

Act Now

Report by the European Cleft Organisation on factors that can improve the provision of care in clinical settings

Introduction

As a partner in the Act Now project, the European Cleft Organisation (ECO) was asked to conduct an analysis of how the provision of care could be improved in a clinical setting and make specific reference to patients with cleft lip and palate and other visible differences. This report has been generated drawing on published research and ECO's own experiences of working with patients and patient groups in Europe. The material will be used in the development of guidance on how health professionals can use ACT as a means of enhancing overall treatment outcomes.

Europe and Health - the context

On average, life expectancy within the EU is 77.5 for males and 83.1 for females. However there is a large variation in national rates with Latvia and Lithuania having the lowest life expectancy for males at around 68. (*Eurostat*) Overall, the population of the EU is ageing which is presenting very significant difficulties in future healthcare planning. Healthcare systems differ widely. The amount of public funding spent on health care (as a proportion of all healthcare funding) ranges from 96.9 % (UK) to 8.6% Georgia with a median of 76.9 % (WHO). In terms of congenital anomalies relating to visible difference the incidence of oral facial clefts in the EU is 14.31 per 10000 live births, craniosynostosis 2.56 per 10000 live births and other ear face and neck anomalies 2.04 per 10000 live births (*Eurocat*). This means that within the EU there are nearly a million people (945000) affected by these congenital anomalies – many of which will have lifelong concerns over the way they look. Of course there are other congenital anomalies that affect appearance, not to mention trauma and illness.

Throughout our European societies there is an increasing value placed on 'looking good'. Bringing together the 'looks culture" and "visible difference", a previous study (*Face Value*) described the inability of many health care professionals to take into account 'feelings'. Surgery/correction is seen as a solution to dissatisfaction with appearance, rather than allowing people to explore their real feelings.

Components of overall patient satisfaction

In all health areas emotional support is seen by patients as a key component of what constitutes overall patient satisfaction. A UK study conducted by the Picker Institute which measured patients' experience of care as well as overall satisfaction, concluded that emotional support was one of the three main contributors to 'feeling good' about their care – the others being physical comfort and respect for patient preferences. Measuring experiences of health care, rather than overall satisfaction, provides a more meaningful indication of the quality of care received.

Another study, again using survey material designed by the Picker Institute to assess experience of care, provides a snapshot of patient experiences across five countries: the United States, the United Kingdom, Germany, Sweden, and Switzerland. The results showed that most problems occurred under two general headings:

- Emotional support and respect for patients
- Information, coordination, and comfort.

i) Emotional support and respect for patients

Many patients felt that they received inadequate emotional support, reporting that it was difficult to discuss their anxieties and concerns with doctors or nurses and indicating that they lacked confidence in some of the health professionals responsible for their care.

Some respondents reported failure to take account of their preferences, complaining that staff sometimes talked about them in their presence as if they weren't there. The most commonly reported problem in the patient preference dimension was failure to involve patients in treatment decisions. The proportion responding negatively to the question about whether they felt sufficiently involved was 46 per- cent in Germany; Sweden, 54 percent; Switzerland, 36 percent; the United Kingdom, 59 percent; and the United States, 37 percent.

i) Information, coordination, and comfort

A fairly high rate of problems was reported across the five countries on the information and education dimension, which included items such as communication in the emergency room, delays in bed allocation, and clarity

of explanations provided by medical and nursing staff. Key items that contributed to negative evaluations of coordination of care included lack of organization of the admission process, not being given the name of the doctor in overall charge of care, scheduled tests and procedures not done on time, and conflicting information from staff. Physical comfort received lower (that is, better) scores in all five countries, but this does not necessarily mean that it was dealt with adequately in all cases.

What is emotional support – and does it comprise a broad spectrum of needs?

Our experience at ECO of working with patients and patient groups across Europe over 10 years leads us to believe that focusing on people's 'feelings' takes us also into the dimensions of communication needs, accessibility of information and clarity of care coordination. Emotional support is not confined to a 'good bedside manner'. The emotionally charged scenario of a child born with a cleft being sent to an orphanage because the parents are told 'they won't be capable of looking after them at home' (ECO, Bulgaria report for UNICEF) is not about delivering a message in a sensitive way but a complete failure to provide medical information and practical support that would allow the child to remain at home. A UK report on cleft care in the period following diagnosis also highlights problems arising from failure to provide correct and timely information and to communicate this in a meaningful way. Parents were left wondering whether they should terminate the pregnancy because they weren't given clear, accurate, understandable information.

