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KNOWLEDGE & SOURCES UMBILICAL CORD BLOOD DONATION

Manuscript Title

KNOWLEDGE AND SOURCES OF INFORMATION ON UMBILICAL CORD BLOOD DONATION IN PREGNANT WOMEN

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Abstract

Background: The use of umbilical cord blood (UCB) holds promise for the treatment of a wide spectrum of diseases. However, information on UCB donation is not widespread or accurate among expectant women. The aim of this study is to evaluate pregnant women's knowledge of UCB donation, their main sources of information and their satisfaction with the knowledge possessed.

Material and Methods: Women (N=375) in the last semester of pregnancy completed questionnaires evaluating sociodemographics, knowledge of UCB donation, past donation, sources of information, satisfaction with the information and the desire to have received more information.

Results: Women were aware of the possibility of donating UCB (97.5%) although, on average, they reported not having enough knowledge of donation possibilities, procedures to be followed and uses of UCB (2.51, on a 5-point scale). Considering knowledge satisfaction, 28% were not at all satisfied. Only 2.8% felt fully prepared and the great majority (75,2%) would have liked to have received more information. The main source of information was the Internet (51.2%). Gynecologists and midwives were indicated by only 24.4% and 18.6% of women, respectively. Age and education were significantly correlated with UCB knowledge. Chi-square tests evidenced that those who reported professional sources of information (gynecologists, obstetricians, prenatal courses) did not need additional information. Conversely, mothers who turned to other mothers for information were more likely to desire further information.

Conclusion: Most mothers report the Internet as the main source of information. Providing accurate information through official sources may result in a more positive attitude toward donation.

Keywords

Umbilical cord blood (UCB), donation, cord blood donation, pregnant women, public cord blood banking.

Significance

There is a lack of clarity and consistency in the information on UCB donation provided to parents, and parents' knowledge of cord blood banking is poor.

Expectant mothers used the Internet as their main source of information about UCB donation. In only a few cases, information about the possibility of UCB donation was provided by health providers or within prenatal courses. In these latter cases, women did not need additional information, indicating that the information received was probably complete or that women trusted these sources more than nonprofessional sources. Providing medical health staff with trainings about UCB donation and banking may result in more accurate and satisfying information for expectant parents.

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Acknowledgments

We are grateful to the pregnant women who participated in this survey.

Knowledge and Sources of Umbilical Cord Blood Donation in Pregnant Women

Objectives

The use of umbilical cord blood (UCB) as a source of transplantable hematopoietic stem cells has received much attention in the past several decades (Danzer et al., 2003) following the increase in hematologic diseases, primary immunodeficiencies, and metabolic diseases that can be treated with hematopoietic stem cells (Bhandari et al., 2017; Danzer et al., 2003; Fox et al., 2007; Katz et al., 2011). UCB is considered an important alternative source to bone marrow transplantation especially in the case of imperfect compatibility. Additionally, its recent use as a source of red blood cell transfusion in neonatology (Bianchi et al., 2018; Harris, 2009), in regenerative medicine and in clinical studies holds promise for the treatment of a wide variety of diseases (Biazar, 2014).

Two options for storing cord blood are available. Cord blood can be collected in public banks that are available to anyone who might be compatible (allogenic) or stored in private banks for potential personal (autologous) use later in life by the child or a family member. However, the main blood and marrow transplantation societies discourage this latter option, since the need for personal use rarely occurs and since scientific evidence for the use of autologous cord blood is limited (Ballen, 2010). Thus, European and US professional organization strongly advocate for the donation of UCB in public institutions (Shearer et al., 2017).

Currently, the establishment of private banks is prohibited in Italy (Zeuner et al., 2013); however, since 2007, parents have the right to export and store cord blood in private banks in countries outside of Italy. This has led to an increasing number of women requiring collection for autologous use (Capone et al., 2011). Concurrently, from 2007 to 2016, the number of cord blood units donated to public banks has decreased significantly (ALLIS,

2017), despite the presence of 320 birth points through the country where it is possible to donate (Pupella et al., 2017). This decrease has been attributed first to new regulations established in 2012, by the National Blood Center and the National Transplant Center with the agreement of the Italian Cord Blood Network and the Italian Bone Marrow Donor Registry. These regulations required that in order to be stored, the unit must contain a higher number of hematopoietic cells. Second, this decrease has been ascribed to the successful use of hematopoietic stem cells from haploidentical donors as an alternative to UCB transplantation (Pupella et al., 2017).

