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Assessing quality of life of cancer patients' caregivers: criticism of past scale validation studies and proposal for new patterns of scale analysis and validation

Abstract

Objective: Providing an overall view on the importance of the population of informal caregivers and cancer informal caregivers, and a clear conceptual definition of the concept based on in-depth interviews and literature review. Proposing a solid scientific roadmap for scales validation, based on mistakes or approximations noticed in the literature on CQOLC scale in different countries.

Design: The American original CQOLC scale was translated and supposedly validated in a number of other countries worldwide. All studies show different dimensionality structures and results, but they also follow different statistical processes: we analyze those. **Setting:** Literature review shows the magnitude of cancer informal caregiving as public health issues, worldwide, as far as information is available. Proposition of a more comprehensive definition, based on 35 pilot interviews conducted in a Spanish hospital. A comparison of 9 studies (including the original American scale) allows a careful analysis of the followed process (scale items selection, translation, sample recruitment, statistic process). This leads us to point out weaknesses or mistakes in the scale validation processes.

Results: Most of the 9 scales, including the original one, suffer from severe limitations in the subjects' recruitment procedures (ex. too few cancer types often from 1 to 3), (very) limited types of caregivers in term of relationship with the patient, removing caregivers who have had a cancer, or with low education level, etc.). Several scales see items removed even before any statistical analysis be performed, because the authors believe that they are not adapted to the population. This impoverishes the scale content and its ability to capture all facets of the concept of QOL. Finally, the factorization leads to removing too many items under the criteria of removing items which are single or which load on two factors; removal reach sometimes till 30% of the scale, impoverishing the scale even more. There are strong discrepancies across studies in how they use statistical criteria for purifying the scale (ex. Kaiser, scree, Cattell tests); too few tests are used except in one study; and in many cases purification is too strict as mentioned here above.

Conclusion: There is no consensus, or maybe even not enough knowledge, of how and why, under which criteria, should the author perform the following actions:

a) Removing items from the original scale
b) Recruiting subjects (here caregivers) in a manner which fully represent the studied population under several important characteristics
c) Conducting a clean and scientifically justified scale factorization, and if necessary, purification process.
d) As a conclusion, we cannot know if the scales dimensionality variations are due to the commented methodological differences, or to true populations' differences.

Keywords: Methodology, scale validation, quality of life, cancer informal caregivers, cross cultural comparison.

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Introduction

Our study tries to help providing a practical and scientifically sound roadmap par validating measurement tool for hospitals and medical doctors, and for caregivers alike, for assessing quality of life of cancer unformal caregivers. After studying the CQOLC (Caregiver Quality of Life scale-Cancer) scale construction[1] and validation processes in 8 countries we analyze some weak points of the publications on the subject. We present a number of measurement scales which have been validated in several countries around the world. Most have been published in major journals, and comment the measurement and validation process, their weaknesses, and the main results concerning the scale properties. The article observes that important discrepancies arise across the scale properties studies and validation procedures. We propose recommendations for harmonizing and respecting better standards in terù of scale validations across countries. We first remind some key figures concerning cancer, highlighting variations across sources. Then we propose an updated definition of an informal caregiver, and then, present the different CQOLC scales validation processes followed across most of the studies published on the matter. We conclude with methodological recommendations for future scales validation procedures.

Cancer: some figures reminding its importance as a major health issue, worldwide

a) The importance of cancer

Cancer is important because of the growing importance of the number of patients, of its still high mortality rate, and maybe, the high level of emotional and psychological load it puts on unformal caregivers and not only on patients. Moreover, this disease is not decreasing but rather, growing in importance, worldwide. More people die every year from cancer, worldwide, than the total number of patients dying from AIDS, tuberculosis and malaria, combined[1] with a total of approximately 8.8 M dead patients every year.[2] It comes ranked first or second (always immediately before or after cardiovascular diseases) in most developed countries,[3–6] including in Europe, and is therefore a major public health issue – the only exception being the increase of death due to the Covid 19, but for the latter statistics are biased because in many of them, we cannot discern whether the dead patients actually died "with" the covid or "because" of the covid", and such topics goes beyond our subject. Due to the strong negative psychological effects of cancer, not only on patients but also on informal caregivers, we can say that such disease impacts two populations: on the one hand patients, and on the other hand, informal caregivers. In addition, we should mention the medical doctors and nurses and care auxiliaries, for whom burden is also important, though, maybe to a lesser extent. We focus here on the population of informal caregivers, that is, caregivers who (partly or totally) live with the patient, and are not remunerated for caring for her. We will provide a precise definition hereafter.

