Care dependence and individual care provision

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Abstract

For policy purposes as well as for the provision of individual care, it is relevant to know which individual characteristics have impact upon the level of care dependence. For purposes of individual care provision, characteristics which can be influenced and which also have an important impact upon the care dependence are of interest. This study showed that the profoundly mentally handicapped are almost all totally dependent upon care, and therefore additional information about individual characteristics is superfluous. The results of logistic regression analyses showed a statistically significant and important impact of ADL-functions. Exactly which other characteristics are relevant to consider depends upon the level of care dependence and the level of mental handicap.

Introduction

The ultimate aim of care provision is to make the residents as independent as possible (i.e. integration in the community and normalization of people with mental handicap) by improving relevant skills. This aspect will be the focal point in this article. This in-

formation is also relevant regarding planning options, as elaborated in Maaskant *et al.* (1994).

One of the goals of Dutch care for people with mental handicap is to let residents function as independently as possible in order to improve their integration in the community and their normalization (a lifestyle based on normal rhythms of the day, week and year). The question is: Which characteristics influence (positively or negatively) the level of independency? These characteristics should be the major focus of attention of individual care provision when trying to improve independency.

Several other studies (e.g. Jacobson & Janicki 1985; Hoefnagel 1989; Janicki & Seltzer 1990) also described differences in the care needs of people with various individual characteristics. In the present research, the main goal is to study the clinical relevance of the characteristics which have the greatest impact on the level of care dependence.

In this regard, it is meaningful to consider to what extent various characteristics impact upon the persons's independence. Age and gender are not relevant because these characteristics can not be changed. On the other hand, challenging behaviour and ADL-functioning are much more relevant because these characteristics can be influenced, and therefore, demand special care.

Currently, the special needs of elderly residents are the topic of discussion in the care for people

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with mental handicap. It is often assumed that people with mental handicap will become increasingly dependent as they age. Although these people may have had varying levels of independence when they were young adults, they need more and more nursing/medical care as they age, despite a level of initial independence. In addition, elderly people with Down's syndrome may be considered as a special subgroup. They are extremely vulnerable to the development of Alzheimer-type dementia, which will lead to an increase of care dependence. Obviously, it is not age itself that determines the level of care needed. The physical and psychological infirmities of old age are also important when considering how much assistance is needed. In order to provide adequate care, an insight is needed into the care dependence of residents. It is also important to know which characteristics of the residents have the greatest impact upon care dependence. It is possible that a certain characteristic may be statistically significant but of little relevance [e.g. odds ratio (OR)=1.2]. Therefore, not only statistical significance but also relevance have to be considered.

The aim of this study is to determine which individual characteristics have the greatest impact upon care dependence. [In this context, great impact means a sufficiently large association measure ($OR \geq 2$ or $OR \leq 0.5$) and a sufficiently reliable determination of this measure.]

Additionally, those particular characteristics which can be influenced by intervention should be of interest. Unchangeable characteristics e.g. age, gender and the aetiological diagnosis (Down's syndrome versus other diagnoses) will only be involved in the analyses in order to determine whether other unknown factors exist which have an impact upon the care dependence and are associated with these unchangeable characteristics.

Materials and methods

Subjects

The University of Limburg and the Pepijn Foundation performed a 5-year prospective cohort study on ageing and mental handicap. The key-question of the study was: 'What are the implications of the

ageing population in institutions and group homes for people with mental handicap in terms of the need and provision of adequate care? The study contained one baseline measurement and three follow-up measurements for the period 1990–1994. All general institutions and group homes for people with mental handicap in the two southern provinces of the Netherlands, Noord-Brabant and Limburg, were asked to participate in the study. Almost all institutions (92%) and group homes (96%) for people with mental handicap participated in the study. One institution in the eastern part of the Netherlands also participated by its own request. In total, 24 institutions and 86 group homes were involved in the research. The individual participants of the study were selected by a stratified random sampling procedure. Stratification was by age, type of facility (institution or group home) and aetiological diagnosis (Down's syndrome versus other diagnoses). Aetiological diagnosis and age were included in the stratification to be certain that the relation between age and Down's syndrome could be sufficiently explored. In each institution, approximately 30 residents were selected in a stratified random sampling procedure; in each group home approximately 10 residents were chosen.

