 5 with an expert consultation according to the Delphi method. In two rounds, the specific characteristics were presented to 21 Dutch and Flemish experts from the care sector. The experts responded independently from each other and a consensus percentage of at least 85% was aimed for. The concept analysis sand the subsequent Delphi study led to the following sharpened definition of PDL care:
Chapter 9

PDL care is a type of emotion-oriented care for an individual who has an irreversible self-care deficit and thus is very dependent on care. The aim of the care is to assist the individual in his/her care situations in daily living as well as helping the individual cope with his/her powerlessness or partial powerlessness and its physical, psychological and social manifestations. The starting point of the care is the perception and wellbeing of the patient and the care itself relies on specific skills, aids and provisions provided by the carer, that are used in a systematic multidisciplinary approach. The care is given on a one-to-one basis and aims to minimise the burden on the patient as well as the carer.

9.2.5 What are the preconditions for using PDL CARE?

In the first round of the Delphi study in Chapter 5 the experts were asked to give preconditions that are important for the successful use of PDL care. In the second round, these were presented to all participants.

The preconditions for the successful use of PDL care, for which there was consensus, were:

- Integration of PDL into the total care for the patient.
- The availability and, if necessary, the involvement of the following disciplines: care worker, ergotherapist, physiotherapist and nurse.
- Staff trained in the use of PDL care.
- Support for the departmental management and top management.
- Focus on creating a good atmosphere on the ward.

Specific competences are desired in the employees. These are mainly concerned with the empathy, co-operation and observation:

- Ability to make good contact with individual patients.
- Ability to create a good atmosphere.
- Ability to respond flexibly to the wishes of the patient
- Be observant about what the patient likes and does not like
- Focussed on putting the patient central: a customer-orientated attitude.
- Be able to work in a multidisciplinary manner.

9.2.6 What is the relation between PDL care and palliative care?

Chapter 6 shows the relation between PDL care and palliative care and provides an example of the application of PDL care in palliative care. The objectives and working method of PDL care are consistent with palliative (terminal) care. The decision to use PDL care is consciously made when there is no possibility of recovery. PDL care is well suited to the outlook of demand-orientated working. In addition, PDL care conforms to current developments within the care sector that seek to stimulate more authority from patients and their families in the care sector. In terminal palliative care, attention will also have to be given to spirituality. Spirituality is increasingly seen as an independent component next to physical, psychological and social components of what it means to be a human being. Spirituality can receive special attention by
emphatically including a chaplain or other psychosocial helpers from the multidisciplinary team in the care process in an attendant and coaching role.

9.2.7 What patient characteristics indicate the use of PDL care and which measuring instrument can be used for this?

In Chapter 7, a search was made for patient characteristics related to PDL care. About a hundred questionnaires were sent out in order to find out which patient characteristics help to indicate the use of PDL care for a given patient and which measuring instrument can be used for this. The characteristics of the patients found in practice, are consistent to the earlier findings at the positioning and analysis of PDL care. At first, the prognosis for recovery seemed to be decisive. If (partial) recovery was expected, PDL care should not be used. A number of characteristics occur more in patients for whom PDL care is considered appropriate than in patients for whom this was not the case. These are: high care burden; confinement to bed; stiffness, contractions, increased muscle tension and defence tension; difficult communication and incomprehension by the patient; problems with chewing and swallowing and saliva production; and disorientation in time or space. The decision to apply PDL is reinforced if one of the following patient characteristics has been demonstrated.

Two measuring instruments proved suitable in practice for measuring the care burden as a factor in whether or not to use PDL care. These are a PDL score list, including a number of questions from the ZZP score list, and the Care Dependency Scale. Both these scales are included in the appendix to chapter 7, as part of the questionnaire. Because either scale can be used, the choice goes to the one that is best suited to the institute or which is already in use there. There is no benefit in using both instruments. The use of PDL care is indicated if a total score of 18 or higher is scored on the PDL score list (including a part of the ZZP score list) or the total score on the CDS is 28 or lower.

The outcome of this research question can also be used in further research such as an effect study, to determine whether PDL care should be used or not.

9.2.8 How is the decision to use PDL care made and how is its implementation for a particular patient set in motion? Can guidelines be established for this process?

Chapter 8 shows that in working practice the decision to use PDL care is mostly taken as a consequence of care problems that occur, and is based on the knowledge or experience of the care worker involved in the care of the patient in question. Within the context of individual decision-making, and transparency and accountability, it is important to further structure and formalise the decision making. The decision whether or not to use PDL care should be taken in a multidisciplinary team meeting together with the patient and/or the patient’s family. The input for this meeting is formed by the recovery potential of the patient and the degree to which the patient characteristics described in the previous chapter occur in the patient, including the score of a measurement instrument of care burden. If the patient and/or their family do not take part in this consultation, the patient and/or their family will have to be
involved in the decision in some other way. If a positive decision is made in the multidisciplinary consultation, a systematic plan is made for starting PDL care for the patient. Decisions are made on which activities the various professionals would undertake in which care situations in order to draw up action plans complete with aids and provisions. The kind of involvement of the patient and family is discussed. A plan for evaluation and assurance is set down and coupled to subsequent multidisciplinary consultations.

For this purpose, the following first steps for guidelines were set up ‘PDL care: decision process concerning the use and way of using’. In this, a distinction is made between two phases. The first phase ‘Measurement of care burden and other patient characteristics’ and the second phase ‘Decision process’.