A further study from Canada tries to further define the nature of emotional support. A qualitative, descriptive approach was used to investigate the perceptions of emotional support received by patients during their hospital stay. Twenty-five patients were recruited to participate in this study. Semi-structured interviews were conducted with patients, as key informants, before they were discharged from hospital. Patients were encouraged to share their thoughts about the emotional care they received during their in-patient hospital stay.

The following eight themes emerged from the data: empathy, informative communication, being present and available, inspiration and hope, personalization, supportive gestures, humour and environmental familiarity. Patients perceived clinicians as giving them emotional support through the use of these strategies. Below are examples of the themes that were raised.

1) Empathy

Care delivery is often focused on the *what* and not the *how*. Patients reported that the way in which care was delivered was vital for making the experience satisfying.

2) Informative Communication

When care was highly satisfying, patients had participated in conversations related to their treatment. Patients reported needing two-way conversations through which they could learn about treatments, outcomes and expectations. This study found that informative communication about treatment plans, diagnosis, procedures and prognosis helped reduce patient anxiety and worries.

3) Being Present and Available

The theme of being present and available refers to patients knowing, through responsive behaviours, that somebody is present. In the study, this left patients with the impression that they were never alone, were safe and there was a sense of connection between caregivers and patients at all times.

4) Inspiration and Hope

Participants viewed inspiration and positive messages from their caregivers to be key to having a positive influence on their minds and uplifting their spirits. They considered hope very similar, in the sense that they expected their caregivers to provide them with an outlook that was positive and to convey that events would turn out for the best.

5) Personalization

'Personalization' refers to getting care that is individualized and that meets each patient's unique needs. Some patients talked about situations where they felt more "like human beings" than just patients. They spoke about interacting with staff or caregivers on a level that was more about one human being helping another, rather than a trained skilled clinician helping a "sick," helpless patient.

6) Supportive Gestures

Three tenths of the participants spoke about gestures that conveyed caring and emotional support. Supportive gestures are acts that are performed by caregivers with the intention of conveying empathy, openness and support to patients. These gestures included:

- Physical touch
- Eye contact
- Smiling
- Proximity of staff to sit down and talk

7) Humour

Humour in the caregiver-patient interaction was appreciated by over three tenths of the participants. For some, humour was a therapeutic tool. It healed their anxieties and turned them away from the grief and worries generated by their illness.

8) Ambient Environment

The ambient environment involves the mood generated from the interactions among people within a given setting. A good ambient environment is usually referred to by patients as a “friendly environment.” This includes the importance of patients knowing the names of not only their care provider but any health workers who they come into contact with.

Thus ‘emotional support’ from the patient’s perspective is provided through a panoply of different means the sum of which dictates the level of overall patient satisfaction.

Perhaps it is worth noting here that the WHO definition of Quality of Life is defined as people’s *“perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns”* This definition dictates that the person themselves, rather than health providers, define the important concepts that bring a sense of positive self-perception. Patient satisfaction is the ultimate validation of the quality of care.

Further considerations specific to clefts and visible difference

With regards to craniofacial and other congenital anomalies such as cleft lip and palate, there is evidence showing there can be a disconnect between the patients desires and expectations and what the clinicians can offer. Attaining functional and aesthetic objectives does not guarantee the happiness of the patient yet enhancement of quality of life and leaving the patient ‘satisfied’ is commonly used as justification for interventions. For children and young people, decisions to proceed with interventions are made by parents and clinicians; the level of input in the decision-making process by the child can be minimal. Research has shown that a significant proportion of adolescents feel left out of treatment decisions – their satisfaction with the clinical outcomes often does not correlate with those who made the decisions for them.

“I had an operation and I was thinking that it is going to change everything and everything is going to be OK. And it wasn’t. It didn’t even look like they did a change- so I was so sad about that ...”

One article reported an absence of a ‘life course approach’ in studies and evaluation of outcomes. The length of treatment and impact is lifelong for craniofacial anomalies and clefts and should be evaluated in the longer term.