Studies conducted in different countries report that pregnant women do not have enough information about the donation and storage of UCB and the differences between private and public banks; furthermore, studies have shown that women do not receive accurate information from health care professionals, such as gynecologists and obstetricians. For example, a Canadian study conducted in 2003 on 650 pregnant women, found that as many as 70% did not have sufficient knowledge about the donation of UCB, even if 69% of them were willing to donate for solidarity purposes (Fernandez et al., 2003). A 2011 multicenter study of 1,785 pregnant women in five European countries (France, Germany, Italy, Spain, England) showed that the majority of respondents (79%) were willing to donate to public banks. However, at the same time, participants claimed to be poorly informed on the uses and methods of UCB donation. Major information sources for UCB donation were the media and the Internet (56%), and only 26% of women were informed by their obstetrician or their gynecologist (Bhandari et al., 2017). A recent review of the literature showed a lack of clarity and consistency in the information provided to parents and that parents' knowledge of cord blood banking is poor overall (Peberdy et al., 2018).

Educational and age differences in knowledge and in intentions to donate have also been reported. A study conducted in 2014 in Australia, in public and private maternity wards,

showed that very young women, those with a low level of education, and those from different ethnic backgrounds were less inclined to donate (Jordens et al., 2014). Consistently, a recent study conducted in 2016 by Bhandari and colleagues (Bhandari et al., 2017) in the USA, found that respondents with higher education were more aware of UCB collection, and the authors report lower rates of donation (58%) among women younger than 30 years of age without a college education. Finally, in the previously cited review, lower education, ethnic minority background, and age of 25 years or younger were associated with less awareness of banking and donation (Peberdy et al., 2018).

In Italy, as in other countries, knowledge among pregnant women of matters related to UCB seems to be scarce. A study conducted in 2012 (Screnci et al., 2012) showed that women had very little knowledge about UCB banking, its usefulness and the difference between private and public banks. In contrast to women in other countries, however, Italian women reported having obtained information about UCB donation primarily from gynecologists and midwives and not from the Internet, as reported in other countries (Ginori et al., 2015). However, in these studies, the women were generally recruited in the waiting areas of hospitals before the beginning of meetings specifically focused on UCB or during antenatal monitoring visits. These women might be more interested in cord blood donation and it is possible that they were more inclined to ask for information from health professionals than were pregnant women in the general population. In other cases, the studies were retrospectively conducted. Moreover, educational level and age, which previous studies reported to be associated with the knowledge that participants have on UCB, were not explored in these studies. There are no studies that target expectant mothers in the general population and that evaluate whether the desire to receive more information differs depending on the sources of information consulted.

In line with this premise, the aim of the present study is to evaluate knowledge of UCB donation among Italian pregnant women in the general population, as well as its possible uses, the procedures to be followed for donating, and the main sources of information consulted. We also aimed to evaluate the extent to which pregnant women in the general population were satisfied with the knowledge they had about UCB donation, whether this was correlated with age and educational level and, finally, whether the desire to receive more information differed depending on the sources of information consulted. It is possible that women who obtained information about UCB donation from official sources are more satisfied and do not need further information. Knowing the main sources of information reported by women and the extent to which women are satisfied with the level of information received by these sources, may help clinicians design interventions aimed at increasing women's knowledge of UCB and the quality of the information.

Methods

Participants

The participants were 365 pregnant women in the third trimester of pregnancy (7^{th}-10^{th} month), directly and opportunistically recruited through a variety of means, including private maternity centers, schools, family associations, and cultural and sporting associations in the center of Italy. To be included in the study, women had to be in the third trimester of pregnancy and be fluent in Italian.

All participants took part on a voluntary basis and were not remunerated.

Procedures

To recruit participants, two master's level students went to different centers attended by pregnant women. After explaining the aims of the research, they asked the women to sign an

informed consent form. Each woman received an information sheet explaining the general aims of the study. They were required to provide an e-mail address and a phone number for further contact. In a second phase, and within a week from the first contact, an email with more complete information about the study and the link to a questionnaire was sent to them. At the same time, a personal code was sent to their mobile phone. Only through this code did women have access to the online questionnaire. The study was approved by the Institutional Review Board of the Psychology Department, Sapienza University of Rome.

Materials

To explore women's knowledge of the donation and storage of UCB, a questionnaire was specifically developed for this study. The construction of the questionnaire was based on previous meetings conducted with expectant mothers and on the analysis of the literature. To ensure understandability of the questionnaire, a pilot version of the questionnaire was administered to 30 expectant mothers who were not asked to complete the final questionnaire later. Following the pilot version, small changes in the phrasing of two questions were made.