b) Cancer in the World and in Europe

Cancer is a major, and a costly disease. It was difficult to find specific data about the current number of cancer patients: if we don't rely on other publications but search for primary data we found a total number of 34.2M cancer patients worldwide dispatched into 35 different cancer types according to CANCER TODAY from the WHO.[7] A total of 18.1 M new cancer cases were declared worldwide in 2018, and 29.5 M new cancer cases are expected for year 2040:[8] that is, it is a major societal health issue, of growing importance. North America counts with 10M cancer patients, 1.8M new cases in 2018 and 0.6M death per year; in 2023 the USA alone counted 1.96M new cancer cases and 0.61M death cases; estimates reach 2M new cases in 2024 (cancer.org, Nov. 2024). Europe counts with varying numbers, from 3 M (statistics ECIS) to 3.4M (statistics WHO-GLOBOCAN) or 3.7 M (statistics WHO-EUROPE) new cases every year, and from 1M (WHO statistics, GLOBOCAN) to 1.9 M.[9,10] deaths per year for a total of 513 M inhabitants. Numbers vary across sources, and ec.europa counts from 1.14M deaths in 2021 (ec.europa.eu/eurostat/statistics) to 2.3M (ecis.jrc.ec.europa.eu/en/cancer). Death rates vary across countries and are established at 23.5% in the USA and 30% in the European community in 2021. The cost of cancer is difficult to evaluate, and is estimated at 1.160 Bl $ or 830 Bl Euros worldwide by the WHO in 2010[9] and at 126 Bl Euros in the European Union alone[11] in 2009. An in-depth and holistic study on such issue would be of a major importance for better developing national health policies including all concerned stakeholders. Current data only takes into account the direct caring costs actually paid, not including the "invisible" loss of a patient who is not working anymore, of an informal caregiver of a patient who is partly (or totally) not working anymore, nor the cost of psychological burden for both actors, not for medical doctors and for nurses and care-auxiliaries. Only direct medical costs are considered. In term of treatment efficiency still, and with such high level of financial investment in our societies, the literature shows that a major part of the (psychological) pain is only partly addressed in the cancer treatment process, for several stakeholders: the medical doctor, the nurses and care auxiliaries, and the informal caregiver. We focus here on the pain and quality of life of the informal caregiver.

Some key information concerning the informal cancer caregiver

a) A definition of the caregiver

Most of the scientific literature on the topic studies caregivers' well-being or quality of life, without specifically defining what an informal caregiver is. A "caregiver" is a person who dedicates a "significant" part of his/her time to take care of patient suffering from a long-lasting disease or a handicap physical or mental handicap, depression, or simply, age. An "informal caregiver" is a caregiver who is not paid for performing such task: as the ACS puts it: "*We define caregiver as the person who most often helps the person with cancer and is not paid to do so (they) may be partners, family members, or close friends. Most often, they're not trained for the caregiver job. Many times, they're the lifeline of the person with cancer.* They actually define here the informal caregiver, not the caregiver in general and this may be confusing.

We conducted in-depth interviews with informal 35 cancer informal caregivers in Segovia general hospital (Spain) in Spain and one of our objectives was proposing a complete definition; based on these, we propose a new definition of a (generic or specifically cancer) informal caregiver as follows: *"an informal (generic or specifically cancer) caregiver is a person who dedicates a significant part of his-her life to help a patient in his-her daily life, for tasks that he-she would hardly or not be able to carry out alone. A simple helper is considered to be an informal caregiver when he-she dedicates more than 10% of her time to a patient. we will consider that the informal caregiver dedicates 30% or more of his-her time to caregiving tasks. Care is normally, but not always, done on a daily basis. Tasks vary from taking news and chatting, having a walk together and going to treatments with the patient, to preparing food, washing-changing-taking the patient to the toilets and being available to him-her from 50% of the time to a full-time, 7/7 and 24/24 (most informal caregivers do actually live with the patient; sometimes they make shifts (typically though not exclusively, spouse and one of the kids, as we could see). What is specific is that the caregiver is not prepared, not trained (or just a little when cancer starts, via a small guide provided by a care association or the hospital), not paid, for such tasks. He-she most often sacrifies (part of) his-her life and career to such caregiving; and she is often seriously impacted in his-her quality of life by such caregiving process. A very partial remuneration is sometimes given to the unformal caregiver, far from covering all costs or loss of salary due to a decrease in the time dedicated to her former job".*