9.2.9 Conclusions

The study that forms the subject of this thesis looked at the situation in the field. It examined PDL care – a model developed by paramedics and care workers in working practice. During the study, there was constant interaction between practice and theory. It started with a literature study, which gave a general picture of how PDL care is used in practice. Working from theory, an analysis of PDL care was made that was then tested in working practice. The patient characteristics and the possibilities for using measuring instruments were then studied using data from working practice. Prototype guidelines were then compiled for the process of deciding at patient level whether or not to use PDL care. In effect, the study went from practice to theory and then returned to practice.

All this has led to greater insight into the intervention model itself and how it is actually used in the Netherlands and Flanders. The study showed for which patients PDL care was indicated, showed how this could be measured and set out the first steps to guidelines for decision-making and implementation. The outcome can and should be used to do further research, such as effect research. The study showed how PDL care should be implemented and which preconditions need to be met in order to do this correctly. These elements: for whom, how and with which preconditions for use gives the basis for the scientifically supported use of PDL care.

9.2.10 Recommendations for the use of PDL care

A. A conscious choice: accepting a permanent self-care deficit. An about-turn in thinking

The decision whether the care for a patient should aim at rehabilitation and recovery or at the patient’s quality of life and their acceptance of their inability to perform self-care activities is both highly consequential and difficult to take. The decision to use PDL care will therefore have to be taken together with the patient and their partner or family and should involve all the relevant disciplines. For carers this will sometimes involve an about turn in thinking that requires some attention. A medical model aimed at recovery is replaced with a biopsychosocial model aimed at improving the quality of life in which the patients find themselves. All employees involved with the patient should have made this about turn. It is not in the patient’s interests
if, at one moment, they are pushed to do something they cannot only to find that the task is then sometimes taken over by a carer. In addition, the methods, facilities and procedures used for the PDL care need to be formalised so that they can be used consistently for a particular patient by different carers.

B. Dealing with partial powerlessness and making maximum use of residual capabilities

During the analysis of PDL care, a number of participants pointed out that powerlessness can also be partial. Where this occurs, there should be particular attention for making maximum use of residual capabilities and encouraging the patient’s use of them. It makes sense that someone should not be made more powerless than he or she is because of his or her handicaps. In the literature on PDL care this mainly comes up with reference to standing and walking – a patient able to walk should not be sitting in a wheelchair in the living room, for instance. Instead, they should be encouraged to walk the distance they can manage. The later literature emphasises the taking over of self-care deficiencies since these generally cause the most problems in caring. This can also be seen in the education, where most and sometimes all of the attention is given to taking over self-care. Partial powerlessness and the maximum use of residual capabilities seem to disappear into the background. It would be good if dealing with residual capability – and not only in standing and walking – received more attention in the literature on PDL care and in its teaching.

C. Palliative care, added spirituality

Although PDL care was not developed specifically for palliative care, its principles and working methods fit in well with it. It is, of course, not the only type of care that can be used in palliative care. A number of elements which are of particular importance in palliative care, such as spirituality, will have to be expressly added to the care provision where PDL care is used in palliative terminal care. These are in fact adaptations to the patient in his or her specific situation.

D. Keeping within formulated boundaries

PDL care was developed in working practice, where it is also undergoing further development. Carers developed new and handier measures and annual meetings were organised in the Netherlands where people could exchange experiences. Gradually, manufacturers of aids and facilities have begun to serve this specific target group – the patients with powerlessness and for the carers who look after them. In order to make PDL care unambiguous, it is important to set out some boundaries to show when something is or is not an aspect of PDL care. The research described in this thesis looked at PDL care as it had been developed in practice. The ‘recipe knowledge’ developed in practice and ‘procedure knowledge’ have been given a theoretical basis by this study.

This theoretical basis creates a framework for PDL care. During the study, there was constant interaction between practice and theory. It began with a literature search. Then a picture was created of the actual use of PDL care in working practice. From the theory, an analysis of PDL care was made that was then tested in practice. The boundaries that need to be respected in the application of PDL care are set out in its definition. It forms the guideline for the practical application of PDL care. In a practical situation its means that if the possibility arises for using PDL care, all elements of the definition would be used. If only a few elements of the PDL care are
used, it cannot be said that PDL care is being used. What can be said is that some skills, aids and provisions from PDL care can be used. In addition, some elements can be added in practice by employees without these then forming part of PDL care.

E. Decision-making regarding the application and implementation of PDL care at patient level

Using data from working practice, the characteristics of patients for whom PDL care is used were studied. A procedure was formulated for deciding whether PDL care was suitable for an individual patient and another procedure was formulated to decide whether or not to actually use PDL care in that case and, if so, how it would be used. The procedures can be used in the follow up of this thesis to do further effect research and to develop guidelines for using PDL care.

F. Use of PDL care in other countries

So far, PDL care has been sued within the Dutch and Flemish language areas and most of the literature in the PDL care workbook is in Dutch. After laying a scientific basis and publishing in other languages, it is recommended to use PDL care in other countries where comparable problems are being discussed. It can be a special addition to the patient centred care as developed in other countries.

