

# Informal care in the Netherlands

## A situational sketch of informal caregivers reached via Informal Care Centres

Job van Exel  
Bernard van den Berg  
Trudi van den Bos  
Marc Koopmanschap  
Werner Brouwer



institute for Medical Technology Assessment (iMTA)

Erasmus MC, Rotterdam

iMTA report 02.58b



National Institute of Public Health and the Environment (RIVM), Bilthoven  
RIVM rapport 282701003

December 2002

# INFORMAL CAREGIVERS

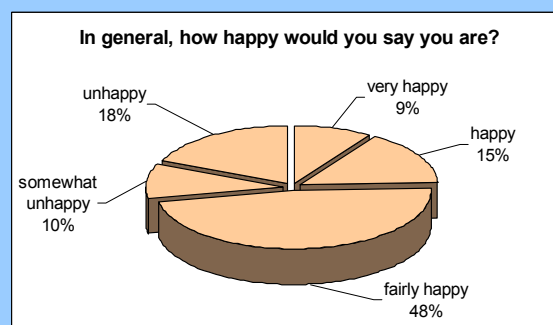
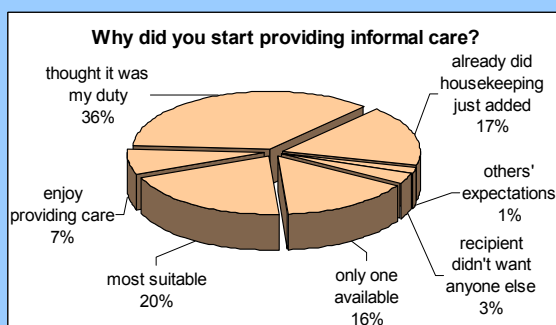
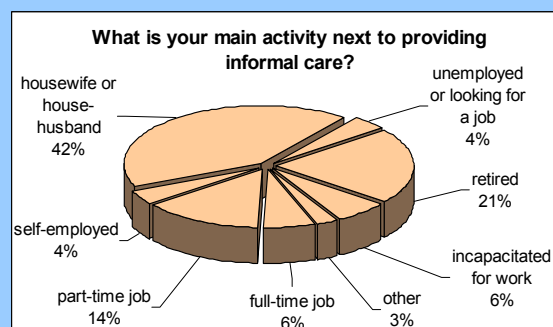
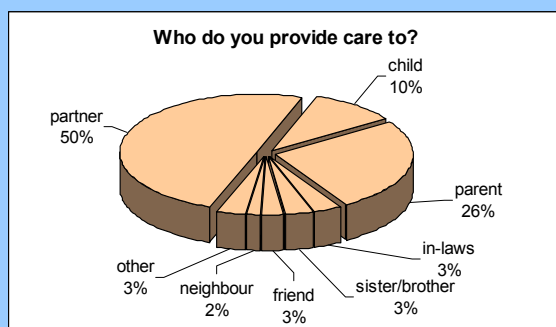
Informal care is a very important form of care. There are approximately 1.5 million informal caregivers in the Netherlands. Despite this large number, little is known about those providing this important service. To address this lack of knowledge, Erasmus University Rotterdam, in collaboration with the National Institute of Public Health and the Environment (RIVM) and the regional Informal Care Centres, carried out a study of informal care in the Netherlands. This is the first study of any size in the Netherlands to survey both the providers and recipients of informal care. A total of 950 informal caregivers took part in the study, which was carried out between November 2001 and February 2002. This report presents some first results.

*Informal caregivers are family members, friends, neighbours or acquaintances who, without payment, take on part of the task of caring for a person who is in need of care.*

The majority are retired (21%) or are housewives/house-husbands (42%). Of this latter group, approximately 15% have given up work in order to be able (to continue) to provide care. The majority of informal caregivers with paid jobs are reasonably well able to combine work and care tasks, though between 10% and 20% experience tensions between care tasks and work. This latter group state that they have less energy for their work, have lost too many working days through having to provide care, are sometimes dissatisfied about the quality of their work, worry about the recipient of their care during working time, regularly have to arrange things for the care recipient during working hours, and sometimes report sick in order to be able to provide care. Generally, employers are sympathetic to their situation. Informal caregivers who are also the breadwinner, who work full-time or are self-employed, or who have fixed working hours, experience the most problems.