b) Estimating numbers of caregivers

The European Union had largely ignored, in its approach of public health, the role of caregivers so far;[12,13] but now in countries like, for instance, France and Spain, the Social security system and Cancer leagues draw more and more the attention on the burden of the cancer caregivers.[14–16] The WHO does not provide accurate data concerning caregivers for Europe or the rest of the world – which shows how little consideration such topic receives - but the European EUROCARERS association provides impacting numbers, confirming the magnitude of the caregivers population in all European countries: the population of caregivers would reach the impacting rates of, for instance, 20% of the total population in France and Spain, 17,5% in Belgium, 15% in UK, and 11% in Germany and Switzerland (see the table hereafter): (Table 1). For the US population, the caregiver rate in 2015 reaches 13,5% (43.5M caregivers for 322M inhabitants)[17] We did not find numbers in Asia, or Africa, nor Oceania. Based on all such numbers we can consider that a ratio of 10-15% of the total population would be close to the real number of caregivers in developed countries. This is a very high number, confirming the importance of dealing with caregivers' pain and quality of life. Still, the absence of numbers or of accurate numbers shows how limited interest they have raised from governments and social security services.

Table 1 Some European figures on the percentage of caregivers in the whole population

Country	Million Caregivers, Official number	% of the population	Million Caregivers, Unofficial number (estim. by associations)	% of the population
Belgium	0.86	8	2	17,5
CH	NA	NA	1	11
Germany	3.3	4	8.91	11
Spain	0.43	0,9	9.5	20
France	8.3	12,4	11	20
Portugal	NA	NA	0,83	8
UK	5.5	8,9	9.8	15

The Official number is the number of registered caregivers who have followed the process to be recognized by the state; Whereas the Unofficial number is the data supplied by the associations active in the area, centralized at the European level by Eurocarers.

c) The population of Cancer Caregivers

Concerning cancer caregivers, the situation is even worst as almost no country provides numbers, even inaccurate ones.[20,21] The French National Cancer League provides the number of 4M unformal cancer caregivers or 6% of the total French population (66M people).[14] We could not find numbers for other European countries such as Germany, UK, Italy, or Spain, though we consulted many statistics. As a conclusion **we propose to consider as a low, conservative estimate, a ratio on the total population of 15% for caregivers overall, and of 5% for the cancer caregivers,** based on the only available data so far, to reflect the proportion of cancer caregivers in the European countries and in the USA. This demonstrates the magnitude of the phenomena. We present now how serious the situation of the unformal cancer caregivers is in term of quality-of-life.

The CQOL scales to date, cross-countries comparison

Assessing caregivers' quality of life is an important issue of pubic health, due to their number in the developed countries populations; moreover in the case of cancer caregivers as cancer systematically ranks amongst the 2 first causes of death in such countries. It might certainly be the case also in low developed countries but no data are available on the caregiver's population size to our knowledge. We present here an overview of the scales analyzing the life quality of cancer informal caregivers, validated till 2019, that is, before the Covid pandemic. The literature shows that that the Covid has had serious impact on patients and caregivers' QOL and we believe that a very precise study should be developed, comparing scales, with specific dual analysis before-during-after the Covid.[16] To assess cancer caregivers' QOL, Weitzner & his colleagues developed and validated the CQOLC (the Caregiver Quality-of-life-Cancer index), now the most widely used scale, worldwide.[18,19] Some other scales have been proposed and validated in several countries; but we focus here on this sole scale. This scale has been (partly) validated in several countries and presents the advantage of being adapted to both curative ad palliative mixed cancer care.[22] Weitzner & colleagues follow the classical process of item generation, item number reduction, and scale validation.[23] The final CQOLC scale consists of 35 items; 27 items are conserved after the scale purification process: 19 items load on 4 factors and 8 items load on no factor, as follows: F1=Burden(10 items), F2=Disruptiveness(7 items), F3=Positive adaptation(7 items), F4=Financial concern(3 items), plus 8 single-items not loading on any factor (Disruption of sleep, Satisfaction with sexual functioning, Day-to-day focus, Mental strain, Informed about illness, Protection of patient, Management of patient's pain, Family interest in caregiving). The fact that some items do not load on any factor does not mean at all that they would be not important, as we can see when reading their content; it just means that they are weakly correlated to the main factors: this is a first observation: such non factorial items DO MEAN and are important indeed; the fact they do not load on one factor does absolutely not mean that they should be ignored, as several scholars do in the following research. This scale has been studied and partly validated in several countries: we can highlight Singapore, France, Turkey, Iran, China, Korea, Portugal, Taiwan, and Spain, using different recruitment and validation protocols.[24–28] We say that they were "partly" validated, because several studies do suffer from some limits: due to the recruiting process (such as a small sample, a limited number of cancer types, a limited type of caregiver-patient relationship or even, gender), or to the scale purification and factors reduction methods, as we see in the Discussion section. We discuss such points in detail hereafter. In the European Union (27 countries) 3 studies have been carried out: in France and Portugal and Spain. Those two first studies (France and Portugal) show interesting results, but it is unsure whether any of those scale can really be used by medical practitioners in a European context, hence the current research. The issues raised by those two first European studies and by other studies, are commented hereafter.

