Survival and quality of life in burns

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Motto: "…Little is the public aware of the obligations it owes to those who led by professional ardour, and the dictates of duty, have devoted themselves to Medicine…"

James Parkinson in "Essay on the Shaking Palsy" 1820

Summary: Advances in medical technology and practices have been associated with increasing medical specialization, but they have developed at a price. This price has included not only enormous financial costs, but the additional cost of dehumanized patient care, diminished confidence in the medical staff and, consequently, human suffering. Burn injuries are catastrophic in scope and require specialized, intensive and prolonged treatment from which ensure ethical and psychological problems often complicated by many individual factors. Some of them arising from the Code of Patients Rights not only in the Czech Republic and contribute to DNR decisions (do-not-resuscitate). Not only "Quantity" of life but also "Quality" of life should be considered, particularly in burns. Critical factor is age. In old patients more sophisticated medical knowledge and practice may actually contribute to suffering. At any age scarring represents a special type of disfigurement. The "burn image" is more likely to evoke public avoidance than sympathy. The non handicapped by their negative attitudes help create and perpetuate the handicap and the consequent burden of suffering in burn patients.

Key words: ethical problems in burns – geriatric burns – paediatric burns – quality of life – futile treatment – DNR orders

Přežití a kvalita života u popálenin

Souhrn: Pokroky v medicíně z hlediska technologie a klinických zkušeností vedly k prohlubování specializace, ale za určitou cenu. Tato cena zahrnuje nejen nesmírné ekonomické náklady, ale i cenu spočívající v „dehumanizaci" péče o pacienta, snížení důvěry k lékařskému stavu a zdravotnictví vůbec a následně k lidskému utrpení. Popáleninové úrazy jsou katastrofou svým charakterem a vyžadují specializovanou, intenzivní dlouhodobou léčbu, s níž jsou spojeny etické a psychologické problémy, často komplikované řadou individuálních faktorů. Některé vyplývají z Kódu práv pacientů nejen v ČR a přispívají k DNR rozhodnutí (do-not-resuscitate-orders). Nejen kvantita života, ale i kvalita života by měla být zvažována obzvláště u popálenin. Kritickým faktorem je věk. U pacientů vysokého věku příliš sofistikovaná léčba může ve skutečnosti přispívat k utrpení. V jakémkoliv věku proces hojení s jizvením představuje zvláštní typ znetvoření. Tento „burn image" vyvolává u veřejnosti spíše odpor než soucit. Nepostižení jedinci svými negativními přístupy a postoji vytvářejí a udržují „handicap" postižených a stupňují trvající břímě utrpení u popálených pacientů.

Klíčová slova: etické problémy u popálenin – popáleniny ve stáří – dětské popáleniny – kvalita života – marné léčení – příkaz neresuscitovat

Surgeons have been placed at the first line of burn care regarding both survival and amelioration of quality of life. The moral career of surgeons has changed with the possibilities of decision and the need for some rules for decision making, which are still called up to lead the care. In 1928 Sir Robert Hutchinson published in the British Medical Journal: "Every doctor must be a judge. We can increase our knowledge by study and experience, but judgement seems to be an inborn faculty – the result of a union of mind and character which a man either has or has not. It may be improved only by general mental culture, and not by pure scientific training." An other quotation – more than 200 years old exemplifies changes in medicine. Then, medical students were taught by Samuel Johnson: "It is our first duty to serve society…"

The true service to the society has changed over centuries, especially, during the last three decades. There emerged ethical problems in the practice of medicine due to advances in science, along with alterations in law and societal perceptions. Traditionally, the doctor's duty has been to the patient and this duty only has extended to the family when the patient has become incompetent.

The Code of Patients Rights in the Czech Republic (set up on February 1992) states that patients are entitled:

- to respectful and professional treatment given by qualified workers;
- to know who is in charge of them;
- to be informed so as to be able make decisions regarding the health care provided;
- to the presence of their own family (very important for burn care);
- to refuse treatment (it does not concern the acute phase of burn care);
- to give or withold consent to students' participation;
- to access to confidential medical records;

Fig. 1. In 1969 kitchen fire. Female: age 73, extent 68% TBSA, full thickness skin loss, inhalation injury. Co-morbidity (diabetes mellitus). Transport to burn centre: i.v. cannula → palliative therapy. No ET tube → DNR order.