Informal caregivers are often women (77%) and married (76%). The informal care is usually provided at home (59%) for a member of the informal carer's family (86%). A sizeable proportion of informal caregivers (38%) have children living at home. One in four informal caregivers perform paid work on a part-time, full-time or self-employed basis in addition to carrying out their care tasks.

The informal caregivers who took part in this study are generally in good health, regard their present income as adequate and feel reasonably happy. However, there are wide differences between individual caregivers. For example, one in five informal care-providers are unhappy, and while it can be said that many informal caregivers experience few problems with their care tasks, for a small group there are major difficulties.



# CARE RECIPIENTS

In order to obtain a clear picture of informal care in the Netherlands, it is of course important to listen to those who receive it. This we did, via the informal caregivers. A total of 552 care recipients of informal care took part in our study; this figure was much lower than the number of informal caregivers because many care recipients are too young, too old or too ill to complete a questionnaire.

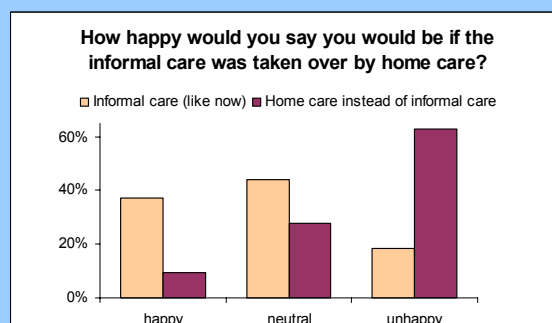
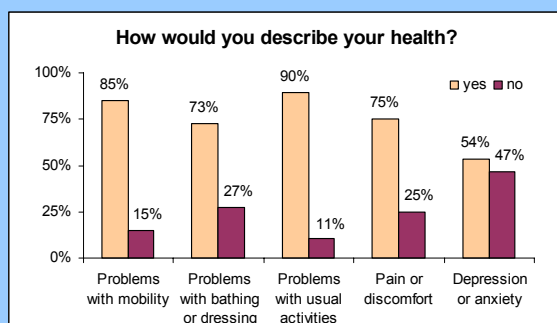
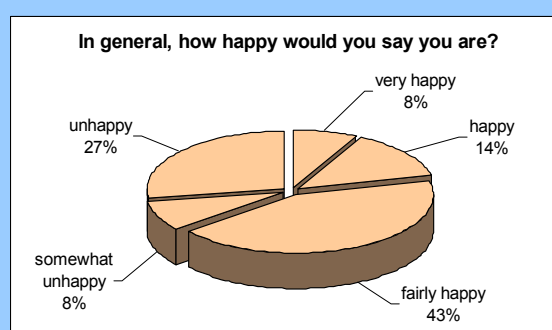
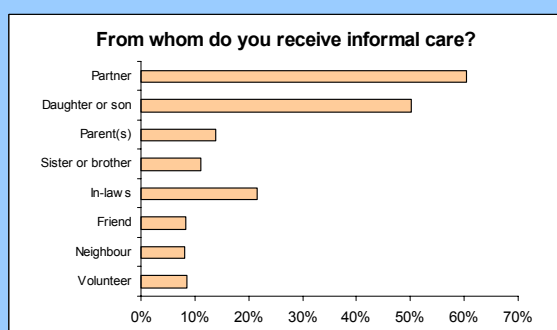
The majority of care recipients are aged over 60 (69%) and married (64%). One in five is a widow or widower. Roughly half are retired, while one in four are unfit for work. The numbers of men and women receiving care are roughly equal.

