Community Dent Oral Epidemiol 2008; 36: 27–33


COMMUNITY DENTISTRY AND ORAL EPIDEMIOLOGY

# Can caregivers be used in assessing oral health-related quality of life among patients hospitalized for acute medical conditions?

**H. W. Zhu[1], C. McGrath[2], A. S. McMillan[1] and L. S. W. Li[3]**

[1]Oral Rehabilitation, Faculty of Dentistry, University of Hong Kong, Hong Kong, [2]Periodontology and Public Health, Faculty of Dentistry, University of Hong Kong, Hong Kong, [3]Department of Rehabilitation Medicine, Tung Wah Hospital, Sheung Wan, Hong Kong

Zhu HW, McGrath C, McMillan AS, Li LSW. Can caregivers be used in assessing oral health-related quality of life among patients hospitalized for acute medical conditions? Community Dent Oral Epidemiol 2008; 36: 27–33.


Abstract – *Objectives:* To assess the agreement between patients' and caregivers' (CGs) assessment of patients' oral health-related quality of life (OHRQoL) during the acute stage of their hospitalization. *Methods:* A sample of 161 consecutive patients admitted to hospital following stroke and their CGs. Patients and CGs were interviewed independently about the impact of oral health status on the life quality of the patient employing the General Oral Health Assessment Index (GOHAI). Agreement of impact was assessed by comparison (agreement at the group level) and correlation analyses (agreement of individual patient–CG pairs). *Results:* The response rate was 76% with 121 pairs of patients and CGs participating. At the group level, variations in patient's own and CG GOHAI scores were found ($P < 0.001$). The CGs underestimated the impact of oral health on life quality, particularly with respect to aspects of psychosocial functioning compared with patients' own perceptions. However, the bias in reports was small (standardized difference = 0.43). The mean absolute difference in overall scores constituted 8% of the possible range of GOHAI scores. At the individual patient–CG pair level, the intraclass correlation coefficient for GOHAI scores was 0.73 (95% CI 0.61–0.82), indicating substantial agreement. *Conclusion:* At the group and individual level there was adequate agreement between patients' and CGs' assessment of patients' OHRQoL during the acute stage of their hospitalization. The findings have implications in the use of CGs as proxies in assessing oral health when patients' own assessment may be difficult to obtain.

Key words: medially compromised; oral health; proxies; quality of life; stroke

Colman McGrath, 34 Hospital Road, Hong Kong SAR, Hong Kong
Tel: +853 2859 0513
Fax: +852 2858 7874
e-mail: mcgrathc@hkucc.hku.hk

Submitted 18 May 2006;
accepted 31 August 2006

The interplay between oral health and systemic health is well recognized (1). Oral health status may affect general health status and general health status may impact on oral health status (2, 3). Moreover, it is acknowledged that oral health status is important to life quality and plays an important role in overall patient care, even among patients with life threatening and terminal conditions (4–6). Thus, there is increasing acceptance of the importance of oral health care in the overall management of patients. Among hospitalized patients it is acknowledged that oral health care is often neglected amidst the burden of other health care-related duties and the priority of medical care (7, 8). This is particularly evident when patients are admitted for acute medical upset, such as stroke, where orofacial motor and sensory deficits occur and frequently result in chewing and swallowing

doi: 10.1111/j.1600-0528.2006.00370.x

problems, as well as unilateral facial palsy that mainly affects the lower face which often compromises communication (9).

It has been suggested that where patients' views are difficult to obtain due to their compromised state, proxies or alternative individuals can be used to rate patient health status (10). The use of caregivers (CGs) in the assessment of health status among those with acute medical conditions has been employed and evaluated in relation to health-related quality of life in a wide variety of different situations (11–13). However, the use of proxies in the assessment of oral health-related quality of life (OHRQoL) among patients hospitalized for acute medical conditions has not been evaluated. Determining whether CGs are alternative or complementary sources of such information is important in deciding whether they may be used in the assessment of OHRQoL and whether CGs may provide valuable information to those providing medical care to such patients and assist in guiding clinical care practices.