There is a preponderance of papers that focus on satisfaction with surgical outcomes (facial profile etc.) but lack components evaluating psychosocial well-being.

The whole clinic and hospital setting was cited in some reports as being detrimental to patient's self-perception. They were there to be offered the opportunity of gaining a better quality of life (through surgery etc.) yet attending clinics was seen as confirmation of their decrepit state, sharing waiting rooms and hospital wards with those who looked like them - or far worse. The feelings were exacerbated when doctors only spoke about technical aspects of treatment and not about holistic whole-person approach, or talk only to their parents or colleagues.

Health care professionals can help attenuate the emotional and social challenges inherent in appearance altering procedures by openly discussing the possibility of potential repercussions with patients (and their parents) prior to surgery and collaboratively devising coping strategies to deal with difficulties as they arise. For example health care professionals can encourage and prepare parents to be their child's advocate and educate teachers in advance of scheduled surgical or other interventions. In addition there is scope to include children and young people to a greater extent in their care, and helping to shape services. Patients may also benefit from development of more child centered resources.

A checklist on factors that should be considered in delivering care for this group of patients appears in Annex 1

Information needs

In the above Canadian study, 'Informative Communication' was seen as a key element within 'emotional support'. In the UK a Picker Institute study funded by the Healing Foundation investigated the information needs of patients with disfiguring conditions and their families, to assess how they were being met. The research was carried out via a literature review, focus groups and one to one survey questionnaires. Within the clinical setting the study provides summaries of the issues inherent in the information process and the difficulties and shortfalls of one to one communication by the health professionals.

In the research what emerged more strongly than anything else was the importance of the way in which patients and clinicians engage in the information process - or in a few cases, choose not to engage. In circumstances where the very way in which patients see themselves has been fundamentally affected, this exchange is particularly sensitive. Some health professionals clearly manage this situation well, but the evidence from the research and the focus groups implied that many more do not. To add to the complexity, the huge amount of information available outside the hospital (today, largely the internet) means that patients can become their own information managers. But the extent to

which patients want or are able to take on this additional responsibility is unclear.

The primary way in which health professionals continue to inform their patients is verbally in consultations. The medical staff interviewed in the Picker study clearly thought this was how patients should be informed and the patients generally endorsed this. However, this form of information provision, essential though it is, relies entirely on the communication skills of the clinicians involved and all the evidence indicates that these are infinitely variable. It is not surprising, therefore, that some of the patients interviewed had had very good experiences and others felt that their information needs had been very inadequately satisfied. Information provision is a two-way process. Patients need to be able to talk to their clinicians about their concerns, articulate the problems they are experiencing and provide feedback on treatment regimes. Professionals need to be able to assess how much and what information a patient can understand and assimilate at any particular time. When diagnoses and outcomes are uncertain, this can be very difficult to judge correctly and there is perhaps an understandable reluctance to provide detailed information about unpleasant side effects and complications if they may not even arise. Although the demand for information is generally growing, some medical staff clearly have not recognised this or risen to the challenge.

As noted above in the section '*Further considerations*' there are continuing information needs for this group of patients. All the conditions have long-term implications. The information needs of the patients change over time, but do not necessarily diminish. Individuals need to be kept up to date with any new research or developments that might improve their quality of life. This can present a problem for clinicians and other health professionals who have to prioritise their work, and place a greater burden on the patient to remain informed. Regular review clinics and support groups can offer a solution, but not all patients choose to access them even when they are available.

Support groups can play an invaluable role in filling information needs but there needs to be some checks and balances on the way this information is provided. There can be situations where shared stories become off-loaded burdens of own worry rather than objective recounting of facts. The Cleft Lip and Palate Association in the UK found it necessary to introduce training for its one to one parent support contacts which covered basic befriending and listening skills drawn from good practice guidelines. A psoriasis support group Nottingham found that it was helpful to have health professionals present at meetings to provide a link with the hospital and suggest routes for professional counselling where needed. But there was no other substitute in many senses for a group of people who could share stories having traveled the same journey.

“I can’t have a good moan with friends who don’t have eczema but with the support group everyone knows what it’s like and you can moan – you can listen to others and take your mind off yourself for a bit”

A note on health literacy

The World Health Organisation states that: *Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.*

Examples of health literacy include a person having the ability to understand instructions accompanying medication appointment slips, medical education brochures, doctors’ directions and consent forms, and the ability to negotiate complex healthcare systems. Health literacy is not simply the ability to read. Health literacy requires a complex group of reading, listening, analytical and decision-making skills and the ability to apply these skills to health situations.

