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# Quality of life and self-efficacy beliefs in young adults with cleft lip and palate

## Abstract

**Background:** The present study aims to determine quality of life and self-efficacy beliefs among young adults with cleft lip and palate (CLP), as compared with a control group of young adults without CLP. The study involves two groups of young adults: 48 with CLP and 48 presenting no disability.

**Methods:** Two questionnaires (Quality of Life Questionnaire and How Much Confidence do I Have in Myself?) were used to assess life satisfaction and self-efficacy beliefs, respectively.

**Results:** Participants with CLP reported greater quality of life than the participants in the control group, in terms of personal financial situation and self-determination opportunities. Moreover, men with CLP showed higher levels of confidence than women with CLP, and more than all the participants in the control group as a whole in terms of the ability to complete tasks and activities.

**Conclusions:** Results suggest that people with CLP do not form a homogeneous category but are characterized by a high degree of variability. Further research is necessary to identify the dimensions and factors characterizing people with CLP as well as the health and social services needed to start using assessment instruments that can shed light on these individuals' experiences.

**Keywords:** cleft; quality of life; self-efficacy beliefs.

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## Introduction

In recent years, Quality of Life (QoL) has become a key topic that has emerged in research focused on disability issues. It is an important concept that is increasingly becoming a

legitimation and validation criterion for administered biomedical, habilitative, and rehabilitative intervention programs. The rationale is based on a growing awareness that the ultimate goal of each treatment is to enable clients to enjoy better life conditions and higher levels of satisfaction than previously experienced.

Although still deemed important and useful, the traditionally used health indicators of mortality and morbidity rates are now considered unsatisfactory when describing an individual's well-being, as they focus on pathology, rather than health. In fact, the World Health Organization's definition [1] of health refers to a complete physical, mental, and social state of well-being and not simply to the absence of disease. This definition suggests that consideration of people's QoL can be a particularly appropriate and sophisticated appraisal of the constructs of well-being and health [2]. QoL has been defined in many ways. For example, after reviewing 87 studies examining QoL, Hughes et al. [3] reported as many as 44 definitions and 1243 QoL measures. Schalock [4] showed that the concept is a particularly complex and multifaceted construct, which includes different dimensions and conditions, i.e., experienced levels of well-being, quality and amount of supportive social networks, work satisfaction, self-determination, possibility of realization, and quality of settings frequented [3, 5, 6]. QoL is also characterized by both objective and subjective aspects. Some of the objective aspects refer to financial opportunity, life environment, health status, skills, and prospects for enhancing them, whereas the subjective aspects of QoL refer to satisfaction for one's own life, psychological well-being, and perceived abilities and needs, to name a few. Perceived competencies and self-efficacy beliefs are also QoL-linked factors. Bandura [7] defined self-efficacy beliefs as "people judgments of their capabilities to organize and execute courses of action required to attain designated types of performance". They include beliefs in one's own abilities to increase one's personal motivation, to activate cognitive resources, and to take any action necessary to take control of the demands of a given task [7]. Hence, the information that people perceive about their own abilities actually regulates their behavior and plays an active role in goal selection and in the actions required to achieve these goals [8, 9].

These aspects can also foster greater perceived well-being and higher levels of experienced QoL [6, 10, 11]. This means that when reality appears to be predictable and under control, people are better able to deal with changes and manage stress [12], and also experience a personal sense of satisfaction [13]. Self-efficacy can also play a key role for people attempting to cope with situations of transition, crisis and stress in their lives, which inevitably put their adjustment- and self-realization potential to the test.

The present study examined the QoL and self-efficacy beliefs of adults with cleft lip and palate (CLP). Petreka et al. [14] reported that, overall, the prevalence rate for this disability in Europe is that of one case for every 500/700 births. Therapeutic procedures are provided by health and social services, and patients typically finish the complete treatment process by the age of 18–20 years. Treatment typically consists of surgical and dental intervention, speech therapy, and psychological support. This approach aims to reduce the malformation's functional and aesthetic damage, minimize language disorders and malocclusion, and improve facial appearance [15, 16], thereby promoting social inclusion. Once these patients did become adults, they usually expressed satisfaction with their physical appearance after reconstructive surgery (with percentages varying from 50% to 80%) although some patients report desiring further improvements [17–19]. As might be expected, patients expressing greater satisfaction with their physical appearance also reported higher levels of health-related quality of life [20].

