www.timeoutintensiva.it:
A NEW ITALIAN HEALTHCARE WEBSITE TO PROMOTE A NEW APPROACH TO INTENSIVE CARE UNIT PROBLEMS

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TOPIC

Design Human Technology Interaction - Good Practice and Ergonomic Solution .

KEYWORDS

Internet Critical Care resource – Intensive care unit - Patient Group – Narration based Medicine

1. INTRODUCTION

Technical progress has contributed to exciting success in the Intensive Care Unit (ICU). Technology has helped us win many battles against death and sometimes made us feel invincible. But it has also led to situations which were beyond our imagination just a few years ago.

Persistent vegetative state, resuscitation of ever more immature foetuses, the artificial nutrition of a dying patient, withholding or withdrawing life-sustaining treatments are all problems we face daily.

We have to make difficult choices leading to hard decisions, often in a brief period of time and completely alone.

Bioethics, which deals with the moral aspects of medical and biological progress, tries to give solutions but has difficulty in finding rules of moral conduct which are impartial and universal. National Ethics Committees often send out documents approved by a narrow majority and strongly contested by members of the same group.

Meanwhile ICU lives through its tragedies in silence, cut off from an outside world which often seems foreign and far away from us. These worlds get closer only when some episode hits the headlines. Then philosophers, church leaders, politicians and jurists give their opinions and put forward their solutions, while society discusses but has difficulty in understanding.

The resuscitation staff are left to apply the rules set down by the " experts", but may become the centre of news when their decisions come into conflict with the law.

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Out of the limelight we, our patients and their families return to our silent world, alien to the majority who prefers not to know, or to forget about these places where we live alongside death, suffering and pain, where we ask if dying is really the worst option. A place from which we would rather run away than give back a helpless but "living" body to parents who had put their child in our care.

Meanwhile the boundaries of life get wider and wider. Science continues to offer cures for illnesses which have been incurable until now, and even more sophisticated machines to substitute organs as we wait for them to heal. These challenges fascinate and excite us, they give us the strength to face the difficulties and solitude of our work.

But so often we live in limbo, suspended between omnipotence and impotence with which we are in constant conflict, thinking we can change the story of a patient and his illness until we realize that our capabilities are limited. Deciding where that limit lies, deciding when we must accept the inevitable, remains our great dilemma.

Regarded as magic healers, burdened by the responsibility of treating the sick and dealing with their families, we are forced into facing emotional and sometimes dramatic situations when patients arrive with their relatives. How does a physical illness differ from an endured illness? How does an illness affect social relationships? What is the role of the Intensivist(ICU Medical Practioner) between the technology required by the physical illness and the emotion aroused by the endured illness? If the staff is united as a team they try to give an answer and take on not only treatment of the patient but also give support to the family who are in need of help too.

Our experience showed that the staff had to go through a group experience phase in order to function as such a team.

2. METHODOLOGY

1) The site is the result of a group experience carried out about ten years ago.

Some of the results of the group work were the boost and the confidence in the publication which then led to narration. The first method was an analytical function group held in an

adapted setting in our department. The setting was built gradually as a formal setting seemed unsuitable at first. As we gained experience the setting also became the topic of analytical discussion, objects became significant. The analytical experience of the group didn't last long but the belief that life could be improved and therefore work could be faced better led us to new routes in scientific research too. Work was no longer a place of toil and suffering but could become somewhere to develop scientific queries.

The patient took on wider limits, no longer confined to the body but was considered more realistically as a whole, together with technological machines and family.

Before any research, a small focus group drew attention to the emotional aspects of work of which we have never been fully aware, although they have always been there emotions which influence our skills and our skills which, in turn, influence emotions, in a full circle. The papers were taken to national and international congresses and while they did not have the success one would expect for original scientific news, they certainly caused a sensation. Someone had dared to break down a wall of silence which kept pain hidden, and started a mechanism which instead of removing pain encouraged more sensitive emotions and the use of this sensitivity in improving the quality of Medicine towards the humanization of treatment which helps both patients and care givers.

Our next step was to leave the single experience and create a virtual base where we could continue as a research group and eventually widen our group. That is how we reached internet and our site. We can publish from and to a wider field which favours initiatives and developments. Obviously we still have editorial group meetings and we became an association in February 2008. Our work is progressing, based on the theory that emotions are the motor of our work not an obstacle.

2) Setting up the site

The search was conducted through the Cochrane library, Cinahl, and MedLine for articles published between 1999 and 2005 relating to family-centred care. Additional searches were conducted. The review included adult, paediatric, and neonatal literature.

Search results were loaded by subheading to a task force e-room of "timeoutintensiva" editor groups.

Authors were assigned a subheading and instructed to retain any articles containing metrics or notable publications of consensus for further analysis.

Cochrane methodology was used to evaluate each article's level of evidence and to grade the recommendations. Most of the research reviewed was Cochrane level 4 or 5 (case series, expert opinion, or survey research). Unless otherwise noted, recommendations apply equally to care in adult, paediatric, and neonatal environments.

Internet web sites were widely read in a search for a site with similar ideas but nothing was found on the concept of "Patient Group" or on the psychological and narrative approach in ICU.

3) The web site is written in HTML, JavaScript and PHP language, version 4.4.7 supported by MySQL Database version 4.1.

PHP language, one of the most important tools in developing dynamic web applications like timeoutintensiva.it, is a pre-processor which generates HTML code in real time linked with the DB needed to complete web pages, when a client makes a request. A LAMP machine (Linux, Apatche web server, Mysql, PHP) is the server support resident in housing of ALICOM, one of the most important and reliable Italian maintainers, which guarantees top security.