For each selected person, data were collected by means of two lists. The first, the medical list, was to be completed by the subject's physician; the second, the gerontological list, by the nursing-staff.

The medical list surveyed presence/absence of chronic diseases/handicaps, medication, referrals to medical specialists and referrals to other health care facilities. The gerontological list contained questions about dependence upon care, skills, behaviour, integration in the house and in the community, day-programmes, allocation of staff, structure of the group (number of residents, age and level of mental handicap), and transfer of residents to other facilities. In total, lists for 743 residents of institutions and 840 residents of group homes ($n=1583$) have been completed for the baseline measurement. In 56 cases (3.5%), the gerontological list was not completed. The medical list was not completed for 9.6% of the cases ($n=152$). At the time of submission of this article only data from the baseline measurement were analysed.

Data from 1424 subjects are included in the analyses.

Variables

Outcome variable

The outcome variable of this study was dependence on care. On the gerontological list, this question has five precoded answers:

- (1) needs intense care because of physical and/or psychological disorders (e.g. chronic illness, dementia, bedridden; minimal psychological, physical or social functioning);
- (2) needs close monitoring/care/treatment (physically and/or behaviourally) because of limited psychological, physical or social functioning;
- (3) has reasonable psychological, physical and social functions; needs some support, stimulation;
- (4) functions well but inconsistently in psychological, physical and social domains; needs support in complex tasks (e.g. financial matters, shopping);
- (5) is totally independent.

In the analyses, the dependence on care was clustered in three groups: (1, 2) dependent, (3) support, and (4, 5) independent. In order to obtain larger frequencies in the cells. Measurement of this item has been proved satisfactory in terms of reliability and validity (Hoefnagel 1969).

Independent variables

Both lists in the study (i.e. the medical and gerontological lists) referred to several items which can influence the dependence on care considerably (the independent variables). Table 1 shows the characteristics, and their operationalizations and explanations in more detail.

Methods

The analyses were performed for three levels of mental handicap: mild ($IQ \approx 50-80$), severe ($IQ \approx 20-50$) and profound ($IQ \approx <20$). This is done because it is likely that various characteristics have different impacts upon the care dependence, depending on the level of mental handicap.

A bivariate analysis was performed to investigate the association between the level of care dependence and the level of mental handicap. In order to study

the impact of individual characteristics on the level of care dependence, multivariate (logistic regression) analyses were performed with help of the BMDP-LR programme (Dixon *et al.* 1990). In logistic regression analyses, the influence of an individual variable (the independent variable) on an outcome variable (the dependent variable) is studied while controlling for other independent variables.

For the purposes of individual care provision aimed at intervention to improve independence, it is relevant to know which characteristics have a significant impact upon care dependence. In this respect, besides statistical significance, the actual impact of a characteristic is important.

The questionnaires of the study consist of characteristics which are supposed to be related to the care needed. Two categories can be distinguished with regard to the impact of characteristics on care dependence: variables which can be influenced by intervention and variables which cannot be changed by caregivers (i.e. gender, age and aetiological diagnosis). The latter two variables certainly are associated with the level of care dependence, as infirmities of old age do have a major impact upon this; elderly residents with Down's syndrome can be regarded as extremely vulnerable.

However, the associations between gender, age and aetiological diagnosis on the one hand and care dependence on the other can be explained by individual characteristics which have an impact upon the care dependence and which are also highly correlated with these unchangeable characteristics. Several of these individual characteristics are involved in the present study but others are unknown. In view of this, it was decided to analyse three models in which the odds ratio (OR) as provided by the logistic regression is presented as the association measure.

