

# Analysis of open answers in the validation of a health-related quality-of-life questionnaire for children

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## Abstract

This paper discusses the contribution of lexical analyses of open answers, based on multivariate statistical procedures, to the validation of the EQ-5D(Child), a health-related quality-of-life (HRQL) questionnaire for pediatric age. The basic idea is that children and adolescents' ideas about health-related concepts may divert from those expected by adults/researchers, thus resulting in misleading interpretations of the intended meaning of the questionnaire's items. In order to overcome this threat to the content validity of the instrument, 415 participants to the validation study of the Italian version of the EQ-5D(Child) were asked to explain, by means of open answers, the reasons why they reported having difficulties (if they had any) in each of the domains explored by the questionnaire profile (i.e., mobility, self-care, daily activities, pain/discomfort, and worry/sadness/unhappiness). Participants who reported having “no difficulty” were asked to figure out why youths their age might have them. A multiple correspondence analysis was performed on the resulting textual corpus in order to: a) describe the semantic fields associated with each domain; b) pointing out the relationships of proximity/distance between each of the five domains. Perspectives for possible further applications of lexical analyses to the questionnaire validation procedures are also discussed.

**Keywords:** quality of life, children, validation, lexical-statistical analyses.

## 1. Introduction

Health-related issues are amongst the most common topics in daily conversations. Though, the frequency of our use of these terms is not a warranty that lay people share a clear and unequivocal meaning for complex concepts such as “Health” or (even more) “Quality of Life”. This is not surprising, since scholars themselves have hardly reached a satisfactory consensus on how health should be defined. Indeed, although the World Health Organization (WHO, 1948) has stated almost 60 years ago that health is a state of complete bio-psychosocial well-being, rather than a mere absence of illness, the focus of medical research has moved only in recent years from a perspective of mortality/morbidity reduction, toward a broader perspective, in which the individuals' perceptions of health is in itself a component of their health state.

At present, health-related quality-of-life (HRQL) is commonly defined as the “*individual's subjective perception of the impact of health status, including disease and treatment, on physical, psychologic, and social functioning*” (Matza et al., 2004, 80). It follows that HRQL should be assessed by taking into account the individuals' perspective, and by eliciting

information directly from them (id.). Acknowledging the importance of taking into account the individuals' perspective, when assessing HRQL, gives rise to major methodological problems, since lay people's representation of HRQL concepts may substantially divert from those expected by expert researchers' (Schober, Conrad & Fricker, 2004). Obviously, the issue becomes far more important when measuring HRQL in children and adolescents, whose naïve conceptions of health and well-being may be even farther from researchers' expectancies.

First of all, it should not be overlooked that children and adolescents, due to their cognitive development characteristics, differ from adult population as to attentional resources, memory span, and knowledge of domain-specific health-related lexicon. Hence, major problems in questionnaire comprehension are likely to occur, and for this reason the appropriateness of items' wording in HRQL questionnaire should be always carefully checked.

Besides, children and adolescents are also likely to differ from adults as to the meaning that they attribute to the same health-related concepts. As a consequence, we may expect children to be able to understand the wording of a certain item of a HRQL questionnaire, and to provide a response, although the information provided by the children might refer to something completely different from what we meant when formulating the item at issue. Another possible source of misunderstanding may derive from the fact that children tend to represent health as state of freedom from physical pain or aches, rather than a condition of comprehensive bio-psycho-social well-being (Seiffge-Krenke, 1998). Hence, some domains figured out by researchers as pertinent to hrql, and therefore inserted in instruments for HRQL assessment (e.g., participation in social and relational activities), may be perceived by children as not related at all to health issues.

Overall, previous literature suggests that children's and adolescents' understanding of health-related concepts is worth being carefully checked, when developing and validating instruments for the assessment of HRQL in pediatric age, in order to avoid possible hidden misunderstandings during the subsequent questionnaire use (Eiser et al., 2000).