Participants accessed the survey through SurveyMonkey®, an online provider. The questionnaire, in addition to sociodemographic information (age, parity, current relationship, education level of expectant mother and father, nationality), included a question evaluating potential illnesses precluding UCB donation (e.g. autoimmune diseases, infectious diseases, etc.), a question evaluating whether the women were aware of the possibility of donating or conserving UCB, and a question evaluating past donation/storage (yes/no). All of these questions were answered on a dichotomous scale (yes/no).

Knowledge of UCB donation and storage was evaluated through 3 items that specifically captured women's awareness of the possibility of donating, their knowledge of the procedures to be followed for donating, and their knowledge on the possible uses of UCB.

An example item was “Do you think you have enough information about the possible uses of UCB in the medical and research fields?” Answers were reported on a 5-point scale ranging from (1) “not at all” to (5) “completely”. The alpha coefficient for these three items was 0.92.

The degree of satisfaction regarding the level of knowledge possessed was assessed with the following item: "In general, are you satisfied with your knowledge regarding the donation and storage of UCB?" The 5-point response scale range from (1) “not at all” to (5) “completely”. Participants were asked if they would have liked to receive more information regarding UCB donation and storage. These questions were answered on a dichotomous scale (yes/no).

Finally, sources of information were evaluated through one item: “Which of the following were your sources of information?” Women were given the possibility of indicating more than one option from a list of different sources of information (e.g.. gynecologist, obstetrician, friends, Internet, prenatal course, informative material, etc.). The questionnaire is presented in Appendix 1.

Statistical Analyses

Prior to the analysis, 11 participants with pathologies that precluded the donation of UCB were eliminated from the analysis, which left a final sample of 365 participants. Analyses of the frequencies and Pearson’s correlations were calculated. Chi-square tests were conducted to evaluate whether there were differences in the desire to have additional information depending on the source of information used. Analyses were run with the statistical software IBM Statistics SPSS version 25. Tests were considered statistically significant if $p<.05$.

Results

Age, parity, months of gestation, current relationship, and education of the expectant mother and father are reported in Table 1. The vast majority of respondents were of Italian nationality (96.1%), followed by Romanian (1.4%), and other nationalities (2.5%).

Almost all the women reported being aware of the possibility of donating or conserving UCB (97.5%) and only 2.8% had previously donated UCB.

Although the percentage of women stating that they were aware of the possibility of donating UCB was very high, when women were asked more specifically about the knowledge they had of the possibility of donating, the procedures to be followed for donating, and the possible uses of UCB in the medical and research fields, the results showed a mean of 2.51 (SD=0.88) on a scale of 5 points, indicating a low level of knowledge of donation, procedures and possible uses of UCB. Indeed, as shown in Table 2, the degree of women's satisfaction with the level of knowledge possessed was quite low, with 28% of them reporting no satisfaction at all and with only 2.8% of women considering themselves completely prepared for UCB donation. In line with these results, the great majority (75,2%) of women reported that they would have liked to receive more information about UCB donation and storage.

Sources of information are reported in Table 3. More than half of the sample (51.2%) indicated that the Internet was a source of information, followed by prenatal classes (32.3%) and informational materials (30.7%). Gynecologists and midwives were indicated as sources of information only by 24.4% and 18.6% of women, respectively. Other mothers and family/friends were indicated in 14% and 11.2% of the cases, respectively.

Correlations among the variables considered are reported in Table 4. Age ($r=0.15$, $p=0.005$) and years of education ($r=0.15$, $p= 0.004$) of the mothers were positively correlated

with their knowledge of the possibility of donating, the procedures to be followed for donating, and their knowledge of the possible uses of UCB. Partial correlations were also calculated with adjustments made for previous children. The results remain substantially identical (age r=0.15, p=0.002; years of education r=0.15, p< 0.001).

Considering the role of past donations (only for those who had other children; N=145), years of education of the mother (r=0.19, p=0.020) and of the father (r=0.17, p=0.042) were positively correlated with having donated UCB in the past.

Knowledge of the possibility of donating, the procedures and the possible uses of UCB were highly correlated with satisfaction with the level of knowledge (r=0.88, p=0.001), with no desire to have received additional information about UCB donation (r=0.49, p=0.001) and with having donated UCB in the past (r=0.30, p=0.001). Satisfaction with the level of knowledge was positively correlated with having no desire to receive additional information (r=0.54, p=0.001), and with having donated UCB in the past (r=0.31, p=0.001).

Considering each source of information, chi-square tests were performed comparing those who reported having searched information through a specific source to those who reported not needing more information. The results of all chi-square tests are reported in Table 5. The findings showed that expectant mothers who acknowledged gynecologists as a source of information were more likely to report that they did not desire additional information [X^2 =16.24, p <.01]. Similar results were obtained for those who acknowledged the obstetricians [X^2=12.08, p =.001] and the prenatal courses [X^2=13.86, p <.01] as sources of information. Conversely, expectant mothers who acknowledged other mothers as a source were more likely to desire more information [X^2=6,82 p =.009]. No other significant differences emerged for the other sources of information (Internet, information material, friends/family, mass media).

