Introduction

In many industrialized countries, the increase in life expectancy, the chronicization of many diseases as a result of advances in medicine, as well as changes in health and medico-social sectors, particularly as a result of the ‘ambulatory shift’, have contributed informal caregivers being delegated with more roles and greater responsibilities.

A caregiver is defined as ‘a non-professional person who provides primary assistance with activities in daily life, either in part or in whole, towards a dependent person in his/her immediate circle. This regular care may be provided on a permanent or non-permanent basis and may assume various forms, in particular: nursing, care, assistance in education and social life, administrative formalities, coordination, permanent vigilance, psychological support, communication, domestic activities, etc.’

Some key figures illustrate the extent of the societal contribution made by caregivers in European countries: despite the variability of the estimates of the number of caregivers (due to a number of factors, such as the definition of a caregiver and the methods used to identify them), there appear to be about 125 million caregivers in Europe. There are thought to be over one million professional nurses throughout the European Union, compared with the 9.6 million family caregivers providing care 35 (or more) hours per week. In regard to their informal economic contribution, the estimated value of informal caregiving in the six European Union member states participating in the EUROFAMCARE study (i.e. Germany, Greece, Italy, Poland, Sweden and the United Kingdom) exceeds public expenditure on formal care and care allowances. In England, the value of the care provided by family caregivers has been estimated to exceed the budget of the National Health Services for the whole of the United Kingdom.

This pressure is expected to increase considerably in coming decades due to demographic changes and economic constraints.

The essential role of a caregiver in regard to catering to the needs of a close relative has been well established, and it often conditions the maintenance of the individual in their care. Although several studies have shown that a limited extent of caregiving can be accompanied by a sense of enrichment, or even improved overall health for the caregiver, providing care beyond a certain threshold tends to have deleterious consequences for the caregiver’s health and their social, professional and financial life, while also increasing their risk of dying. A study by Mellon et al. in regard to cancer survivors and their caregivers even suggests that compared with their close relatives, caregivers tend to have a poorer quality of life and less social support, while they also worry more about the future health of the ill member of their next of kin.

Faced with these established facts, recognition and support for caregivers has become a major issue for public authorities. The World Health Organization recommends that the caregiver/care receiver’s dyad is viewed as a care entity. Despite the lack of legislative consensus in Europe, some countries have recently added the term ‘caregiver’ to their legislative lexicon.

Caregiver assessment refers to a systematic process of gathering information that describes a caregiving situation and identifies the particular problems, needs, resources and strengths of the family caregiver. It approaches issues from the caregiver’s perspective and culture, focuses on what assistance the caregiver may need and the outcomes the family member wants for support, and seeks to maintain the caregiver’s own health and well-being. Research in the field of caregiver assessment took off in the early 1980s and has expanded considerably since then. This research agrees on the singular and dynamic characters of caregiver profiles. This variability suggests that it is not possible to consider an intervention model that
proposes a standardized pathway, that interventions for caregivers should be varied, and that they should respond to the dynamic nature of the caregiving experience.

Researchers have developed a variety of indicators to assess caregivers, many of which explore subjective concepts related to the individual caregiver’s perception. These indicators initially incorporated dimensions with ‘negative’ connotations such as stress, burden or depression; and then increasingly ‘positive’ dimensions such as well-being and satisfaction, which are equally essential for proper assessment of the situation. All of these indicators are closely related, although any one of them cannot be used to explain or predict another. The choice of concepts to be assessed depends on the subject and the objectives.

Assessment of the caregiver’s needs is a fundamental step, which is at the heart of the issue of caregiver support. In terms of the population and the area in question, it enables the design and the deployment of adapted support schemes, and thus to rationalize the supply of services. At the individual level, a detailed understanding of the caregiver’s needs and the dynamic nature of the role in which they are engaged is an integral part of the support and a prerequisite for its orientation towards the most suitable devices.

To our knowledge, no universal self-administered reference instrument exists to date to provide a global overview of caregiver’s needs. It is, therefore, important to identify how and to what extent the assessment of caregiver’s needs by self-administered instruments can meet this objective, whether for epidemiological research purposes on the one hand, or operational purposes, on the other hand. The choice of the self-administration process has been mainly driven by its feasibility, its low cost, and its potential to be automated.