In the first model (extensive aetiological model), the fitting procedure starts with all independent variables that can be intervened upon. Thus, gender, age and Down's syndrome are excluded. In this part of the study, the analysis primarily concerns clinical relevance. Nevertheless, the association measures (i.e. ORs) have to be determined with sufficient reliability. Therefore, a backwards stepping procedure was performed in which only the variables which pass the 15% significance level are allowed to remain in the model.

Table 1 The research variables and their operationalizations

Characteristic	Operationalization	Explanation (scores and Cronbach's α)
Demographic aspects		
Age	Age in years	0=0-17, 1=18-29, 2=30-49, 3=50-59, 4=60+
Gender	Evident	0=male, 1=female
Aetiological diagnosis	Down's syndrome, other diagnoses	0=DS-, 1=DS+
Functional status		
Activities of daily life	Sum of scores on four items; bodycare, dressing, use of toilet and eating. Scores per item refer to the level of functioning and vary from 0 (1X) or 1 (3X) to 4	3-16, a high score indicates good ADL-functioning $\alpha=0.93$
Epilepsy	Seven different categories: no; simple partial seizures; complex partial seizures; secondary generalized seizures; absences; convulsive seizures; other seizures. Frequency of seizures	0=no, 1=yes, without falling, 2=yes, with falling (both 1 and 2 with insults with a frequency of at least once a month)
Cerebral palsy	Eight different categories: no; hemiplegia; diplegia; tetraplegia; ataxia; dyskinesia; dyskinesia/athetosis; others	0=no, 1=yes
Visual impairment	Five different categories: normal; normal with glasses/lenses; moderate; poor; progressive deteriorating	0=normal (eventually with glasses/lenses), 1=impaired
Hearing impairment	Five different categories: normal; normal with hearing aids; moderate; poor; not determined	0=normal (eventually with hearing aid), 1=impaired
Dementia	Four stadia: no; disorder in short-term memory/orientation, disturbance in new environment; disorder in long-term memory; orientation, disturbance in own environment/apraxia/incontinence/loss of skills/eventually epilepsy; bedridden/lethargic	0=no, 1=others
Psychiatric disorders	Affective disorders, organic disorders, schizophrenia, other non-organic disorders, neurotic disorders, personality disorders, and/or other disorders	0=no, 1=others
Hip dysplasia/luxation	Three different types: no; hip dysplasia; hip luxation	0=no, 1=yes
Chronic diseases*	Sum of diseases: endocrine disorders (i.e. hepatitis B, malignancies, diabetes, others); neurological disorders (i.e. muscular disorders, Parkinson's disease, Parkinsonism, tardive dyskinesia, others); cardiovascular diseases (i.e. congenital heart disease, hypertension, decompensatio cordis, angina pectoris, myocardinfarct, claudicatio intermittens, CVA (cardiovascular accident), other atherosclerotic disorders, arrhythmia), respiration disorders (i.e. chronic non-specific lung diseases, tuberculosis, other lung diseases); gastro-intestinal disorders (i.e. disorders of oesophagus/stomach, constipation, disorders of large intestine, disorders of liver/gallbladder, other disorders), disorders of urogenital system (i.e. kidney stones, recurrent infection of urinary tract, enlarged prostate, (post-)menopausal problems, other disorders, catheter), skin disorders (i.e. pressure ulcers, mycosis, acne, other disorders), musculoskeletal disorders (arthritis, arthrosis, disorder of back/neck)	0-39; indicating the number of present diseases $\alpha=0.54$
Mobility	Four different categories: not mobile (bedridden, at most sitting in a wheelchair/special chair); semi-mobile, limited radius of action (can only move with help of others/wheelchair); semi-mobile (more or less independent, uses walking stick, needs help by climbing stairs); mobile (independent, eventually uses cane)	1-4, a high score indicates good mobility
Incontinence	Five different categories: stoma care; is incontinent for urine and faeces; is continent, because s/he is ordered to go to the toilet; otherwise incontinent; continent (sometimes incontinent related to seizure activity); not incontinent	0-4, a high score indicates good bladder control

