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CRITICAL ANALYSIS OF THE SCALES ASSESSING ASSISTANCE PROVIDED BY FAMILY CAREGIVERS

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SUMMARY

Background: While the literature on caregiver-assessment scales often focuses on the quantitative and psychometric aspects of the scales, we wished to examine the discourse on caregiving, caregivers and care-recipients (particularly, people with dementia) produced by these scales. What discourse does it help to crystallise and naturalise by dint of being used widely, with unresolved ethical and political issues?

Methods: We analysed two well-known scales that are widely used in both research and clinical settings and conceived among others for people with dementia: Zarit and, offering a sharp contrast, the CRA. We performed semantic network analysis using EVOQ software (<https://www.evoq.be/>) to visualise the links between the terms.

Results: Whereas the Zarit scale is entirely built around a view of caregiving and the care-recipient as a burden, the CRA offers a different discourse. Instead of considering the provision of help as an emotional load, the desire to help is highlighted. Rather than considering the care-recipient as a weight, the recognition of his or her contribution to the relationship with the caregiver is suggested. Moreover, the caregiver is presented as a relative who is capable of active strategies in order to cope with the reality of care without becoming exhausted.

Conclusions: The comparison of our two analyses shows the extent to which the scales produce a discourse which needs to be examined before use, given its epistemological, ethical and political significance. Clinicians and researchers need to make choices between the many existing instruments and be able to justify them. Their reasons should include not only the psychometric qualities of the chosen tool, but also the discourse that it underpins, so as to avoid contributing to the promotion of a vision of care and its givers and recipients that would be reductive, moving us further away from a caring society.

Key words: structural analysis – burden - caregivers assessment – Zarit – CRA - people with dementia

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INTRODUCTION

In the literature on caregivers, scales measuring the effects of caregiving on carers are widely used. These scales claim to objectify these effects in one or more scores, allowing correlation with other measures: for example, those for caregivers' welfare, depression, stress or health. The methodological work on these scales has focused on the psychometric qualities of the measurements obtained (using indices such as Cronbach's alpha or test-retest procedures) (Antoine et al. 2010, Iecovich 2012). Instead of focusing on the data obtained, we wished to examine the discourse on caregiving, caregivers and care-recipients, produced by these scales conceived (among others for CRA) for people with dementia. Indeed, the prevailing discourse on dementia continues to stigmatize those affected (Behuniak 2011, Bailey 2021), hence the interest in questioning the extent to which the widely used grids reflect and contribute to this discredit. We decided to stand back from the numerical data and turn our attention to the instrument: the questions submitted to families. As families are required to provide their answers in terms of the options presented by the questions, we wondered if this semantic field is wide enough to reflect the diverse range of representations of

care given by loved ones and of the people they help. What discourse does it help to crystallise and naturalise by dint of being used widely, if only by the medical and social literature devoted to caregivers? What are the blind spots of this discourse and the unresolved ethical and political issues?

We hoped to show the importance of questioning the discourses of the scales evaluating care given by families, using an appropriate method.

METHODS

Research design

Working from the outset on a representative sample of scales would have been excessively demanding. One of these was quickly imposed on us, given the frequency of its use in different languages and cultures, as well as the high number of citations in the literature dedicated to caregivers: Zarit burden interview which was originally designed for people with dementia (Whalen & Buchholz 2009, Zarit 1986). Consequently, it is not surprising that the discourse of care as a "burden" provided by Zarit's scale has become a cliché in the literature (Rigaux 2009). With Zarit's scale, we are at the heart of a common discourse regarding the care of loved ones. The CRA scale (Given et al. 1992, Ogura 2013),

conceived for caregivers of persons with chronic physical impairment and people with Alzheimer's disease, seemed interesting for its sharp contrast with Zarit, allowing us to refine our questioning. Would the CRA offer real alternative(s) to the discourse of caregiving as a burden produced by the Zarit scale?

Our choice was also due to the fact that we were associated in various ways with two combined research projects that used these tools, among other things, to evaluate care stress experienced by caregivers, one involving close relatives aged 75 years and older (Blinded for Review), and the other a cohort aged 50 to 65 years. Having worked closely with these two scales, we wished to examine them in order to discern their effects on the results produced.