G. Supplementary effect study

In the inventory made for the application of PDL care in Dutch and Flemish institutes for care of the elderly, respondents were also asked about the effects experienced from the use of PDL care – for the patient, for the family and for the carer. The effects given in the replies were predominantly based on the experiences of the carers. As a result of subsequent theory formation, there is now a basis for scientific effect studies. The following items were established as necessary for effect studies:

- A measurement procedure for determining which patients will receive PDL care.
- A procedure for determining whether a patient will receive PDL care and in which way this will be done.
- The preconditions for using PDL care.
- The specific characteristics of PDL care, which all must be applied when PDL care is used.

This means that the results of this study can be used for further scientific research.

9.3 Quality of Life is beyond figures

If we put PDL care back into the context of the care of the elderly, this type of care fits in well with current thinking about care,, namely that it is demand-orientated, takes into account the workload of the employee, involves an active role for the management of the care home and is primarily aimed at improving the patient’s quality of life. PDL care is used by care institutes to improve the quality of care.
### 9.3.1 Quality elements in the care sector

Currently, quality is at the focus of attention in the care sector – for the patient, for patient’s partner and family, for the carer, the management, the health insurer and the government. Nevertheless, quality is experienced and approached differently by different people in the care sector – all of these participants in care define quality in their own way. Often they will admit they have a different interpretation of quality, but it often goes no further than that. Judging by the statements of the various participants, PDL care is aimed mainly at the quality of life of the patient, their partner and family and the carer. At the same time, PDL care can involve a number of quality elements, such as those experienced by management, health insurer and the government. An overview of how the concept of quality is seen from different perspectives in the care sector and examples of used means in order to achieve this quality is given below. It draws on the experiences of people who work in the sector and the experiences of the researcher during the study itself.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Quality</th>
<th>Means</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>- Living as normally as possible</td>
<td>- Small-scale living</td>
</tr>
<tr>
<td></td>
<td>- Pleasant living, eating well</td>
<td>- Individual budget</td>
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<tr>
<td></td>
<td>- Little or no pain</td>
<td>- Individual plan for care and wellbeing</td>
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<tr>
<td></td>
<td>- Little or no trouble from handicaps</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Approached as an individual</td>
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<td></td>
<td>- Control of care provided</td>
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<tr>
<td></td>
<td>- Being helped quickly and effectively</td>
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<tr>
<td></td>
<td>- Reliably professional quality</td>
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<tr>
<td></td>
<td>- Wellbeing</td>
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<tr>
<td></td>
<td>- Good relations with carers</td>
<td></td>
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<tr>
<td></td>
<td>- Good relations with people around them</td>
<td></td>
</tr>
<tr>
<td>Partner, family</td>
<td>- Good care for the patient</td>
<td>- Participation in the multidisciplinary consultation</td>
</tr>
<tr>
<td></td>
<td>- Authority</td>
<td>- Family participation</td>
</tr>
<tr>
<td></td>
<td>- Information</td>
<td>- Supply of voluntary care</td>
</tr>
<tr>
<td></td>
<td>- Involvement in care process</td>
<td></td>
</tr>
<tr>
<td>Carer</td>
<td>- Job satisfaction</td>
<td>- From task-orientated to patient-orientated</td>
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<tr>
<td></td>
<td>- Opportunity to develop</td>
<td>- Team meetings</td>
</tr>
<tr>
<td></td>
<td>- Able to act professionally</td>
<td>- Health and safety policy</td>
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<td></td>
<td>- Good relations with the patient</td>
<td>- Lift-and-transfer aids</td>
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<tr>
<td></td>
<td>- Good relations with colleagues</td>
<td></td>
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<tr>
<td></td>
<td>- Participation and appreciation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Health</td>
<td></td>
</tr>
<tr>
<td>Management</td>
<td>- A financially healthy organisation</td>
<td>- Financial reports</td>
</tr>
<tr>
<td></td>
<td>- Market orientated</td>
<td>- Registrations</td>
</tr>
<tr>
<td></td>
<td>- Customer orientated</td>
<td>- Links with the neighbourhood</td>
</tr>
<tr>
<td></td>
<td>- Competitive</td>
<td>- Protocols</td>
</tr>
<tr>
<td></td>
<td>- Efficiency and efficacy</td>
<td>- Certification</td>
</tr>
<tr>
<td></td>
<td>- Flexibility and care</td>
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Participant Quality Means

<table>
<thead>
<tr>
<th>Participant</th>
<th>Quality</th>
<th>Means</th>
</tr>
</thead>
</table>
| Health insurer | - A good and wide reputation  
- Many customers  
- Competitive  
- Finances in order | - Customer satisfaction  
- Positive news coverage  
- Customer choice  
- Registration/certification |
| Government | - Financially viable at macro level  
- Satisfied citizens  
- No emergencies  
- Equal treatment (for right to care) | - Care dependency packages  
- No bad publicity  
- Protocol creation and registration  
- Indication-for-treatment statement  
- Inspection |

Table 1. Quality aspects for different participants and examples of the used means in order to achieve them

The patient

Patients will, despite having a disorder or disability, want to live as normally as possible. They will want to suffer as little pain as possible and suffer the minimal possible problems from physical and mental handicaps. They will want to live pleasantly, eat well, have clean clothes, etc. Moreover, they will want to be treated as individuals by carers and those around them – as people with their own idiosyncrasies, wishes and habits. They will want to have a say in the care given to them and if they can no longer do this, others will have to do it for them while taking into account the patient’s character, preferences and idiosyncrasies. The care is considered to have good quality if they are helped quickly when and where they want to be helped and the professional quality of the care must be high as a matter of course.