Table 1 (continued) The research variables and their operationalizations

Characteristic	Operationalization	Explanation (scores and Cronbach's α)
Psychological functioning	Sum of scores on 11 items: apathetic behaviour, maladaptive behaviour irritation, incoherent behaviour, being drowsy, fear, crying, rest during night, unhappiness, suspicious behaviour, appetite. Scores refer to frequency and varies from 0 or 1 to 4 or 5: almost always; often, in general once or more times a day; sometimes, in general once or more times a week; seldom, less than once a week	10–45, a high score indicates good functioning $\alpha=0.77$
Challenging behaviour	Sum of scores on nine items: self injurious behaviour, screaming, agitation, nagging, hurting others, stereotype behaviour (with objects, movements, sounds). Scores refer to frequency and vary from 1 to 4: almost always; often, in general once or more times a day; sometimes, in general once or more times a week; seldom, less than once a week	9–36, a high score indicates little challenging behaviour $\alpha=0.76$
Aggressive behaviour	Sum of scores on two items: threatens others, hitting others. Scores per item refer to frequency and vary from 1 to 4: almost always; often, in general once or more times a day; sometimes, in general once or more times a week; seldom, less than once a week	2–8, a high score indicates little aggressive behaviour $\alpha=0.59$
Orientation	Six different types: not applicable (s/he cannot move independently); no orientation; orientation varies; orientation only in the nearby environment; orientation also in environments, where s/he incidently is; orientation also in new environments	0–5, a high score indicates good orientation skills
Communication	Sum of scores on two items: can be understood by others; can make him/herself understood. Scores: 1–4 (good–poor)	2–8, a high score indicates good communicative skills $\alpha=0.81$
Memory	Sum of scores on six items: remembers familiar persons who s/he hasn't seen for a long time on a photo; knows the name of the house, knows where s/he has put something down (not longer than 5 min ago); remembers an order (given no longer than 5 min ago); remembers people who were introduced to her/him in the last few weeks. Scores (0–3) refer to frequency: (almost) always; sometimes; (almost) never; not to determine.	0–18, a high score indicates good memory $\alpha=0.92$

*Some remarks have to be made regarding chronic diseases. The intent was to include chronic diseases in the analyses. In order to avoid including 39 disorders as independent variables in the models, it was decided to construct one variable, albeit that the diseases and the severities are rather diverse. Consequently, Cronbach's alpha is low: 0.54.

In the second model (limited aetiological model), only the remaining variables of the first model which are judged to be clinically relevant (i.e. $OR \geq 2$ or $OR \leq 0.5$) are included.

After controlling for the variables of the second model, age, gender and Down's syndrome can still be strongly related to care dependence, as would be indicated by a high value of the OR. This would mean that unknown factors exist which impact upon the care dependence and which are also highly correlated with these unchangeable characteristics. To verify this, in the third model (intermediate model), the variables of the second model are included, as well as age, gender and aetiological diagnosis. These latter three characteristics are not allowed to be removed.

Results

Results of the bivariate analysis

Table 2 shows the study group according to the level of mental handicap and the level of dependence on care. The relationship between the level of mental handicap and the level of care dependence is statistically significant ($P < 0.01$).