### ***1.1. Qualitative methods in pediatric HRQL studies: the use of interviews and open answers***

Qualitative methods are consistently viewed as a powerful tool to collect respondents' points of view about health-related issues – at least to a deeper level than quantitative methods do. The main advantage is that qualitative measures – e.g., open answers in a questionnaire, semi-structured interviews, and so on - leave the respondent the highest degrees of freedom in the response formulation. Therefore, such verbal and textual data provide an access to the meaning of the investigated issue in the user's words, rather than through the mediation of a set of items formulated in the researcher's language. This feature becomes far more important in the case of pediatrics population, whose language might be very different from the experts' or the adults' one.

The integration of a qualitative phase, based on textual data gathered from target population members, is already recommended in the standard procedures for translation and adaptation of HRQL questionnaires (Wild et al., 2005). Namely, a cognitive debriefing phase is often included in pilot validation studies, in which target users are interviewed and asked to evaluate the instrument's understandability and adequateness.

A number of recent studies has included qualitative tools and methods in the development of HRQL questionnaires, in order to explore in depth children's and adolescents views about either the issues explored by the instruments, or their understanding of questionnaires' items.

Among others, Detmar et al. (2006) have illustrated the use of focus groups during the preliminary phases of item generation, in the development of the KIDSCREEN questionnaire. Ravens-Sieberer and Bullinger (1998) have included open-answer questions in the validation procedure of the German version of the KINDL, in order to illustrate respondent's conceptions of health and disease. Recently, Davis et al. (2007) have adopted the think aloud technique during children's and parents' completion of the KIDSCREEN questionnaire, in order to explore in depth the reasons of the commonly reported mismatches between self-reported and proxy (i.e., reported by parents) HRQL measures in pediatric age. Their results suggest that mismatches may be quantitative (i.e., different importance attributed to the same experience affecting children's HRQL), but also qualitative (i.e., different understanding of the meaning of the same dimension explored by the questionnaire). As to differences in understanding the wording of items, for example, authors report that children and parents provided different meanings to expressions of very common use, such as "feeling sad", "having time for yourself", "being treated fairly", or "paying attention". In another study, concerning the preliminary phases of the translation and adaptation of the Italian EQ-5D(Child), Tomasetto et al. (2006) found that a variety of unexpected meaning was attributed by children and adolescents to the phrase "taking care of myself". Namely, a number of interviewees having difficulties in taking care of oneself means "being too concerned with one's aesthetic appearance", "not being careful enough", "taking *cures*" (due to the homography between *cures* and *cares*, in Italian), living in straights, and so on.

### ***1.2. Integrating lexical-statistical analyses in pediatric HRQL studies***

Although verbal data may provide very useful and insightful information reflecting the interviewees' perspective, some critical aspect should also be underlined, e.g. those related with the procedures of data analysis commonly used with verbal data. Traditional content analysis, based on post-coding of respondents' answers, may be affected by major shortcomings: 1) they fail to assure complete adhesion to the participants' points of view, since their answers are re-coded and summarized in categories defined by the researchers; 2) a lack of inspectionability affects the coding phase; there is no assurance that all the answers collapsed into the same category share an overlapping meaning in participants' view (this warranty is completely up to the researcher); 3) the procedure is time-consuming and highly demanding from a cognitive point of view; for instance, when the corpus to analyse is large, it is impossible for the researcher to devote a constant and sufficient cognitive load to the task, throughout the whole coding process, thus undermining the stability and reproducibility of the procedure. In order to avoid such possible flaws, the qualitative phase of the pilot validation studies is often limited to the collection and in-depth analysis of no more than 7-8 interviews (Wild et al., 2005).