Having chosen the scales on which we wanted to focus our efforts, we searched for valid heuristic methods for analysing discourse on these scales. To capture the meaning of these scales, we directed our research to semantic methods rather than logico-aesthetic or formal methods (Mucchielli 2006). Those that seemed particularly relevant to us were semantic network analysis and in particular structural analysis (Greimas 1966, Hiernaux 1977), as adopted by the EVOQ project (Wallemacq et al. 2004), the fundamental principle of which is to uncover meaning not by focusing on terms taken in isolation and their frequency but on their relationships. Structural analysis is built around two fundamental types of relations: opposition and association. The whole of these relationships associated with a term constitutes its semantic field or network, which makes it possible to perceive its meaning and colour, regardless of the intention of the speaker. In order to reflect our material more closely, we focused our analysis on the relationship between three terms: the caregiver, the care-giving and the care-recipient. We interpreted the notion (specific to structural analysis) of opposition between terms as a relationship (with caregiving or with the care-recipient) to the *detriment* of the caregiver and that of association as a relationship in *favour* of the caregiver. To do so, we relied on the expert judgement of the co-authors.

Beyond the use of structural analysis, the EVOQ software allowed the semantic network to be presented graphically, increasing intelligibility and making perceptible the semantic associations and circumscribed fields discovered (Clarival et al. 2018).

RESULTS

We will first present our results with a network schematising the dynamics of the items in each scale. We will then examine what the comparison of the two graphs teaches us.

Results for the Zarit scale

The scale consists of 22 items. The last one may be considered as a synthesis of the others: "Overall, how

burdened do you feel in caring for your relative?" Graphically, this is marked by the fact that the terms from the first 21 items are contained in a set called "burden". Our starting question becomes more accurate: if the discourse of caregiving produced by Zarit is that of a burden, what does this discourse encompass? In other words: what is its semantic network or "semantic landscape" (Linden et al. 2020)? We will explore this in the analysis that follows.

Three terms can be found in the various items (yellow on the diagram) whose representation we will consider: you (the caregiver), your relative (the care-recipient), and the caregiving. For each word used in the items associated with your relative/the caregiving, we will draw in red the relationship to the caregiver if it is detrimental to them and in green if it is favourable to them (Figure 1).

Results regarding CRA and its comparison with Zarit

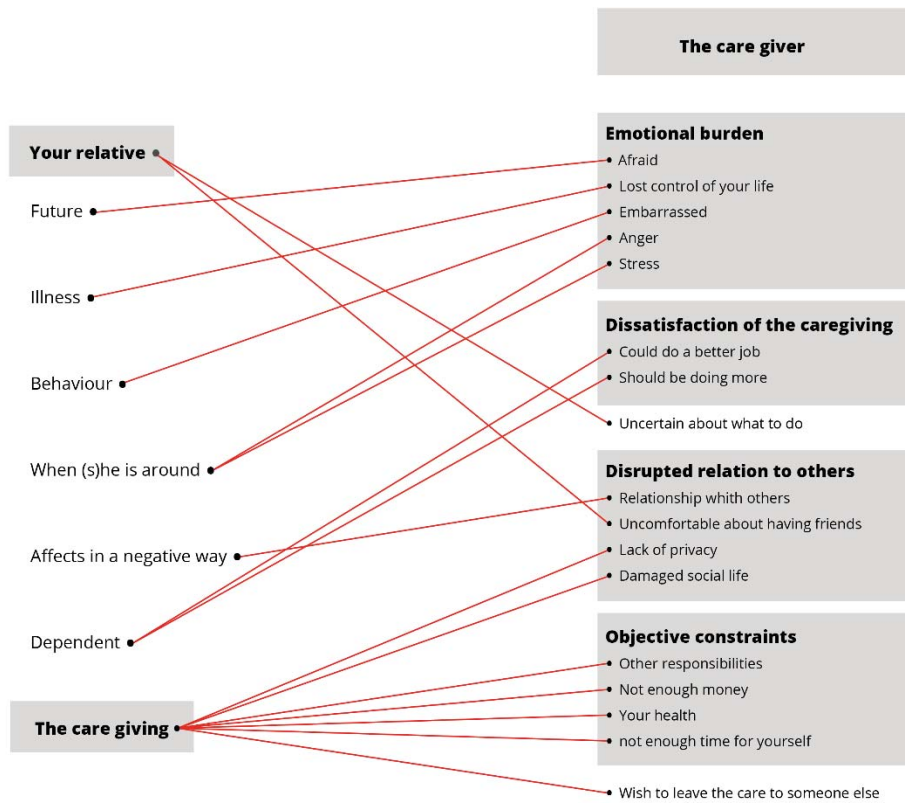
As in the previous graph, we reserve the left side of the scheme for "him/her" - the way the CRA names the care-recipient - and the care that is given, and the right side to the caregiver - designated as "I" in the scale, with the emotional dimension at the top and the objective dimension of care at the bottom. As before, green and red lines link a term to its favourable or unfavourable effect for the caregiver (Figure 2).

