

# Caregiver burden (from the perspective of the client with a substance use disorder) and the amount of pleasant activities undertaken

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Status paper	Final version
Date	28 <sup>th</sup> June 2018
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Target journal	The American Journal on Addictions; Am J Addict.
Criteria for reporting	STROBE checklist: Strengthening the Reporting of Observational Studies in Epidemiology
Reference style	Vancouver Reference Style
Word count paper	3.630
Word count abstract	299
Word count samenvatting	296

## Caregiver burden (from the perspective of the client with a substance use disorder) and the amount of pleasant activities undertaken

### ABSTRACT

**Background:** The importance of informal caregiver (here after: caregiver) is growing. Balancing the burden of care giving and pleasant activities is essential. For better outcomes of addiction treatment, the role of the social network, and therefore of the caregiver, is of great importance. However, people with a substance use disorder (SUD) have a tendency to undertake less pleasant activities than people without a SUD.

Unknown is whether the burden experienced by the caregiver, from the perspective of clients with a SUD, has an influence on the number of pleasant activities undertaken together.

**Aim:** To determine the correlation between the experienced burden of the informal caregiver, from the perspective of clients with a SUD, and the amount of pleasant activities undertaken with and without the caregiver.

**Method:** Between February and May 2018, a quantitative survey was conducted, among clients with a SUD. An estimation of the burden experienced by the caregiver was measured with an adjusted Caregiver Reaction Assessment–Dutch and the amount of pleasant activities with the Pleasant Activities List. A total of thirty-one clients participated.

**Results:** No significant relation was found between the estimated burden and the amount of pleasant activities undertaken with ( $r=0.09$ ,  $p=0.63$ ) or without the caregiver ( $r=-0.10$ ,  $p=0.60$ ). Significant relations were found between the amount of activities with and without the caregiver ( $r=0.79$ ,  $p=0.00$ ). No significant relation was found between clients who lived together with the caregiver and the estimated burden ( $p=0.48$ ).

**Conclusion:** In this study the number of pleasant activities that are undertaken with the caregiver, does not depend on the estimated burden.

**Recommendations:** Recommendations would be to analyse the social system of clients to see if they have a social network and how these social contacts are involved in the lives of the client.

**Keywords:** Informal caregiver, burden, pleasant activities, substance-related disorders.

## **Draaglast van de mantelzorg vanuit het perspectief van een cliënt met verslavingsproblematiek en het aantal ondernomen plezierige activiteiten**

### **SAMENVATTING**

**Achtergrond:** De zorg in Nederland is verschoven van de overheid naar het sociale netwerk van mensen. Als de persoon die zorg nodig heeft, een psychiatrische of psychosociale aandoening heeft, bijvoorbeeld een verslaving, is de kans op overbelasting van de mantelzorg groter. Het ondernemen van plezierige activiteiten kan dit verminderen. Mensen met verslavingsproblematiek zijn geneigd om minder plezierige activiteiten te ondernemen omdat er meer focus is op druggebruik. Samen plezierige activiteiten ondernemen, zou voor beide partijen positieve ervaringen kunnen geven. Onbekend is of de ervaren draaglast van de mantelzorg invloed heeft op het aantal activiteiten dat samen wordt ondernomen.

**Doel:** Onderzoeken of er een relatie is tussen de geschatte draaglast van de mantelzorg, vanuit het perspectief van iemand met verslavingsproblematiek, en het aantal plezierige activiteiten dat samen wordt ondernomen.

**Methode:** Een cross-sectioneel, kwantitatief onderzoek, waarbij een vragenlijst is afgenomen tussen februari en mei 2018, bij cliënten met verslavingsproblematiek. De geschatte draaglast is gemeten met een aangepaste Caregiver Reaction Assessment–Dutch en het aantal plezierige activiteiten met de Pleasant Activities List. De vragenlijst werd door 31 mensen ingevuld.

**Resultaat:** Uit het onderzoek kwam naar voren dat er geen significante relatie is tussen de geschatte draaglast en het aantal ondernomen activiteiten met ( $r=0.09$ ,  $p=0.63$ ) of zonder de mantelzorg ( $r=-0.10$ ,  $p=0.60$ ). Tussen plezierige activiteiten met en zonder de mantelzorg was een significante relatie ( $r=0.79$ ,  $p=0.00$ ). Er was geen significant verschil tussen de geschatte draaglast en het samenwonen met de mantelzorg ( $p=0.48$ ).

