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Severe adult burn survivors. What information about skin allografts?

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Short running head: Burn survivors. Skin allograft information.

Tables: 3

Abstract

Background and objective: During the acute phase of a severe burn, surgery is an emergency. In this situation, human skin allografts constitute an effective temporary skin substitute. However, information about the use of human tissue can not be given to the patients because most of the allografted patients are unconscious due to their injury.

Objective: This study explored the restitution of information on skin donation to patients who have been skin allografted and who have survived their injury.

Method: A qualitative study was conducted due to the limited number of patients in ability to be interviewed according to our medical and psychological criteria.

Results and discussion: Twelve patients who had been treated between 2002 and 2008 were interviewed. Our results show that 10 of them ignored that they had received skin allografts. One of the two patients who knew that they had received allografts knew that skin had been harvested from deceased donor. All patients expressed that there is no information that should not be delivered. They also expressed their relief to have had the opportunity to discuss their case and at being informed during their interview. Their own experience impacted their view in favor of organ and tissue donation.

Conflicts of interest: None.

Key-words: ethics; burn, skin allograft; skin donor; organ and tissue donation; information.

Introduction

Early excision and immediate grafting has been shown to be a major advance in the surgery of severe burn patients (Ong et al. 2006). In practice, using the same surgical procedure, burns are excised as soon as possible after the onset of the injury, and excised areas are covered by skin grafts. Ideal coverage is skin autografts. However, when burn injuries are both deep and extensive, autografts are not available and skin substitutes have to be utilized.

In this situation, human skin allografts, harvested from deceased or living donors, constitute an effective temporary skin substitute. It is well known that, when allografts are applied on excised burns, they limit hydro-electrolytic losses and pain through the mechanical effect on the wounds they cover; they reduce infection risk; and they improve (enhance) recipient tissue granulation by providing the factors needed for healing (Herndon and Parks 1986; Cuono et al. 1987; Kreis et al. 1992; See et al. 2001; Vloemans et al. 2002; Naoum et al 2004). After grafting on burn patients, allografts are usually rejected between two and four weeks (Burke et al. 1978; Ninnemann et al. 1978; Koller and Orsag 2006). The main drawbacks of this therapeutic human tissue are the risk of disease transmission (Clarke 1987), and in France poor availability due to lack of donors and lack of harvesting.

In our practice, human skin allografts are harvested from multi-organ and tissue donors, transferred in a tissue bank where they are prepared and stored in liquid nitrogen until total assessment versus putative transmitted diseases. Then only, allografts can be delivered to burn centers to be grafted on severely burn patients. Most of the time, burned recipients are unconscious due to the circumstances of the injury or due to their sedation treatment. Their prognosis is always engaged. Our habit is to inform verbally the relatives or the person of trust on skin allografts considering that consent is not required by the law.

Literature on impact of skin allograft in burn patient and ethical issues related to this treatment is poor. Most of the studies examined the life-quality, especially due to the impact of the scars (Patterson et al. 2000; Sheridan et al 2000; Van Loey et al. 2001; Cromes et al. 2002; Landolt et al. 2002; Anzarut et al 2005; Brewster et al. 2006; Falder et al 2009; Ullrich et al. 2009; Brusselaers et al 2010).

The aim of our study is to evaluate the knowledge of massive burns survivors about being recipients of donor skin, their perception of skin donation, and the impact of their history on donation in general (organs and tissues).

Methodology

Population

A list of patients who have both been admitted in the adult burn unit of the Cochin hospital during the period 2002-2008 and have received skin allografts for their surgical treatment was established.

The following criteria were used to select those to be interviewed: 1) the patient is still living; 2) his/her physical and psychological conditions are compatible with being interviewed; 3) he/she has the ability to move and come to the clinical centre; and 4) there is a minimum of 2 years follow-up from the date of onset of burns (which is the minimum delay till scar maturing).

The evaluation of ability to be interviewed was made by both the surgeon and the clinical psychologist who were in charge of the patients both at the acute period of the burns and during the rehabilitation follow-up.