Heller et al. [21] found that 67% of individuals with CLP showed adequate levels of psychosocial functioning. Of the rest, 23% reported having some problems and 10% reported marked functioning difficulties, which is due to malformation severity and length of hospital stays and/or of treatment, rather than to dissatisfaction with their appearance. In another study, Strauss [22] showed that many adults (including some with residual medical problems) can cope effectively with their condition, thanks also to the rehabilitation program they completed. In fact, they reported higher sensitivity toward others, greater ability to accept and deal with changes, and ability to see the positive side of events and to establish qualitatively good and satisfactory relationships. A QoL comparison examining normative data of individuals without disability revealed significantly lower levels in persons with CLP only for social functioning, emotional role [23], and perceived mental health [24]. As highlighted by Sinko et al. [23], these findings suggest that adults with CLP are characterized by good general health and rather sound psychological adjustment. Collett and Speltz [25], however, indicated

that individuals with CLP can experience more interpersonal problems.

The literature on QoL and CLP reports mixed results with respect to gender effects. For example, Marcusson et al. [26] found that women with CLP showed lower QoL than men with the same malformation, while Cheung et al. [27] found no significant differences. Moreover Mani et al. [24] found that women showed fewer problems with work or other daily activities as result of emotional problems than men, as compared with the matched normative population.

Thus, although people with CLP report levels of overall health status satisfaction that are similar to those of people without disability, some studies pointed to a tendency in this population to experience difficulties in interpersonal relationships and in managing emotions. Therefore, we examined the quality of life experienced by people with CLP in key life areas.

Based on the literature, we expected to find that satisfaction with personal well-being would be similar to that of people without disability. We also expected, however, to observe lower levels of satisfaction in areas involving an important role for social relationships, such as areas linked to support received, relationships with neighbors, and work experiences. We examined the participants' self-efficacy beliefs in decision-making tasks and significant adult situations, expecting to observe lower levels of confidence in ability to manage one's emotional sphere. We also analyzed the sample for gender differences. Finally, we verified whether any surgical treatment satisfying participants [23–25] would be associated with higher levels of QoL and self-efficacy beliefs, as compared with other types of intervention, such as speech therapy, which does not involve aesthetic change and, in some cases, could indicate that the facial structure was less affected.

## Methods

### Participants

The present study examined 96 participants: 48 young adults (21 men and 27 women;  $M_{age}=26.92$ ;  $SD=5.72$ ) with CLP, 34 (70.8%) of whom received speech therapy, and 14 (29.2%), reconstructive surgery. The other 48 participants (21 men and 27 women;  $M_{age}=26.71$ ;  $SD=5.96$ ) were matched for gender and age, but had not disability. Among the CLP participants, 2 (4.2%) were unemployed, 14 (29.2%) were university students, and 32 (66.6%) had a job. Among the non-CLP participants, one (2.1%) was unemployed, 14 (29.2%) were university students, and 33 (68.7%) had a job.

## Procedure

Individuals with CLP, but no other syndrome or malformation, were recruited from two public health centers in northern Italy to participate in the study. The participants were informed by the first author via telephone or e-mail about the study's aims, confidentiality, and their right to withdraw from the research program at any time. The following materials were sent to the prospective participants: (1) a letter describing the study and providing contact details for any doubts or difficulties they might have experienced during the study, (2) a demographic data-collection form, (3) the study's questionnaires (described below), and (4) a stamped and addressed envelope. Overall, 60 questionnaires were sent out, and 49 were returned. One was excluded due to missing data.

The control group participants were recruited from a wide range of sources by circulating the request among hospital and university staff. The contact sources were asked if they knew individuals matching our criteria (the same gender and age) and who might be willing to participate in the research. Similar to the CLP participant recruitment protocol, the control participants were first asked whether they would be willing to participate, and the surveys were then sent to who agreed to participate. Only individuals with no CLP, learning disability, or significant medical history were included in the control group.

## Statistical analyses

A series of analyses of variance were conducted with Group (CLP adults vs. control group) and Gender as independent variables, in order to verify whether significant differences would be observed for QoL levels and confidence in one's own abilities. Univariate analyses of variance were also conducted to examine whether CLP participants who had undergone reconstructive surgery and/or speech therapy differed from CLP participants receiving only speech therapy. Bonferroni's correction was applied to assess the significance level ( $\alpha=0.05$ ) of all the results yielded.