This study aimed to describe the impact of oral health on life quality among patients during the acute stage of their hospitalization for stroke and to assess the agreement between patients' and CGs' assessment of the patients' OHRQoL in such a situation.

## Materials and methods

### *Sample*

A sample of 161 consecutive patients admitted to hospital following acute stroke between September 2003 and May 2005 were recruited at the Stroke Rehabilitation Unit, Tung Wah Hospital, Sheung Wan, Hong Kong. The hospital is part of the publicly founded Hospital Authority network throughout Hong Kong that provides in-patient medical service for the vast majority of the Hong Kong population. The stroke sufferers were stabilized in the intensive care unit at Queen Mary Hospital, Hong Kong for the acute event for up to 7 days before their transfer to the rehabilitation unit. The selection criteria were moderate to severe stroke with lateral paresis due to hemispheric or sub-cortical stroke. Recruited patients were asked to nominate a CG (family member or other person) who they perceived as knowing them well to act as a proxy. Informed consent was obtained from both patients and proxies. The study was approved by the Institutional Review Board of The University of Hong Kong and the Hospital Authority, Hong Kong.

### *Data collection*

All patients (and their proxies) were interviewed within 7 days after admission to the stroke rehabilitation unit using the General Oral Health Assessment Index (GOHAI) (14). Both the patients and their proxies were blinded to each other's responses; interviews were conducted consecutively and independently. Patients and proxies were asked to rate the occurrence of oral health events 'since the stoke' employing the GOHAI measure. The GOHAI is a 12-item instrument intended to measure three different aspects of OHRQoL, namely, physical functioning, pain and discomfort and psychosocial functioning. There are five response categories for each question (1 = always, 2 = often, 3 = sometimes, 4 = seldom and 5 = never). Scores from the positively worded were recoded and the GOHAI score was computed by adding up the scores of the response to the 12 statements. The GOHAI score ranges from 12 to 60, with a higher score indicating a better reported oral health status. The GOHAI has been translated into Chinese and validated for use previously (15). Demographic information of patients and proxies was also collected.

### *Data analyses*

Frequency tables were produced of patient and proxy responses to individual GOHAI statements. Next, GOHAI scores were derived by summating responses to all items to provide an overall GOHAI score and within respective domains to provide domain scores from both patients and proxies' responses.

Patient–proxy agreement was examined using several analytical strategies. Firstly, the mean directional differences between the patient and proxy GOHAI scores were calculated (proxy minus patient score). Then a paired *t*-test was performed to evaluate whether the mean directional difference was significantly different from zero. A mean directional difference significantly different from zero provides evidence of systematic bias between patient and proxy. To examine systematic bias the effect sizes were calculated by dividing the mean difference score by the standard deviation of the difference score (16). Secondly, the mean absolute difference was calculated. In contrast to the directional difference, the absolute difference ignores the positive and negative signs of the

difference between patient and proxy. Thirdly, intraclass correlation coefficients (ICC) between the patient and proxy GOHAI evaluations were computed using the one-way analysis of variance random effects parallel model (17). Guidelines used for the ICC as a measure of strength of agreement were based on the following standards: <0.2, poor agreement; 0.21–0.40, fair agreement; 0.41–0.60, moderate agreement; 0.61–0.80, substantial agreement; and 0.81–1.0, excellent to perfect agreement (18). Subsequently, the distribution of responses to the individual GOHAI items were compared between the patients and proxies employing the McNemar test (as variables were related). Thereafter, agreement on individual GOHAI statements was measured using the weighted kappa statistic which was computed as the ICC because the two statistics are mathematically equal (19).