Literacy varies by context and is not necessarily related to years of education or general reading ability. A person who functions adequately at home or work may have marginal or inadequate literacy in a healthcare environment. These days, patients are often faced with complex information and treatment decisions. These involve the need to evaluate information for credibility and quality, analyse relative risks and benefits, calculate dosages, interpret test results or locate health information. In order to accomplish these tasks, individuals need to be visually literate (able to understand graphs or other visual information), and able to calculate or reason numerically. They need to be computer literate, information literate (able to obtain, assess and apply relevant information). And with the development of the internet as a source of health information, they need the ability to search and evaluate websites. Oral language skills are also important, as patients need to be able to articulate their health concerns and describe their symptoms. They also need to be able to ask relevant questions and understand spoken medical advice and treatment directions. However, if patients have poor basic skills in literacy, even information deemed relatively simple to access, understand and use may prove otherwise.

Most recent data from 8 EU countries suggests that only 40 per cent of the population is adequately health literate. This presents doctors, planners and politicians with huge challenges in terms of providing effective support for patients in all needs areas which in turn impacts massively upon the effectiveness of healthcare in general.

Discussion and conclusion

This paper has focused on what factors might contribute to the improvement of care in clinical settings. The report began by looking at what patients have said about what is important to them in the overall care experience. The actual reported experience of care in various areas is a more effective way of measuring whether care is good or bad rather than overall satisfaction and it was found that patients valued emotional support as a key component of 'good care'. It was then felt that it was important to unwrap exactly what is meant by "emotional support" and it was suggested that effective emotional support is fact about addressing multiple needs, perhaps at the core of which lie the need for fluid two-way communication (between the caregiver and the patient) and access to clear, understandable information. In the context of disfigurement and visible difference the additional considerations are that treatment and care can go on for a very long time and that long term adjustment to appearance has to be supported well beyond the clinical setting.

In this context, the adoption of ACT as an effective means of improving long term care would seem to be entirely relevant. Because of resource limitations, it is unlikely that all the broad emotional support needs will ever be met in the hospital environment, but even if they are, there is still the need in the long term to ensure the patient is able to cope and manage beyond the walls of the hospital. Patients need to be equipped to take active control, learn resilience and discover the social skills needed to deal with altered body image and ensure independence.

Annex 1

Summary good practice guidelines by experts – improving experiences of those undergoing procedures that lead to altered appearance (taken from CET study, a previous Erasmus grant - see references)

Preparation	<ul style="list-style-type: none"> - Ensure surgeon and patient share same expectations of outcome - Parents and children may have different expectations and views of surgery – encourage agreement - Timing of surgery - medical need and individual psychosocial and practical need taken into account equally - Focus on functional outcome rather than aesthetic outcome - Proper informed consent, dealing with questions such as <ul style="list-style-type: none"> • Why do I need surgery? • What happens if I don't have the surgery? • What may go wrong? – health outcomes often unpredictable • How long will positive effects last? - Involving partners and loved ones for adults - Exploring other options such as camouflage and cancer prosthetics - Show projections of how a patient will look as it is difficult for them to picture – use of computer programmes - Talking to peers who have already had the surgery - More input about practical advice re day to day realities following surgery - Encouraging contact with patient groups to share experiences (good and bad)
Follow up/long term support	<ul style="list-style-type: none"> - Everyone should have the option of long term psychology or counselling. The experience of undergoing appearance changing procedures can negatively impact education, relationships and confidence – but with the right support this can be mitigated - Focus on whole environment – family, schools workplace. Managing return to work and return to school - Peer support programmes - Promoting a long term open partnership / relationship between patient/family and HCP's

The experts all stressed the importance and need for educating healthcare professionals in communication skills so that they become aware of words used

and what effect they have on the patient. All healthcare professionals working in this area should have knowledge of the psychosocial issues faced patients with conditions that affect appearance and who will be undergoing appearance changing procedures. This is especially important where there no psychologists are available - it is good practice to train up one or two other members of the multidisciplinary team in psychological issues

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