a) Limits of the original American study and of the subsequent European studies: cancer types and subjects, scale items removals

The original US scale validity suffers limitations as they consider originally only 4 cancer types in the initial items-generation process, and later in the purification process, only 3 cancer types (lung, breast, prostate). They also do not consider caregivers who are parents of a patient; this very strange choice is not justified (spouses, children, parents caregivers, are discarded!). Those draw important limitations to the study. Likewise, the French study (conducted in 2013) suffers huge limitations. First, the sample used concerns only spouses (N=300) while there are many other types of cancer caregivers (children, parent, friend, companion, brother-sister, etc.). The analysed scale consists of 33 items, as 2 items are initially removed. I am concerned about our insurance coverage, and It bothers me that I need to be available to chauffeur my loved one to appointments). The official reason proposed for removing item 7 is that French social security system covers all expenses; but that is wrong: our caregivers and expert interviews show that financial cost is a real issue for caregivers, due to direct expenses (home equipment) and non-direct costs (loss of working time and direct salaries, additional costs due to caregivers' exhaustion). In addition, caregivers often do need to get rid of their job (partly at least) or to get repeated medical leaves from "kind" medical doctors in order to attend their beloved and not lose their job, and they are under constant fear (of being fired) and financial strain indeed. The reason for removal of item 24 in the French scale is even worse, and due to a misunderstanding (probably due to a poor level in English of the authors?): they say that we do not use "chauffeurs" in France, which shows a deep misunderstanding of the meaning of the item, while the item simply refers to the fact that caregivers often have to drive and go together to the hospital with their beloved one, for visits and/or treatments- the caregiver accompany the patient, driving her to hospital sessions. We have contacted the authors twice, with no answer. Then, the factorization leads to a drastic scale "purification", as 10 more items are removed due to "low saturation index or reliability statistics" (items 4, 10, 12, 16, 22, 23, 27, 28, 34, 35). Moreover they do not indicate the threshold and statistics or index used, leaving a final CQOLC scale of 35-10-2=23 items. That is, we "lose" a lot of information in such process. The final scale displays "1, or 9 factors" (as they put): the authors actually provide two options: a solution with 1 single factor of 23 items (following the screen-test or Cattell criterion), or 9 factors (following the Kaiser criterion). They finally opt for the first 1-factor solution of 23 items (with only 38.8% of extracted variance); we note that this is not a "weakness" of their study, as deciding of the number of factors may be complex and subject to discussion ; in fact, the Kaiser criterion selects the solution for which Eigen-values are superior to 1, which is a mathematical and statistic criteria; it is safer that the scree-test, which is very useful but us a rule of thumb as it is only visual, and based on a "feeling" at viewing the screes formed in the Eigen-values curves. But getting only 38% of extracted variance is indeed a poor result: we lost lots of information in this drastic factorization and the resulting scale is close to useless. This only justifies our concern for another study in a European and specifically in French populations.

