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An analysis of decision making in cord blood donation through a participatory approach

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In memory of Professor Brian O' Connell

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ABSTRACT

We analysed knowledge, comprehension, opinions, attitudes and choices related to cord blood donation in seven heterogeneous focus groups including pregnant women, future parents, cord blood donors, midwives and obstetricians/gynaecologists. Comparative evaluations focused on attitudes before versus after delivery and preferences of public versus private banking. The study outlined large support to altruistic cord blood donation and need for better health professionals education in this field. Collected information was presented in a public conference and used to develop an informative brochure which was tested for readability and clearliness in four workshops and finally distributed to 26 regional delivery suites.

1. Introduction

The efficacy of cord blood hemopoietic stem cells for the treatment of a number of severe conditions is convincingly supported by several studies and general consensus [1–3]. Nevertheless, the cord blood worldwide inventory is still sub-optimal to fully satisfy the needs for unrelated transplantation, in particular for small ethnic groups [4]. In addition, a large number of commercial programs of cord blood banking for private, autologous use, despite the prevalent lack of support from the scientific community, seem to gain popularity among the population, thus competing with 'solidaristic' donation programs.

In the last few years, several studies have tried to understand which factors may influence this social behaviour. Most of them have focused on the need to understand motivations to donate cord blood or to refuse it, others have analysed the reasons to prefer private to public banking [5–13]. In particular, Surbek et al. [5] and Fernandez et al. [6] analysed retrospective and prospective decision making processes related to cord blood donation respectively. Knoppers et al. [9] highlighted the relevance of cord blood banking in the bioethical debate, focusing on the issue of what women need to know before deciding. Kiatpongsan [13] questioned the accuracy of the translation of a 'business-on-hope' model to the context of cord blood donation.

All the mentioned studies explored separately prospective or retrospective decision making processes. Moreover, they mainly used quantitative tools (as, for example,

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questionnaires and interviews) for the collection and the analysis of citizens opinions and attitudes.

Due to the importance to understand motivations underlying cord blood banking in its full process, we performed a qualitative study in our setting to explore prospective as well as retrospective decision making processes concerning cord blood donation and to improve information and service as good practices. To this aim, we followed a deliberative participatory approach involving all the actors at stake [14–24]. Accordingly, we established a task force (TF) to manage focus groups, questionnaires, a public round-table and several workshops.

This article reports the methodology and outcomes of this study, which involved pregnant women with or without knowledge on cord blood donation, future parents, donors, midwives and obstetricians/gynaecologists. Together with the TF, the study participants contributed to the development of a good informative practice related to cord blood donation.

2. Materials and methods

2.1. The 'participatory' approach

Our project was based on the evidence that a donation process implies a plurality of actors, with their own baggage of experience and values, and makes the intimate relationships between choice and knowledge explicit. In this process, co-operation makes the clinical and research applications of donated cord blood possible. In parallel, knowledge co-production by researchers, operators, managers and citizens makes the donation possible. In fact, in order to donate, citizens need to know not just that it is possible, but also what kind of care and research possibilities does cord blood donation open. Moreover, health professionals and managers need this kind of knowledge too, in order to improve the service.

We considered that a 'participatory' approach [14–24,27–30] was needed to face this complexity [17] and guarantee the conditions of service as good practice. The participatory feature of our project required the involvement of the three principal actors at stake: citizens – single women or couples – health professionals and institutions. In this phase, we did not anticipate the involvement of patients such as cord blood transplant recipients or candidate recipients – which could be considered in future project extensions – except in moments of results disclosure. In order to ensure smooth management, a steering group coordinated the project with a 'virtual office', a participatory tool facilitating communication, opinion exchange, improved understanding of the complexities of decision making and interacting with the focus groups and the laboratories (see below). Moreover, we designed the analysis of the state and need of "knowledge" at stake as the first crucial participatory passage in order to tailor the donation process and to improve the cord blood donation service as good practice. To work within the different interactive groups, we implemented a formal deliberative methodology [18–20].

2.2. Task force

We established a task force (TF) including midwives from the hospital maternity department, the local public health services and the local university, obstetricians/gynaecologists from the hospital maternity department and private practice, hematologists, cord blood bank professionals, a bioethicist, jurists, philosophers and psychologists. Briefly, the TF first developed a personal letter of invitation and a specific informed consent to participate in the study, which was randomly distributed to citizens, potential donors, donors and health professionals during March–April 2007. Second, the TF planned the topics to be explored in a number of focus groups and by supplementary questionnaires. Third, the TF presented the collected data in a public round-table including study participants and citizens. Fourth, the TF coordinated the development of an informative brochure for pregnant women, future parents, health professionals and citizens based on the study results.

2.3. Focus groups

In agreement with the deliberative participatory approach, we planned to manage a number of focus groups (FG) aimed at hearing all categories of individuals more directly involved in cord blood donation practice, as pregnant women (categorized as 'informed' or 'unaware' for the purpose of this study according to their previous exposure to information on cord blood donation programs), future parents, donors, midwives and obstetricians/gynaecologists. Number of FG participants, session time and FG management methodology were defined according to the international literature [25,26]. Seven heterogeneous FGs were scheduled. Each FG included a maximum of 10 participants, was led by two psychologists, explored

Table 1
Number and socio-demographic data related to focus group participants.

	Hospital midwives	Obstetricians/ gynaecologists	Midwives practicing outside hospital	Informed pregnant women	Unaware pregnant women	Future parents	Donors
No. of focus groups participants	12	10	10	10	9	4	7
Mean age (years)	37	44	43	32	32	32	38
Education	Graduate/degree	Degree	Graduate	Graduate/degree	Graduate/degree	Degree/post degree	Graduate/degree
Nationality	Italian	Italian	Italian	Italian, Spanish	Italian, Spanish	Italian	Italian