Semi-directed interviews

Questions to guide the interview were built by the Ethic Research group and validated by the clinical psychologist of the burn unit.

Patients were first contacted by phone by the surgeon. They were informed of the anonymous character of the interview. After receiving their assent, interviews were conducted during a face to face consultation and a dedicated time of about 2 hours. When possible, a first “yes or no” answer was sought before comments. Interviews were transcribed by taking notes.

Themes of the interviews

Themes are the information they had received about their surgical treatment as well as the impact on their position about organ and tissue donation through their experience of being a human tissue recipient.

Each patient was asked if he/she was aware of having received skin allografts. When the patient ignored it, the surgeon in charge of the interview gave him/her the information. This information was essential for conducting the rest of the interview. Then questions were asked about expectations in term of information concerning donation, followed by questions about their position relative to donation before and after burn injury. The interview was ended by asking if some information should not be issued to patient in this situation and their perception of the emotional level of the interview (open question).

Results

Interviewed patients

During the period 2002-2008, 1295 patients had been admitted in the adult burn unit of the Cochin hospital. Among them, 79 were treated with skin allografts harvested on deceased donors (multi-organ and tissue donors) (Table 1). Among these allografted patients, 24 deceased during their hospital stay whereas 55 survived. Twelve of them met the criteria of the study as specified in the methodology. All of the 12 patients agreed to be interviewed.

There were 4 men and 8 women. Mean age was 40 years (range 17-66) at the onset of injury. Mean percentage of total burn area was 50 % (range 23-64). Burn injuries occurred from domestic accidents for 5 patients, aggression for 3, accident at work for 2 and immolation for 2. None of them had been informed about skin allograft treatment at the time of the surgery due to medical sedation.

Patients' knowledge about skin allograft and expected information

Table 2 shows that, in response to question 1, 2 of the 12 patients knew that they had been grafted with skin allografts during their treatment. When these 2 patients were asked an additional question about skin procurement, only 1 knew that allografts had been harvested on deceased donors (data not shown). The 10 others were informed that they had received skin from a donor before conducting the interview.

In response to question 2, 3 patients declared that they did not wish to get any further information about the procurement of the allografts (Table 2). Among the 9 patients who wish to have more information, their expectations were to be informed about the donors profile, i.e. age, identity, living or deceased status. They also had questions about technical aspects. They wanted to know how did the allograft act (perform) on their wounds, which burned areas were concerned, and if skin allografts were still present on their body.

Impact on their position concerning donation

Table 3 shows that the position of patients is modified in favor of donation after the onset of burn injury.

In response to question 3, before the injury onset, 2 patients declared their agreement to be a skin donor, whereas 9 declined. Among these, 6 commented that they were not aware that this procedure existed. After injury onset, the number of patients in favor of skin donation increases from 2 to 8. Four responded negatively or expressed their doubt of being able to give anything because of their scars. One commented that he would willingly give his skin but declared: "My skin is out of use. When someone gives something, he/she gives a nice thing".

In response to questions 4 and 5 about other tissue donation (except skin) and organ donation, the number of potential donors also increases (7 out of 10 expressed positive answers in both cases). One patient commented: "Before my injury, my will was to be cremated. Currently, my opinion changed and I avoid all that deals with fire. Furthermore, I want that my death be useful for others by being a donor." Another patient expressed: "I needed the others, now I

have to give back". Three other patients said that since their medical care for burns, they explicitly told to their relatives their desire to be a multi-organ and tissue donor and they undertook the necessary steps for that, whereas they never did it before.

In all cases, none of the patients who were initially in favor of donation did change their mind after their accident.

Impact of the interview

It has to be mentioned that all the 10 patients who had been informed during the interview of having been allografted, expressed their satisfaction at receiving this information.

All 12 patients said there is no information about what they underwent (during both their medical care and the present interview) that should not be given. They highlighted the importance of the temporality for the delivery of information and suggested a step by step process.

Three patients express the wish to see pictures of their acute burns in order to evaluate what they have been through and the progress they made.