Automatized procedures of lexical-statistical analysis are widely proved to overcome such shortcomings, especially by allowing the systematic analysis of large textual corpora drawn from open answers or interviews (cfr., i.a., Lebart, Salem, 1988; 1994; Bolasco, 2005). Dedicated software allow to extract and retrieve information directly from participants' words, thus avoiding the time-consuming hand-made pre-coding of participants' answers. Moreover, once the text has been automatically numerized and prepared in a convenient format, multivariate statistical treatments may be applied (e.g., Correspondence Analyses, Discriminant Analysis, Multidimensional Scaling, Cluster Analyses), in order to reduce the complexity of raw textual data, extract the most relevant information, and provide a synthetic representation of the semantic structure conveyed by the text. Hence it is possible to provide a multidimensional description of the contents of interviewees' answers, either across different

fragments of the textual corpus (e.g., comparing the semantic fields of different questionnaire's areas), or in relationship to relevant partitions of the respondents' sample (e.g., comparing answers according to participants' age levels, gender, health status, etc.).

In the following paragraph we report an empirical illustration of the application of a lexical analysis based on multivariate statistics (namely, a multiple correspondence analysis, MCA) in the validation procedure of the Italian version of EQ-5D(Child). The main aim of the study were to: 1) clarify the meanings attributed by children/adolescents to the domains of the EQ-5D, in order to detect possible sources of semantic ambiguity; 2) clarify the semantic relationships among the domains explored by the EQ-5D profile. For instance, the detection of possible ambiguities in the meaning attributed to single domains, and/or a lack of specificity of one or more domains in relationship to the others, would seriously undermine the content validity of the questionnaire, in the former case because it would assess something different from what is expected, and in the latter because the description of children's HRQL that the questionnaire provide might be less extensive and exhaustive than it would be desirable.

## 2. Empirical illustration

The adult version of EQ-5D is a standardized, non-disease-specific instrument for describing and valuing health. Currently available in more than 100 different language versions, EQ-5D is being applied in many different settings worldwide and is now an integral feature of many studies like clinical trials (Brooks, 1996). At present, the EQ-5D(Child), a version of the instrument for pediatric population aged 8-15, is under validation and cross-cultural adaptation in six countries: Germany, Italy, North Africa, Spain, Sweden and United Kingdom. The EQ-5D(Child) profile consists of five domains: *Mobility* (walking), *Taking care of myself* (washing and dressing), *Doing usual activities* (going to school, hobbies, sports, playing, doing things with family or friends), *Pain or discomfort*, and *Feeling worried, sad or unhappy*. For each dimension, respondents have to report whether they do have no difficulty (response level 1), or whether they have some (response level 2), or a lot of difficulties (response level 3). Either the adult or the child version of the instrument also integrate the profile with a Visual Analogue Scale, which allows respondents to score their health state on a 0 (the worst imaginable) to 100 (the best imaginable) scale. The present study only refers to the EQ-5D(Child) domains.

### 2.1. Method

#### 2.1.1. Participants

Four-hundred-and-fifteen Italian children and adolescents were recruited from general population (females: 48%; age: 8-15; mean: 11.75; SD: 2.117) and voluntarily agreed to take part to the study; either participants or their parents were asked to sign an informed consent for their participation. The total sample previously included 457 participants; those who did not meet the inclusion criteria, in particular those requiring help by their back-up teachers because handicapped or those still not capable to understand Italian because non native speakers, were invited to fill in the questionnaire as well as their schoolmates, but their data were not considered for subsequent analyses.

#### 2.1.2. Procedures

Participants received a questionnaire to be self-completed. Questionnaire administration took part at school, in presence of one of the authors and/or their collaborators (who were provided

with adequate training). By means of open answers, after having completed the current Italian version of the EQ-5D(Child), participants were asked to: a) explain the reason why they reported having “some” or “a lot of” difficulties (response levels 2 and 3), if they did, at each domain of the profile; b) in case they had reported having “no difficulty” (response level 1), they were asked to figure out a reason why youths their age may experience some or a lot of difficulty in the domain.

