39 Quality of Life in Lacrimal Disorders and Patient Satisfaction Following Management

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Introduction

Lacrimal disorders need not necessarily always have only a physical or a functional dimension, there may be emotional, social, and economic or a combination of these aspects to them. Understanding the different facets of patient and the caregiver's perspectives of the disease before and after medical or surgical interventions contributes significantly to overall patient satisfaction. Rather than objective anatomical outcomes of a surgery alone, patient satisfaction is what all surgeons should ideally aim for. It is in this context that the validated quality of life (QOL) questionnaires help the health-care providers. They are also a very useful tool for clinical research and standardization of outcomes.

CNLDO: Patient and Parental Quality of Life

Congenital nasolacrimal duct obstruction or CNLDO is the commonest pediatric lacrimal disorder that affects up to 20 % of newborns with spontaneous resolution in a vast majority [1]. The symptomatology or the success rates have been largely assessed using isolated elementary questionnaires that included both parental perception and examinations [2, 3]. Holmes et al. [4] published a novel and comprehensive parental questionnaire addressing symptoms and health-related QOL in CNLDO. The questionnaire included 17 questions with the first 3 questions having 4 subtypes each. All the questions were evaluated on 5 parameters (always, often, sometimes, rarely, and never) with scoring for each parameter. The questionnaire is briefly listed in Table 39.1. Holmes et al. [4] enrolled 87 children, 56 with

Table 39.1 Brief Holmes questionnaire for CNLDO

1. Tears "well up" in my child's eye(s) (Has 4 subtypes and 5 parameters to score).
2. Tears run down my child's cheek.
3. My child has gunk in the corner of the eye(s).
4. My child's eye(s) looks glassy.
5. The skin around my child's eye(s) is red.
6. My child's eyeball is red.
7. My child rubs his or her eye(s).
8. The appearance of one or both of my child's eyeballs bothers me.
9. The appearance of one or both of my child's eyelids bothers me.
10. Child is bothered by his or her eye(s)
11. Child's eye condition interferes with his or her daily activities.
12. Child's eye condition interferes with my daily activities.
13. I feel fine about my child's eye(s).
14. I worry about my child's eye(s).
15. Other people comment about my child's eye(s).
16. I feel fine about the way my child's eye(s) appears in photos.
17. Other children tease my child about his/her eye(s).

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and 31 without NLDO. The Cronbach's values were impressive for not only the overall questionnaire (0.95) but also for its two subscales, namely, symptoms scale (0.95) and health-related quality of life (HRQL) scale (0.85). The CNLDO patients had worse scores for both the scales as compared to normal children and the affected eye had worse score as compared to the normal fellow eye. Both these scales showed improvement in scores following intervention in the form of probing. The study found that the questionnaire is very useful in quantifying parental perception of symptoms and HRQL in CNLDO.

The author's (Ali MJ) group has compared the parental quality of life (QOL) in CNLDO children who were successful following intervention versus complex CNLDO with poor outcomes. However, we did not include the last two (16, 17) questions. The early analysis has shown the Holmes questionnaire to be very useful for comparisons within the CNLDO group as well.

Quality of Life After DCR Surgery

The QOL after a DCR surgery has been usually assessed using the Glasgow-Benefit Inventory or GBI Questionnaire which was developed by Robinson et al. [5] for evaluating otorhinolaryngology procedures. This questionnaire is well known and validated in many studies across subspecialties of otology and rhinology [6, 7]. It consists of 18 questions, each assessed on a 5-point Likert scale; 12 questions are related to general perception of well-being and 3 each for physical health and social parameters. A positive GBI score represents a beneficial effect. The range of scoring extends from −100 (maximal negative benefit) to 0 (no change) to +100 (maximum positive benefit). Table 39.2 lists briefly the 18 questions that constitute the GBI.

Bakri et al. [8] assessed the benefits of external DCR versus endoscopic laser-assisted DCR and found no statistical difference in GBI scoring between the two groups. Mansour et al. [9] studied the long-term patient satisfaction following an external DCR and concluded that long postoperative times negatively affects the exact subjective symptom scoring after surgery. Yeniad et al. [10] compared the patient satisfaction between external and transcanalicular laser DCR and found that the mean symptoms scoring reduced from 24.2±4.6 at baseline to 3.5±1.8 in the external group and 22.8±3.4 to 3.37±1.2 in the transcanalicular group ($p=0.67$). The GBI scoring was similar and did not reach statistical significance in either group. However, there were concerns regarding follow-ups [11].