**Conclusie:** Het aantal plezierige activiteiten dat samen met de mantelzorg wordt ondernomen, hangt niet af van de geschatte draaglast van die mantelzorg.

**Aanbevelingen:** Het wordt aanbevolen om het sociale netwerk van de client in kaart te brengen en te onderzoeken hoe het sociale netwerk wordt betrokken in het leven van de cliënt.

**Trefwoorden:** Mantelzorg, verslaving, plezierige activiteiten, draaglast.

## INTRODUCTION

Drug (ab)use is a worldwide phenomenon. It is estimated that a quarter of a billion people used drugs in 2015.<sup>1</sup> For 0.6 percent of these people, that is 29.5 million people, the drug usage is problematic. This means that these people suffer from a drug use disorder, which includes (but is not limited to) drug dependence.<sup>1</sup>

Approximately 65.000 people in the Netherlands sought help at specialized health centres for their drug use in 2015.<sup>2</sup> Since 2011, a decreasing trend has been seen in the number of people looking for specialized addiction care. However, this does not mean that there are fewer people with an addiction.<sup>2</sup> The amount of people who seek anonymous treatment on the internet has increased, and this does not fall within specialized addiction care.<sup>2</sup>

The healthcare law in the Netherlands changed in 2015, the management of care was transferred from the central government to the local governance.<sup>2-4</sup> The Social Support Act (Dutch: Wmo 2015) focuses on strengthening the participation of the social network of people who are not self-reliant. This means that the role of informal caregivers has become more important.<sup>4</sup>

More than four million people provided informal care to a family member, partner, neighbour or friend in 2014 in the Netherlands.<sup>3</sup> The care given can be diverse, from emotional support, transportation or companionship to more intensive care, such as bathing and dressing up. Giving informal care to a family member, neighbour or friend can be satisfying, but also has its downsides. The informal caregiver (here after referred to as caregiver) can experience difficulties letting the situation go or struggling with fatigue.<sup>3</sup> Balancing the burden of caregiving is essential. According to the Netherlands Institute for Social Research (SCP), approximately 400.000 (9.5%) caregivers are overburdened.<sup>3</sup> The burden is especially high when the person cared for is a partner, child or parent, when the person has psychiatric or psychosocial problems, is aggressive or asks for a lot of attention.<sup>3</sup> If the caregiver is a family member, it is mentioned that tensions, such as anger, guilt, shame, financial strain, physical effects of stress, worry and a reduced quality of life, affect the caregiver's burden.<sup>5-9</sup> Research suggests that several risk factors may increase the burden of the caregiver, such as age, living together with the care recipient, social isolation and financial stress.<sup>10,11</sup> Despite the risk of overburdening the caregiver, positive sides are also seen.<sup>12</sup> Caregivers encounter positive experiences by helping another and enjoy pleasant moments with the person they care for.<sup>3,13</sup>

However, several studies show that people with a substance use disorder (SUD) have a tendency to undertake fewer pleasant activities than people without a SUD.<sup>14-18</sup> To change the mind-set of a person with a SUD, from a drug-centred environment to an environment without drugs, it is important to promote the frequency of activities that are not drug-related, but still positively affect the pleasure-rewarding system.<sup>19-27</sup> Modifying the environment seems essential in the treatment of people with a SUD.<sup>28,29</sup> Activities that could help change the mind-

set of people with a SUD should be behavioural reinforcing and have a short reinforcement schedule.<sup>14</sup> Involving the social network in the treatment of people with a SUD, and therefore the caregiver, has positive effects on the outcomes of treatment.<sup>30–33</sup> However, involving the social network can be difficult as people with a SUD seem to have insecure attachment and have less effective help-seeking behaviour, including an underuse of social support.<sup>34–36</sup>

Clinical experience from the researcher confirms these difficulties in reaching the social network of clients with a SUD. In general, there seems to be an understanding of the role of the social network and the importance of involving it in treatment. However, reluctance to apply this to their own person is common, as is willingness for the involvement of their personal social network. On exploring various ways to reach these social networks there are multiple hurdles and reasons that can prevent involvement. Common reasons given are a lack of a social network all together; the social network is not interested or too busy; the social network has given up on them or is not aware of their addiction. Shame and feelings of rejection from a community or from family members, may contribute to a reluctance to involve family members or the social network.<sup>7</sup>

Therefore, this study will focus on the perspective of people with a SUD and the way in which they see the burden of their caregiver, so the caregiver does not have to be approached. It will also consider whether their view of the burden of their caregiver is related to the number of pleasant activities they undertake with their caregiver.