*"I have worked hard all my life and I really hate being dependent on others. But it's wonderful that my family gives me so much support and helps me to continue living at home. I couldn't imagine being shut away in an institution ..."*

The most commonly cited reasons for needing informal care were hip or knee arthrosis (32%), the consequences of a stroke (23%), dizziness and falling (23%), depression (20%), a chronic disorder of the neck or shoulder (19%), of the elbow, wrist or hand (19%), back injury or

hernia (18%), and dementia or Alzheimer's disease (16%). Roughly one in three care recipients suffers from one disorder, but the vast majority have to cope with two or more disorders. The average health status of the care recipients is moderate.

Their health problems limit the activities of care recipients, and they therefore state that they need support with household activities (55%), personal care (42%), organisational matters (58%) and mobility outside the home (44%); social support is also very important (59%). Care recipients are dependent for this support on informal caregivers, home care services and private help. More than one in three recipients of care are totally dependent on informal care, while around one in five depend on just one informal carer. Roughly half the recipients of care receive home care services for an average of six hours per week, and 5% are on the home care waiting list. The quality of home care services is assessed by the vast majority as good to very good. In addition, one in five care recipients receive private help, for an average of eight hours per week.



# CARE TASKS & SUPPORT

For many informal caregivers, the task of caring for someone takes up a large slice of their life. On average informal caregivers provide care for nine years. They spend seven hours a day providing care, and often seven days a week. The most important care task is support with household activities, such as doing the shopping, preparing meals and drinks, cleaning the house and doing washing. In addition, social support (chatting, comforting, etc.) and providing help in contacts with health care professionals (such as a visit to a doctor or hospital) are also important. Informal caregivers with children at home or who provide care for someone who has children spend a considerable proportion of their time caring for those children. Informal caregivers who live in the same home as the care recipients take on the most care tasks and also spend the most time on them by a clear margin, providing care for an average of nine hours per day. Most of this

additional time is spent in providing social support. Informal caregivers who do not live in the same home as the recipient spend an average of 40 minutes travelling to the recipient.

Roughly two out of three informal caregivers receive support from other informal caregivers or domestic helpers. If the provider and recipient of the informal care share the same home, other informal caregivers are less likely to be present but there is more likely to be domestic help. Around 30% of care recipients state that they would like extra help from informal caregivers,

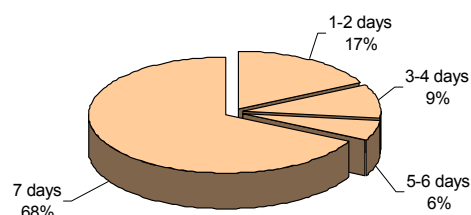
domestic helpers or home care, with a clear preference for informal caregivers or home care and, to a lesser extent, domestic help.

*"The rest of my family leave the job of providing care entirely to me. They say: you live close by and you don't work. Maybe, but I do have four school-age children, you know!"*

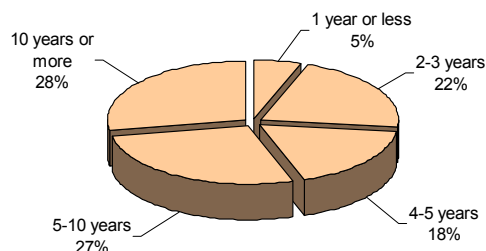
Some informal caregivers have given up work entirely or partially in order to provide care. This reduces their income. Many of them also incur

additional expenses as a result of providing care. Three out of four informal caregivers consequently feel that they should receive financial help from the government to cover the care they provide and the costs they incur.

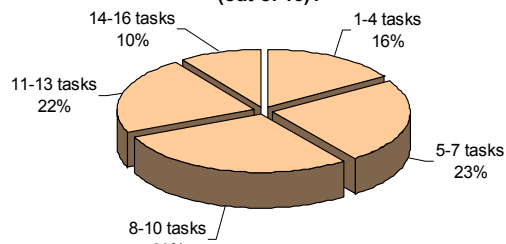
How many days a week do you provide care?



