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

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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.

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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. Kiatpongson [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

Table 2

Prevalent (P) or unanimous (U) answers collected during FG with potential and actual cord blood donors.

Questions	Informed pregnant women	Unaware pregnant women	Future parents	Donors
What do you mean by “cord blood”?	<ul style="list-style-type: none"> • Precious resource for clinical use (U) 	<ul style="list-style-type: none"> • Useful resource for clinical and research use (P) • Gift of social value (P) • Altruistic reasons (P) 	<ul style="list-style-type: none"> • Useful resource like organ (U) 	<ul style="list-style-type: none"> • Useful resource for clinical and research use (U)
Which factors may/did influence your choice towards cord blood donation?	<ul style="list-style-type: none"> • Altruistic reasons associated to moral value (P) 	<ul style="list-style-type: none"> • Altruistic reasons (P) 	<ul style="list-style-type: none"> • Altruistic reasons (P) 	<ul style="list-style-type: none"> • Moral value (U) • Efficacy of unrelated cord blood donation (P)
Which role do/did health professionals play in cord blood donation?	<ul style="list-style-type: none"> • Subsidiary role (P) • Obstetricians and gynaecologists provided poor and conflicting data (P) 	<ul style="list-style-type: none"> • Subsidiary role (P) • Health professionals provided poor data (P) 	<ul style="list-style-type: none"> • Subsidiary role (P) • Health professionals provided poor data (P) 	<ul style="list-style-type: none"> • Subsidiary role (P) • Health professionals provided poor and fragmented data (P)
What do you think about private cord blood donation?	<ul style="list-style-type: none"> • It is a fraud (P) 	<ul style="list-style-type: none"> • No participant expressed attitude towards private collection 	<ul style="list-style-type: none"> • Negative evaluation for its commercial nature (P) 	<ul style="list-style-type: none"> • Negative evaluation in light of moral and scientific reasons (P)

Table 3

Prevalent (P) and unanimous (U) answers collected during FG with health professionals.

Questions	Hospital midwives	Midwives practicing outside hospital	Obstetricians/gynaecologists
What do you think about cord blood donation?	<ul style="list-style-type: none"> • Act with moral and social value (P) • Private cord blood donation is a trendy and selfish act (U) 	<ul style="list-style-type: none"> • Social value act (U) • Association between cord blood donation and organ or blood gift (U) 	<ul style="list-style-type: none"> • No acknowledgment of a specific moral or social value to cord blood donation (U)
Which role obstetricians/gynaecologists presently play in cord blood donation practice?	<ul style="list-style-type: none"> • Crucial role in providing future parents with information as well as in collecting cord blood (P) 	<ul style="list-style-type: none"> • Crucial role in providing future parents with information on cord blood donation (P) • Specific role of education towards pregnant women and their partners (P) 	<ul style="list-style-type: none"> • No active role in present cord blood donation practice (U)
How could obstetricians/gynaecologists promote cord blood donation?	<ul style="list-style-type: none"> • Providing pregnant women and their partners with accurate information (P) 	<ul style="list-style-type: none"> • Providing pregnant women and their partners with accurate information (P) 	<ul style="list-style-type: none"> • Providing pregnant women and their partners with accurate information (P)
How cord blood banking should evolve to better promote cord blood donation?	<ul style="list-style-type: none"> • Specific education for health professionals (U) • Continuous weekly, day and night banking process (U) 	<ul style="list-style-type: none"> • Development of a network among cord blood banks, hospital and not hospital services, and family doctors (P) • Arrangement of dedicated documents (e.g., brochures, informed consent, maternal evaluation) for not Caucasian pregnant women (P) 	<ul style="list-style-type: none"> • Establishment of dedicated health professionals to cord blood banking service (P) • Development of simple informed consent and maternal evaluation documents (P)

four focal themes and was planned to last 2 h. FG participants did not receive any form of compensation for their participation. Number of FG participants, their mean age and the questions that were asked and discussed are reported in Tables 1–7.

2.4. Questionnaires

Anonymous self-administered questionnaires were prepared by the TF to integrate themes explored during FGs and distributed to all participants at the end of each FG. In addition to a common section asking socio-demographic data including age, educational level, site of residence and nationality, four different types were prepared (see questionnaires details in Section 3 below).

2.5. Public multidisciplinary round-table

A public round-table involving all FGs participants and open to other health professionals and citizens was held

in May 2008. An introductory session described the whole process of cord blood donation by focusing on the following themes: what is cord blood, how is it collected, what clinical uses are presently made, what research uses are or could be made in the future, what criteria regulate cord blood banking in public facilities, what does “education” mean with regard to cord blood donation. These issues were discussed by hematologists, midwives, biologists, geneticists and bioethicists. A second session presented the data collected during the FGs. A discussion time was scheduled at the end of the round-table.