## Measures

Participants completed two questionnaires, namely, the Quality of Life Questionnaire [28] and How Much Confidence do I Have in Myself? [28].

### Quality of Life Questionnaire [28]

This 35-item self-report instrument aims to evaluate the QoL of individuals with physical disabilities. Respondents are asked to use a five-point scale to rate the extent to which each statement describes their usual way of thinking and behaving (1=does not describe me at all; 5=describes me very well). A series of exploratory and confirmatory factor analyses provided support for an 8-factor structure. The first factor refers to Satisfaction with Family Relations (7 items, e.g., I am happy with the relationships I have with my family). The second refers to Sense of Well-being (4 items, e.g., On the whole, I would say my life is really OK). The third factor refers to Satisfaction with

Provided Support and Back-Up (4 items, e.g., I know who to turn to in times of need and despair). The fourth factor refers to Job Satisfaction [4 items, e.g., What I do (study, work, etc.) personally enriches me]. The fifth factor refers to Economic Satisfaction (3 items, e.g., I have no financial worries). The sixth factor refers to Satisfaction with Self-Determination Opportunities (6 items, e.g., I can say I am a free person able to autonomously organize my own life). The seventh factor refers to Satisfaction about Life Environments (3 items, e.g., I am happy with the relationships I have with my neighbors). In the original instrument, the eighth factor refers to satisfaction with health service-provided treatment (4 items, e.g., I am happy with how I am treated in rehabilitation activities). In the present study, this factor was replaced only for participants with CLP by using 10 items that probed Satisfaction with Current Situation (e.g., I am happy with my current facial look). Specifically, the 10 items were used in the analysis of variance conducted on scores of participants who had undergone surgery and/or those who had undergone only speech therapy. Participants without disability answered only the first 7 factor items, thus the 8-factor structure was not considered in the analysis of variance between them and CLP individuals. The authors estimated Cronbach's  $\alpha$  values to be 0.91, 0.83, 0.77, 0.95, 0.74, 0.73, 0.61 and 0.81 for the eight sub-scales, respectively [28]. In the present study, reliability estimates for the subscales were 0.93, 0.86, 0.90, 0.92, 0.81, 0.48, 0.71 and 0.83, respectively, for the participants with disability and 0.92, 0.66, 0.89, 0.91, 0.47, 0.71 and 0.60, respectively for the participants without disability.

### How Much Confidence do I Have in Myself? [28]

This 20-item self-report questionnaire is often used to measure self-efficacy beliefs. Participants are asked to use a five-point scale to rate the extent to which each statement describes their usual way of thinking and behaving (1=does not describe me at all; 5=describes me very well). A series of exploratory and confirmatory factor analyses provided support for a 4-factor structure [28, 29]. The first factor refers to Confidence in one's own Decision Making Ability (7 items; e.g., If others knew me better they would say I am one who strongly believes in his/her decisional abilities). The second factor refers to Confidence in one's own Emotional Self-control (6 items; e.g., I can manage my emotions effectively). The third factor refers to Confidence in one's own Ability to Complete Tasks and Activities (3 items; e.g., If I can't solve a problem the first time I try, I tend to give up). The fourth factor refers to Confidence in one's own Ability to Deal Successfully with Different Activities and Situations (4 items; e.g., I am so sure of my abilities that sometimes I like to devote myself to very difficult things). The instrument's authors estimated Cronbach's  $\alpha$  values of 0.84, 0.74, 0.72 and 0.77, respectively, for the four sub-scales [28]. Reliability estimates for the present study were 0.85, 0.76, 0.82, and 0.82 for participants with disability and 0.89, 0.68, 0.67 and 0.77 for the participants without disability, respectively.