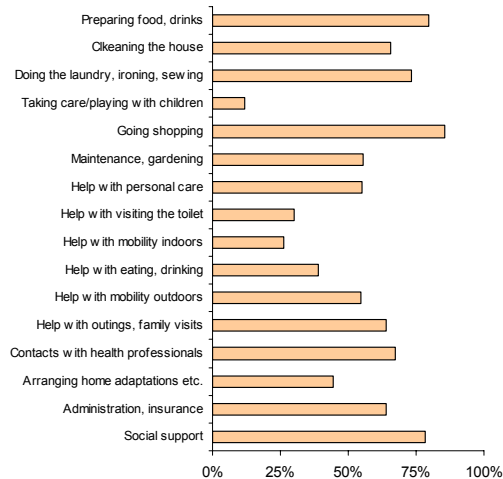
How long have you been providing care?



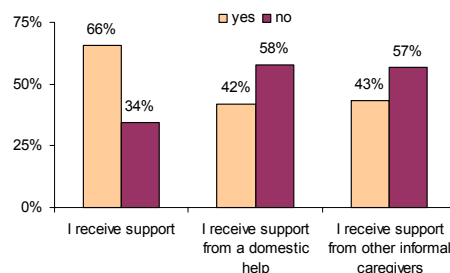
How many care tasks do you perform (out of 16)?



Which tasks do you perform?



Do you receive support in providing care?



# BURDEN & RESPITE

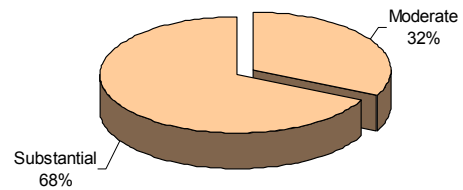
Providing care imposes a considerable burden on many informal caregivers. No fewer than two in five state that providing the care is a (much too) heavy task. And according to an objective criterion, providing care imposes a 'considerable burden' on two out of three informal caregivers.

On the other hand, providing care gives many informal caregivers satisfaction. Half indicate that they would rather not hand over the care task to someone else, even if they were able to select the person themselves and that person were to provide all the care needed free of charge. Possible explanations for this may be that many informal caregivers think - not incorrectly, as happens - that the care recipient would not like this and, to a lesser extent, because in the reverse situation, if they were the care recipient, they would themselves not like this. How happy informal caregivers feel depends both

on the burden the care imposes on them and the satisfaction they derive from providing that care. Both caregivers and recipients assign a score of 6.2 out of 10 to their current care situation.

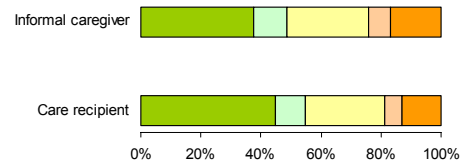
Great emphasis is often placed on the importance of respite care as a means of enabling informal caregivers to continue providing the care for longer and more effectively. The majority of informal caregivers who took part in this study stated that they desired support, to share the burden of care with other informal caregivers, or occasionally to be completely free of their care task. Half would like more information or psychological or emotional support from professionals, or would occasionally like to talk to others in the same situation. A large group would like to keep part of a day free on a regular basis, for example to pursue a hobby. An occasional weekend or week off, or being of to go on holiday free of worry once a year for two weeks (with or without the care recipient) is also high on their list of wishes. Some informal caregivers would like to hand over the care task entirely, for example by having the care recipient admitted to a nursing home. If the informal care were to reduce or cease altogether, informal caregivers would like to spend the resultant free time mainly on more leisure activities or hobbies (71%). A small proportion would like to spend more time on paid or unpaid work.

How burdensome is the care you provide?



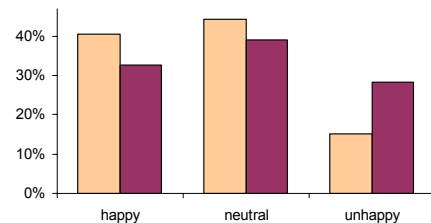
Proposition: I would find it unpleasant if my informal care tasks were taken over free of charge by a person I selected myself

■ totally agree ■ agree ■ neutral ■ disagree ■ totally disagree



How happy would you say you would be if the informal care was taken over completely?