Wellbeing is important to people and is one aspect of the quality of life. Often they are mentioned in the same breath – ‘care and wellbeing’ – when people talk about care these days. In general, a patient values a good relationship with carers and the people around them.

The means aimed at the above-named elements of a patient’s quality of life are small-scale living, an individual budget and the individual care plan.

We talk about small-scale living where a small group of people, with the intensive care and support they need, live with each other in a group house that makes it possible for them to have as near normal life as possible. Cleaning the house, going shopping, cooking and washing up are all aspects of a normal household and take place within the residence group.

An individual budget (PGB) is a sum of money that someone receives in order to buy their own care. With this money, people choose their own carer. With an individual budget, someone can buy-in care and in that way determine whether and in which way the care is provided. An individual budget allows the patient to exercise maximum influence on the sort of care they receive.

An individual care plan is used in different care situations. The Health Care Inspectorate has set out what constitutes ‘standards for responsible care’ and, in this way, they have involved themselves with the nature of the care provided. They emphasise the quality of life of the patient. They state that the starting point for the
care should be the needs, interests and capabilities of the patient and that the individual care plan should contain clear guidelines for daily procedures. Where patients have dementia, they add that a respectful, warm treatment of patients is important. To this end, Actiz has developed a Treatment and Care Plan, called the ‘care-live-plan’ (in Dutch: ‘zorgleefplan’), which is now being introduced into many Dutch institutes for care of the elderly and is connected with the ‘standards for responsible care’.

PDL care connects with what the patient experiences as quality. PDL care, as a form of emotion-orientated care, is aimed at the experiences and wishes of the patient. In this biopsychosocial model wellbeing is an important element of the quality of life of the patient. The effects that employees observe on patients from the use of PDL care involve both physical and mental comfort. In providing care, the aim is as far as possible to accommodate the wishes, the capabilities and the habits of the patient. The patient is regularly asked what they like or, if they cannot express this verbally, non-verbal expressions are looked for. The employee, naturally, needs sufficient social competences to do this.

The partner and the family

The quality that the partner and family want in the care is a continuation of what the patient wants. The partner and family are, incidentally, often rather more critical than the patient because they are in a less dependent position with respect to the carers. Sometimes feelings of guilt play a role in this because they can no longer provide the care themselves or because of the simple fact of the admission to a care institute. The partner and family will want to be involved in the care – certainly to be kept informed and, possibly, to provide voluntary care themselves and to have a say in decisions about the care provided – the latter particularly when the patients cannot do this for themselves.

In his book ‘Het refrein is Hein’ (in English: ‘The Refrain is Hein’), the nursing home physician Bert Keizer gives several examples of patients in a nursing home, particularly in the last phase of their lives. The ‘Standards for Responsible Care’ set out by the Health Care Inspectorate state that the individual care plan should come about in consultation with the patient and people within the patient’s social network. Care also needs to be taken to ensure that people from the patient’s network are important sources of information for setting up a good care plan.

Family participation is a good way to meet the wishes of the family and this makes it a topical subject within care institutes. Discussion with the family takes place within many institutes and in some they also contribute to the multidisciplinary consultation. At the same time, the Inspectorate also noted that patients and patient representatives are still little involved with the care plans of institutes.

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1 A care plan describes the current and desired situations for the patient. Objectives are set for a given period based on the wishes, capabilities and limitations of the patient in question. Because the care plan describes how these aims are to be reached and who is responsible for doing this, the care plan gives a concrete description of the care and support involved. The care plan stays with the patient (Ministerie van VWS, 2007).
The role of the partner or family has, with PDL care, grown in recent years. The family is involved with the care provision and can say what the patient likes and dislikes if the patient is not able to indicate this for him or herself. The partner or family should also be involved in choices made in the care provision. The decision to use PDL care is one in which the family or partner must be involved as they can also offer the patient practical support. In practice, the family is indeed informed about the use of PDL care but is not always involved in the decision-making. Although the role of the family in PDL care has grown over the last few years, in the coming years the role of the family or partner in PDL care will increase and will have to be elaborated further.

The carer

The carer will want to do their job well and gain jobs satisfaction from it. They will want to derive pleasure from their work and to develop in it. Being able to act professionally is a quality element for the carer. Relationships in their work are also important – with the patient, with their colleagues and with their superior. Just as with other employees, the carer has a need to feel appreciated in their work. From the patient this does not have to be literally expressed: if the patient feels better as a result of what the carer does, this in itself gives the carer satisfaction. With respect to colleagues and their superior, the carer will want to be taken seriously and to have some say in matters affecting their work.

The switchover from task-orientated to patient-orientated working gives the carer more responsibility and a better relationship with the patient. A national project called ‘The Workfloor in Focus’ (In Dutch: ‘De werkvloer centraal’) is concerned with work motivation in the care of the elderly. Its aim is to reduce work stress and raise job satisfaction. The project is a continuation of a study carried out by Anne-Mei The in a Rotterdam nursing home. This study brought to the fore, amongst other things, the problems of care workers caring for demented patients in combination with limited financial means. The ‘Workfloor in Focus’ study involved mainly brainstorming and intervision sessions for carers and their superior, the carer will want to be taken seriously and to have some say in matters affecting their work.

