# What do parents of newborn babies with cleft lip and/or palate want to know?

## Does the leaflet from the Cleft Lip and Palate Unit at Red Cross Children's Hospital fulfil these needs, and what is its grading for 'readability'?

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**Objectives**. This study was undertaken to ascertain information about parents' attitudes to the Cleft Lip and Palate Parent Information Leaflet (PIL) used at Red Cross War Memorial Children's Hospital, Cape Town, and to assess the readability of the English version of this PIL.

**Design.** A descriptive study for the PIL combined with a questionnaire for parents of children born 5 months - 16 years previously.

**Subjects.** Participants were 36 parents of children with cleft lip and/or palate (CLP) who attended appointments at Red Cross Hospital. They had been given the PIL, and were telephoned 2 weeks later and asked 15 questions.

**Outcome measures**. The reading statistics, design elements, grading and readability of the PIL were assessed. Parental experiences were recorded on the questionnaire.

**Results**. The PIL is well designed and easy to read. Most parents were informed of their children's clefts at birth by a physician, gynaecologist or nurse, but felt that health professionals' knowledge of CLP was lacking. Inadequate information about feeding was common.

**Conclusions.** The Cleft Lip and Palate PIL can be read and understood by the average 14-year-old. There is parental dissatisfaction with aspects of CLP care, and the PIL is useful to improve parents' understanding of this condition.

The birth of a baby with a cleft defect is traumatic for most parents. Informing the parents is difficult for medical professionals,[1] yet it is crucial to give relevant advice.[2,3] The family's ability to adjust to the diagnosis depends on the information given at the first consultation, and circumstances associated with this consultation.[2,4] There are reports of parental dissatisfaction about the amount of information given,[5] in addition to incorrect (or no) information on feeding.[6-8]

It is usually the obstetrician or the paediatrician who informs the parents of the presence of a cleft lip and/or palate (CLP), and this usually happens shortly after the baby's birth.[1] However, it is beneficial for parents to have a consultation with a professional with expertise in cleft-lip management as soon as possible.[9] If leaflets are given, people's retention of information can increase from 20% to 50%.[10] Patients' satisfaction with health care professionals increases when information and clinical advice is given and understood.[11] There is also evidence that dissatisfaction with the initial consultation improves with the provision of leaflets.[6,11,12] In one study leaflets were desired, used and valued by 75% of patients, with 80% reading them.[13] Leaflets reinforce information, can be referred to outside the stressful environment of a consultation room, and can answer additional questions.[14]

The Cleft Lip and Palate Parent Information Leaflet (PIL) contains information on the different types of clefts, the different treatment options, the possible surgical approaches and parallel treatments that may be required such as speech therapy and dental, orthodontic, and ear, nose and throat treatment.

Design elements to enhance readability, were considered in the writing of the PIL. University lecturers in Literacy, English, Xhosa, Afrikaans and Psychology assessed the use of language and translated the PIL.

Readability formulae assess the structural elements of a text and measure the reading difficulty. They produce a score or number that indicates how readable the text is. Most formulae premise that long words and/or sentences make text harder to understand. Reading ability varies widely across populations, so it is important that information be pitched at a suitable level to be understood by the maximum number of patients. In South Africa 46% of the population has achieved Standard 7 (around 14 years of age), with 11% never having been to school.[15]

PILs and information on web pages are often written at too high a level for the general public.[16] The writing should be easy to read and understood by people who have attained the educational level of a 12-year-old.[17] People with a higher education are not offended by leaflets that appear simple to read. PILs should be available in the parents' first language. The Cleft Lip and Palate PIL is available in English, Xhosa and

Afrikaans, which are the three most common languages in the Western Cape.

## Objectives

The objectives of this study were:

- to record subjective information concerning parents' preferences in relation to leaflets and consultations
- to assess the readability of the Cleft Lip and Palate PIL (English version).

## Design

A descriptive study for the booklet combined with a retrospective questionnaire for the parents of children born 5 months - 16 years previously.

## Materials and methods

### Study participants

Participants were the biological parents of 36 children (5 months - 16 years of age) who attended appointments at Red Cross War Memorial Children's Hospital, Cape Town. The parents were given the PIL, and telephoned 2 weeks later and asked 15 questions. The response rate was 100%, and the final data set included 36 participants.

### Questionnaire

The questionnaire used in this report recorded the experiences of parents when they were initially informed that their child had a CLP. The questions evaluated parental satisfaction with regard to 15 main elements of the consultation and separately with the PIL.

### Reading statistics

The PIL was in Microsoft Word, 2004. Readability statistics were obtained via the 'Tools' menu:

- Flesch Reading Ease score
- Flesch-Kincaid Grade level
- mean number of words per sentence (sentence length)
- number of passive sentences expressed as a percentage of the whole text
- total number of words
- mean number of words per sentence.

### Design elements

The design elements of the PIL were assessed using a 20-item checklist compiled from guidelines of the Centre for Health Information Quality (CHIQ, available at http://www.hfht.org/chiq/). The PIL was given a percentage score expressing the number of criteria that were satisfied.