DISCUSSION

The first observation that can be made of the diagram is that all the features that pass through it are red. In other words, all the terms associated with caregiving and the caregiver indicate difficulties or disorders. The only exception is item 16 (Do you feel that you will be able to take care (...) much longer?) which is more undetermined.

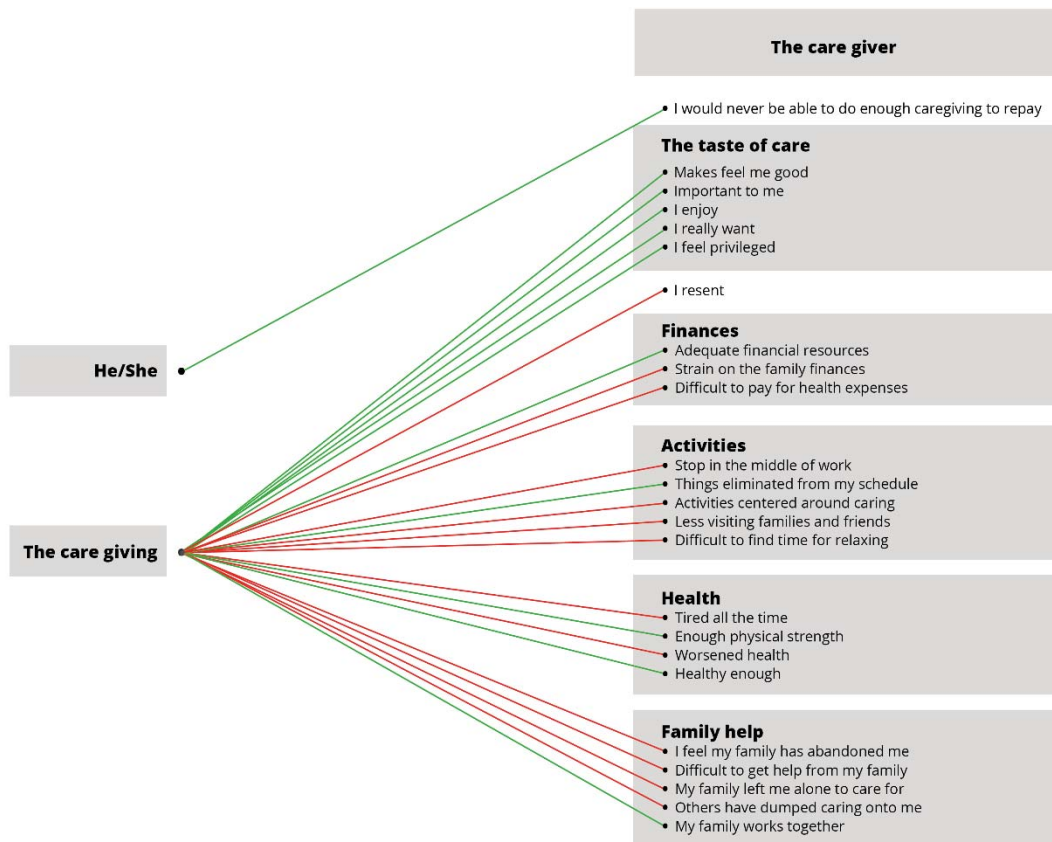
The distinction made by the scale between "caring for your relative" and "your relative" has a very strong impact: it is not only the caregiving that is the burden, but the care-recipient themselves (who are people with dementia in the Zarit design). How does Zarit's discourse formulate this? This is what the second observation enables us to explain.