Fig. 2. In 2004 fall on stove → unconscious. Male: age 92, extent 4% TBSA, right half of head and neck, full thickness skin and skull loss. Transport to burn centre: i.v. cannula → fluid therapy, ET tube → futile treatment 6 weeks.

- to continuity of treatment after discharge (very important for burn care);
- to be informed when non-standard or experimental treatment will be used;
- to respectful care when dying;
- to respect the internal order of the health care establishment.

Recently, the focus on the patient's right to refuse treatment has shifted to the patient's **right to demand treatment**, even if doctors believe that such treatment is futile.

"Right to care" cases are the next step in defining the boundaries of patient autonomy. These situations involve a conflict of values as some families demand continuation of care even if there is no chance of recovery. That is an other aspect to the dilemma we now face: whether a health care system already affected by rapidly increasing costs should force doctors to go against their expert judgement when families insist on maintaining prolonged care for reasons that are defensible only in **emotional** terms.

There is growing trend among doctors to accept death of patient without a sense of failure. This trend is illustrated by the acceptance of "Do – NOT – RESUSCITATE" orders, concept unheard over the past 200 years. Resuscitation medicine has established its place in health care and consists of emergency resuscitation and long-term resuscitation (intensive care) that represent **life-support chain** called also **critical care continuum**. Previously inconceivable possibilities have been developed, but at a price. This price has included not only tremendous **financial costs**, but also the additional **cost of human suffering**. The principles stating that access to the "aggressive supportive care" or so-called "titrated therapy" is the right of each individual, creates a whole complex of **ethical decisions**:

- when and whether – if at all – should therapy be started (Fig. 1)?
- when should the therapy be discontinued (Fig. 2)?
- what quality of life are we able to provide to the patient (Fig. 3a–3g)?
- what are our responsibilities when patient, family or surrogate demand futile treatment?

From Greek mythology (collecting water in leaky sieves) has come the concept that futile acts, including medical interventions (Luce, 1995), are ineffective and incapable of achieving a desired result or goal. A treatment that **cannot end dependence on critical care** should also be considered futile.

Recently, the doctors have been reminded that offering care to every patient without estimating the severity of injury and thus quantifying the risk of death, is an approach of the past. Various models for **prognostic prediction** provide rough evaluation of patient outcome, but there are statistical reasons why they may not work when they are tested in different populations. Prediction rules suffer from criticisms that are not based upon their design.

However there is also disagreement on how much computer predictions should influence medical decision. In addition to the fact that outcome cannot be perfectly predicted, the concept of futility is limited in that doctors, patients, family (surrogates) and other parties may view futility differently.

Especially in **Burn Medicine**, there are encountered manifold factors contributing to DNR decisions. Modern burn care often leads to the dilemma of what should or should not be done for patients with clinical deterioration

Fig. 3a. In 1973 fall on stove unconscious. Girl: age 18, extent 18% TBSA, right half of head and neck, upper extremities; full thickness skin and mimic muscles loss; eye lids; auricle and n. facialis loss; transport to burn centre: i.v. cannula → fluid therapy, no ET tube (when awake lucid and cooperative).

Fig. 3b. Reconstructive surgery by means of double tube pedicle flaps in lower abdomen.

Fig. 3c. Transfer of flaps to face and neck by means of forearm.

Fig. 3d. Flaps detached and rough modelling.

Fig. 3e. The third tube pedicle flap.

Fig. 3f. Completed modelation.

Fig. 3g. 35 years after accident (still working, married, and acting as grandmother).

and organ system failure with no response to therapy.

Already in 1992, Frantianne recommended a structured conference to address these issues and to help decide whether to continue invasive diagnostic and therapeutic interventions or to allow the patient die with dignity. This conference is a meeting of the whole burn team.

The decision made by the group is indispensable, though the final and principle responsibility – according to our experience – lies always with the head of the burn center, who has to communicate with the patient's family continuously.

One of the most difficult question in **burn care** is whether one should base decisions of withholding or withdrawing therapy on potential **quality of life**. The critical factor is **age**. The most distressing problems are encountered in **old persons**, who are made by the injury completely dependent on others for all their functions.

Fig. 4a. In 1981 flame burn when playing with her brother. Girl: age 4, extent 15% TBSA, face neck, hands, full thickness skin loss, inhalation injury. Transport to burn centre: i.v. cannula → fluid therapy, ET tube (parents requested withdrawal of treatment to prevent whole life suffering of their daughter because of loss of face).

Fig. 4b. Early necrectomy (as soon as surgical procedures started the parents changed their mind completely and cooperated in all respects perfectly).