### Plain English Campaign

The Plain English Campaign assessment (available at http://www.plainenglish.co.uk/) includes checks for:

- a good average sentence length (about 15 - 20 words)
- more active than passive verbs
- everyday English
- appropriate use of the first person pronoun
- language that is clear and unambiguous
- clear, helpful headings with consistent and suitable ways of making them stand out from the text
- a good type size and clear typeface
- a reasonably short average line length.

## Results

### Parental experiences

Thirty-three of the parents (91.7%) were informed of their child's CLP at the time of birth by a physician, gynaecologist or nurse.

All the mothers had had ultrasound scans during pregnancy but only one had been informed of the cleft after the scan, and most would have liked more concrete reasons for the cleft occurring.

Only 4 parents (11.1%) felt that they had been given adequate information in the first few days. Others had been too shocked to absorb or understand the information.

Thirty-two parents (88.9%) reported being in shock at the time of the birth, and appreciated receiving reassurance about the treatability of the cleft defect.

Thirty-one parents (86.1%) reported that they had only felt comfortable with feeding once they had been referred to the feeding specialist or the specialist unit, and that trying to achieve weight increase by the first operation had caused considerable anxiety.

None of the parents felt that the cleft was painful for the child and all understood that it could be surgically repaired.

All the mothers (and some of the fathers) felt that they might have done something during the pregnancy to cause the cleft, with guilt feelings lasting up to 3 years.

Parents also suggested that the leaflet be made available in all antenatal clinics.

### Grading and readability of the PIL

**Leaflet length:** 3 258 words.

**Sentence length:** 16.2 words per sentence (ideal 15 - 20 words).

**Passive percentage:** passive percentage score 12% ('excellent' in terms of clarity).

**Flesch Reading Ease (FRE):** 62.5 ('standard' ease to read).

**Flesch Kincaid Grade level (FKGL):** 8.5 (the booklet is 'standard' to read at level of 14-year-old).

**Reading difficulty:** 'standard', meaning that up to 46% of the South African population would understand it.

**Design criteria:** the booklet satisfied 18/20 of the criteria. The criteria that were not satisfied were:

- a sans serif typeface
- indenting the first line of each paragraph.

### Comments on the PIL

All of the parents interviewed felt that the PIL would have

*Only 4 of the 36 parents felt that they had been given adequate information in the first few days.*

been beneficial at the time of their child's birth, and some felt that the information would have been helpful even before the birth.

Parents reported that the information in the PIL was clear, understandable and readable. Most noted that they could take it home for repeated reference.

Some parents wanted actual photographs of other children before and after surgery rather than diagrams, but two parents said they would have found photographs too disturbing on the first day or two after the birth of their own baby.

The additions suggested by parents were more information on genetics, and a list of counselling and support groups.

Most of the parents felt that further PILs should be available giving details about other procedures that children with a CLP might need as they grow.

## Discussion

The leaflet is rated as 'standard'. This means that an IQ of 90+ would be required to understand it. The FKGL is 8.5, meaning that up to 46% of the South African population would be able to read it with ease, based on the level of education in this country.

Readability formulae should be used as a guide for assessing reading difficulty. They do not account for other factors that can influence the comprehension of a text, such as the use of active and passive verbs or how the information is organised and looks on the page. Other factors that are not accounted for are the reader's motivation and level of prior knowledge. Also, a professional vocabulary may be incomprehensible to the layman and the readability formulae may therefore under-estimate the difficulty of a text. They should be used in conjunction with CHIQ and the Plain English Campaign criteria.

It is recommended that verbal information given to patients be supported by written and/or visual information.

PILs are effective in increasing knowledge, but should be written at a suitable level to be understood. It has been shown that highly educated patients do not mind if leaflets are oversimplified, and giving leaflets in addition to a consultation may be seen as a sign of respect and caring, whether or not patients actually read them.

Informed consent means that patients need to have enough information to understand what treatment involves, the available alternatives and the risks and benefits of various treatment options. Leaflets can help the patient information process only if they are readable and understandable.

It has become common practice in some parts of the world to use patients and the public in lay reader panels to assist in the production of suitable and readable PILs.

In South Africa there are 11 official languages. PILs need to be available in other languages to ensure patient understanding and that patients are able to give their informed consent.

## Conclusions

The CLP PIL was assessed 'excellent' to read, well designed and 'standard' on the FRE score, and should be understood by the average 14-year-old.

We found that parents of children who are patients at Red Cross Children's Hospital expressed a desire and need for PILs. Specifically, they felt that the PIL they assessed would have been of great value to them at the time of the birth of their own child.

The results suggest that there is parental dissatisfaction, particularly with feeding, and that improvement in the communication of this kind of information to parents is desirable.

The PIL should therefore be a useful tool to improve parents' understanding of CLP treatments and enable them to be better informed in the consent process.

It is proposed that other PILs be created giving more detailed information on the separate specialities involved in cleft care.

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