The health of the carer is also a quality element for the carers. A low rate of sickness absence is good not only for the organisation and the institutes but also for the carer. The working conditions are currently a matter receiving attention within the sector providing care of the elderly. The most important physical causes of work-related sickness absence in the care sector are physical complaints caused by working conditions and excessive pressure at work. Mentally, it is behaviour problems and/or aggression of patients that cause the stress. Carers are educated and coached to deal with these problems, with the coaching taking place in the daily work situation. Regarding physical burdens it is also possible to lighten the care provision by using aids such as lift-and-transfer apparatus.

In PDL care, the reduction of the load on the carer is an important item. PDL care makes a lot of use of aids of this sort, and this makes one-on-one care possible. Caregivers experience less behavioural problems and aggression by using PDL care and more job satisfaction. It is likely that both are the result of the greater attention
that can be given to the patient and the carer that can be tailored to the patient. Next to this there is the attention for the communication with the partner and the family of the patient, the attention for the workload and the opportunity to make a personal contribution of ideas by the carer in the care of the patient.

The management
A managerial position within the care system is increasingly entrepreneurial. The financing system for care institutes is changing in a way that requires building financial reserves to cover risks. This means that the manager is increasingly involved in financial management and 'production'. A financially healthy organisation is a quality element for a manager who, to keep track of these matters, needs to use financial reports and registrations. To make use of market forces, the organisation needs to be market orientated: a manager these days is expected to make strategic decisions about care provision at a time when the government is shedding responsibilities and the 'civil society' is ambivalent. In order to be market-orientated the manager will seek to integrate the organisation into its environment – literally in terms of the village, town or district where the institute is, but also in the sense of making contact with certain customer groups.

One part of the market-orientation quality aspect is the flexibility of the care – it must be possible to adapt to changes in the market. Sometimes the manager is forced unwillingly into competition with fellow institutes. When that happens, it is not just a matter of the price, with its efficiency and efficacy aspects, because the quality of the care provision also plays a role. This means that customer orientation and flexibility are quality elements from the viewpoint of the manager. The means in order to achieve this include protocols and the certification of institutes.

Eventually, then, the quality and content of the care reappears as a quality element. The final responsibility therefore lies with the manager, who is the one who ultimately determines which care methods are employed by the institute. These not only have consequences for the care provision itself but also for the institute as a whole.

PDL care in a strongly customer-orientated approach. Many care institutes in Flanders and the Netherlands use PDL care with the aim to improve both the quality of care for the patients and the patients' quality of life. In addition, the implementation of PDL care has consequences for the institute, namely that there should be a good atmosphere and that good preconditions need to be created. The patient must be central to the outlook of the institute; there should be integrated multidisciplinary care provision. PDL care requires input from the management of the organisation. The management needs to stand behind the decision to use PDL care. Only then can the other preconditions be met.

The health insurer
For the health insurer, quality takes the form of good brand awareness, a large number of customers, a competitive position, and a financially sound and smooth-running organisation. Customer satisfaction also plays a role but this applies both to customers who receive care and to those who only pay premiums. Customers are
attracted mainly on price. Advertising campaigns concentrate also on the image of
the health insurer and the image of its customers.

Health insurers try to get positive news coverage for themselves, in part by sub-
sidising high-profile projects through sponsorship. In addition, the customers’ abil-
ity to choose between different packages is seen as a way to be competitive.

From the health insurer’s point of view, quality in care provision consists of ‘get-
ting good value for money’. The ‘value’ in this case is based on to certification of
health care providers, their standing in quality league tables and any complaints that
occur. The certification of institutes should also involve the content of the care that
is delivered. When proved effectfull PDL could form part of this value. So far, how-
ever, the certification has been concerned mainly with setting down procedures.

The government

The government is striving to play a smaller role and allow care institutes to do more
themselves while still keeping a guiding hand on the care sector. For the government,
financial viability at macro level is a quality aspect. It tries to achieve this by setting
fixed tariffs for, amongst other things, the care dependency packages, which are
intrinsically customer-orientated. The government ultimately looks for quality in the
care sector in the form of satisfied citizens.

To keep customers satisfied there should be little fuss or bad publicity about the
care sector in the media. Quality is mainly screened via protocol creation and registra-
tion. Equal treatment with respect to the right to care – which is a quality element for
the government – is ensured by the indication for treatment. The test for intrinsic
quality is carried out by the health care inspectorate. The ‘Standards of responsible
care’ is an example of this, as mentioned earlier. The inspectorate not only looks at
whether the competences of carers are directed at the daily care procedures and the
necessary technical nursing procedures, it also tries to see whether there is a good
individual approach and a good treatment that makes a good quality of life possi-
ble.

These competences connect with competences like those that are named in PDL
care. In addition, the emphasis that PDL care places on patients and their families
accords with the wishes of the inspectorate and therefore the government.

9.3.2 New roles for improving quality of life

As described earlier, everyone has from their own perspective their own ideas and
wishes about care and the quality of care. In practice, these different perspectives do
not always accord with each other. For example, money set aside by the management
cannot be used to buy transfer equipment and giving control to a patient or the fam-
ily can lead to inefficiency in the care process. Despite this, all action from the differ-
ent perspectives, and from different levels, should converge and lead to one aim – the
quality of life of the patient. Without going through the different theories concerning
quality of life, one could say that the focus on quality of life requires reconsideration
on everyone’s part. We have to get back to cohesion, to a linking up of the different
actions. Not from an economic perspective, but from the perspective of the patient.
Everyone naturally thinks that they are working towards that goal and just as naturally everyone has the best of intentions for patients dependent on care. But more is needed.