■ Informal care (like now) ■ Informal care taken over



The burden imposed by providing informal care is heavier for informal caregivers who:

- are caring for a partner or child;
- live in the same house as the care recipient;
- provide informal care for longer periods or for several days a week;
- are (relatively) young;
- have financial problems;
- have (relatively) poor health and experience (physical) difficulty in carrying out their daily activities;
- began providing informal care because they felt it was their duty or thought it would be expected of them by others;
- have given up work in order to provide informal care;
- experience a heightened degree of tension between paid work and informal care;
- are caring for someone with psychological disorders or, in particular, a combination of physical and psychological disorders.



During the study we received many reactions from informal caregivers via the special telephone number that had been set up and via the questionnaires. A small selection of these reactions is given below:

*"After 23 years the end of my period of providing informal care is coming in sight. I hate to say it, but I'm looking forward to it already."*

*"... in many cases the burden of care falls on the shoulders of the partner or other members of the household. They take on the burden as a matter of course and aren't even aware that they are informal caregivers. A bit of financial support from the government, simply because help is being provided, wouldn't go amiss, so you could afford a few extras now and again..."*

*"The only thing I want is for my son to get better."*

*"The various organisations associated with the personal budget scheme took almost three years to discover what my problem was as an informal carer. The bureaucracy and regulations you have to get through to obtain the right kind of care is so enormous that as an informal carer it's more than I can cope with... I know that taking the recipient of the care as the starting point is a hot issue, but the reality is really very different."*

*"Sorry, but I really think these are such stupid questions; I would say, come and spend four weeks doing this yourself."*

*"... a house friend for him."*

*"It would be really good if there was someone on call for emergencies."*

*"In your head you are never really free of the problem."*

*"I don't know if I'm now an informal carer. My husband has been in a nursing home since January 2001, in the psychogeriatric ward. Shortage of staff means I have to go there every day to visit my husband and do all sorts of things for him."*

*"I received your questionnaire on informal care. I also received your letter of 30 November 2001, in which you urgently request me to fill it in. I can understand your request, because this is obviously very important. Unfortunately, ... the tank was just about empty."*

*"As an informal carer I can't find the time to fill in your questionnaire, nor to help my friend to do it. I realise the importance of the survey, but I have other priorities."*

*"... am happy if I have a few minutes when I don't have to do something."*

*"... I would like to say that the informal care organisation in our town spends a lot of time, money, etc. on itself, but that informal caregivers and those they care for don't derive much benefit from it in practice, because there's no concrete help. All you get are requests to attend meetings, contact with other informal caregivers during office hours, etc."*

*"I'd like to be able to spend just one day going carp fishing again; it's five years since I've been able to."*

This report was compiled by Erasmus MC, institute for Medical Technology Assessment (iMTA), in collaboration with the National Institute of Public Health and the Environment (RIVM). No part of this publication may be reproduced without the written consent of iMTA. The data were collected between November 2001 and January 2002 in collaboration with the regional Informal Care Centres (Steunpunten Mantelzorg) affiliated to the Xzorg organisation. Our thanks go to all recipients and providers of informal care who took the time to take part in this survey. The study was funded by the Netherlands Organisation for Health Research and Development (ZonMw) (project number 945-10-044). Copies of the report can be downloaded from: [www.bmq.eur.nl/imta/reports](http://www.bmq.eur.nl/imta/reports)

Further information may be obtained from: Job van Exel  
Erasmus MC – iMTA, Postbus 1738, 3000 DR Rotterdam  
Telephone: +31-10- 408 25 07. Email: [vanexel@bmq.eur.nl](mailto:vanexel@bmq.eur.nl)

Correct source reference: NJA van Exel, B van den Berg, GAM van den Bos, MA Koopmanschap, WBF Brouwer. Informal care in the Netherlands: A situational sketch of informal carer-providers reached by Informal Care Centres. iMTA report no. 02.58b and RIVM report 28270 1003. Rotterdam: Erasmus MC. 2002.