2.6. Informative brochure

An informative brochure draft about cord blood donation, banking and use was developed by the TF in light of data and comments collected during FGs, from questionnaires and during public discussion. Then, the brochure draft was tested in four workshops with future parents attending prenatal courses organised by our hospital

Table 4

Answers collected from pregnant women and future parents questionnaires.

Questions	Informed pregnant women	Unaware pregnant women	Future parents
Is this the first time for you to hear about cord blood donation?	No (8/10)	No (8/10)	No (3/4)
How did you hear about cord blood donation?	Prenatal courses (10/10) Media (2/10)	Prenatal courses (5/9) Media (2/9)	Prenatal courses (2/4) Media (2/4)
How would you describe your knowledge about cord blood donation?	Poor (5/10) Sufficient (4/10) Very good (1/10)	Poor (9/10) No answer (1/10)	Poor (2/4) Sufficient (1/4) Good (1/4)
Who should provide information on cord blood donation?	Gynaecologists (7/10) Obstetricians (6/10)	Gynaecologists (9/9) Obstetricians (8/9)	Gynaecologists (3/4) Obstetricians (3/4)
When information on cord blood donation should be provided to future parents?	Prenatal courses (9/10) Pre-conception checks (1/10)	Prenatal courses (8/9)	Prenatal courses (2/4) Pre-conception checks (2/4)
Would you prefer allogeneic (solidaristic) donation or autologous (private) storage?	Allogenic (10/10)	Allogenic (9/10) Autologous (2/10)	Allogenic (3/4) Autologous (1/4)
Why?	Altruistic reasons (9/10) Cost of private banking (1/10)	Altruistic reasons (9/10) Moral duty towards my child (2/10)	Altruistic reasons (3/4) Health insurance for my child (1/4)
Besides transplantation, how would you use the given cord blood?	Research (9/10) Drug development (2/10)	Research (9/10)	Research (3/4) Drug development (1/4)
Do you think cord blood donation choices should be shared between future parents?	Yes (10/10)	Yes (8/9)	Yes (4/4)
In case of conflicting opinions, who do you think should decide?	Pregnant women (4/10) Others (5/10)	Pregnant women (7/9)	Pregnant women (4/4)

Table 5

Answers collected from donors questionnaires.

Questions	Answers (no.) from seven donors
How did you hear about cord blood donation?	Media (3); prenatal courses (1); brochure (1); during blood donation (1); at work (1)
Why did you choose to donate cord blood in a public bank?	Altruistic reasons (3); joy to donate (2); to support research (1); no answer (1)
How would you qualify your motivation to donate cord blood?	Very high (7)
Did you have additional thoughts concerning your choice?	No (7)
Would you choose to donate cord blood again?	Yes (3); yes, for altruistic reasons (4)
How should a public hospital promote cord blood banking?	With more specific and capillary information (7)

maternity clinic during October–November 2008. Workshops aimed at testing language simplicity, content clarity, information coherence and the usefulness of the brochure to perform administrative tasks. Workshops included a reading time aimed at identifying unusual, difficult or illogical words and sentences, and a discussion time aimed at collecting comments and suggestions.

3. Results

3.1. Task force meetings

Sixteen TF meetings, each lasting about 1 h, were held from February 2007 to September 2008. During the TF meetings, the current cord blood donation practice was reviewed according to a deliberative participatory approach based on a unique, integrated and multidisciplinary vision and regulation of cord blood donation including information, collection, banking and use. The review aimed at improving the clarity and transparency of the banking process.

3.2. Focus groups

All FG participants signed an informed consent to participate in the study, which had been approved by the hospital ethics committee.

3.3. Focus groups with potential and actual donors (pregnant women, future parents, donors)

FGs with potential and actual donors revealed that donation for public banking is considered a gift of moral and/or social value while donation for private banking is associated to egoism and fraud (Table 2). Almost all participants expressed their personal attitude to donate cord blood for altruistic reasons. Only one unaware pregnant woman reported her attitude to donate cord blood for a mixed banking. Almost all participants requested more information as well as clear procedures on cord blood banking processes. They particularly underlined the need for the use of simplified informed consent and maternal evaluations. Many of them suggested that all health professionals involved in cord blood donation (including fam-

Table 6

Answers collected from health professional questionnaires.