## **AIM**

The aim of the current study was to determine the correlation between the burden experienced by the informal caregiver, from the perspective of clients with a substance use disorder, and the number of pleasant activities undertaken with and without the informal caregiver.

## **METHOD**

### **Design**

The study was conducted as a quantitative, descriptive, cross-sectional study. Data collection was done on one specific moment without a follow-up. This design made it possible to gain insight into whether there was a relationship between the perspective of the client about the burden of the caregiver, and the number of pleasant activities undertaken with the caregiver at one given time.

### **Setting and participants**

The study population consisted of adults with a SUD, who received treatment at a specialised addiction care facility. The sample was taken from a specialised addiction care facility in the north of the Netherlands, Verslavingszorg Noord Nederland (VNN). Data was collected from

February 2018 to May 2018. Recruitment was performed in both inpatient and ambulatory care departments. Participants were eligible if they were 18 years or above, were diagnosed with a SUD according to DSM-5 criteria, able to read and speak Dutch and received care from an informal caregiver. Participants were excluded if they had an active psychosis, had aggressive behaviour and/or suicidal tendencies.

Ten departments were approached to cooperate. One department declined participation, due to circumstances. Three departments did not reply to the request to participate. Eleven participants declined participation. Two participants were excluded because the inclusion criteria were not met. One questionnaire was filled out but was lost. A total of thirty-one (68.8%) participants were found eligible to participate.

### **Data collection**

The estimated burden was measured with the Caregiver Reaction Assessment (CRA).<sup>37</sup> This questionnaire was translated in Dutch; the Caregiver Reaction Assessment-Dutch (CRA-D).<sup>38</sup> The internal consistency of the five domains of the CRA-D were: daily schedule ( $\alpha = 0.81$ ), financial situation ( $\alpha = 0.83$ ), relationships with others ( $\alpha = 0.62$ ), physical health ( $\alpha = 0.68$ ) and self-esteem ( $\alpha = 0.73$ ).<sup>38</sup>

Because the study was about the perspective of the client, the CRA-D was adjusted together with the research supervisor. The final questionnaire to measure the burden contained ten questions. Three questions were about daily schedule and self-esteem, and two questions were about financial situation and physical health. Questions could be answered with; 'totally disagree (1)'; 'disagree (2)'; 'neutral (3)'; 'agree (4)'; 'totally agree (5)'. The range of the questionnaire was from 10 to 50. A score above the median could be considered an increased burden.

Pleasant activities were measured using the Pleasant Activities List (PAL).<sup>14</sup> The PAL has seven subscales with a total of 139 questions. The PAL was divided in frequency of the activities and the pleasantness. The Cronbach's alpha of the seven subscales on frequency ranged from 0.67 to 0.94, the Cronbach's alpha for the pleasantness ranged from 0.69 to 0.96.<sup>14</sup>

One scale was about social activities (SA), in this study only the scale about SA was used for analysis. This scale contained twenty-nine questions. Ten of these questions were, in consultation with the research supervisor, transformed into SA with the caregiver. The other nineteen stayed the same, SA without the caregiver. Each question could be answered with 'not at all (1)'; 'a little (2)'; 'some (3)'; 'fairly (4)'; and 'a lot (5)', on the frequency (F) and how pleasant (P) the activity was experienced. For the SA with the caregiver the range was from 10 – 50, and for SA without the caregiver the range was from 19 – 95. Scores above the median can be considered an increased frequency and pleasantness of SA.

Baseline characteristics were age, sex, education, living in the same house as the caregiver, quality of the relationship with the caregiver, primary addiction, and AS II diagnosis. The final questionnaire consisted of questions regarding the baseline characteristics, the adjusted CRA-D (ten questions) and the PAL (139 questions) with the ten adjusted questions.