## Results

### *Sample characteristics*

One hundred and sixty stroke survivors were enrolled on admission to the stroke unit. Twenty-five stroke patients claimed they did not have a proxy who they could nominate. Fourteen proxies declined to participate in the study. The overall response rate was 76% and comprised 121 stroke patients and 121 proxies. Stroke patients were predominantly male (70%) with a mean age of 67.7 years (SD 11.9) and most had attained no higher than primary school education (70%). Seventeen percent (20) were edentulous. Most of the proxies were female (74.4%) and approximately 50% were the spouse of the patient, 42% other family members and 8% other CGs.

### *Patient and proxy responses to GOHAI*

Both stroke patients and proxies reported at least one or more problems with respect to the patient's oral health. Table 1 illustrates responses to the GOHAI questions from the patients' perspective and Table 2 illustrates responses from the proxy's perspective. Aesthetic problem of 'not pleased with the look of teeth' was the most prevalent problem reported; all stroke survivors reported the problem and 99% of proxies reported that they perceived that the stroke patient encountered this problem. Problems speaking were also highly prevalent with over 80% of patients reported that they were unable to speak clearly, and over 80% of proxies perceived that the stroke patients encountered this problem as well. Experience of problems eating were also highly prevalent, over 70% of patients reported that they encountered difficulties chewing and had to limit their food intake or choice of foods, and likewise over 70% of proxies also perceived that the stroke patients encountered these problems.

### *Comparison and correlation analyses of patient and proxy GOHAI scores*

There was a significant difference between the patients' and proxies' overall mean GOHAI scores and the mean directional difference of GOHAI was significantly different from zero ($P < 0.001$) (Table 3). The significant mean directional

Table 1. Distribution of subjects according to responses of stroke patient to individual GOHAI questions ($n = 121$)

| | Number of subjects (%) | | | | |
|---|---|---|---|---|---|
| | 1 = Always | 2 = Often | 3 = Sometimes | 4 = Seldom | 5 = Never |
| Physical functioning | | | | | |
| Have to limit food intake/choice of food | 42 (34.7) | 19 (15.7) | 11 (9.1) | 19 (15.7) | 30 (24.8) |
| Trouble biting/chewing[a] | 48 (39.7) | 16 (13.2) | 4 (3.3) | 23 (19.0) | 30 (24.8) |
| Unable to speak clearly[a] | 11 (9.1) | 42 (34.7) | 20 (16.5) | 33 (27.3) | 15 (12.4) |
| Pain and discomfort | | | | | |
| Discomfort during eating | 10 (8.3) | 21 (17.4) | 18 (14.9) | 24 (19.8) | 48 (39.7) |
| Sensitive to hot/cold/sweet/sour food | 3 (2.5) | 11 (9.1) | 14 (11.6) | 6 (5.0) | 87 (71.9) |
| Use medication to relieve pain | 0 (0) | 0 (0) | 4 (3.3) | 2 (1.7) | 115 (95.0) |
| Unable to swallow comfortably | 3 (2.5) | 11 (9.1) | 33 (27.3) | 26 (21.5) | 48 (39.7) |
| Psychosocial functioning | | | | | |
| Worried about teeth problems | 4 (3.3) | 11 (9.1) | 17 (14.0) | 21 (17.4) | 68 (56.2) |
| Limit contacts with people | 3 (2.5) | 16 (13.2) | 12 (9.9) | 16 (13.2) | 74 (61.2) |
| Uncomfortable eating in front of people | 2 (1.7) | 3 (2.5) | 5 (4.1) | 5 (4.1) | 106 (87.6) |
| Self-conscious of teeth problems | 7 (5.8) | 8 (6.6) | 16 (13.2) | 21 (17.4) | 69 (57.0) |
| Not pleased with the look of teeth[a] | 19 (15.7) | 16 (13.2) | 56 (46.3) | 30 (24.8) | 0 (0) |

[a]Response of the positively worded items were reversed.