b) Problems of sampling in data collection

The Portuguese study (conducted in 2003). This study suffers from sampling limitations as only 3 types of cancer are represented (Breast, Digestive, and Gynaecologic-Urologic), and less than 3 months must have passed since the diagnostic was done: that is, no long-duration cancer treatment is considered - and those are the majority of the cases. Caregivers who themselves have had a cancer in the past are also excluded, limiting the findings' generalizability. Indeed removing caregivers who have had a cancer themselves is a mistake: they are part of the caregivers' population; having had a cancer is just a covariate, that may impact different feelings and behaviors; but removing them is scientifically unjustifiable – and most studies do the same, removing caregivers who had a cancer. The second limitation is that 8 items are withdrawn from the scale before all analysis, and, without any explanation (removed items: 2-Sleep less restful, 4-Satisfied with sex life, 13-Bothers limiting my focus, 15-Increased mental strain, 23-Adequately informed about illness, 30-Need to protect bothers me, 32-Manage pain overwhelming, 35-Family members showed no interest). Two more items are withdrawn during the scale purification process (4-Satisfied with sex life, 17-Feel guilty), theoretically leaving only 35-8-2=25 items in the scale. The resulting scale is said to consist of 4 factors (42.2% of extracted variance); but the final table actually shows a 4-factors structure with 33 items: that is, the final factorial structure is unclear for the reader. As a conclusion, though both studies are useful for practitioners, they present several limitations that make us propose new studies in the European Union and in particular for France and Portugal. China removed QOL5-Maintenance of outside activity, saying that people had no activities outside, which is very strange…, while shopping, going to work, etc are such outside activities; and they removed QOL12-Increased spirituality by saying Chinese people would not understand it: if subjects have no spiritual activities maybe they would actually understand the question, they will chose to put a low grade to that item. We note that in both cases several items are withdrawn before the analysis, generating important issues in term of validity (validity refers to the issue: "do we measure the construct we want to measure?"). Of course, as different scales have conserved different items, as will be shown in the general table that means that we do not measure anymore the same construct. Moreover, the sampling method raises strong issues (caregiver types in the French study; cancer types and time since diagnostic for Portugal), putting limitations to the generalizability of the findings. The scale structure and the conserved items after the scale purification do not match at all from one country to the other, France displaying 1 factor and Portugal 4 factors: it might be that the differences in the scales content be not due to the cultural differences among both countries, but rather to the differences in the sampling process. We therefore need a new study in France and Portugal.

c) Items formulation that needs to be modified

Some items of the CQOLC scale may effectively raise some issues. For the Spanish scale first study,[29] an analysis of the literature and expert interviews (medical oncologists and psycho-oncologist in different Spanish hospitals), plus a pilot testing (N=35, questionnaire administration + in-depth interview) led to propose modifying several items: Item 7-Concerned about insurance may not be adapted in ex. The European Union or any country where all citizens benefit from full medical coverage; and this question was actually confusing the subjects. But should we remove it? In a pilot study in Spain subjects did not understand why this question was made, and then, it would destabilize them in answering the rest of the questionnaire. Probably a more accurate formulation could fit with all countries? Where there is a developed social system and where there is not? We would suggest a modified item 7, named item7modif-Concerned about non-covered additional health costs and salary loss.

Spanish authors also removed item 16-Support from friends and neighbors, which raised two issues: it was perceived as partly redundant with items 34-Family Support from friends and family, and 35-Interest from other members of the Family, and this argument is acceptable; above all it was seen as unnecessary by most subjects, as, in Spain, families (and not neighbors or others) area fully involved in caregiving. Again, subjects could simply have answered on 0-level to this question, but its mere presence troubled them. It was clear for them that caregiving is the job of the family or companion, and friends-neighbors were never mentioned, so the Spanish team removed it (we contacted the authors to obtain such detailed explanations). The weight of the family structure must be taken into account into the item formulation: our interviews with Chinese, Arabian (North African) and Persian subjects led us to suggest that a similar situation would occur as it did in Spain: the family still knows where their role and place is, and they show up to bring support. They seem to be still far more of a support than in occidental countries. But still, avoiding redundancy is useful, to avoid having unnecessary long scales. Previous publications do not detail the reasons for modifying items, but several medical journal editorial lines show interest into it, due to the issues raised with not only scales translation, but "adaptation" to different cultural contexts. Item 3-My daily life is imposed on is often not easy to understand, and not well understood. It taps into the loss of control by the caregiver and some subjects asked to the Spanish authors: "but who is imposing me something?", especially aged persons. Consequently, the Spanish team reformulated it into Item 3modif-Having lost the control of my daily-life bothers me". Item 4-Satisfied with sex-life was judged as problematic and difficult to accept in several other countries and several items simply removed it: China, Singapore, Portugal, Taiwan. Pilot testing conducted by us in Spain and France showed it was indeed perceived as unproper in that many caregivers had an age where talking about sex life is seen as not only shocking, especially among Spaniards, but also irrelevant, as 5 pilot interviews confirmed. Still, it is used in several quality-of-life scales such as the Ferrell scale for oncological long survivors and medical oncologists considered that it was a relevant QOL indicator. Moreover, experts and caregivers' interviews showed that not only sexual life, but affective life in general was extremely important in caregivers' QOL and there were NO items at all about such issue (such aspect was not captured yet). The item was then reformulated for the Spanish scale into: item 4modif-I am satisfied with my affective or sexual life, and such decision is scientifically much better in term of scale validity than removing the original item. As a conclusion, we believe that removing "disturbing" items is not a good and justified solution; a reformulation for future uses of the CQOLC scale seems to us a better option: we therefore do not lose the expected information; rather, we collect even more and more accurate information, which is key for the scale validity (measuring what we are supposed to measure) in our review we find many scales in which authors do remove items without thinking as much as they should. We always must keep in mind that removing an item means losing information.[30,31]