The graph gathers in its upper right part the emotions felt by the caregiver (fear, anger, embarrassment and so on), in a set that we will name the subjective or emotional dimension of the burden. In its lower right, there are aspects referring to the objective dimension of caregiving, including the assessment of its effects on the caregiver's health, time, financial resources and social relationships. This distinction makes it possible to go further in describing the Zarit scale's vision of care-recipients and the care they require.



Legend: Your relative: the care recipient; Red line: unfavourable effect for the caregiver

Figure 1. The semantic landscape of the burden (Zarit scale)



Legend: He/She: the care recipient; Green line: favourable effect for the caregiver; Red line: unfavourable effect for the caregiver

Figure 2. The CRA scale: discourse on care, caregivers and care-recipients

Significantly, the care-recipient is associated only with a set of emotions on the part of the caregiver, all negative. The image of care-recipients presented by the scale according to the emotions they arouse in the caregiver is really unattractive: it devalues and discredits them (the care-recipient harms social relations, creates discomfort and anger, is too demanding, and so on). We find here all the stereotypes associated with dementia in common discourse (Behuniak 2011, Bailey 2021). As a result, the care-recipient's dependence (which in item 8 is named without any negative connotation - "Do you feel that your parent is dependent on you?") is itself part of this dark picture. Since all the items seem to reinforce the negative image of both caregiving and the care-recipient, it is difficult to see how dependence could escape this negative connotation. We are facing here a discourse based on ageism and disablism against the impaired elderly people targeted by the scale.

It is necessary to point out the extremely reductionist nature of such a discourse, which makes itself blind and deaf to the reality of a possible return for the caregiver who, of course, gives but also receives a great deal. Regarded in such a reductionist manner, caregiving can only be viewed in a negative light: as a duty, a moral obligation or a sacrifice. The emotions felt by the caregiver are thus presented as the opposite of care ethicists' definition of the relational character of care (Tronto 1993, Feder Kittay & Feder 2002). While experiencing fear, anger, discomfort, embarrassment and tension in the presence of the care-recipient, how could the caregiver identify and meet his or her needs in a way that is positive for both partners in the relationship?

In order to be able to account for the complexity of the care relationship and not reduce it to a burden on the caregiver, it is necessary to be able to understand it precisely as a relationship. Yet the Zarit scale does not present us with two partners connected by care, but only one, the care-recipient, who is a "drag", ruining the bond with the caregiver and with other people around them.

A third observation can be developed with regard to care, which is associated with objective time, money and health constraints. We are confronted here with an instrumental vision of care (Caradec 2009): caregivers perform a series of tasks on behalf of a care-recipient, which necessarily gives them the impression that they are wasting their time and sacrificing their own health. Two items (20 and 21) deal with how caregivers assess the care they provide ("you should do more", "you could give better care"), and here there appears to be a form of dissatisfaction with the quantity and quality of the caregiving. It should be noted that this dissatisfaction or devaluation by caregivers of the caregiving they provide is contrary to one of the factors in the fulfilment experienced by caregivers:

their pride in managing to provide quality care to their loved ones, as reported by certain authors (Caradec 2009).

One final finding deserves to be highlighted: the examination of the objective constraints associated with care involves a number of questions, each exploring one aspect that is distinct from the others (with the exception of the two items assessing the quality/quantity of the assistance provided). Only one theme is further developed: how relationships with others are disrupted. Four items detail this, two associated with care (which leads to a deterioration of social life (item 12) and a lack of intimacy (item 11)), and two relating to the role of the parent receiving the car (which harms relationships with family and friends (item 6), and makes the caregiver uncomfortable about receiving visits from his or her friends (item 13)). It can be seen that for the Zarit scale, the isolation of the caregiver is an important factor in the burden: caregivers are taken away from their family and friends, leaving them with only one relationship - and moreover a very unsatisfactory one - with the person they help.