Questions	Hospital midwives (n = 12)	Midwives practicing outside hospital (n = 10)	Obstetricians/gynaecologists (n = 10)
Is there a service of cord blood banking where you are working?	<ul style="list-style-type: none"> • Yes (12) 	<ul style="list-style-type: none"> • No (10) 	<ul style="list-style-type: none"> • Yes (6) • No (4)
Who should provide information on cord blood donation?	<ul style="list-style-type: none"> • Obstetricians/gynaecologists (11) • Midwives (10) 	<ul style="list-style-type: none"> • Midwives (10) • Obstetricians/gynaecologists (9) 	<ul style="list-style-type: none"> • Obstetricians/gynaecologists (10) • Midwives (8)
When should information on cord blood donation be provided to future parents?	<ul style="list-style-type: none"> • Prenatal courses (6) • Pre-conception checks (6) 	<ul style="list-style-type: none"> • Prenatal courses (10) 	<ul style="list-style-type: none"> • Prenatal courses (8) • Pregnancy checks (3)
Based on your experience, what are the reasons of growing demand of private banking?	<ul style="list-style-type: none"> • Media influence (7) • Biological insurance for the child (4) 	<ul style="list-style-type: none"> • Biological insurance for the child (6) • Media influence (4) 	<ul style="list-style-type: none"> • Biological insurance (9) • Media influence (6)
Based on your experience, what are the reasons to request cord blood banking in a public facility?	<ul style="list-style-type: none"> • Altruistic reasons (10) • Better quality controls than in private bank (3) 	<ul style="list-style-type: none"> • Altruistic reasons (10) 	<ul style="list-style-type: none"> • Moral duty towards society (7) • Altruistic reasons (5)
Do you think cord blood donation choices should be shared between future parents?	<ul style="list-style-type: none"> • Yes (6) • No (6) 	<ul style="list-style-type: none"> • Yes (9) 	<ul style="list-style-type: none"> • Yes (10)
In case of conflicting opinions, who do you think should make a decision on cord blood donation?	<ul style="list-style-type: none"> • Pregnant women (6) 	<ul style="list-style-type: none"> • Pregnant women (10) 	<ul style="list-style-type: none"> • Pregnant women (5) • Others (5)

Table 7

Brochure sections and focal themes.

Brochure sections	Focal themes
Introduction	<ul style="list-style-type: none"> • Cord blood donation is a free, personal, and voluntary choice • Cord blood donation is a choice without risks to the mother and her baby
Definitions	<ul style="list-style-type: none"> • Cord blood donation is a choice of participation to clinical and the research development
Motivations	<ul style="list-style-type: none"> • Cord blood is not anymore a waste biomaterial • Cord blood is a precious source for clinical and research uses
Donation/collection options	<ul style="list-style-type: none"> • For transplantation: cord blood is presently used to treat a number of blood diseases and genetic conditions • For research: cord blood is a promising material for research
Procedures	<ul style="list-style-type: none"> • Unrelated cord blood donation: for any patient in need • Directed cord blood donation: for a family related actual or potential recipient • Private cord blood collection: for the exclusive use by the donor • Informed consent • Maternal evaluation • Administrative aspects
Contact for more information	<ul style="list-style-type: none"> • Department of obstetrics and gynaecology and/or Milano Cord Blood Bank

ily doctors and nurses) should be specifically educated about cord blood banking and inform future parents during pregnancy. Most FGs participants complained for the lack of an uninterrupted, 24 h/7 d cord blood banking service.

3.4. Focus groups with health professionals

While most midwives recognised the social and/or moral value of cord blood donation and associated it to other human biomaterial gifts (e.g., blood or organ donation), obstetricians/gynaecologists did not explicitly associate a particular value to cord blood banking (Table 3). Hospital midwives unanimously expressed a negative moral assessment of private donation, mostly considered as a “trendy, grim, useless and selfish act”. Similarly, midwives professionally active outside the hospital qualified private banking as a selfish act as well as a practice of doubtful efficacy. Although obstetricians/gynaecologists did not express moral evaluations of cord blood donation, they said that health professionals should provide future parents with

accurate information about the different possibilities to donate cord blood and let parents completely free to choose unrelated versus private uses. All health professionals requested more information on cord blood donation, as well as more detailed guidelines on both biomedical and legal aspects. Hospital midwives especially requested feedback on cord blood banking and use.

3.5. Questionnaires

Sixty-three questionnaires (100%) returned almost completely filled. They generally confirmed focus group data and showed a remarkable lack of knowledge about cord blood donation both by future parents and health professionals (Tables 4–6). They reported an explicit attitude or choice towards cord blood donation for unrelated use in light of altruistic motivations or scientific reasons. Questionnaire results support the need for more information on cord blood donation and specific education for health professionals.