Table 2. Distribution of subjects according to responses of proxy to individual GOHAI questions ($n = 121$)

| Individual question | Number of subjects (%) | | | | |
|---|---|---|---|---|---|
| | 1 = Always | 2 = Often | 3 = Sometimes | 4 = Seldom | 5 = Never |
| Physical functioning | | | | | |
| Have to limit food intake/choice of food | 39 (32.2) | 20 (16.5) | 15 (12.4) | 15 (12.4) | 32 (26.4) |
| Trouble biting/chewing[a] | 48 (39.7) | 14 (11.6) | 6 (5.0) | 25 (20.7) | 28 (23.1) |
| Unable to speak clearly[a] | 21 (17.4) | 24 (19.8) | 26 (21.5) | 36 (29.8) | 14 (11.6) |
| Pain and discomfort | | | | | |
| Discomfort during eating | 6 (5.0) | 9 (7.4) | 27 (22.3) | 34 (28.1) | 45 (37.2) |
| Sensitive to hot/cold/sweet/sour food | 3 (2.5) | 4 (3.3) | 8 (6.6) | 13 (10.7) | 93 (76.9) |
| Use medication to relieve pain | 0 | 0 | 1 (0.8) | 5 (4.1) | 115 (95.0) |
| Unable to swallow comfortably | 3 (2.5) | 11 (9.1) | 31 (25.6) | 34 (28.1) | 42 (34.7) |
| Psychosocial functioning | | | | | |
| Worried about teeth problems | 1 (0.8) | 3 (2.5) | 7 (5.8) | 33 (27.3) | 77 (63.6) |
| Limit contacts with people | 0 (0) | 5 (4.1) | 6 (5.0) | 22 (18.2) | 88 (72.7) |
| Uncomfortable eating in front of people | 1 (0.8) | 0 (0) | 5 (4.1) | 8 (6.6) | 107 (88.4) |
| Self-conscious of teeth problems | 1 (0.8) | 2 (1.7) | 6 (5.0) | 29 (24.0) | 83 (68.6) |
| Not pleased with the look of teeth[a] | 4 (3.3) | 16 (13.2) | 59 (48.8) | 41 (33.9) | 1 (0.8) |

[a]Response of the positively worded items were reversed.

Table 3. Agreement between patient and proxy reports for GOHAI and its subscale ($n = 121$)

| | Patient, mean (SD) | Proxy, mean (SD) | Directional difference[a] | | | Absolute difference[b], mean (SD) | ICC (95% CI) |
|---|---|---|---|---|---|---|---|
| | | | Mean (SD) | $P$[c] | $d$[d] | | |
| GOHAI | 45.32 (8.2) | 47.43 (6.3) | 2.11 (5.0) | <0.001 | 0.43 | 3.94 (3.7) | 0.85[e] (0.78–0.89) |
| Sub-scale | | | | | | | |
| Physical functioning | 8.55 (3.6) | 8.59 (3.7) | 0.04 (2.1) | 0.768 | 0.01 | 1.24 (1.6) | 0.91[e] (0.88–0.94) |
| Pain and discomfort | 16.79 (2.6) | 17.19 (2.1) | 0.40 (2.3) | 0.043 | 0.17 | 1.74 (1.5) | 0.75[e] (0.64–0.82) |
| Psychosocial functioning | 19.98 (3.9) | 21.65 (2.4) | 1.67 (3.0) | <0.001 | 0.56 | 2.25 (2.5) | 0.69[e] (0.56–0.78) |

[a]Difference between stroke patient and proxy score accounting for directional difference (indicator of bias).
[b]Difference between stroke patient and proxy scores irrespective of the direction of differences (indicator of agreement).
[c]$P$-values obtained from pair $t$-test.
[d]Standard difference = mean directional difference/standard deviation of directional difference.
[e]Interclass correlation coefficient: $P < 0.001$.

difference were also observed in the sub-scales *pain and discomfort* ($P = 0.043$) and *psychosocial functioning* ($P < 0.001$). The systematic bias effect ranged from 0.17 for *physical functioning* to 0.56 for *psychosocial functioning*.