## Results

Table 1 presents correlation indices between self-efficacy beliefs and perceived QoL. These indices reveal that

**Table 1** Correlations between self-efficacy beliefs and quality of life.

	1	2	3	4	5	6	7	8	9	10	11	12
1	–	0.51 <sup>a</sup>	0.49 <sup>a</sup>	0.63 <sup>a</sup>	0.23	0.41 <sup>a</sup>	0.25	0.57 <sup>a</sup>	0.35 <sup>b</sup>	0.36 <sup>b</sup>	0.22	0.43 <sup>a</sup>
2	0.63 <sup>a</sup>	–	0.36 <sup>b</sup>	0.40 <sup>a</sup>	0.06	0.37 <sup>b</sup>	0.34 <sup>b</sup>	0.35 <sup>b</sup>	0.18	0.17	0.14	0.51 <sup>a</sup>
3	0.48 <sup>a</sup>	0.23	–	0.49 <sup>a</sup>	0.24	0.33 <sup>b</sup>	0.41 <sup>a</sup>	0.44 <sup>a</sup>	0.22	0.20	0.09	0.48 <sup>a</sup>
4	0.67 <sup>a</sup>	0.46 <sup>a</sup>	0.43 <sup>a</sup>	–	0.20	0.34 <sup>b</sup>	0.38 <sup>a</sup>	0.60 <sup>a</sup>	0.16	0.35 <sup>b</sup>	0.21	0.48 <sup>a</sup>
5	0.48 <sup>a</sup>	0.31 <sup>b</sup>	0.55 <sup>a</sup>	0.37 <sup>b</sup>	–	0.42 <sup>a</sup>	0.57 <sup>a</sup>	0.49 <sup>a</sup>	0.40 <sup>a</sup>	0.63 <sup>a</sup>	0.86 <sup>a</sup>	0.46 <sup>a</sup>
6	0.44 <sup>a</sup>	0.32 <sup>b</sup>	0.16	0.26	0.33 <sup>b</sup>	–	0.58 <sup>a</sup>	0.42 <sup>a</sup>	0.46 <sup>a</sup>	0.40 <sup>a</sup>	0.41 <sup>a</sup>	0.70 <sup>a</sup>
7	0.41 <sup>a</sup>	0.29 <sup>b</sup>	0.56 <sup>a</sup>	0.35 <sup>b</sup>	0.65 <sup>a</sup>	0.44 <sup>a</sup>	–	0.49 <sup>a</sup>	0.26	0.41 <sup>a</sup>	0.53 <sup>a</sup>	0.75 <sup>a</sup>
8	0.55 <sup>a</sup>	0.50 <sup>a</sup>	0.29 <sup>b</sup>	0.34 <sup>b</sup>	0.33 <sup>b</sup>	0.38 <sup>a</sup>	0.50 <sup>a</sup>	–	0.36 <sup>b</sup>	0.45 <sup>a</sup>	0.51 <sup>a</sup>	0.62 <sup>a</sup>
9	0.20	0.07	–0.01	0.11	0.25	0.39 <sup>a</sup>	0.02	–0.01	–	0.38 <sup>a</sup>	0.39 <sup>a</sup>	0.38 <sup>a</sup>
10	0.65 <sup>a</sup>	0.50 <sup>a</sup>	0.48 <sup>a</sup>	0.55 <sup>a</sup>	0.66 <sup>a</sup>	0.34 <sup>b</sup>	0.60 <sup>a</sup>	0.46 <sup>a</sup>	0.26	–	0.60 <sup>a</sup>	0.48 <sup>a</sup>
11	0.39 <sup>a</sup>	0.26	0.36 <sup>b</sup>	0.33 <sup>b</sup>	0.78 <sup>a</sup>	0.29 <sup>b</sup>	0.60 <sup>a</sup>	0.40 <sup>a</sup>	0.34 <sup>b</sup>	0.60 <sup>a</sup>	–	0.45 <sup>a</sup>

Note. 1=Confidence in one's own ability of decision making, 2=Confidence in one's own ability of emotional self-control, 3=Confidence in one's own ability of completing tasks and activities, 4=Confidence in one's own ability of dealing successfully with different activities and situations, 5=Satisfaction with family relations, 6=Sense of well-being, 7=Satisfaction with provided support and back-up, 8=Job satisfaction, 9=Economic satisfaction, 10=Satisfaction with self-determination opportunities, 11=Satisfaction about life environments, 12=Satisfaction with one's own current situation (specific for CLP adults). <sup>a</sup> $p < 0.01$ , <sup>b</sup> $p < 0.05$ . The values recorded by the CLP group are shown above the diagonal, while the values recorded by the group without disability are shown below the diagonal.

self-efficacy beliefs and perceived QoL were positively related in both participant groups.