Discussion

The small number of respondents is a recurrent problem in studies concerning the outcome of burn survivors (Anzarut et al. 2005; Brewster et al. 2006). This calls for a qualitative reflection. Indeed, among the 79 patients who had been skin allografted in our adult burn unit between 2002 and 2008, 55 survived to their injury but only 12 were in ability to be interviewed according to our medical and psychological criteria.

Considering the principles of biomedical ethics described by Beauchamp and Childress (2004), it appears that when skin allograft has to be performed, the patient clinical status does not allow for the respect of the concept of autonomy and the process of informed consent. Prognosis is engaged, surgery is an emergency, and patients are unconscious due to their injury or sedation (artificial coma). Medical teams have a duty to act in the principle of beneficence (Konigova 2008). However, at the time where medical paternalism is no longer conceivable, the question is to know how to reintegrate the process of patient information about his treatment. When managing an acute event, the French law recommends informing either the relatives or a person of trust, about the condition of their relatives. The question of post-emergency information is found in other medical care contexts and clinical research programs in situations of unconsciousness (Law N°88-1138 of December 20th, 1988 on the protection of persons accepting biomedical research (Huriet Law) revised July 25th, 1994. Journal Officiel 1988; 26 juillet 1994).

From a medical point of view, information on donor skin is mandatory. Allografts are a human product and it remains that, despite the quality of safety procedures, a potential risk of transmission of pathogenic agents exists. From an ethical point of view, this information is imperative due to the respect to the donor, his family and the recipient. In our study, none of the 12 patients were able to be informed about the use of skin allograft at the time of surgery, and only 2 of them knew that they had been grafted with donor skin. Thus, doubts remain whether patients have really received all information (Enoch et al. 2005), and if they did receive the information, did they understand it and assimilate it ? The right timing for delivering such information is not an easy task. A lot of information needs to be delivered *a posteriori*, from the circumstances of the accident to the treatment of burn sequels. Caregivers should determine more precisely what can be told and be repeated at the different steps of patient recovery, and if there is a best time for delivering specific information to patients (i.e., at the regain of consciousness, at following-up dressings, at the entry in rehabilitation, etc...). Physicians also have the duty to respect the wishes of patients who do not want any further information, as 3 of our respondents who did not want to know more details about skin procurement modalities.

Regarding the content of the information, our study showed that during the interview several elements appeared essential to provide the patients with a concrete vision of their treatment, such as the origin of the allografts, the modalities of skin harvesting on the donor, the necessity of multiple donors for a single recipient, and the outcome of allografts (delay of rejection). Answering these questions allowed to alleviate their vision of the donor being “flayed alive”. This also allowed discussion of donation principles which are based on generosity, anonymity and consent. Furthermore, informed patients will be able to testify about the importance of the donation. Patients who had benefited from a gesture of solidarity are grateful (Sanner 2003). Our results show that our patients have modified their position in favor of donation (organ and tissue) after their accident. This highlights the importance of

communication, considering that tissue donation is less valued than organ donation in the society, that skin donation is less known than other tissues such as cornea (Chua et al. 2007) and that situations of skin allografts unavailability are regularly encountered.

In conclusion, all our respondents were grateful to receive more information on their treatment and especially on skin allograft. They perceived the interview as a help for them, a relief, a catharsis, an opportunity to express their feelings and a new step for their reconstruction (Gueniche and Hadengue 2000).

What is already known about this subject?

- Skin allograft has improved the outcome of patients with severe burns.
- Consent is not required. Information of the relatives on skin allograft is recommended.
- There is no recommendation regarding the patient information on skin allograft after recovery.
- The awareness of the patients about skin allograft has not been evaluated.

What does this study add?

- Patients are ignorant of having been grafted with donor skin.
- Patients want to get information about skin allografts.
- Through their experience, patients modify their position in favor of donation (organ and tissue).
- Reflection should be conducted by health professionals' about when and how to give information about skin allografts
- There is a need to improve communication about tissue donation which is less known than organ donation.

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