Residents with profound mental handicap

The results show that two out of 95 people with profound mental handicap need support only, whereas the other residents need intensive care or close monitoring. Therefore, these residents are almost all totally dependent on care, regardless of any other in-

Table 2 Level of mental handicap according to level of dependence on care, absolute numbers (between brackets: percentages)

Level of care dependence	Level of mental handicap			
	Profound	Severe	Mild	Total
Independent	0 (0)	43 (6)	277 (42)	320 (23)
Support	2 (2)	245 (37)	313 (48)	560 (39)
Dependent	93 (98)	386 (57)	65 (10)	544 (38)
Total	95 (7)	674 (47)	655 (46)	1424 (100)

Tau = -0.564; SEM = 0.016; $P < 0.01$.

dividual characteristics. Consequently, additional information is superfluous and further analyses are irrelevant.

Residents with severe mental handicap

Only 6% of the severely mentally handicapped residents are more or less independent of care; more than one third of them need support, while the other residents (57%) need intensive care or close monitoring.

Residents with mild mental handicap

About four out of 10 of the mildly handicapped residents are more or less independent of care; 48% need support and only 10% are dependent.

Results of multivariate analyses

Following the bivariate analysis, the three multivariate models (extensive aetiological model, limited aetiological model and intermediate model) were analysed for the severely and mildly mentally handicapped residents, as explained in the 'Methods' section. The reference group of skills and handicaps is always the best performing category.

Residents with severe mental handicap

Because only 19 residents out of the 467 subjects are more or less independent of care, it was decided to dichotomize the variable dependence on care. The first category is 'needs intense care/needs close care, monitoring'; the second is 'needs support, stimulation/is more or less independent'.

In the extensive aetiological model, in which all intervening variables are included, only the characteristics ADL, psychiatric disease, psychological

functioning, chronic diseases and memory passed the 15% significance level. Residents with limited ADL-functions, a psychiatric disease, limited psychological functions or limited memory are more likely to be dependent on care than those without limitations in this respect. It is not easy to understand why those, having two or more chronic diseases, are more likely to come into a category of less dependency (OR = 0.6). The results also show that only ADL and psychological functioning have an OR of at least 2.¹ No characteristics with a significant impact have an OR less than 0.5. Thereafter, only these variables were included in the limited aetiological model. Table 3 shows the results of the three models. In the intermediate model, age, gender and Down's syndrome were also involved as well as the variables of the limited model (i.e. ADL and psychological functioning). It shows that elderly residents (50+ years) were more likely to be in a group of less intense dependency than young residents (0-17 years). Gender did not show any significant impact. People with Down's syndrome were more likely to be in a less intense category of care dependence than people with another aetiological diagnosis, while correcting for the other independent variables. Some comments about these results will be given in the 'Discussion'.

Residents with mild mental handicap

Needing support versus being independent. Table 4 shows the results for the mildly handicapped, com-

¹ADL is a continuous variable. For such variables, the formula to be used is: $OR_{X_2X_1} = \exp[\text{coeff}(X_2) - X_1]$. Therefore, the OR of a person with an ADL score of 10 (X_2) compared to someone with a score of 8 (X_1) is: $\{\exp[0.582(10-8)-3.2]\}$.

Table 3 Predictors for care dependence based on results of logistic regression analyses (extensive aetiological, limited aetiological and intermediate modes) for residents with severe mental handicap; being dependent versus needing support

Term	Extensive aetiological model ¹			Limited aetiological model ²			Intermediate model ³		
	P	OR	90% CI	P	OR	90% CI	P	OR	90% CI
ADL (continuous)	<0.01	1.79	1.62–1.98	<0.01	1.82	1.68–1.98	<0.01	1.88	1.70–2.07
Psychological functioning:									
limited (36–40) vs good (41+)	0.12	1.51	0.97–2.36	<0.01	2.06	1.37–3.11	<0.01	2.02	1.32–3.10
bad (–35) vs good (41+)	0.01	2.15	1.31–3.53	<0.01	3.58	2.33–5.48	<0.01	3.49	2.20–5.53
Psychiatric disease (yes/no)	0.04	1.64	1.11–2.43						
Chronic disease									
(1 versus 0)	0.32	0.77	0.49–1.20						
(2+ versus 0)	0.06	0.61	0.40–0.94						
Memory:									
limited (–16) versus good (17–18)	0.04	1.60	1.10–2.34						
Age:									
18–29 versus 0–17							0.47	0.73	0.36–1.49
30–49 versus 0–17							0.51	0.75	0.39–1.50
50–59 versus 0–17							0.06	0.45	0.23–0.89
60+ versus 0–17							<0.01	0.28	0.14–0.59
Gender (f/m)							0.95	0.99	0.69–1.42
Aetiological diagnosis (DS+/DS–)							0.07	0.65	0.45–0.96
Constant term	<0.01	0.13	0.08–0.20	<0.01	0.11	0.07–0.16	<0.01	0.20	0.10–0.40