d) The sampling procedure

To increase the results' generalizability, we must ensure that recruiting was as "open" as possible. For example some studies recruited only one type, or a limited number, of cancer type (ex. the original American one: considered only 4 types initially and then 3 types in the scale validation process; 5 studies do not specify how many cancer types they selected (mention "NC" in Table 2), among them the French study (we can then assume that they accepted all types but we are unsure); the Portuguese study selected only 3 types of cancer and recently diagnosed (less than 3 months); the Iranian study, only women with Breast cancer, recently diagnosed (less than 3 weeks)). A good benchmark could be the Spanish study: they tried to extend the generalizability of their findings by selecting all types of cancers, classified in 10 cancer types: (Table 2) With the same idea of extending the results' generalizability, no socio-demographics were used to exclude subjects: all family-relationship types were included (vs France conserved only husband-wife caregivers, which is very limitating; USA excluded all parents). We put no restriction in term of education level, as the non/low educated caregivers are part of the population (though USA and Portugal studies excluded subjects with a low level of education (Table 2). Indeed the US scale, which is the original created scale by Weitzner & alli, is the one which suffers most pitfalls in term of methodology, because of the lack of representativeness of the caregivers' population. Some other issues are to be highlighted concerning the CQOLC scale per se that is the initial (USA) one, in term of nomological validity, but that point goes beyond the scope of the present article and will be addressed in another study. Table 3 summarizes important characteristics of each selected study: the sample size, and the selected subjects based sociodemographic and cancer types or family relationship motives, and the main results. We underline the characteristics that may put a limit to the generalizability of the results found in the past, reminder to the reader that we only include hereafter the existing (or mention or missing) data that we find the most relevant in our methodological reflection presented in this paper. We therefore notice many variations, often, not justified scientifically. We therefore can hardly guess whether the varying scales' dimensionality are due to the fact that the caregivers psychology, behaviors and feelings vary across populations, or whether this is due to differences generated by the varying methodologies used in each study.[32]

Table 2 Types of cancers

No.	Cancer types
1	Digestive
2	Breast
3	Lung
4	Orl
5	Gastric
6	Pancreatic
7	Prostatic
8	Gynecologic
9	Urothelial
10	Miscellany

Contributions, limitations and research avenues

This paper proposes a reflexion on some limitations of past publications on one of the most used QOL scales, the CQOLC measuring the quality of life of cancer caregivers. We classify our remarks per sections; following the order normally followed. Discrepancies are to be noted in the items-removal step: several studies removed many items without explaining why (Portugal 8 items, Taiwan 4 items); some countries removed items for reasons which can be questioned: France removed 2 items for wrong reasons. Portugal and Taiwan did not even justify the removal. Overall, we suggest that researchers try to consider very carefully when removing original questionnaire items because each time we remove an item, we lose information; and cross-cultural comparison is later made very difficult, or impossible. The Spanish study proposes a good idea: adapting the item formulation when it seems inappropriate or non-understandable. In general, the issue of "questionnaire acceptability" is an important, unaddressed issue: should we remove an item which is a bit "disturbing"? More research on such issue could be useful, to propose common and valid procedures to researchers and practitioners. There are discrepancies in the recruitment process concerning the types of cancer. As can be seen in Table 1, the original US scale only considered 4, then 3 cancers, therefore the seminal US study should be re-conducted in order to be validated in the USA. Very few cancer types are also considered in Portugal (3 types), Iran (1 type not in the table), and the others do not communicate on that issue (Korea, Taiwan where we only know they consider terminal cancers only, France, Singapore and China)