The mean absolute difference of the GOHAI score was 3.94, representing 8% of the maximum possible score that could be obtained. For the subscales, the mean absolute difference ranged from 1.2 to 2.3, with the lowest for *physical functioning* and highest for *psychosocial functioning*, representing 10.3% and 11.5% of the maximum possible subscale score, respectively.

The ICC for the overall GOHAI score was 0.85 and it ranged from 0.69 to 0.91 for the three subscale scores. The ICC was highest for *physical functioning* (ICC = 0.91) and lowest for *psychosocial functioning* (ICC = 0.69).

## *Comparison of patient and proxy responses to the individual GOHAI items*

When comparison analysis was carried out, stroke patients reported that they encountered more frequently the problem of sensitive teeth compared with that reported by proxies ($P = 0.011$) (Table 4). Stroke survivors more frequently reported that they were self-conscious of their teeth compared with their proxies' views of them ($P < 0.001$). Likewise, the stroke patients more frequently reported that they were worried about their teeth compared with what the proxies perceived them to be ($P < 0.001$). Furthermore, patients more frequently reported that they had limited contact with people because of their teeth than the proxies perceived them to experience ($P < 0.001$).

Table 4. Distribution of responses for GOHAI items (% for 'always/often/sometimes')

| | Patient ($n$ = 121) | Proxy ($n$ = 121) | $P$ value |
|---|---|---|---|
| Physical functioning | | | |
| Trouble biting/chewing[a] | 56.2 | 56.2 | 1.000[b] |
| Have to limit food intake/choice of food | 59.5 | 61.2 | 0.815[b] |
| Unable to speak clearly[a] | 60.3 | 58.7 | 0.845[b] |
| Pain and discomfort | | | |
| Discomfort during eating | 40.5 | 34.7 | 0.337[b] |
| Sensitive to hot/cold/sweet/sour food | 23.1 | 12.4 | 0.011[b] |
| Use medication to relieve pain | 3.3 | 0.8 | 0.250[c] |
| Unable to swallow comfortably | 38.3 | 37.2 | 0.874[b] |
| Psychosocial functioning | | | |
| Worried about teeth problems | 26.4 | 9.1 | <0.001[b] |
| Limit contacts with people | 25.6 | 9.1 | <0.001[b] |
| Uncomfortable eating in front of people | 8.3 | 4.1 | 0.267[b] |
| Self-conscious of teeth problems | 25.6 | 7.4 | <0.001[b] |
| Not pleased with the look of teeth[a] | 75.2 | 65.3 | 0.082[b] |

[a]Response of the positively worded items were reversed.
[b]McNemar test.
[c]McNemar exact test.

Table 5. Agreement between stroke patients and proxies for each item of GOHAI

| Item | Weighted kappa[a] | $P$ value |
|---|---|---|
| Physical functioning | | |
| Have to limit food intake/choice of food | 0.89 | <0.001 |
| Trouble biting/chewing[b] | 0.92 | <0.001 |
| Unable to speak clearly[b] | 0.82 | <0.001 |
| Pain and discomfort | | |
| Discomfort during eating | 0.71 | <0.001 |
| Sensitive to hot/cold/sweet/sour food | 0.62 | <0.001 |
| Use medication to relieve pain | 0.42 | 0.002 |
| Unable to swallow comfortably | 0.64 | <0.001 |
| Psychosocial functioning | | |
| Worried about teeth problems | 0.61 | <0.001 |
| Limit contacts with people | 0.68 | <0.001 |
| Uncomfortable eating in front of people | 0.30 | 0.030 |
| Self-conscious of teeth problems | 0.54 | <0.001 |
| Not pleased with the look of teeth[b] | 0.64 | <0.001 |

[a]Calculated as ICCs.
[b]Response of the positively worded items were reversed.