¹Goodness of fit Chi-squared (Hosmer–Lemeshow)=5.06; d.f.=8; P=0.751.²Goodness of fit Chi-squared (Hosmer–Lemeshow)=4.68; d.f.=8; P=0.791.³Goodness of fit Chi-squared (Hosmer–Lemeshow)=2.84; d.f.=8; P=0.944.**Table 4** Predictors for care dependence based on results of logistic regression analyses (extensive aetiological, limited aetiological and intermediate modes) for residents with mild mental handicap; needing support versus being independent

Term	Extensive aetiological model ¹			Limited aetiological model ²			Intermediate model ³		
	P	OR	90% CI	P	OR	90% CI	P	OR	90% CI
ADL (continuous)	0.02	1.43	1.11–1.83	<0.01	1.60	1.25–2.05	<0.01	1.58	1.23–2.02
Epilepsy:									
without falling versus no	0.04	0.43	0.22–0.85	0.05	0.46	0.24–0.88	0.08	0.49	0.26–0.95
with falling versus no	0.98	0.99	0.52–1.88	0.38	0.73	0.40–1.32	0.57	0.81	0.44–1.49
Challenging behaviour:									
some (33–34) versus none (35+)	0.09	1.49	1.02–2.18						
much (–32) versus none (35+)	<0.01	1.83	1.26–2.68						
Orientation:									
limited (1–3) versus good (4+)	<0.01	1.88	1.33–2.65						
changing versus good (4+)	0.52	0.81	0.47–1.39						
Age:									
30–49 versus 18–29							0.77	0.64	0.42–0.98
50–59 versus 18–29							0.79	1.07	0.70–1.64
60+ versus 18–29							0.52	0.83	0.53–1.32
Gender (f/m)							0.67	1.08	0.79–1.48
Aetiological diagnosis (DS+/DS–)							<0.01	3.43	1.87–6.31
Constant term	<0.01	0.57	0.41–0.77	<0.11	0.94	0.78–1.12	0.75	0.94	0.66–1.32

¹Goodness of fit Chi-squared (Hosmer–Lemeshow)=3.06; d.f.=8; P=0.930.²Goodness of fit Chi-squared (Hosmer–Lemeshow)=11.2; d.f.=7; P=0.130.³Goodness of fit Chi-squared (Hosmer–Lemeshow)=9.47; d.f.=8; P=0.305.

Table 5 Predictors for care dependence based on results of logistic regression analyses (extensive aetiological, limited aetiological and intermediate models) for residents with mild mental handicap; being dependent versus needing support