The objective of this work was to compile a critical inventory of the self-administered caregiver’s needs assessment instruments by a review of the literature. The research was in regard to instruments having undergone a rigorous process of development/validation, and that had demonstrated good psychometric properties. A psychometric validation is the process by which the reliability and validity of an instrument are determined by the establishment of a series of tests on the target population for which the instrument was devised. Reliability refers to the reproducibility and the coherence of the instrument. Validity aims to confirm that the instrument measures what it is intended to measure.

### Methods

#### Database search

The Medline database was searched to identify resources related to the assessment of caregiver needs. The research equation dealt with the association of Medical Subject Headings (MeSH) Caregivers and Needs Assessment using the Boolean operator ‘AND’ (table 1).

#### Inclusion/exclusion criteria

The selection aimed to identify relevant articles dealing with self-administered caregiver’s needs assessment instruments that had demonstrated their psychometric robustness. It was carried out by two independent operators as follows: Step 1/from the titles and abstracts, the articles for which the main topic was in regard to the assessment of caregiver’s needs were retained; Step 2/articles dealing with the assessment of a single type of need (e.g. the caregiver’s spiritual needs) were excluded as they were too restrictive for our specifications; Step 3/reference lists of the pre-selected articles were reviewed in the same way (Step 1, then Step 2), in order to identify additional relevant resources; Step 4/from the Step 2 and the Step 3 pre-selection, the original research articles dealing with the psychometric validation of self-administered instruments were identified; Step 5/finally, articles were retained only if the instrument’s psychometric properties were acceptable. The psychometric acceptability of the self-questionnaire was defined by its reliability, as assessed by its internal consistency, which in turn was determined by the value of the Cronbach α correlation coefficient, which varies from 0 to 1. The overall internal consistency of the instrument or, if not available, the internal consistency of each of its dimensions had to be greater than or equal to 0.70, which is the accepted threshold of acceptability. At each stage of the selection, any discrepancies were discussed by the operators in order to obtain a consensus.

### Analysis of the instruments

The instruments were analyzed in terms of the context of their development (e.g. country and language), target population (e.g. characteristics of the caregiver, the care receiver, and the caregiving experience), objective, concept, structure (e.g. the number of items and dimensions) and psychometric properties (e.g. content validity, reliability, induced load and sensitivity to changes—if any).

### Analysis of the dimensions of needs

The constitutive dimensions of the instruments were collated and then categorized on the basis of their title and content explanations that were provided in the articles. The objective of this work was not only to compile the information, but also to identify the dimensions most frequently used in the context of a caregiver’s needs assessment process.

### Results

The Medline database was searched on 29 September 2016. Figure 1 shows the process of querying the database and of article selection.

#### Characteristics of the instruments

Nine caregiver’s needs assessment instruments were identified and their characteristics were analyzed. These instruments were the Family Needs Questionnaire (FNQ)16; Needs Assessment of Family Caregivers-Cancer (NAFC-C)17; Cancer Survivors’ Partners Unmet Needs (CaSPUN)18; Scale Of Needs (SON)19; Cancer Survivors’ Partners Unmet Needs Survey (SPUNS-SF)20, which is an evolution of the Support Person’s Unmet Needs Survey (SPUNS)21; Comprehensive Needs Assessment Tool for cancer-Caregivers (CNAT-C)22; Supportive Care Needs Survey-Partners & Caregivers (SCNS-PC)23; Unmet Resource Needs (URN)24; and the
Needs Of Family Caregivers of Advanced Cancer patients (NOFC-AC). The characteristics of these instruments are presented in (Supplementary Appendix S1).

Of these, four were developed in North America and two in Australia, and they were in English; three were developed in Asia, including two in Chinese and one in Korean.

All were developed for adult caregivers, and they were specific for a subpopulation characterized by the care receiver’s affection. Most were developed in the field of oncology \( \left( n = 6 \right) \). Seven were intended for caregivers regardless of their relationship to the care receiver, one for family caregivers (FNQ), and one for the spouse of the care receiver (CaSPUN).

All of them were designed for epidemiological research purposes. None of them permitted the establishment of individual support for the caregiver.