Let us summarise all the features of the "burden" depicted in the discourse of the Zarit scale. It consists not only of objective constraints (temporal, financial, etc.) linked to caregiving, but also of the negative emotional load associated with the care-recipient and the dissatisfaction of caregivers with the sufficiency and quality of their intervention. This burden cuts caregivers off from their relational context and isolates them in a degraded relationship with the care-recipient.

Caught in this straitjacket, the care relationship can only be seen as a burden, both for the caregiver and for the care-recipient, which inevitably leads to a devaluation of the care relationship itself. To understand this, one can refer to what Fineman (2014) calls the "myth of autonomy". It shows that our vision of autonomy is closely associated with the concepts of independence and self-sufficiency. Thus, the autonomous human is seen as not dependent on others or the State. The self-governing human being is also self-sufficient in his or her relations with society and institutions. Defined in this way, the autonomous human being is increasingly the Western ideal. How can we then escape a negative moral judgment when life leads us to have to depend on others for certain acts and sometimes for all the acts of daily life? Asking for care becomes a form of suffering and those who are called upon to provide such care, whether professionals or families, will themselves be assessed negatively (Barnes 2006, 2012). Given the importance accorded in our society to the independence of individuals with regard to the State, it is not surprising that the professionals are noticeable by their absence from the Zarit scale. However, in most OECD (Organisation for Economic Co-operation and Development)

countries, it is known that professional assistance represents a significant proportion of the care required by dependent people and an essential support for many caregivers (Masuy, 2010). A political concern in the scale appears here. It presents the family caregiver as the sole person responsible for the care and helps to spread this questionable idea. In doing so, the Zarit scale contributes to devaluating the very important role of professionals (and the public policies that support them) in supporting the family caregivers and contributing with them to a caring society.

As expressed by the scale, the discourse of care as a burden opposes the way care ethicists reflect on care (Tronto 1993, Feder Kittay & Feder 2002). Firstly, caregivers' emotions hinder their provision of care. Secondly, dependence appears as a defect specific to the care-recipient and not as a constituent of our common humanity. Thirdly, caregivers' health is compromised by caregiving; they fail to care for both the care-recipient and themselves. Far from defining their identity by concern for others, they gain nothing positive. Inevitably, they wish to leave the care to someone else (item 18).

We can therefore conclude that the discourse of the Zarit scale crystallises and diffuses an image of care which, if common, is not the only one. This image devalues both the dependent person, reducing him or her to being a charge, and the help given by a loved one, seeing it only as a burden. This scale therefore deserves to be questioned for how it undermines our moral identities, both as care-recipients and as caregivers. Another ethics of care and of dependence is available and observed in certain persons, as we have just shown.

The discourse produced by the Zarit scale does not open up any alternative to the vision of care and of care-recipient as a burden. Caregivers can do no more than answer that they "never" feel what the items in the scale propose, which does not allow them to explain what the care or the care-recipient means in their eyes.

Does the CRA consider alternatives to care as a burden? To put it in a more technical way, does its discourse produce an alternative vision (i.e. a set of antitheses/associations reversing the discourse of the burden) of caregiving, care-recipient and caregiver to that of Zarit? These are the questions that we will now discuss.