The resulting textual corpus was submitted to preliminary treatments by means of the dedicated software TALTAC2<sup>©</sup> (Bolasco, Baiocchi & Morrone, 2005). Open answers in which participants provided reasons for their own *reported* difficulties (i.e., those who justified their choice of response levels 2 or 3), were analyzed altogether with those in which participants *figured out* a possible reason of difficulty at the domain for a youth their age<sup>1</sup>. A words\*fragments matrix was then created, with all the words with at least 13 occurrences (n = 100; 65% of the whole text covered) in the rows, and the five domains of the EQ-5D profile in the columns. The matrix was submitted to a multiple correspondence analysis (MCA), by means of the software Statsoft Statistica 8.0<sup>©</sup>.

## 2.2. Results

The first two factors extracted (38.17% and 28.83% of Inertia respectively; total explained Inertia: 67.00%) will be described. In the Cartesian plane reported in Figure 1, we follow the convention to draw the first factor on the horizontal axis<sup>2</sup>.

Factor 1 (see Table 1) shows an opposition between Domain 5 (Felling worried, sad or unhappy), projected on the positive semi-axis, and all the other domains, which share either a marginal contribution to negative semi-axis of the factor (Domain 1), or fall very close to the null point<sup>3</sup>. Such a configuration indicates that Domain 5 holds an outstanding specificity in relation to all the other domains explored in EQ-5D(Child). As to the contribution of single words to the factor, we can observe that the lexicon projected on the positive semi-axis deals with school, friends and family (parents in particular). Words expressing negative emotions (*fear*), and references to events which may cause suffering also appear (*quarreling, death/died, (bad) notes, assignment of homeworks*).

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<sup>1</sup> Preliminary checks confirmed that open answers provided in the two conditions – reported vs. imagined reasons of difficulty – shared a comparable lexicon. Comparison of the lexicon produced by respondents in the two conditions was performed on the most frequent words in each domain (up to the 15<sup>th</sup> frequency rank). The ratio of shared words in the two conditions ranged from 47.22% (Domain 2 – Taking care of myself) to 56.25% (Domain 3 – Daily activities – and Domain 4 – Pain or Discomfort). It is worth noting that most of the non-shared words refer in any case to the same conceptual domain (e.g., in Domain 1 respondents reporting reasons for their own difficulty cite the word “*knee*”, whereas those describing inferred reasons cite more frequently the word “*ankle*”). Moreover, a part of non-shared lexicon is made up by temporal specifiers (e.g., *yesterday, today, sometimes, always*, etc.), which are used only by those who report reasons for their own difficulties.

<sup>2</sup> In the subsequent Figures and Tables words have been translated in English for clarity sake, although participants’ answers were collected in Italian.

<sup>3</sup> Although MCA is not a test aimed at hypothesis verification, a test for discriminating cases or variables with significant A.C. to the Factor is commonly used ( $1/[N-1]$ , where N indicates the number of the rows/columns of the matrix).