Only two instruments were based on a formal conceptual model: NAFC-C and URN. The NAFC-C was based on the Need Fulfillment Theory introduced by Vroom. According to this theory, the product of importance and satisfaction is the key indicator of the degree to which a need has been fulfilled. In other words, when a need is very important and when the individual is completely satisfied with the need having been met, the level of fulfillment is greater. By contrast, when a need is very important and the need has not been satisfactorily met, the insufficiency is greater and therefore the need has largely remained unmet. The URN, which evaluates the missing resources for caregivers, is itself based on the Stress and Coping Model of Moos and Schaefer. This model suggests that stressful events trigger coping processes in order to restore balance in the individual’s life. Contextual factors (e.g., background, illness, and socio-environmental factors) influence the coping process (e.g., appraisal [threat], coping [problem-solving], resource need and use), which in turn influences physical and socio-emotional adaptation outcomes. Moos and Schaefer emphasized the use of both internal and external resources in coping with a health crisis, such as the sudden onset of a severe physical disability.

The identified instruments consisted of a self-questionnaire only, and they did not contain any other information or instructions for use. They had an average of 32 ± 10 items (median = 36, min = 12, max = 42). Only the CaSPUN had an open need item in which the caregiver could indicate another unlisted need. All instruments relied on Likert scale-type response devices, whereby the interviewee expressed their level of agreement or disagreement with an assertion (statement). Items from seven of the nine instruments were assessed by a single Likert scale (five rated the extent of the needs, one rated the level of the unmet needs, and one rated the resources needed by the caregiver); the items of the FNQ and the NAFC-C were evaluated based on two successive Likert scales (namely the importance of the need, then the extent to which the need had been met; and the importance of the need, and then the level of satisfaction with the fulfillment of the need). The NAFC-C and URN instruments were the only ones to propose the construction of an absolute value score reflecting the level of the caregiver’s unmet need.

Of the nine instruments analyzed, only the NAFC-C had been validated at various stages of the caregiving experience; i.e. at the time of the care receiver’s cancer diagnosis, and at 2 and 5 years post-diagnosis. Eight instruments had satisfactory content, based on literature reviews and qualitative caregiver and professional surveys. The content validity of the NAFC-C was questionable due to the method used to generate the items. All of the instruments had an acceptable reliability, as evidenced by their internal consistency, with regard to the criteria adopted in this review. The effort required to complete the questionnaire was seldom reported in the articles. The level of education required, as well as sensitivity to change, was not assessed for any of the identified instruments.

**Analysis of the dimensions of need**

Items from eight of the nine instruments analyzed were grouped into dimensions of need. The URN contained items not grouped into dimensions. The eight multidimensional instruments averaged 5.4 ± 1.3 dimensions (median = 5.5, min = 4, max = 7).
A total of 43 dimensions of need were listed. Of these, two dimensions, which included items that were too disparate, were not included in the categorization. The results for the dimensions of need categorization are presented in Supplementary Appendix S2.

Eight categories were hence constructed. The 'Health and Care' category is in regard to the caregiver and/or the care receiver, and it includes the dimensions of care, health, healthcare professionals, structures and trajectories. The category 'Psychological—Emotional support' refers to mental needs and the management of emotions. The category 'Information—Knowledge' refers to the information needed in regard to the care receiver's affection, treatments, care, symptom management, possible supports. The 'Social Life—Work—Finance' category includes dimensions relating to the balance between the caregiving role and other social and professional activities, interpersonal communication, community support, and the caregiver's finances. The category 'Future—Bereavement—Spirituality' refers to concerns about the future, religious and spiritual support, and support for funerals. The 'Instrumental Support—Respite' category refers to the caregiver's need to temporarily detach himself/herself from his/her responsibilities, to be joined by a trusted individual, and to take time out for himself/herself. The 'Satisfaction' category assesses the positive consequences of the caregiving experience for the caregiver. Only the CaSPUN had such a dimension.

The categories 'Health and Care' and 'Psychological—Emotional support' were systematically included in the multidimensional instruments analyzed.

**Discussion**

After more than three decades of research, caregiver’s needs assessment remains a complex process for which there is lack of consensus. Indeed, there is no single definition of the term ‘needs’. In the 1950s, Maslow formulated a hierarchy of needs as a universal model for understanding human behavior. Wingate and Lackey defined ‘needs’ as a drive toward rectifying a perceived deficiency in equilibrium. The following year, Hileman and Lackey refined the definition of ‘needs’ to include a condition that is important to the subject and that is not being satisfied in the subject’s present environment. Stevens and Gabbay defined the ‘need for health care’ as what will benefit the individual in terms of morbidity and effectiveness of care, referring to the professional vision, unlike the ‘demands’ of the individual. Sanson-Fisher et al. defined the ‘unmet supportive care needs’ as the gap between the services received and those which the individual perceives as being required to achieve optimal well-being. Phelan et al. suggested that a good scale for needs assessment should take both parties’ perspectives into account in order to comprehensively assess caregiver’s needs.