3. RESULTS

The Intensivist has to face three main problems in total solitude:

- The consequences of being constantly involved in highly emotional situations. Speaking to a patient who isn't there.
- Difficulties in communicating with our patients' relatives.
- The risks involved in high-technology environment which may cause us to forget the person who is in each of our patients.

SPEAKING TO A PATIENT WHO ISN'T THERE. The title refers to the emotional situation encountered by anyone working in ICU.

The Intensivist often works in extremely urgent conditions but patients rarely interact because they are in coma or critically ill. It is therefore impossible to establish the classical doctor-patient relationship which gives the doctor useful information about the patient's symptoms and feelings and creates that empathy which leads him to calling the doctor "my doctor". This is an awkward situation because it shifts the doctor's attention from the patient to the signs of his pathology, excluding all the knowledge that only a human relationship can give.

That's why we must not shut out emotions from our work, but recognize, understand and channel them in the right direction. There is a need for Intensivists who are trained not only in the scientific aspect of their work, but also in the affective aspect. Emotions must not be alienated from the medical profession , they should be in the intensivist's training because "Emotion is to the mind as oxygen is to the body, so we consider lack of emotional contact equivalent to anaerobic work".

DIFFICULTIES IN COMMUNICATING WITH RELATIVES OF THE CRITICALLY ILL. When a patient is taken into ICU, the family is suddenly out of touch with their loved one. Relatives entrust him or her to the staff but are shocked by the great emotional upheaval. The fear of death, the abrupt separation, the change of roles in the family circle and perhaps even economic worries all contribute to the anxiety. Reactions vary: some people may accept the situation, others refuse or are unable to admit how serious the illness is, while others are incredulous, afraid, aggressive or untrusting.

Relatives don't only ask about their loved one but also want to tell about themselves and their "suffering" made up of fear, anger, uncertainty, desperation and distrust according to their own experience and what they are going through. They too need our attention and care, so in ICU the doctor/patient relationship is widened to include care of the family too. Here again the intensivist's training is inadequate to deal with the complex affective level called "the sentiment of illness".

In Western Medicine the emphasis is on the treatment and cure of an illness, very little attention is given to the psychological aspects of the question. Generally we give medical treatment because we want to find the cure, but if we also pay attention to the patient's feelings then we are really taking care of them.

WORKING IN A HIGH-TECH ENVIRONMENT. PATIENT UNIT versus PATIENT GROUP. Intensivists face great difficulties in the humane-ethic field, because the therapeutic possibilities go far beyond the patient's biological possibilities.

Intensive Care Units are places of high technology where patients' beds are surrounded by monitors, respiratory machines and electric syringes needed for diagnosis and treatment.

The Intensivist tends to consider the patient and the surrounding equipment as a whole ("Patient Unit"), focusing more on the equipment than on the patient himself, so becoming an expert analyser of complicated data and a skilful follower of guidelines based on theoretical illnesses rather than real patients.
Our aim is to modify the concept of the "Patient Unit" (the patient and the surrounding life- supporting equipment) towards "Patient Group" which means not only patient and technological equipment but also relatives, ourselves, and the time and place given to care.
This concept of treatment therefore means taking care not only of the patient but also of everyone surrounding him. The whole group can support the patient by "Narration in ICU". When we doctors start a new shift we talk during the change over and give a clinical report but we also give further details of what we have learned about the patient or family and our own feelings. All this encourages the formation of a team spirit and work as a team.
Narrated-Medicine transfers so-called "tacit knowledge" (Polanyi). Narration, telling about patients, our emotions and our feelings or perceptions about their treatment allows us to express concepts which have no scientific terminology, but go beyond its restrictions.
By narrating, we Intensivists (alone or in a work group) can choose from several diagnostic and therapeutic options and give our opinion about the possible development of the illness in the future. We no longer deal just with the "Patient Unit" but with the "Patient Group" which includes the patient, equipment, his family and the ICU staff involved. So the doors of ICU should be opened not just for visits to patients or meetings with doctors but also to help the family cope with the break in relationships by allowing them to help look after the patient. By spending time in ICU relatives learn about this often misunderstood and puzzling world.

4. CONCLUSIONS

This site was founded to pass on our experience and to augment and improve ideas by corresponding with others. On the website we deal with both Narration Based Medicine (NBM) and Evidence Based Medicine (EBM) which are complementary to each other , not in opposition. In short, EBM helps us feel our choice is shared by the scientific community, while NBM helps us feel that the work group and family agree with the same choice.
Timeoutintensiva is a bridge between NBM and EBM which allows ICU caregivers to give voice to their experience which has been hidden too long and to show the human side of our world to those who do not know ICU. Timeoutintensiva traces out a new way of life in ICU, centred on the "Patient Group" and treating the patient through a narrative and psychological approach.
Technè and Archives provide scientific articles in Italian and English. A Forum allows to share ideas and opinions with our readers who can submit photos, post and news. to our post-box for publication. There is news on books, music, theatre, exhibitions and cinema. Space is given to Intensivists in training, nurses and to our roots with biographies and works by the founder of modern resuscitation.
Timeoutintensiva is a quarterly on-line journal in Critical Care edited by an ICU medical staff. It has been on-line since June 2006, in one year has had 1.700.000 accesses, 60.000 visitors from 100 Countries worldwide, 500 people booked to our newsletters .The site is indexed on MedHunt and on the most important research motors and is licensed (qualified) ISSN (ISSN 1970-424). It was licensed by the Health of the Net Foundation (HONConduct 175368) in October 2007.
Timeoutintensiva follows the moral code of the medical profession and respects the aim of humanizing Intensive care. There is open access to all parts of the site following the Budapest Open Access Initiative. The growth of scientific culture also goes through open access to scientific material which we believe should be tax free, open and transparent, especially in the field of medicine. .All our journals are on the web and you can go from the latest(5) number to the first (0) by a single click.

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