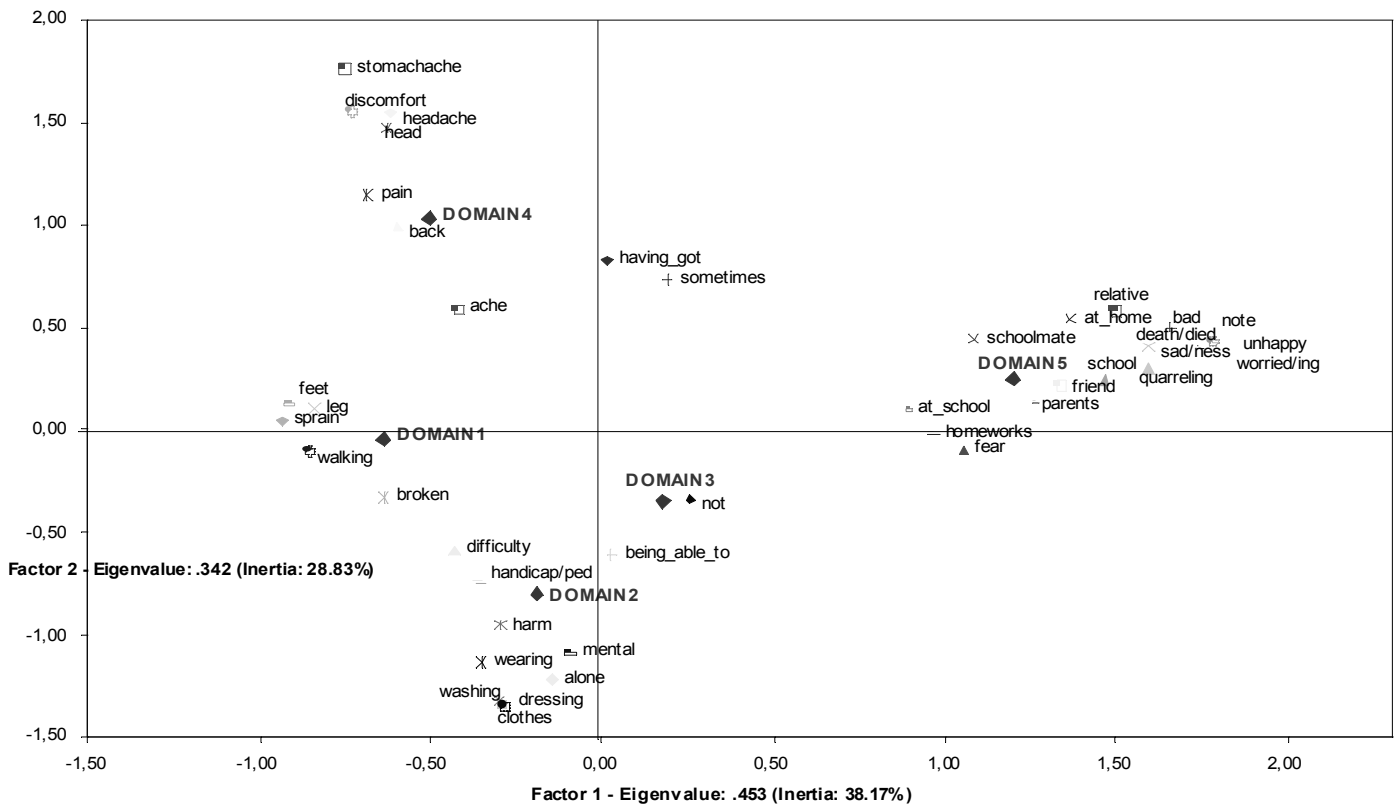


Figure 1: Cartesian plane defined by Factors 1 and 2. Only words and domains with significant A.C. on at least one factor are represented in the Figure

Words contributing to the negative semi-axis of the factor share the common reference to physical pain, ache or discomfort. Most of these words deal with specific pathological states (*headache, sprain, broken*), or to body parts which may hurt (*leg, feet*). In a greater detail, the lexicon with significant contribution to the factor, on the negative semi-axis, mainly describes physical injuries which prevent from walking (Domain 1).

In sum, it appears that the lexicon related to psychological (lack of) well being deals specifically with Domain 5, whereas all the other domains share a common reference to physical pain.

The exploration of factor 2 (see Table 2) allows to go in depth in the description of the lexical fields associated with (the lack of) physical well-being. An opposition emerges between Domain 4 (Pain or Discomfort), which is projected toward the extremity of the positive semi-axis, and Domain 2 (Taking care of myself), which is projected on the negative semi-axis. On the positive semi-axis we can find words which describe pathologies in which localized pain is the one of the main symptoms (*headache, stomachache, back(pain)*). Temporal references (*sometimes*) and verbs (*having got*) suggest that the positive semi-axis of the factor mainly refers to acute and episodic diseases, rather than stable and long lasting disabilities. Conversely, words projected on the negative semi-axis mainly describe difficulties in washing and put on clothes in autonomy. In particular, it appears that children/adolescents represent such difficulties as related to stable impairments of a certain severity (such as physical or *mental handicap*), or to the lack of sufficient skills (*not being able to*), although also the word *harm* (i.e., injure at an harm) is associated with the same domain. Hence, Factor 2 seems to outline an opposition between two kind of physical impairments: on the one hand, episodic