The level of agreement between patient and proxies for individual GOHAI items is shown in Table 5. The level of agreement was above 0.80 for the items relating to chewing, intake of food and speaking. There was poor agreement between patient and proxy reports for 'being uncomfortable to eat in front of other people' ($\kappa$ = 0.30) and the 'use of medication to relieve pain' ($\kappa$ = 0.42). There was moderate agreement between patient and proxies with respect to the other GOHAI items.

## Discussion

The study response rate was high (75%) and this indicates the feasibility of assessing OHRQoL among patients hospitalized for an acute medical condition, even conditions with high morbidity such as stoke. The favourable response rate may also have been achieved through the use of brief OHRQoL measures such as the GOHAI (with only 12 items) and thus the burden on the stroke patients and proxies was minimal (20). In addition, as most patients were visited by a CG in hospital it was possible to recruit them as proxies.

All stroke patients reported at least one impact on OHRQoL as assessed by the GOHAI measure. The mean GOHAI scores of the stroke patients constituted 75% of total possible GOHAI score which indicates that the severity of impact was high. Mean GOHAI scores among stroke patients was lower than what has been reported among community dwelling older people in Hong Kong (15). In addition, the mean GOHAI scores observed among the stroke patients was considerably lower than among other study groups/populations where GOHAI has been used to assess OHRQoL (21, 22). This suggest that OHRQoL is markedly poorer among patients hospitalized for acute medical upset such as stroke than other groups of patients or populations.

Frequently encountered oral health problems by the stroke survivors were aesthetic problems (not pleased with the look of teeth), speaking difficulties, eating and swallowing difficulties. This concurs with other findings that have reported that

stroke-related oral motor impairments are disabling on speech, mastication and swallowing (23–25). However, it is notable that there is lack of previous reports on perceived aesthetics among stroke survivors (which the current study highlights) as most studies focus only on the functional status of stroke survivors (26). Aesthetic effects of stroke occur as a result of unilateral facial palsy which most frequently affects the appearance of the lower face, the general appearance of the mouth and teeth.

There were significant differences in overall mean GOHAI scores between patients and proxies. The proxies had higher overall GOHAI scores compared with the patients themselves. This indicates that proxies underestimated the impact of stroke on OHRQoL compared with patients' own views. This is contrary to many stroke studies which have reported that proxies were likely to rate the patients as being more impaired than patients rated themselves to be (10, 27, 28). Nevertheless, these other studies evaluated general health-related QoL as opposed to OHRQoL.

An effect size of 0.2 can be considered a small bias, 0.5 a moderate bias and 0.8 a large bias (16). The bias of reports in this study (as indicated by the standard difference values) suggests that the agreement was small to moderate. The mean absolute difference provides an indicator of agreement between patient and proxy (29). The absolute difference of overall GOHAI scores between patients and proxies was approximately 10%, and among its domains ranged from 10% to 12% which again suggested that disagreement exists but can be interpreted as small. There was general agreement in the frequency of impact (events occurring 'sometimes/often/always') with the exceptions of aspects relating to psychosocial functioning. Thus, overall at the group level proxies maybe suitable as alternative sources of information with respect to OHRQoL where patients' own views are difficult to obtain.

At the individual patient–CG level, the agreement of overall mean GOHAI scores between patients and proxies could be interpreted as excellent (ICC = 0.85). Among the GOHAI domains the level of agreement (ICC values) was highest with respect to *physical functioning* and lowest for *psychosocial functioning*. In addition, there was substantial agreement on frequency of events at the item level, the expectation being items relating to psychosocial functioning. This is consistent with the other studies on stroke patients which suggest that agreement is best for observable rather than subjective attributes (30, 31).

In conclusion, during the acute stage of hospitalization for stroke, patients report that their oral health impacts considerably on their life quality. At both the group and individual level there is adequate agreement between patients' and CGs' assessment of the patients' OHRQoL. The findings have implications for the use of CGs as proxies for patients during hospitalization when a patient's own assessment may be difficult to obtain.

## Acknowledgement

This study was supported by a CRCG grant from the University of Hong Kong.

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