Term	Extensive/Limited aetiological model ¹			Intermediate model ³		
	P	OR	90% CI	P	OR	90% CI
ADL (continuous)	<0.01	2.66	1.88–3.76	<0.01	2.70	1.88–3.88
Epilepsy:						
without falling versus no	0.34	2.17	0.56–8.36	0.34	2.31	0.54–9.83
with falling versus no	0.04	3.06	1.22–7.70	0.03	3.50	1.33–9.25
Psychological functioning:						
limited (36–40) versus good (41+)	<0.01	5.18	2.16–12.38	<0.01	6.00	2.43–14.82
bad (–35) versus good (41+)	<0.01	24.75	8.36–73.31	<0.01	30.39	9.77–94.54
Psychiatric disease (yes/no)	<0.01	3.47	1.80–6.71	<0.01	4.00	2.01–7.99
Challenging behaviour:						
some (33–34) versus non (35+)	0.08	2.82	1.07–7.45	0.09	2.75	1.03–7.39
much (–32) versus none (35+)	0.58	0.71	0.25–1.96	0.44	0.61	0.22–1.72
Age:						
30–49 versus 18–29				0.20	0.50	0.21–1.21
50–59 versus 18–29				0.16	0.49	0.21–1.14
60+ versus 18–29				0.40	0.63	0.25–1.56
Gender (f/m)				0.97	1.02	0.54–1.90
Aetiological diagnosis (DS+/DS–)				0.27	1.92	0.72–5.17
Constant term	<0.01	0.01	0.00–0.03	<0.01	0.01	0.00–0.04

¹Goodness of fit Chi-squared (Hosmer–Lemeshow)=3.76; d.f.=8; P=0.878.²Goodness of fit Chi-squared (Hosmer–Lemeshow)=2.10; d.f.=8; P=0.9780.

paring those who need support to those who are independent.

In the extensive aetiological model, the following characteristics passed the 15% significance level: ADL, epilepsy, challenging behaviour and orientation. Limited ADL-functions, challenging behaviour and limited orientation skills are indicators for needing support. Those who have epilepsy without falling are surprisingly more likely to be independent than those without epilepsy. However, only ADL² has an OR of at least 2 and epilepsy has an OR less than 0.5. Consequently only ADL and epilepsy were included in the limited aetiological model. In the intermediate model, age, gender and aetiological diagnosis were also entered. Only aetiological diagnosis showed a significant impact (OR=3.4).

Being dependent versus needing support. Table 5 shows the results for people with mild mental handicap who are dependent versus those who need support.

²A difference in ADL-score of two results in an OR of 2: {exp[0.355(2)]=2.04}.

The extensive aetiological model shows that limited ADL, having epilepsy, having limited or bad psychological functions, having a psychiatric disease and showing challenging behaviour are indicators for being dependent upon care, while correcting for the other characteristics. All these characteristics have an OR larger than 2, so the extensive and limited aetiological models are the same. After analysing the intermediate model, it became apparent that age, etiological diagnosis and gender have neither a significant nor a relevant impact upon the dependence on care once other variables are included. The other characteristics still have important impact upon the outcome (dependence on care).

Discussion

This article concerns the impact of individual characteristics upon care dependence with respect to individual care provision. The purpose of the study was to find out which individual characteristics have an independent impact upon care dependence and are amenable to change. The results for people with

severe mental handicap (Table 3) show that limited and bad psychological functioning and poorer ADL-functions are significant and important indicators for being dependent on care. Besides these characteristics, it shows that aetiological diagnosis (Down's syndrome versus other aetiological diagnoses) has a significant influence on care dependence ($OR=0.65$). Older (60+ years) residents are much less likely ($OR=0.28$) to be dependent than young residents.

When distinguishing people with mild mental handicap who need support from those who are independent, the results show that limitations in the ADL-functions, as measured in this study, are indicators for needing support (Table 4). Surprisingly, people with epilepsy (without falling) are less likely to need support than those without epilepsy.