conditions which provoke acute pain or at least discomfort (positive semi-axis), versus stable but uncommon impairments which prevent from taking care of oneself (negative semi-axis). In the Cartesian plane defined by the first two factors, Domain 3 holds a neutral position and is projected very close to the null point; in other terms, MCA does not allow to detect, in children/adolescents' answers, a unequivocal and specific lexical profile associated with this domain.

FACTOR 1				FACTOR 2			
NEGATIVE SEMI-AXIS		POSITIVE SEMI-AXIS		NEGATIVE SEMI-AXIS		POSITIVE SEMI-AXIS	
WORDS	A.C.	WORDS	A.C.	WORDS	A.C.	WORDS	A.C.
leg	.044	worry/ied	.110	wearing	.053	pain	.106
walking	.038	sad/ness	.071	washing	.050	headache	.098
pain	.029	unhappy	.060	difficulty	.035	discomfort	.086
ache	.022	friend	.053	not	.035	ache	.057
sprain	.020	school	.047	handicap/ped	.024	stomach-ache	.055
feet	.019	parent	.040	harm	.023	back	.039
difficulty	.015	note	.029	clothes	.018	head	.021
discomfort	.014	bad	.027	putting_on	.017	getting	.012
headache	.012	death/died	.024	alone	.017	sometimes	.012
broken	.011	quarreling	.019	mental	.014		
		relative	.019	being_able_to	.014		
		not	.015				
		at_home	.014				
		homeworks	.013				
		schoolmate	.013				
		fear	.013				
		at_school	.012				
DOMAINS	A.C.	DOMAINS	A.C.	DOMAINS	A.C.	DOMAINS	A.C.
MOBILITY	.217+	FEELING WORRIED, SAD OR UNHAPPY	.657	TAKING CARE OF MYSELF	.367	PAIN OR DISCOMFORT	.531

Table 1: Words and domains with significant Absolute Contributions (A.C.) to factors 1 and 2. [+The A.C. of the domain Mobility on Factor 1 falls slightly beyond the significance threshold.]

### 2.2.1. Qualitative exploration of Domain 3

If we explore in detail the open answers of participants reporting having *some* or *a lot of difficulties* in Domain 3, we can see that children/adolescents mainly report feel tired because of an overload of duties and occupations (“*There are too many things to do and one gets tired*”, “*I get tired just thinking of how many things I have to do*”). A number of participants report that they lack time to do everything they should (“*Because I have so many occupations and I cannot take some time for myself*”, “*Time is not enough*”, “*I cannot combine all my occupations together*”). The overload of activities is refereed either to school tasks (“*I have difficulties in doing daily things because school is exigent*”, “*I am a bit charged of school assignments and sometimes I am a little tired*”, “*School is demanding*”), or because of extra-scholastic activities (sports in particular), or to the problematic integration of the two (“*It is hard to do sports and go to school and think*”).

In sum it appears that difficulties in domain 3 are not imputed by children and adolescents to pathological contingencies, but rather to normal everyday activities which become exceedingly demanding, and hence are subjectively perceived as a cause of troubles. In other terms, it appears that children/adolescents interpret this domain not as asking whether health impairments prevent them from doing daily activities, as researchers would expect, but rather whether an exceeding amount of daily activities does interfere with their health or well-being. This is a subtle inversion of meaning that might account for the lack of specificity of the Domain emerged from MCA, and should be carefully taken into account in the subsequent validation procedure of the instrument.