With respect to QoL, significant group differences were yielded [Wilks's Lambda=0.792,  $F(7,86)=3.231$ ,  $p=0.004$ ]. The univariate analyses highlighted significant differences in Economic Satisfaction [ $F(1,95)=12.146$ ,  $p=0.001$ ] and in Satisfaction with Self-Determination Opportunities [ $F(1,95)=12.699$ ,  $p=0.001$ ], which were higher in CLP participants (Table 2). No significant gender differences or interaction effects were observed.

With respect to self-efficacy beliefs, non-significant Group and Gender differences were recorded. However,

significant differences emerged for the Gender×Group interaction [Wilks's Lambda=0.869,  $F(4,89)=3.349$ ,  $p=0.013$ ]. Univariate analysis highlighted significant differences in Confidence in One's Own Ability of Completing Tasks and Activities [ $F(1,95)=10.404$ ,  $p=0.002$ ], given that men with CLP showed higher levels on this variable than men without disability. Meanwhile, women with CLP, similar to women without disability, showed intermediate levels (Table 2).

The analysis of variance results for CLP participant scores only yielded no significant differences. Thus, neither speech therapy nor reconstructive surgery

**Table 2** Means and standard deviation as regards QoL and self-efficacy beliefs

	CLP adults				Control group			
	Men		Women		Men		Women	
	M	SD	M	SD	M	SD	M	SD
Confidence in one's own ability of decision making	25.48	4.70	24.96	5.40	24.38	5.75	24.70	4.49
Confidence in one's own ability of emotional self-control	19.33	3.79	17.74	4.16	19.38	3.79	18.56	3.46
Confidence in one's own ability of completing tasks and activities	13.43	1.54	12.78	2.74	10.71	2.17	12.93	1.88
Confidence in one's own ability of dealing successfully with different activities and situations	13.86	3.35	13.93	2.69	13.10	2.70	13.22	2.89
Satisfaction with family relations	28.05	6.35	29.48	4.78	24.43	3.74	28.44	6.07
Sense of well-being	13.86	3.20	13.41	3.66	13.71	2.26	13.26	2.33
Satisfaction with provided support and back-up	15.67	4.02	16.78	3.37	14.62	2.31	16.85	3.17
Job satisfaction	15.24	4.16	15.78	3.15	14.57	3.04	14.59	3.61
Economic satisfaction	10.95	2.71	11.19	3.09	9.71	2.22	8.67	2.30
Satisfaction with self-determination opportunities	24.90	2.91	25.89	2.72	21.71	3.59	24.22	3.87
Satisfaction about life environments	11.57	2.54	12.22	2.01	10.33	2.06	10.89	2.64

significantly affected QoL confidence levels among these individuals.

## Discussion

The aim of the present work was to examine any significant differences in the QoL and perceived self-efficacy beliefs between individuals with and without CLP.

First, no differences in satisfaction for perceived well-being were observed. The same occurred for presence of support and encouragement, study or work activities, relationships with family members, and life environment. Participants with CLP also reported being more satisfied with their financial situation and self-determination opportunities than the non-CLP participants. Therefore, not only do these individuals have well-being levels that are similar to those without disability, as was expected, they also reported higher satisfaction levels in several life areas. These results are in line with the findings of Sinko et al. [23] who reported that CLP individuals have a good general QoL.

With respect to support received and relationships with neighbors, the CLP participants showed levels of satisfaction similar to those of individuals without disability, and not lower levels as expected. Perhaps, the ability to establish sound and supportive relations is context-dependent [30, 31]; furthermore, as with individuals with no disability, the CLP individuals presented a certain amount of heterogeneity, thereby leading to different results. In any event, this outcome is consistent with satisfaction with family relationships, and is very similar to data recorded in previous studies [27, 32]. In discussing their results, the authors of the cited studies hypothesized that these individuals were able to overcome the difficulties caused by their disability, also thanks to help and support received from important others and family members. This type of support may positively characterize the quality of family relations and give persons with CLP a sense of not being alone – a perception that, in turn, can enhance the ability to establish supportive social relations [32].