The patient
The patient gets a new role. He can and will and must say what is important to him. And if the patients can’t do this, their partners or family must do it for them. For many old people these days that is difficult. Many old women in particular are used to decisions being made for them by, first, their partners and then, later, by the children.

Some patients regularly respond to a request for a decision with ‘What would you do in my situation doctor?’ Some carers regularly answer, even if it is not asked: ‘If I were you, I would…’.

This means that carers and the patient’s family have to help in order to find out what is important to a patient. Insight into ways of life is important. At the same time, the things that are important to a patient can change. It is important that the patient is involved in decisions relating to care provision. The patients themselves get control over the care. The patient’s participation in the multidisciplinary team meeting (MDT meeting) where the outline of the care is set out, is also a very logical step. Something care institutes incidentally have trouble with. It is naturally not a question of ‘Your wish is our command’. The health care provider can set limits to what can be provided in each case. Together with the patient, the possibility that certain diagnostic procedures and treatments might not be meaningful will be discussed from a quality of life perspective. But at the forefront stands the striving to meet the wishes of the patient. Moreover, if the patient is not able to express himself in a multidisciplinary team meeting, another form of communication will have to be found. What is important is that the last word comes from the patient in such a way that he can give it. It is about giving a fully valued place to the patient when it comes to the care that he or she receives. The decision lies with the patient. Only when the patient is not of sound mind can they be replaced in this role by their partner or family.

What can I get you?

‘What can I get you?’ said the nurse:
‘Coffee or tea?’
‘Co..co..cognac’,
said the aphasia patient.
The nurse laughed.
‘You mean coffee, of course?’
‘Yes’ said the man with a red face,
but he actually did mean cognac.

Gea van Dijk
The partner and the family

The role of the partner or family depends to some extent on the patient. They take an active role in the care process in the sense that they, who know the patient best, speak for the patient when the patient cannot speak for himself. The people the patient knows.

This means that the partner or family retains their responsibly for their partner or parents even if someone has been admitted to an intramural setting. Often a partner or family member will feel in the first instance a sense of relief when someone is admitted. Admissions are always preceded by a period of either worry or support and care at home. The admission remains a big step and is an emotional time. There is often a feeling of guilt. If the admission itself goes well people feel a sense of respite. Naturally, there is a sense of well-earned rest but it is important that the partner or family remain involved in the interests of the patient, as they have been part of the patient’s life for a long time and thus belong to the patient’s ordinary life. This applies equally in reverse to the partner or family. If the partner or family cannot be at least occasionally present, another way must be sought to keep in touch with them. If that fails, a gap is created and the patient suddenly comes very much back into the picture when they contract a complicated illness or enter the terminal phase. It is in this situation above all others that the role of the family and partner in making decisions becomes important, and this only works as it should if there has been regular contact.

Situations that lead to conflicts with the family are often those in which the family only enter the picture when the patient becomes suddenly ill or terminal. ‘She’s been here two years now and we only have seen the son before when she was admitted’.

There are situations in which the partner and family cannot come to an agreement to which policy should be followed or which decision should be made. When this happens, the decision is often shifted to the care staff, who are then left not knowing what to do or take decisions themselves. It remains, however, the responsibility of the partner and family to come to an agreement and take the decision themselves. In order to do this they must naturally be well informed and supported by the care staff, the doctor and, where necessary, by other disciplines.

The participation of the partner or family in a multidisciplinary team meeting (MDT meeting) can, in view of this, be seen as binding for both the health care provider and the family to partner. Here again, if the family or partner is not able to take part in an MDT meeting another form of communication must be sought.

Sometimes the partner or family also provides voluntary care. The voluntary carer will have to be involved in the total care process in a fully valued way. The activities of the professional health care providers and the voluntary carers will have to be coordinated. If that does not happen by itself, an extra effort will have to be made to bring it about.
The carer is trained to follow professional standards. Professional standards show how a specific disorder is best diagnosed, cared for, supervised and treated. In practice, the care giver not only has to deal with the patient but also has other people looking over their shoulders – colleagues from the same or other disciplines, the partner, the family, the manager, the health insurer, the government, the media and, often, the carer’s own social network as everyone knows how to talk about care. They have to take everybody into account – it is not enough just to do the job they were trained for.

Why do carers sometimes do things ‘in the best interests of the patient’ against the express wishes of the patient, calling him by his first name?

The carer will have to invest more in relationships than before – in the relationship with the patient, the partner, the family and with colleagues. In the relationship with the patient he or she will, first of all, have to see him as an individual. An individual with his own habits, desires and preferences. Someone who has had experiences that have made him the way he is. At the same time, the carer will have to realise that everyone is different and, consequently, that the appropriate approach or manner of treatment will also be different for each person. The living environment has different effects on different people. To provide good care directed at the quality of life of the patient, the carer will have to remain flexible and attentive to the patient and allow for differences between patients. Habits play an important part in this. Patient’s habits that affect the care process and habits of the carer that they might have to be prepared to put aside. As mentioned above, the carer will have to involve not only the patient but also the family or partner in the provision of care, which includes the decision on whether or not to use PDL care. It is important to reach agreement about this.