The extensive aetiological model for people with mild handicap (comparing residents who are dependent on care to those who need support) shows that several individual characteristics (i.e. limited ADL-functions, epilepsy, limited or bad psychological functions, presence of a psychiatric disease and challenging behaviour) are indicators for being dependent upon care (Table 5). After adding age, gender and the aetiological diagnosis to this model, it appears that these unchangeable characteristics show neither a statistically significant nor an important impact upon the level of care dependence. As in this study, the findings of Halloran (1985) indicate that ADL-functions are good predictors for care dependence. The latter study showed that nursing workload is predicted better by a patient's nursing condition (e.g. incontinent and non-ambulatory) than by the medical condition. In order to improve the level of independence of residents, it seems advisable to improve the ADL-functions. Other characteristics to be taken into consideration depend upon the level of mental handicap and on the level of care dependence one wants to predict (Tables 3–5). Some characteristics did not show a major impact on the level of care dependence. However, rather rare conditions (e.g. cancer, diabetes and pressure ulcers) are of importance in dealing with individual needs, of course. Because of the low prevalence even in this rather large sample, these characteristics did not show statistical significance. Of course, such cases need extra care.

The results for the group of severely handicapped show that the residents with Down's syndrome are more likely to be in a category of less care dependence than those with another aetiological diagnosis (Table 3). In the group of mildly handicapped, on the other hand, residents with Down's syndrome are more likely to need support than being independent of care than residents without Down's syndrome (Table 4). It seems reasonable to conclude that residents with Down's syndrome are, in general, the least dependent in the group of severely handicapped and the most dependent within the group of mildly handicapped, correcting for the other variables of the models concerned. The results of the severely mentally handicapped also show that elderly (60+ years) residents are less dependent on care than young residents (0–17 years), correcting for characteristics of ADL and psychological functioning. This possibly can be explained by cohort effects (only relatively healthy persons reach old age) and a shift in admission policy (currently primarily young people with multiple handicaps are admitted).

Surprisingly, the results show that people with severe mental handicap having 2 or more chronic diseases are more likely ($OR=0.6$) to be less dependent on care than those having no chronic diseases. Similarly, the results show that mildly mentally handicapped residents having epilepsy without falling are more likely ($OR=0.4$) to be more independent than residents without epilepsy. It was expected that the risk would be much larger than one, rather than being smaller than one. An explanation for these findings could be that residents with these infirmities are less active, and therefore, less difficult to handle, consequently being more likely to be regarded as less dependent. Such phenomena have been observed in a Dutch study in nursing homes: fewer staff are needed for patients who are completely bedridden than for patients who are slightly less handicapped. Apparently, the lack of mobility results in the need for less supervision (van Drunen & van Montfort 1981).

It has to be stressed that the study group consists of residents of institutions and group homes only. Only 40% of people with mental handicap in the Netherlands live in general institutions or group homes. Further studies will have to investigate whether these results are applicable to people with

mental handicap who live elsewhere (e.g. with their families or independently). In addition, there is a need to study to what extent ADL-training actually improves the independence of care.

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References

- Dixon W.J., Brown M.B., Engelman L. & Jennrich R.I. (1990) *BMDP Statistical Software Manual*, Vol. II. University of California Press, Berkeley, CA.
- Drunen P.H.C. van & Monffort A.P.W.P. van (1981) Een analyse van de kostenstructuur van verpleeghuizen in Nederland. *Gezondheid en Samenleving* 2, 246-65.
- Halloran E.J. (1985) Nursing workload, medical diagnosis related groups, and nursing diagnoses. *Research in Nursing & Health* 8, 421-33.
- Hoefnagel C.W. M. (1989) *Oud en Zwakzinnig*. Swets & Zeitlinger, Lisse.
- Jacobson J.W. & Janicki M.P. (1985) Clinical need variations of disabled persons residing in group homes. *Journal of Community Psychology* 13, 54-66.
- Janicki M.P. & Seltzer M.M. (eds) (1990) *Aging and Developmental Disabilities: Challenges for the 1990s*. Special Interest Group on Aging, American Association on Mental Retardation, Washington, DC.
- Maaskant M.A., Kessels A.G.H., Frederiks C.M.A., Haveman M.J., Schrojenstein Lantman-de Valk H.M.J. van, Urlings H.F. & Sturmans F. (1994) Care dependence and services planning. *Journal of Intellectual Disability Research* 38, 299-315.

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