3.6. Public multidisciplinary round-table

Seventy-seven individuals, including health professionals (midwives, obstetricians/gynaecologists and nurses), pregnant women, future parents, donors and citizens participated in the round-table. The first and second sessions lasted 95 and 45 min respectively. FGs participants confirmed the TF interpretation of the collected data and suggested to establish an information service about cord blood donation, as a first step to develop a *good practice* of cord blood donation.

3.7. Informative brochure

Based on the collected information, the TF developed a draft educational brochure on cord blood donation. The brochure, presently available only in Italian through the secretariat of the Milano Cord Blood Bank, focused on critical themes identified during the study (Table 7). Forty future parents participated in four workshops planned to test the brochure draft. Each workshop lasted about 45 min. Main suggestions included: (a) to use familiar rather than technical words (e.g., “private” was preferred to “autologous”, “altruistic” was preferred to “allogeneic”; (b) to give more specific information on cord blood and its uses (e.g., differences between the cord itself and the placental blood, or differences between cord blood and bone marrow transplantation), on the potential of stem cells derived from donated cord blood, on service times (e.g. for collection, banking, use), on appropriate times for distribution of informed consent and maternal evaluation, on the efficacy of altruistic cord blood donation versus private collection, on cord clamping time; (c) to outline that public cord blood banks follow international quality standards; and (d) to better explain cord blood donor recruitment criteria.

Based on these comments, the TF reviewed the informative brochure on cord blood donation that was subsequently presented to citizens and health authorities during a press conference and finally distributed to 26 delivery suites collecting cord blood for our regional cord blood bank.

4. Discussion

Cord blood banking is presently at the core of a striking international debate about the choice to donate cord blood for solidaristic or store it for private use. In the last few years, a number of studies have tried to identify which factors may influence this social behaviour, focusing on perspective or retrospective decision making processes [5–13].

Our study supports and expands the main results of these investigations. In fact, with regard to cord blood donors we simultaneously investigated the prospective and retrospective decision making processes, thus allowing a more meaningful comprehension. Moreover, according to the participatory methodology, we engaged lay and professional actors of cord blood donation. A comparison between fancies and choices showed that positive attitudes

of pregnant women (“candidate donors”) towards unrelated cord blood donation found a practical confirmation in the actual choices made by the donors. Consequently, we believe that our data support the reliability of the decision making process related to cord blood donation. This correspondence is particularly relevant for cord blood donation because potential and actual donors choose to donate cord blood for a public use in light of altruistic reasons. Therefore, according to our study, altruism and solidarity are verified reasons to choose unrelated cord blood donation.

Our data may be useful to develop policies as well as good practices of cord blood donation. In fact, the knowledge of decision making processes applied to cord blood donation and the comprehension of underlying motivations may orient institutions, health professionals and public organisations to develop guidelines giving accurate information on cord blood donation.

Furthermore, regarding controversial issues related to private versus public banking, the prevalent verified attitude or actual choice to donate cord blood for an altruistic use may support the development of public informative campaigns on the lack of consolidated scientific background of commercial banking for autologous storage. Furthermore, it may be used as a reinforcement of theories that question the applicability of the ‘business-on-hope’ model to clinical and banking contexts [13].

Methodologically, our experience was very useful to design the prototype of a participatory model [27–30] suitable to innovate informative processes and to centre the donation service on its actors. Moreover, the shared project has facilitated field training of the different stakeholders and outlined the virtuous relationships between good practice, its governance and training.

In spite of these positive results, we wish to acknowledge some limitations of our study. First, we could not expand our investigations outside the boundaries of our urban setting, neither could we include ethnic minorities in our study, which limits the transferability of our conclusions to other geographical and social environments. Second, we could not manage specific focus groups with nonpregnant women of childbearing age and with pregnant women relatives who may influence maternal and paternal choices by contributing to commercial autologous storage expenses. Third, in our study decision making processes related to cord blood donation were analysed following only a traditional cognitive perspective [31]. Although this kind of analysis is widely supported, new technologies, as functional magnetic resonance imaging (fMRI) or positron emission tomography (PET), are increasingly being utilised in the field of cognitive neuroscience to view how the human brain works when a moral decision (e.g., charitable donation) has to be taken [32–36]. All the above issues could be considered in future investigations.

Finally, additional studies need to be developed to address the broader issue of clinical decision making of hematologists choosing cord blood or bone marrow as their preferred choice for the treatment of their patients and the decision making of transplant recipients with regard to the different sources of hematopoietic progenitors.

Such future studies could extend our knowledge to the entire process of therapeutic use of hemopoietic stem cells.

5. Conflicts of interest

None declared.

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