Fig. 4c. Scar disfigurement due to shrinkage of autografts.

Fig. 4d. Physiotherapy (elastic mask, rigid plate, collar, performed by her mother under control).

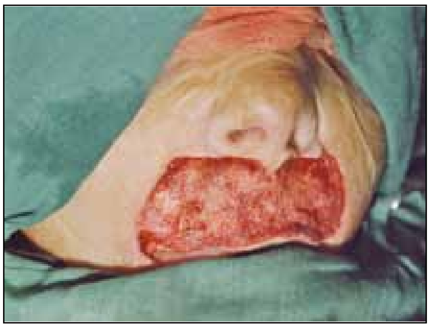

Fig. 4e. Reconstruction of the “esthetic units” after 2 years in stages: upper lip, lower lip and chin.

Fig. 4f. Reconstruction of checks and nose after 4 years.

Fig. 4g. 15 years after accident she started to study art academy abroad.

A conflict occurs in the treatment of an individual patient between the aim of prolonging life – quantity of life – and the aim of promoting quality of life.

This brings us to the paradox that in old patients more sophisticated medical knowledge and practice may actually contribute to suffering. Nevertheless, the full physical, emotional and financial impact is usually not felt until the time a patient is discharged from the protected environment of a burn center. There arise several questions regarding **quality of life**:

- Are survival and decreased length of stay in the hospital really the measure of progress and success in the burn speciality?
- What is the real outcome of patients with severe burns?
- What is the long – term effect on the patients’ families?
- Do we return our patients to a society which is **not ready** psychologically, socially or financially to accept them [2]?

In **children** decisions about the futility of care are extremely complicated. In clinical practice we faced the alternative scenario of parents requesting withdrawal of care because of fear of child’s disfigurement (Fig. 4a–4g). Do burn specialists have a responsibility for the quality of life? Our cases of pediatric burns who were operated on in phases (staged reconstructive procedures) and followed up for decades may prove, life was worth striving for.

Scarring represents a special type of disfigurement. It produces a **stigma** and the stigmata are interpreted by society as a moral or personal defect. Furthermore, unlike other most severe forms of trauma (head or high spinal injuries) the "burn image" is more likely to evoke public avoidance than sympathy. Here let me point out the role of patients **family background**. It is the essential factor to mitigate the individual stress response of the patient during all phases of burn care. Particularly, after discharge an appropriate attitude of the family members may recuperate the **quality of life**.

Nevertheless, the nonhandicapped by their negative attitudes help create and perpetuate the handicap itself and the consequent burden of suffering [3]. Quality of life has been estimated by Ian Ramsey Centre (Oxford, 1995) under five headings:

1. degree of pain, distress or discomfort experienced, whether physical or emotional;
2. degree of normal activity attainable;
3. nature of personal relationships achievable;
4. extent of capacity to undertake and complete projects;
5. extent to which hopes and ambitions can be fulfilled.

The first two items seem **"objective"** when contrasted with the remaining three.

We should be able to predict how much pain or discomfort the patient is likely to experience from a given treatment and what degree of activity the treatment will allow. At least, in principle, as patients differ in all sorts of respects.

The other three items might be called **"subjective"**. Success in relation to them depends upon the personality of the patient. What really matters is what the patient feells as **satisfaction**. In **competent** patients quality of life should be assessed entirely by the individual person.

In **incompetent** patients (including young children) there can be no question of discovering their preferences. By what standard is their quality of life to be assessed and who is to do it?

The attempt to measure quality of life is an attempt to make comparisons regarding the life of the same individual under different circumstances and to compare the different states of an individual's life to the lifes of different individuals.

In conclusion let us bring back the initial reflection on judgement and decision making. To estimate roles of scientific evidence and of authority or fashion in determining our choise of treatment I wish to remember words of A. B. Wallace in the talk which he gave at Buenos Aires in 1974. "Humanity has three aspects – science, art and faith. Just as science and faith without art produce the fanatic, and art and faith without science produce the mystic, so science and art, unleavened by faith, produce the virtuoso, the technical expert".

What Sir Robert Hutchinson meant in 1928 by mental culture and character, that A. B. Wallace comprehended in "faith".

We cannot disregard the social and historical circumstances in which we live, but they do not change the justification of morality and ethics. We must remember that outcome prediction, quality of life assessment and also cost efficiency are significant tools for meeting the challenges of today and of tomorrow.

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