A first point contrasts strikingly with what is found in the Zarit scale. Here, all aspects of the emotional dimension of care (covered by six items) and of the care-recipient are worded in a way that is positive for the caregiver, with the exception of one item ("I resent having to take care of...", item 7). Far from constituting an emotional burden, care is seen by the CRA (5 items out of 6) essentially as corresponding to

the aspirations of the relatives, to what they want to do, enjoy doing, and consider important. Here we find an alternative to the discourse of the Zarit scale, and the item 9 (the desire to help) is distinct from the emotional burden of care. In the CRA's discourse, the opposite of the emotional burden is not lightness or ease (as a formal analysis using the dictionary might suggest), but the desire to help and the importance of helping. This makes clear the value of a structural approach to discourse, which allows us to understand how the discourse produces antitheses which are not reducible to a lexical approach. Although the desire to help is expressed by a series of similar terms (desire, pleasure, importance, privilege, well-being), the CRA's discourse does not offer explanations of the source or reasons for this desire. Various reasons can be found in the literature: love for the assisted person, a sense of responsibility towards a relative, a sense of give and take (reciprocity) with family members (Lewis & Meredith 1988). The CRA does not reflect this.

The care-recipient is much less present in the CRA than in the Zarit scale: only one item (12) concerns him or her ("I will never be able to do enough caregiving to repay...") which suggests that the care is given in repayment of a debt. This view of care as an act of reciprocation is not for what the care-recipient gives in the present - for example, his or her gratitude, whose importance for the caregiver is highlighted by the literature (Taylor 2010) - but for something given in the past.

Thus, for the first time, the care-recipient appears as a contributor and not exclusively as a debtor. This brings us closer to an anthropological understanding, which can be found in the ethics of care but also in authors who develop a relational approach to autonomy (Mackenzie & Stoljar 2000), stressing that vulnerability is unique to human beings (Killackey et al. 2020). At different times of life, they pass through phases where they are more a donor or more a recipient of care. This vision is likely to radically transform our view of the giver/recipient pair: there is no longer a dichotomy between those who are disabled and totally passive on the one hand and those who are autonomous on the other, but the sharing of a common vulnerability. This vision echoes the (re)creation of intergenerational habitats and the inclusion of the elderly in the daily lives of certain households. Far from being a simple economic solution, the inclusive presence of several generations is also an opportunity for the preservation of family values, for experiences and memories that contribute to a "relational eudaimonism".

The alternative to the view of caregiving as an emotional burden is therefore both a desire to help and an awareness of the past contribution of the care-recipient, which motivates the care-giver to reciprocate with the care he or she provides.

Let us look at the objective dimension of care for caregivers. At this level, the CRA gives more space to the burden that care may represent: 2 out of 5 health-related items, 2 out of 3 finance-related, 5 out of 6 on family support, and 3 or 4 out of 5 on time organisation emphasise the burden of care, one of them explicitly (item 2: “Others have dumped caring for ... onto me”). Thus, reference to the idea of burden has not been removed from the discourse on care, but refers only to the care itself, not to the care-recipient, and essentially objectively. Moreover, the CRA includes two types of terms differentiating from the objective dimension of burden: resources are outweighed by constraints (in terms of finance, health and family support) and also what could be called a coping strategy of the caregiver (Hawken et al. 2018). With regard to the resources on which caregivers can rely, emphasis is placed on family members. Relatives appear not only as bringing potentially links important to the caregiver, but also as potential contributors to the giving of care (item 13, “mobilisation” of the family, plus 4 other items expressing regret at the lack of assistance provided). With regard to the management of their time, caregivers are described as having room for manoeuvre in order to provide the required assistance: they can thus eliminate certain things from their schedule (item 14), or even focus their activities on care (item 4) without it being exclusively or necessarily a problem for them. A discourse with regard to caregivers that stands in contrast to the notion of a burden thus arises in the CRA: instead of being overwhelmed by a burden, caregivers can actively, with their own resources and those in their environment (their family), find a way to cope with providing the assistance required. However, it should be noted that, as in the Zarit scale, the resources that care professionals can offer are again completely absent from the table of assistance provided by relatives.

Let's go back to what we highlighted up till now in the comparison of our two scales. Whereas the Zarit scale is entirely built around a view of caregiving and the care-recipient as a burden, the CRA offers a different discourse on caregiving, caregivers and care-recipients. Instead of considering the provision of help as an emotional load, the desire to help is highlighted. Rather than considering the care-recipient as a weigh the recognition of his or her contribution to the relationship with the caregiver is suggested. Moreover, the caregiver is no longer presented as crushed under the weight of objective constraints, but as a relative who can rely on resources (his or her own and those from the family) and is capable of active strategies in order to cope with the reality of care without becoming exhausted.