The factor of satisfaction with working life and earnings suggested that individuals with CLP enjoyed positive working conditions, both in terms of the personal growth opportunities and financial benefits that work provides. Indeed, as Blustein [33] reported, work not only represents a means to make a living, but presents opportunities to participate in social exchanges and confers social status, which can enhance one's sense of personal prestige and

power. The opportunity to work can, therefore, be characterized by either intrinsic or instrumental value or by both, given its crucial role in people's psychological well-being.

In the present study, the participants perceived and possessed the psychological, financial, and social advantages of work. Previous research had shown that the income of people with this disability was lower than that of people without disability [19, 26]. Yet, our own data did not reveal this type of situation; in fact, the participants conversely underscored the idea that the experiences of people with CLP can actually be quite diverse and characterized by a good work and financial situation.

Finally, we wanted to highlight the CLP participants' greater satisfaction with own self-determination. For example, they reported being satisfied with the opportunities they have to autonomously decide how to organize their lives, freely make important decisions, etc. In general, as Wehmeyer [34] asserted, self-determined behavior refers to volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's QoL. Therefore, the construct is linked to actual possibilities to make choices, choice options to lead an autonomous life and to be independent. Self-determination status had shown evidence of predicting higher QoL [35], and the self-determination levels of people with this disability are highly and positively correlated with measures of QoL [36, 37]. Most likely, disability did not negatively affect the people involved in our research.

Concerning self-efficacy beliefs, once again, participants with CLP showed confidence levels that were similar to those of individuals without this disability. This was also true in terms of having confidence in managing emotions. Similar outcomes have been published elsewhere. For example, according to Strauss [22], people with CLP are probably able to somehow restructure their condition and develop effective life management strategies, i.e., positive reframing of one's thoughts and feelings, utilizing resources, valuing what one can contribute to the family and the community, and collaborating effectively with professionals [38]. This may also be seen in parents of children with disability who are able to develop life management strategies in response to their child's condition. In particular, they reported becoming more compassionate and self-confident, making a difference for others, and gaining more authentic views about what is valuable and important in life for them. These parents also reported that not only did they learn to cope more efficiently with the problems they encountered over time, but that they also continued to experience positive transformation, in spite of the stress they frequently experience [39, 40]. It can also be reasonable to presume that, more than what

common sense suggests, some people with CLP meet with similar perceptions and experience the positive benefits deriving thereof. These observations may also underlie other results yielded in the present study, which that highlighted similar QoL and self-efficacy values among people receiving reconstructive surgery or only speech therapy.

Finally, we verified whether any surgical treatment that satisfied participants [23–25] would be associated with higher levels of QoL and self-efficacy beliefs, as compared with other types of intervention, such as speech therapy, which does not involve aesthetic change.

The present study also found no gender differences in QoL and confirmed the results obtained by Cheung et al. [27]. With respect to self-efficacy beliefs, men with CLP were more confident in persistence abilities than women with CLP and men and women without disability. These data suggest that CLP differentially affect men and women, and that women might benefit from targeted forms of support when involved in difficult situations requiring long resolution times. Further research is thus needed to explore these gender differences.

## Conclusions

With respect to previous literature findings, our results highlighted how persons with labiopalatoschisis did not make up a uniform category, but were characterized by a high degree of variability. Future research should, therefore, focus on determining which dimensions and factors can positively characterize these individuals.

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Health and social services should also have available assessment instruments that can shed light on the experiences faced by this population. The instruments should emphasize strengths and be used to reinforce them. They should also be able to detect individuals at greater risk of low satisfaction levels in one or more life areas and low self-efficacy beliefs; all these are important considerations in promoting their mental health and implementing preventive interventions. This approach would allow for in-depth investigation and further assessment [41–43].

It must be noted that the small sample size of our two groups did not allow for generalization and that the data presented herein were self-reported. To obtain further confirmation of the hypotheses proposed, objective measures of the variables examined in the present study could provide useful information. Moreover, it must be remembered that the replies obtained were from approximately 80% of all the people initially recruited. Thus, they might represent the point of view of the most highly satisfied respondents only.

### Conflict of interest statement

**Author's conflict of interest disclosure:** The authors stated that there are no conflicts of interest regarding the publication of this article.

**Research funding:** None declared.

**Employment or leadership:** None declared.

**Honorarium:** None declared.

Received April 8, 2013; accepted August 1, 2013; previously published online September 13, 2013

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