## **Procedures**

The researcher personally introduced the study during team meetings at several departments for official caregivers or during coffee breaks at the clinic for clients. Reminders were sent to the official caregivers by email. Also, the researcher visited departments to answer questions about the research personally.

Ambulatory participants were suggested by their official caregiver. Either the official caregiver handed out the questionnaire, or the researcher was introduced by the official caregivers, so the participants would not be overwhelmed when the researcher contacted them. The researcher approached the participants personally or by telephone to make an appointment to fulfil the questionnaire. Clinical participants were approached by the researcher or by a fellow researcher.

It was not necessary to fill out the questionnaire immediately. The client had time to consider taking part in the study and was able to hand over the questionnaire to the researcher or official caregiver at a later date.

The questionnaire contained instructions about how to fill out the questions. If the participant had more questions, the researcher or the official caregiver was approached to answer the questions.

## **Data analysis**

Before analysing the data, linearity was checked with a scatterplot, no clear geometric pattern was visible.<sup>39</sup>

To calculate the sum score of the burden of the caregiver with the CRA-D, SA with the caregiver F and P, and SA without the caregiver F and P, a mean sum score was calculated when a maximum of 20% missing values were present.<sup>40</sup> Results from the questionnaires CRA-D and PAL F and P, were analysed with a Pearson's correlation. Internal consistency was calculated for the adjusted version of the CRA-D ( $\alpha = 0.55$ ).<sup>41,42</sup> The several subscales (self-esteem, financial situation, physical health problems and daily schedule) were also tested for internal consistency, but showed no improvement of the overall internal consistency.

Age and quality of the relationship with the caregiver were handled as continuous, a mean and standard deviation (SD) was calculated. For gender, highest completed education, primary addiction, AS II diagnosis, and living in the same house a percentage was calculated.

All statistical analyses were performed using IBM SPSS Statistics Version 21 (Armonk, New York, USA, 2012).

### **Missing data**

Missing values were estimated with the Little's Missing Completely at Random (MCAR) Test. If the proportion of missing data did not exceed 20%, and the data missing was completely at random, available case analysis was applied.<sup>43–49</sup>

Three questionnaires had missing values of more than 20%. The participants were asked, either in person or on telephone, to complete the remaining questions. The questionnaires were then returned.

The variables Burden, SA with the caregiver F and SA without the caregiver F did not have missing data of more than 20%, a mean sum score was calculated for all questionnaires. One questionnaire had more than 20% missing for the SA with the caregiver P and two questionnaires had more than 20% missing for the SA without the caregiver P. For these questionnaires it was not possible to calculate a mean sum score for the SA with the caregiver P and SA without the caregiver P. The overall missing data on SA with the caregiver P was 3.2% and for SA without the caregiver P 6.5%.

All data was analysed as completely missing at random according to Little's MCAR test ( $p = 1.00$ ).

### **Ethical issues**

This study was conducted according to the principles of the Declaration of Helsinki (version 8, 19<sup>th</sup> October 2013).<sup>50</sup> The questions in the questionnaire were not harmful or burdensome. Participants have given informed consent by filling out the questionnaire. Participants had no direct benefits by cooperating. All data is presented anonymously.

The Ethics Committee at the Radboud University Nijmegen Medical Centre has reviewed the study on the basis of the Dutch Code of conduct for health research, the Dutch Code of conduct for responsible use, the Dutch Personal Data Protection Act and the Medical Treatment Agreement Act (Wbp).<sup>51</sup> The study does not fall within the remit of the Medical Research Involving Human Subjects Act (WMO),<sup>52</sup> and the committee has passed a positive judgement on the study, file number CMO 2018-4035.

## **RESULTS**

### **Participants**

The mean age of the thirty-one participants was 47 years old ( $SD = 13.8$  years) and ranged from 19 to 71 years old, 74.2 percent were male. Of the participants, eleven (35.5%) were living together with the caregiver. The quality of the relationship with the caregiver was given



an average of 8.1, on a scale of 1 - 10. Table 1 shows the demographic characteristics of the participants.