The carer needs his relationship with colleagues in order to reflect, for support and to draw on each other’s expertise. This is true whether the colleagues come from the carer’s own profession or from another – a process that depends on equality of esteem and mutual respect. The different levels of training and the related difference of status of the different disciplines have for a long time led to a lack of understanding between professions. The emancipation of the carers and nurses happened in the face of resistance from the other disciplines.

An artificial opposition is created between the disciplines, which has to be repeatedly broken down. The multidisciplinary care provision, which is characteristic of PDL care, is one of equity and makes use of the different professions within the care sector, which all need to keep and open mind, listen to each other and acknowledge the limitations of their own capabilities (knowledge and skills). Good teamwork between the various professionals that provide the care to the patient as a team is essential to the patient’s quality of life.
Good multidisciplinary care is like your favourite dish – you taste the different ingredients, none of which can be missed, but then they merge into the one taste you love so much.

While on the subject of the carer, another element is the carer’s need to look after their own health. Caring with patients with high a care requirement – such as those affected by powerlessness – demands a lot from the carer. Attention needs to be given to the physical and mental load on the carer. The physical burden can be eased by the use of mechanical aids such as lift-and-transfer equipment. The mental burden can be eased by people knowing that they can rely on each other, whether from within the carer’s own discipline, from carers in other disciplines or from the management. This allows professionals with a higher level of training to offer support to care staff by way of an approach that consists of guidance rather than interference. Here again, this involves the use of expertise that is either in-house or available form elsewhere and an open attitude on both sides is essential.

Carers will often want to do everything for themselves, which makes asking for help difficult. This help question is especially important for good care provision in smaller types of residence. Open teams, hospitable for others – for partners, for family and for other carers.

Providing feedback to colleagues and to other disciplines is often difficult, but nevertheless essential. A physiotherapist or social worker should also bring attention to the things they notice by joining the discussion and giving space to others.

New carers – and school leavers in particular – are enthusiastic and at the same time also vulnerable. They are full of what they have learnt in theory and then come up against a reality that is often quite different. Their colleagues and the management will have to listen carefully to these care workers to ensure that they can continue to work enthusiastically. They should naturally also have the opportunity for self-development.

The management
The management will have to be aware of its responsibility for creating the conditions with respect to the content of the care, directed at the patients’ quality of life.

The current focus on finances is evident. The economists and financial experts, accountants and bookkeepers in an organisation have an important voice that is being increasingly heard. But in addition to this, every manager will have to look more deeply into the care that is provided and what is important about it. Many managers do not have a background in the care sector and have no real affinity with it. This makes communication with the carers harder but at the same time also more important. The manager relies on the carer to say what is important and necessary to improve the patient’s quality of life. The manager will have to learn to listen to the carer, to interpret the signals and modify his actions accordingly.

A chef needs to taste all courses before it goes to the customers. Why, then, can a team leader in the care sector shut himself up in an office at the busiest time of the day to study financial data?
The manager will have to create space for flexibility and allow ‘his’ money to facilitate patient care. At the same time, the manager also needs to pay attention to the care workers themselves. As already described, work satisfaction and opportunity for self-development are important for care workers.

The manager will have to take this into account along with the vulnerability of starting care workers. It is not for nothing that PDL care calls on the management for support and encouragement. Special aids will have to be purchased and attention paid to the living environment of the patient, which is also the work environment of the carer. A good personnel policy that takes these things into account leads to low sickness absence and satisfied carers and this, in turn, facilitates good care and quality of life for the patients.

When new carers are taken on, it is not sufficient to look at their expertise in their chosen disciplines. Their skills in communication and ability to forge a good relationship with their patients and colleagues also have to be examined. It is in these latter skills that language plays an important role. In her study, Anne-Mei The spoke about the problems that occur when coloured care workers are employed in our culture11. In the care for the vulnerable group of elderly people that is the subject of this thesis, the risk of language and cultural problems should not be taken. Foreign personnel are better employed in situations where there is more emphasis on purely professional, discipline-specific skills, but not for this group of vulnerable old people as the patient-carer relationship is too important. However, if this is unavoidable due to staff shortages, a lot of time and energy will have to be put into bridging the linguistic and cultural gap. For the same reason it is advisable, when the patients have a different linguistic and cultural background from the country where they now live, to use carers with the same linguistic and cultural background. This also links up with the fact that old people with dementia or a chronic somatic disorder often fall back on their original language and culture. It is important in this respect to take action to deal with the personnel shortage so that culture can be matched to culture. This is, however, mainly a matter of the finances available for care provision.

The **health insurer**

The health insurer will have to create preconditions for the care institute. They often find themselves in the situation of a manager – devoted to the businesslike management of the care for ‘their’ policyholders, or of all insured persons in the region or even for all citizens.

The insurer is the financier and rule setter, and thereby looks after the money that people make available to insure themselves against health problems. Under the existing health system, health insurers are set up in the same way as any other insurers – they exist to distribute profits to the shareholders14.

It can sometimes look as if the health insurance company is more a keeper than a provider of the money of the insured, like an ever-watchful dragon seated on its hoard of gold.

The health insurance company will have to direct to direct itself more at making available the money needed or providing the care. With the necessary flexibility,
adapting to the different and changing wishes of the patients and tailored to their habits. The solidarity on which all insurance is built requires the commitment of money to those that need it at the time, and this is equally true of health insurance. The money now being paid in is used to pay for those who presently need it – the solidarity principle. The practice of hoarding has no place here, neither profit making. The premium goes up when the costs go up. Those who need something, should be seen in the context of the quality of life.