The CRA scale therefore has the advantage of allowing the interviewed caregivers to share other visions in addition to and opposed to that of the burden,

avoiding the stigmatisation of the care-recipient. This is important from an epistemological point of view: diverse visions of caregiving will be able to express themselves, which is closer to the multiplicity of realities experienced, rather than making the view of caregiving as a burden seem like the norm. From an ethical point of view, by suggesting the possibility of the care-recipients contributing to the relationship and of resources of various kinds among other family members, the CRA scale offers a more rewarding discourse on care-recipients and caregivers, escaping the caricatures of victims and tormenters. On the other hand, the underlying political perspective of the CRA scale remains that of family-based support without hinting at the importance of the contribution that professionals can make to enable relatives to help without becoming overwhelmed.

CONCLUSION

Using the example of two evaluation scales of assistance provided by relatives, we wanted to show the relevance of analyzing the discourse of the scales used in research and clinical practice. Every evaluation scale, through the questions it asks and the terms it uses, projects a vision of the people and care concerned that deserves to be examined, and not only through the numerical data it generates. By doing so in our case studies, we help avoid the dissemination and naturalisation of narrow discourses on care and its protagonists, discourses which do not accurately reflect the diversity of reality and which are problematic from an ethical and political point of view. These discourse analyses, often used by the human and social sciences, deserve to be used more extensively to examine the assessment tools used in research and clinical practice, even more so in the field of dementia studies, which is still marked by the stigmatization of people with dementia.

The contribution of our study also consists in proposing a method of discourse analysis, in this case, the tools of structural analysis and their visualization by the EVOQ software. The use of structural analysis of the discourse proved to have greater heuristic value than simply examining each term taken in isolation. Thus, instead of regarding lightness as the opposite of the concept of a burden, we saw the emergence of a fundamental antithesis between the burden on the one hand and the desire to give care and recognition of its importance on the other. In other words, the alternative to the image of the care-recipient producing a set of emotions with negative valence (anger, discomfort, etc.) that appeared was not that of a kind person, but of a contributor to the relationship between caregiver and care-recipient. The CRA scale's presentation of caregivers as people with resources that they can actively mobilise thus illuminates the way in which the

Zarit scale implicitly presents caregivers as passively crushed under objective constraints, without any room for manoeuvre.

Working on the explicit but also implicit antitheses of the natural discourse has therefore enabled us to reveal what that discourse contained without this always being obvious. This makes possible a form of questioning that is simultaneously epistemological, ethical and political in nature. Without this questioning, the criteria used to assess the assistance provided by family caregivers is likely to consolidate a reductive discourse, moving us further away from a caring society.

The main limitation of this study is the limited choice of scales analysed. This is offset by the choice of the Zarit scale, which has attracted the most interest in clinical and research settings. Although a structural analysis of a larger number of contrasting scales would have led to richer results, this becomes less important if the approach used is regarded as a form of advocacy for the analysis of discourses and the search for a method for such analysis. Finally, it should be noted that while our approach questions the discourse contained in the tools used to study the care given by relatives, it does not fundamentally call into question the very use of these tools at the expense of purely qualitative approaches such as interviews.

Ethical approval statement:

We adhere to all research ethics guidelines of our discipline. The research proposed does not involve human or animal subjects.

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Our materials – the Zarit and CRA scales – are available (see bibliography: Zarit, 1986 and for CRA: Ogura, 2013). Our method – EVOQ software – is freely available for research purpose at <https://evoq.info.unamur.be/>. Our study is not pre-registered. This work was supported by University of Namur, NaTRIP (Namur Transdisciplinary Research Impulse).

Conflict of interest: None to declare.

Contribution of individual authors:

Natalie Rigaux, Laurent Ravez & Martin Desseilles contributed to the design of the study, the literature searches and analysis, interpretation of data as well as manuscript writing and reviewing.

Natalie Rigaux, Isabelle Linden & Joëlle Berrewaerts contributed to the qualitative analyses and reviewing.

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