Ho et al. [12] studied the impact of endonasal DCR on QOL and found GBI scores of +34 in successful cases as compared to −19 in failed cases. The mean total GBI for endoscopic DCR in another study was +15.04 (95 % CI: 9.74–20.35). Hii et al. [13] compared patient satisfaction

Table 39.2 Brief Glasgow Benefit Inventory Questionnaire

1. Has the result of operation/intervention affected the things you do?
2. Has the result of the operation made your overall life better or worse?
3. Since your operation, have you felt more or less optimistic about the future?
4. Since your operation, do you feel more or less embarrassed when with people?
5. Since your operation, do you have more or less self-confidence?
6. Since your operation, do you find easier or harder to deal with company?
7. Since your operation, do you have more or less support from your friends?
8. Have you been to your family doctor, more or less since operation?
9. Since your operation, do you feel more or less confident about job opportunities?
10. Since your operation, do you feel more or less self-conscious?
11. Since your operation, are there more or fewer people who really care about you?
12. Since you had the operation, do you catch colds or infections much or less often?
13. Have you taken more or less medicine for any reason, since your operation?
14. Since your operation, do you feel better or worse for any reason?
15. Since your operation, do you have more or less support from your family?
16. Since your operation, are you more or less inconvenienced by health problem?
17. Since your operation, have you participated in more or fewer social activities?
18. Since your operation, are you more or less inclined to withdraw from social situations?

between external versus endonasal DCR and found no difference. When patients who underwent external DCR on one side and endonasal on the other side, retrospectively reported preference of endonasal DCR [14, 15]. In cases of bilateral NLDO, simultaneous bilateral DCR was shown to confer significant improvement of QOL with a statistically significant GBI score difference between 1 month and 3 months postoperatively [10].

Quality of Life in FNLDO and Minimally Invasive NLDO Treatments

Functional nasolacrimal duct obstruction is an underdiagnosed entity [16]. Epiphora in the presence of a patent lacrimal pathway and absence of alternative etiology could be the simplest description. Cheung et al. [17] conducted a detailed study on 33 FNLDO patients and studied their symptoms in relation to the vision, reading, driving, moods, work, and embarrassment. All these parameters were affected, specifically vision, reading, and embarrassment, resulting in lower quality of life. Overall symptom scores significantly reduced after dacryocystorhinostomy (DCR) from a mean preoperative score of 3.50 (SD = 2.07) to 2.0 (SD = 1.65) in the postoperative period ($p < 0.05$).

Kabata et al. [18] studied the effects of silicone intubation using Nanchaku-style tube on vision-related QOL in patients with lacrimal passage obstructions. They used the 25-item National Eye Institute Visual Function Questionnaire (NEI-VFQ). Silicone intubation showed a significant improvement in NEI-VFQ composite score ($p = 0.0001$), ocular pain score ($p < 0.0001$), and mental health score ($p = 0.0003$).

Specific Lacrimal QOL Questionnaires – The Way Forward

Most of the questionnaires used so far in lacrimal surgery are general in nature and most are administered postoperatively. The morbidity with lacrimal obstructions should ideally not be assessed using questionnaires that were designed for more general conditions where systemic morbidity may change a lot of parameters. This need for lacrimal-specific questionnaires has resulted in two new models, one for NLDO and another for DCR. Smirnov et al. [19] conceptualized the NLDO-symptom score survey (NLDO-SS), which has six parameters that need to be scored on a scale of 0 (no symptoms) to 10 (severe symptoms). The timing of administration can be individualized based on the follow-up protocols of each surgeon but is usually carried out at 1 week, 1 month, and 3 months. Five of these parameters are symptoms related to NLDO. Hence, this is not only more specific but also simpler to use once validated. Table 39.3 lists the parameters in the NLDO-SS questionnaire.

Mistry et al. [20] reviewed 100 consecutive patients of lacrimal duct obstruction and studied their symptomatology and subsequently developed the Lac-Q questionnaire. The questions were specific to lacrimal disorders (four questions with multiple subparameters) including their social impact (five questions). They showed that not only is Lac-Q useful in pre- and postoperative comparisons but also correlates well with objective methods of assessment. Table 39.4 lists the parameters of the Lac-Q questionnaire:

Table 39.3 The NLDO-Symptom Score (NLDO-SS) parameters

1. Tearing (0–10 scale scoring for each)
2. Irritation
3. Pain
4. Discharge
5. Swelling
6. Visual acuity

Table 39.4 The brief 'Lac-Q' questionnaire parameters

Lacrimal parameters	Social parameters
1. Watery eye	1. Watery eye comment by family or friends
2. Soreness of eyelids	2. Watery eye causing embarrassment
3. Sticky eye	3. Watery eye interfering with daily activities
4. Swelling at medial canthus	4. Watery eye causing blurred vision
	5. Medical consultation for watery eye

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