If the insurer forgets the solidarity principle, we would be better off putting our money in a sock in a safe in a cellar to which the most important people in our private lives have a key.

The government
The welfare state provides care for people who cannot function adequately as a result of physical or cognitive handicaps. The government worries about whether this will be financially viable in the future in the face of the double aging of the population. However, the ‘Wetenschappelijke Raad voor het Regeringsbeleid’ (in English: Scientific Board for Government Policy) found that this was more a problem of sharing between the richer and less wealthy elderly than of financing per se. The government will have to act as facilitator for the health insurer, the care organisations and the carers.

The government and the health insurers are closely interlinked – the government sets rules within which health insurers can collect money and spend it and, in the case of the AWBZ (in English: Chronically Sick and Disabled Persons Act), the government itself acts in the role of collector and financier, albeit by way of various regional care offices manned by the largest health insurer in the relevant region. In this case, everything written above about the health insurers is also true of the government. The AWBZ is a social insurance system – that is, it is also subject to the solidarity principle and money that comes in should also be spent now.

People are willing to spend a lot of money on their own health and care. Therefore the government should be willing to spend a lot of money for everyone whose health and care needs come under its remit.

The government also sets the rules for the while process of financing, all the way to the point of delivery of care. When talking about the government we are talking about money. From the macro budget that the government makes available, the facilities and provisions are paid for but also a large part of the personnel costs. Health care salaries are generally low, and salaries in the care of the elderly are amongst the lowest in the health care sector. If the salaries and their associated status were to rise, more people would remain in the care sector or seek a future within it.

Looking at the ‘right to care’ there is at the moment much that needs to be done in the Netherlands about indication for treatment and care dependency packages for the AWBZ. A patient is indicated by an independent official, who is bound by various rules, for a certain amount of a certain type of care, which is then set out in a care
dependency package. The care can then be provided by various organisations that have a contract with the regional care office. There is however another route available, namely a PGB. With a PGB, the patient makes a contract separately with a health care provider, though it is open to question whether a PGB, with all its rules and the burden of administration, is really appropriate to the sort of patient whose care forms the subject of this thesis. Then there is the problem of the ‘care gap’ – with the money that intramural organisations receive, they can prescribe less care than is prescribed in the indication. In other words, less care than the patient needs.

There is no reason to suppose that this care gap will disappear in the future as a result of any new financial rules. The care gap will also compel intramural organisations to agree with the patient and/or patient’s family about which care services will or will not be provided.

The government will have to play a facilitative, supportive and precondition-creating role for the care sector. It will have to provide room for flexible effort, adapted to the wishes and habits of the patients. To do this, they will have to ensure they are kept well informed by care organisations. Patient organisations also form a good source of information for this. In this way, the patient’s quality of life should be improved.

The government also has the role of a controller and supervisor of the care sector, both via inspection and by its power to set quality standards. It does the latter in consultation with, amongst other sources of information, groups of care organisations, and health insurers. This is how the ‘Standards for Responsible Care’ and the certification system like HKZ (‘Harmonisation of Quality Review in Health Care and Welfare’). Both these tests still consist primarily of protocol creation, the setting out of guidelines and data and providing insight to the patients and third parties about the care provided. There has been a lot of debate about this because the approach deals in a lopsided way with the quality of the organisation at the expense of the actual provision of care. To correct this imbalance, customer satisfaction studies have been used that offer more insight into the quality of care as experienced by the patients and their families.

The key word where all components that involve care is involved is ‘relationship’. A relationship is fed by communication. The precondition for providing care directed at the quality of life of the patient is good communication between the various actors.

To start with, good communication between the carer and the patient, the carer and the partner or family, the partner or family with the patient, and the partner and family amongst themselves. This takes place at the level of care provision itself.

Then a good relationship and communication is needed between managers and carers; between care organisations and the health insurer, the regional care office and the government. A good relationship between the government and health insurers and the patient and patient interest organisations.

Despite the range of modern communication technology available, it is personal contact which is important here. Only by meeting face to face nuances can be made apparent and the real issues become evident. The current regime of stimulated mar-
ket processes and competition make communication even more difficult because people are then influenced by their own interests and assume that others are influenced in the same way.

Openness is the only answer to this – let people know what you are doing, explain why you are doing it and say why you have chosen to do it one way rather than another. Similarly the other has to be open and have a positive fundamental attitude to provide together a good quality of life for those who can no longer look after themselves.

Regarding PDL care, I hope that this study will make a contribution to this openness and communication and that it can also serve as a basis for further study of the effects of PDL care on patient quality of life.

Within the care of the elderly, much has been developed by the carers themselves. It is passed on to others with the words ‘Do it like this and you’ll see that it works’. Pragmatic as he or she might be, the average carer has little interest in research: ‘It works. Can’t you see that?’ or ‘The patient likes it. That’s obvious, isn’t it?’ or ‘What’s so special about what we do here?’ However, to give the care of the elderly an equal place within the healthcare system, research will be needed. Not research into some medical tour de force, but into forms of demand-oriented care and into how to provide care demand-orientated.

And in so doing, reveal the knowledge such that it can be passed on to others.

*It’s not a matter of how old you get; it’s about how you get old.*

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