One of the main findings of this research was to confirm the absence of a formal and unambiguous conceptual basis relating to the concepts of ‘needs’ and ‘needs assessment’, which leads to a heterogeneity of instruments, as evidenced in particular by the fact that some instruments assess the needs, while others assess the satisfaction with the fulfillment of the needs, or the resources needed by the caregiver. The definition of the concept is an essential prerequisite for the development of such instruments in the field of health. In fact, future research on the assessment of caregiver’s needs would benefit from a precise definition of the concept on which it is based.

From the first stages of their conception, all analyzed instruments had the characteristic of being ‘specific’ for a sub-population of caregivers. Nevertheless, our dimensions of need analysis highlighted that all caregivers have a baseline of needs in common (this is the case for dimensions regarding the health and care of the caregiver and the care receiver, psychological and emotional support, information and knowledge, social life, and work and finances, which were found in three quarters or more of the multidimensional instruments analyzed). This result corroborates the position of some authors, such as Vitaliano et al. and Given et al. These authors have suggested that it may be appropriate, as part of the development of caregiver’s needs assessment instruments, to adopt the same strategy as the quality of life instruments FACT (Functional Assessment of Cancer Therapy) which, starting from a generalist instrument (FACT-G), was subsequently declined in different instruments, specific to each type of cancer.

It should be noted that, surprisingly, none of the identified instruments were intended for caregivers for the elderly, or even for children and teenagers. Further research would be desirable in order to define the specificities of such evaluations.

The objective of this research was to determine the extent to which self-administered caregiver’s needs assessment instruments that have been devised to date can contribute to the development of a reference instrument in the European context, either for epidemiological research or operational purposes. Analysis of the literature has shown that representations of situations and life events are largely influenced by the cultural context. Consequently, if the direct use of an existing instrument, without adaptation or validation, may at first sight appear to be the most efficient implementation strategy, this should nonetheless be avoided as in practice it will encounter a number of barriers stemming from these cultural differences. As none of the nine instruments analyzed has been developed in a European context, let alone in French, it would appear that none of the analyzed self-administered instruments are directly usable in Europe, and a fortiori in France.

All of the instruments analyzed were devised for epidemiological applications, and they were intended to describe the caregivers’ needs at the population level in a given area and at a given time. All had undergone a rigorous process of development/validation, and from a psychometric perspective, this work has not identified any instrument which was a priori superior to others. Although used systematically in the analyzed instruments, use of Likert scales is, however, questionable as these scales tend to favor the maximum and minimum scores (ceiling and floor effects), limiting the variability of results and consequently the prioritization of needs. In the future, other measurement techniques should be considered, such as the item response theory, as proposed by Wen et al. Another way to go about this could be to characterize the specific needs of caregivers according to the stages or characteristic events of the caregiving experience (e.g. diagnosis, treatment, post-treatment, bereavement, etc.).

This review did not identify a self-administered caregiver’s needs assessment instrument which, on its own, can provide operational and personalized support for the caregiver. There are several reasons that may explain this. First, given the number of caregivers and the potential needs to be covered, needs assessment should identify the ‘priority’ caregivers, or, in other words, those who are a priori the most in need of support. Therefore, the instrument should lead to a caregiver’s level of risk gradation, as a score for example. Two of the nine analyzed instruments allow for the generation of a score: a score of need. Similar to Prue et al., we believe that the meaning of such a score for individual support is subject to interpretation. Thus, do most important unmet needs (or a greater score of need) result in an increased level of caregiver distress, a poorer quality of life, or a lower satisfaction with the care? It is possible that high-level needs cause as much distress as other needs of lesser intensities. For this reason, the score of need is probably not a valid indicator of the priority for the provision of support to the caregiver. Although the needs of the caregiver significantly change over time, and taking into account this, dynamic is an essential component of their support, none of the analyzed instruments enabled iterative assessments under longitudinal caregiver monitoring, as evidenced by the lack of sensitivity to changes in the assessment. Lastly, the identified instruments rarely encompassed an evaluation of the positive dimensions of the caregiving experience; although in the context of individual coaching, joint
knowledge of the positive and negative dimensions, difficulties but also satisfactions, and the balance between the two are important elements that warrant being understood. 37