(Table 3). All types of cancer should obviously be considered and only one study does so (the Spanish one). We see other limitations in the subjects' recruitment: several studies excluded low educated subjects, though they are part of the population and should be part of the sample: as long as they can fill-out a questionnaire they should not be removed. And even if they cannot fill out a questionnaire alone, shouldn't we conserve them alike? Under those two aspects we could desire studies to be conducted again in those mentioned countries, with an harmonized recruitment process, in order to ensure results generalizability, based on a common process for all countries: all cancer types should be considered; all adult subjects (though they had a cancer themselves and though they have a low education level) should be included in the sample. Half of the studies excluded caregivers who had been diagnosed a cancer in the past: this is not justified from a scientifically standpoint and that, again, biases the results. If a caregiver has had a cancer she is still a caregiver and is indeed part of the studied population. It is important to take a peculiar care in the translation process (ex. the mentioned poor example in the French study) and also in a real understanding of the meaning of a word (again French scale: misunderstanding of the word "to chauffeur"…). The Korean study provides a useful avenue, as they detail the obstacles they encountered and how they bypassed them; the Spanish study alike proposes a careful reformulation to make sure the translation be adapted and…accepted. This may avoid removing items unnecessarily: for instance, the French and Spanish studies removed the item concerning financial pressure because there is a social security system: but that was wrong, a healthcare system does not cover all costs and does not remove all financial strain.

Table 3 Selection of important characteristics and results noticed across CQOLC scales validations

The important need for a harmonization of the dimensional analysis procedures: It must be noted that the same scale structure varies a lot across countries, worldwide as can be seen in the recapitulative table. Is that due to the cultural differences…or to the varying dimensionality processes? Most studies wrongly use a Varimax (orthogonal) rotation in the factorial analysis, though in psychology, orthogonally among items and dimensions in a same concept is never observed. Second, there is no information in more than half of the studies on the criteria used for removing items along the factorial analysis; still, when loadings of an item are inferior to 0.40 on any factor, should we really remove it as many studies do? A too drastic "purification" leads to loosing much information (ex. the French and Portuguese studies, which eliminate one third of the CQOLC scale). Communalities are ignored by all studies except by the Spanish one only, while they are necessary[28]; the loadings must be taken into account but there is no reason for removing single items not loading enough on some factor[20, 28]; the issue of removing items loading on two factors is delicate: all studies remove them and this is unjustified: precisely because in psychology, dimensions are never orthogonal: therefore conserving muti factor items conserves much higher reliability to a measurement scale. We have tried to point out severe limitations of CQOLC "validation studies" and CQOLC scale creation by Weitzner & al. we therefore formulate methodological recommendations for the future. By non-respecting the above-mentioned recommendations, a scale may not be valid (it does not fully measure the concept that it is supposed to measure); and a sample may be strongly biased and fail in providing representativeness, which is a key for being able to generalize the results to the whole population when a significant result is obtained; we repeat it: if the sample is biased, results cannot be generalized. And the scale is not valid. A last point that should be studied is how many levels on the Liker scales should be assigned: all studies since the American scale use 5 levels except China (6 levels) and Spain (9 levels). Indeed using only 5 levels raises a strong methodological issue, as statistical tools should not be allowed with so few levels as the studied scales are assimilated to "continuous scales". The scientific community should carefully analyze such point – even though most scholars use 4 or 5 levels on Liker scales and ignore such important methodological issue. A limitation of this study is that we have not included all the last CQOLC studies; but our objective was merely to point out some of the strong limitations of existing studies, and we believe this paper is the first one of that sort in the medical literature. Considering absolutely all studies was not necessary. Another limitation is that we have not carried out an exhaustive cross-cultural scales dimensionality comparison: but this is so far impossible, because we do not know if the cross cultural dimensionality differences observed are due to cultural differences or … to differences in the scales' dimensionality studies, as was highlighted here above. We hope that our comments will encourage future studies in such direction to guaranty a more solid scientific process in scales' validations in general, and in CQOLC scales validations in particular.

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Conflicts of interest

The authors declare that there are no conflicts of interest.

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