[Table 1]

### **Estimated burden caregiver**

The mean sum score of the estimated burden was 24.2 ( $SD = 4.3$ ), minimum 13 and maximum of 34. The median score was 24.0. Of the participants, 41.9 percent had a score above 24.0, which means that the burden estimated had increased.

### **Social activities**

#### *Social activities with caregiver*

The frequency of the social activities with the caregiver had a mean sum score of 25.3 ( $SD = 8.1$ ), minimum 15 and maximum 42. The median score was 24.0. Of the participants, 45.2 percent had a score above the median, which means that the frequency of the social activities was more than average.

The pleasantness of the social activities with the caregiver had a mean sum score of 29.3 ( $SD = 8.7$ ), median 28.4, minimum 15 and maximum 47. Half of the participants (50%) had a score above the median, which means that that the pleasantness of the social activities was more than average.

#### *Social activities not with caregiver*

The frequency of the social activities without the caregiver had a mean sum score of 38.3 ( $SD = 12.9$ ), minimum 22 and maximum 72. The median score was 35.0. Of the participants, 48.4 percent had a score above the median, this means that the frequency of the social activities without the caregiver was more than average.

The pleasantness of the social activities without the caregiver had a mean sum score of 46.3 ( $SD = 16.9$ ), minimum 23 and maximum 82. The median score was 45.0. Of the participants, 48.3 percent had a score above the median, this means that the pleasantness of the social activities without the caregiver was more than average.

### **Correlation**

No significant relation was found between the burden of the caregiver and the frequency of the amount of pleasant activities undertaken with the caregiver ( $r = 0.09$ ,  $p = 0.63$ ) or without the caregiver ( $r = -0.10$ ,  $p = 0.60$ ). Also no significant relation was found with the pleasantness and the burden, with ( $r = 0.17$ ,  $p = 0.37$ ) or without the caregiver ( $r = 0.08$ ,  $p = 0.70$ ). This means

that the severity of the estimated burden did not influence the frequency or the pleasantness of activities that were undertaken with or without the caregiver.

However, a strong correlation was found between the frequency of the social activities with and without the caregiver ( $r = 0.79$ ,  $p = 0.00$ ) and a very strong correlation was found between the pleasantness of the activities with or without the caregiver ( $r = 0.85$ ,  $p = 0.00$ ). This means that the participants did not make a distinction between activities with their caregiver or without.

No significant relations were found between the estimated burden and when the client and the caregiver were living together in the same house ( $r = 0.13$ ,  $p = 0.48$ ). This means that the height of the estimated burden was not affected if the caregiver and the participant were living together.

## **DISCUSSION, CONCLUSION AND RECOMMENDATIONS**

In this study, no significant relationships were found between the estimated burden of the caregiver, from the perspective of the client with a SUD, and the amount of pleasant activities undertaken with and without the caregiver. Significant relations were found between the activities with and without the caregiver, meaning that the participant does not make a distinction between social activities with the caregiver and without them. No significant relation was found between clients who lived together with the caregiver and the estimated burden.

The estimated burden of the caregivers in this study, was estimated as increased (41.9%). Previous research showed that usually a much lower percentage (9.5%) of the caregivers were overburdened. Especially when the person cared for had a psychiatric or psychosocial problem.<sup>3</sup> Because this study is about the estimated burden of the caregiver, from the perspective of the client with a SUD, it is questionable whether the clients were able to estimate the burden due to a possible lack of understanding what another person is experiencing. Research showed that people with a SUD are underestimating the consequences of an addiction.<sup>53–55</sup> This may be linked to a lack of the normal subtlety of understanding and tact in interpersonal relations.<sup>56</sup>

In this study the social activities that the participants undertook with their caregiver (45.2%) or without (48.4%) was above average. People with a SUD have a tendency to undertake less pleasant activities than people without a SUD, as they undertake primarily substance use related activities as opposed to non-drug related activities, like social activities.<sup>14–18</sup> The results in this study indicate however that the participants in this study did undertake and participate in social activities, which seems to contradict the results of previous research showing that people with a SUD undertake less pleasant activities, although no figures are known about the number of activities people with a SUD would undertake.