For all of these reasons, the role of self-administered instruments in assessing the caregiver’s needs in clinical practice can rightly be questioned. Indeed, while their use can be relevant in many regards (e.g., cost criteria, feasibility, limited risk of results interpretation by a third party compared to hetero-administered instruments, etc.), it seems insufficient on its own, and should be supplemented by two additional elements: upstream, a ‘caregiver’s risk gradation device’ allowing the identification of subjects whose physical and/or mental well-being is most impacted by unmet needs (this device would be based, for example, on a ‘distress thermometer’, as advocated by Hollingworth et al. in their work on the patient’s needs assessment 38); and downstream, the assistance of a third party with expertise of support systems, including the establishment of a relationship of trust, partnership and co-expertise 39 that results in the implementation and monitoring of an action plan. Lastly, democratization of access to information technology and decision support now offers new opportunities for the development and use of self-administered assessment instruments with the development of computerized instruments including calculation algorithms, or of connected applications that could limit costs and facilitate their use. 31,40

The limitations of our study lie primarily in the non-exhaustive nature of the database search process. First, only one bibliographic database (Medline), characterized by a medical approach, was searched. The use of additional databases in the field of social and human sciences may have proven useful in complementing the research process so as to find other self-administered instruments. Second, the use of other European languages, besides English or French, in the search equation would have made it possible to identify instruments that are easier to transpose into the French cultural context.

In conclusion, the assessment of the caregiver’s needs represents a key step in their coaching, although the concepts involved are still insufficiently defined. Development of self-administered instruments is a complex research field that has undergone only a limited amount of study at the international level, and which must meet a strict set of specifications in addition to an appropriate psychometric validation. In particular, the device may associate a base level of general criteria with specific components of the care receiver’s affection, and will be integrated into a device comprising upstream: the recognition, identification and assessment of the overall situation; and downstream: orientation, establishment, and maintenance of an appropriate action plan. Future research is needed to clarify the scope (e.g., geographic, population-based, etc.) and modalities of these evaluations to best combine the singularity of the caregiver’s needs and services in a given area.

Supplementary data

Supplementary data are available at EURPUB online.

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Key points

- The needs of the caregivers warrant to be rigorously defined in order to develop appropriate and efficient services.
- To date, there is no gold standard self-administered instrument for assessing the needs of the caregivers.
- Self-administered instruments have many advantages including ease of use, low cost and ability to standardize the assessment process.
- Self-administered instruments have to undergo rigorous development and validation process.
- Although all the instruments analyzed were specific to a subpopulation of caregivers, a common set of needs for all informal caregivers may be highlighted.

References

Do hospital characteristics influence Cesarean delivery?

Analysis of National Health Insurance claim data

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Background: The rates of Cesarean delivery in South Korea are high among the Organization for Economic Cooperation and Development countries. We analyzed the relationship between hospital characteristics, in particular hospital volume and market competition and Cesarean delivery. Methods: We used data from National Health Insurance claims (n = 53,591) at 51 hospitals to analyze the relationship between hospital characteristics and Cesarean delivery between 2010 and 2013. We performed logistic regression analysis using generalized estimating equations models that included both inpatient and hospital variables to examine factors associated with Cesarean delivery. Results: Among 53,591 hospitalization cases, 14,425 (26.9%) patients underwent Cesarean delivery. Hospital volumes for deliveries were inversely associated with Cesarean delivery (per increases 100 deliveries = OR 0.896, 95% CI 0.887–0.905). Market competition had inverse relationship with Cesarean delivery (per increase in 10 Hirschmann–Herfindal index points; OR 0.982, 95% CI 0.979–0.985). Conclusions: Our findings suggest that hospital characteristics affect Cesarean delivery. These situations might be caused by maintaining profit with regard to survival or competition, and protecting themselves against unexpected delivery risks. Therefore, based on our findings, health policy makers must make an effort to implement effective strategies for the optimal management of excessive Cesarean rates in South Korea.