### 3. Discussion and perspective

In this contribution we illustrated the application of qualitative methods to the validation procedure of the Italian version of the EQ-5D(Child), with the aim of understanding the meanings attributed by children and adolescents to each of the five domains of the profile. Participants were asked to explain, by means of open answers, the reasons why they reported having some or a lot of difficulties in each domain (if they had any), or to imagine possible reasons why youths like them might experience such difficulties.

Lexical analyses based on multivariate statistical procedures, carried out on the wording of participants' open answers, allowed us to attain two main goals: identify the main semantic fields associated by respondents to the EQ-5D(Child) domains, and describing the relationships of proximity/opposition between these latter.

Two main results are worth being noticed. On the one hand, it appears that the instrument captures a variety of aspects that children and adolescents perceived as related to their quality of life, and clearly discriminates between social/relational and physical aspects of HRQL. On the other hand, some critical aspects emerge concerning the meanings attributed by children and adolescents to some of the explored domains. In brief, we underlined that answers reporting difficulties in Domain 3 (doing usual activities) might entail a subtle misunderstanding on the part of children and adolescents. The intended meaning of the question dealt with the negative impact of health-related states on children's possibility to engage in satisfactory daily activities. Conversely, participants' answers deal with the negative impact of the huge amount of daily activities in which they are involved (school attendance, extra-curricular activities, home-works, sports, etc.) on their health and perceived quality of life (tiredness, injuries, sleep depletion, anxiety, and so on). Moreover, a critical consideration should also be made concerning Domain 5 (feeling worried, sad, or unhappy). On the one hand, the domain is clearly understood by respondents, and allows to assess - as expected in principle - the relational and emotional dimension of their well being, which is not covered by the other four domains. Though, we should further think over the fact that children and adolescents in general population (i.e., the population from which participants to the present study were sampled) frequently provide positive answers to this domain, although their worry, sadness, or unhappiness are not related to health issues, but rather to relational troubles with family and peers, or to school problems. In other terms, developers should consider that although EQ-5D(Child) was conceived to specifically assess health-related, and *not* generic, quality of life in pediatric age, it actually captures a broader variety of experience related to children's and adolescents' well-being.

In sum, it appears that the integration of qualitative and quantitative tools in the validation procedure of the questionnaire has provided a deal of useful information, which were not



accessible if we did not ask participants to explain, in their own words, the meaning of their answers. Besides, the use of lexical-statistical procedures allowed us to analyse a considerable amount of verbal data in a systematic and reliable way, thus preventing possible flaws due to traditional procedures for hand-made content analyses.

The detection of some problematic aspects has had an immediate application in the ongoing validation procedure of the instrument, since possible amendments in the item formulation are being discussed, following the presented results as well as other qualitative studies run out in parallel. The main expected outcome is to prevent possible threats to the content validity of the instrument, which is candidate to large scale applications in the next future. Indeed, amendments designed on the basis of these results should be tested again, in a step-by-step amelioration process (Woolley et al., 2006), in order to assess whether children's and adolescents' understanding of the item wording has become more coherent with researchers' expectations. Again, verbal data gathered from target population members, in which children and adolescents will explain their answers in their own words, will be an effective tool to assess the improvement in the instrument's performance.

In a wider perspective, multivariate statistics applied to the lexical analysis of open answers appear to be a promising tool for qualitative studies in the field of HRQL, whose number is rapidly growing up in the last few years. In this paper we limited our illustration to the application of a MCA, that is one of the most widespread exploratory analyses which may be applied to lexical data in order to reduce the complexity of the textual corpus and to extract from it the most relevant information. Other promising application might be found for other techniques, such as discriminant analyses, canonical correlations or also modified versions of correspondence analyses (Bécue, 2006), in order to combine a stricter way information obtained by means of quantitative indicators (e.g., numeric scores of HRQL) with qualitative descriptions of individuals' experiences in relevant health-related domains.

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