This study showed no significant relation between the estimated burden of the caregiver and living together with the client. Research suggests that several risk factors may increase

the burden of the caregiver, such as age, living together with the care recipient, social isolation and financial stress.<sup>10,11</sup> The difference may be due to the fact that, in this study, the burden is subjectively estimated from the perspective of the client, and is not the experienced burden from the caregivers himself. Empathetic understanding of people with SUD may have played a factor, not appreciating or understanding the impact of their condition on their caregiver.<sup>11,53–55</sup>

A strength of this study is, that no previous research has been done about these specific parameters (estimated burden of a caregiver, from the perspective of the client with a SUD, and the amount of pleasant activities undertaken). Clients from inpatient units and outpatient clinics were approached to ensure diversity in the population. Also the ages of the participants were from a wide range. The diversity in age and treatment, makes this study generalizable as long as the same definition of caregiver is used.

However, the results of this study should be interpreted with some care. First, the definition of 'informal caregiver' may not have been interpreted consistently by the researcher and the official caregivers. The definition of informal caregivers can be interpreted in different ways.<sup>3,57–59</sup> The care from a caregiver can vary from emotional support, transportation, help with grocery shopping or companionship to more intensive care, such as bathing and dressing.<sup>3</sup> In the instructions to the official caregivers and participants, the importance of the emotional support may have been underestimated and been overpowered by practical support. Therefore, this may have excluded potential eligible participants who receive more emotional support than practical support from their caregivers. This makes that this study may only be applied to clients who receive more practical support than emotional support from their caregiver.

Second, with thirty-one participants, the sample size is small. However, the very weak correlations between the estimated burden, from the perspective of the client with a SUD, and the amount of pleasant activities undertaken with or without the caregiver, suggest that a larger sample size, would not yield a much stronger correlation.

Finally, the adjusted questionnaire CRA-D had a poor internal consistency. The poor internal consistency may influence the estimated burden of the caregiver. However, despite the estimation of the client about the burden to be high or low, it does not influence the amount of pleasant activities undertaken with or without the caregiver. The strong correlations between the frequency of social activities with and without the caregiver, implies that the clients with a SUD who are still participating in social activities, involve their caregiver. Because involvement of the social network can have positive effects on the outcomes of treatment of people with a SUD, it is important for professional healthcare organizations, to invite the social network to participate in the treatment.<sup>30–33</sup> Targeting the social network for further support or encouraging their participation in the treatment plan may be invaluable in improving the treatment outcomes for people with a SUD and could possibly a focus of further research.

Because of faced difficulties gathering participants for this study, a small sample size and low internal consistency, further research would be advisable. Recommendations would be to analyse the social system of the client to see if they have a social network and how these social contacts are involved in the lives of the client. If further research would be done about the caregivers, the definition of the role of caregiver must be properly defined. Conducting semi-structured interviews is recommended to depict how clients involve their social network in the treatment and to what extent this influences treatment outcomes and quality of life.

In conclusion, clients with a SUD, who undertake social activities, are involving their social network and their caregiver, regardless of the estimated burden of their caregiver.

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## Tables

*Table 1 Demographic Characteristics*

<b>Characteristics</b>	<b>Population N = 31</b>
Male, n (%), no missing	23 (74.2)
Age (years), mean $\pm$ SD [range], no missing	47.3 $\pm$ 13.8 [19-71]
Highest completed education, n (%), no missing	
- Primary school	5 (16.1)
- VMBO	5 (16.1)
- MAVO	4 (12.9)
- HAVO	3 (9.7)
- MBO	7 (22.6)
- University	1 (3.2)
- None	2 (6.5)
- Other	4 (12.9)
Primary addiction, n (%), missing 2 (6.5%)	
- Alcohol	10 (32.3)
- Cannabis	3 (9.7)
- Cocaine	2 (6.5)
- GHB	1 (3.2)
- Opiates	13 (41.9)
AS II diagnoses, n (%), missing 2 (6.5%)	
- Anti-social	2 (6.5)
- Personality disorder NOS	4 (12.9)
- Postponed	4 (12.9)
- Schizophrenia	1 (3.2)
- Weakly gifted	1 (3.2)
- None	17 (54.8)
Living in the same house (no), n (%), no missing	20 (64.5)
Quality of the relationship, mean $\pm$ SD [range]	8.1 $\pm$ 1.2 [1-10]