Discussion

The aim of the present study was to evaluate the knowledge that pregnant women reported of UCB donation, the procedures to be followed for donating, the possible uses of UCB in the medical and research fields, and their level of satisfaction with this information. We were interested in evaluating whether women's knowledge was correlated with their educational level and age. Finally, the study aimed to evaluate the information sources most frequently consulted and how the level of satisfaction changes based on the type of source consulted.

The findings from the present study show that the majority of women were aware of the possibility of UCB donation; however, when asked about the knowledge they possessed, the procedures to be followed for donating, and the possible uses of UCB in the medical and research fields, they reported, on average, not having enough knowledge, with the great majority of them stating that they would have liked to have received more information about UCB donation and storage. Similarly, the study by Jordens et al. (2014) conducted in Australia, found that despite being aware of the existence of the UCB banks, 70.7% of pregnant women did not possess specific knowledge of the potential uses of cord blood, with the great majority of them (93.1%) expressing the desire to be informed about UCB banking (Jordens et al., 2014). Overall, these findings seem consistent with the review of Peberdy, in which awareness of cord blood banking was found to be higher than knowledge (Peberdy et al., 2018).

It has been previously observed that a lack of knowledge can lead to negative emotional states and fears regarding potential unethical or nonlegitimate uses of UCB, which, in turn, may hinder choices related to donation (Danzer et al., 2003). Conversely, a small amount of basic information may lead women who are undecided to become more likely to

donate. Indeed, in the previously mentioned study on Australian women, the percentage of women willing to donate doubled, going from 30% to 67.7%, after they were informed by hospital maternity staff about the importance of the donation of UCB (Jordens et al., 2014). Further studies are necessary regarding the potential utility of giving this information to mothers.

Our findings are also consistent with those of other studies previously conducted in Italy reporting similar percentages of pregnant women who were not satisfied with the information they had on the donation and storage of UCB (69%) (Screnci et al., 2012). However, in contrast to these Italian studies, women in our study stated that the information on UCB they possessed was largely obtained from the Internet and rarely from health providers or prenatal courses. This may be due to the different samples in those studies. In fact, it is possible that women recruited in hospitals before participating in meetings specifically focused on UCB or during antenatal monitoring may be more prone to say that they would seek information on UCB from health professionals than would women recruited outside medical settings, as is the case in our sample. Another possible explanation is that the use of the Internet has become more widespread in recent years, leading more women to search for information through this resource.

However, information obtained through the Internet may be incomplete, unclear, and not always independent. Interestingly, the chi-square statistics in our study evidenced that the few expectant mothers who referred to gynecologists, obstetricians and prenatal courses to obtain information about UCB were more likely to state that they did not need additional information, indicating that the information received was probably complete or that they trusted these sources more than the others examined in the present study. Conversely, those who referred to other mothers were more likely to state that they wished to have received more information. It is also possible that parents do not turn to professional sources for

answers about UCB when they do not receive adequate information from their health providers. Indeed, a study conducted in the USA, has recently shown that pediatric providers rarely inform parents about UCB donation and storage, and may themselves benefit from further education on this matter (Armstrong et al., 2018). Providing medical health staff with more training about UCB donation and storage may also result in more accurate and satisfying information for expectant parents. As suggested by Peberdy's study, information on cord blood banking and donation should be incorporated as a regular intervention in antenatal care and education (Peberdy et al., 2018).

Age and years of education of the mother were positively correlated with knowledge of the possibility of donating, the procedures to be followed for donating, and information on the possible uses of UCB, even after adjustments were made for the presence of previous children. This is consistent with previous findings reporting that undecided women and those who were unaware of UCB donation were younger and less educated (Jordens et al., 2014; Peberdy et al., 2018). Similarly, other studies have found that the level of education was positively correlated with the degree of knowledge of UCB (Ozturk et al., 2017). Future interventions may specifically target young and less educated expectant mothers.

Finally, some limitations of the study need to be acknowledged. First, only expectant mothers were surveyed about UCB knowledge and satisfaction. It would also be of interest to survey expectant fathers since decisions on UCB donation are generally made by the parental couple. In our study, we only asked mothers to report on sociodemographic data of their partners. We also found that father's education was related to having donated in the past, thus supporting the idea that the role of both parents needs to be investigated.

Second, expectant mothers in the present sample volunteered to participate. Participants in a convenience sample may have a different opinion from individuals who are not available and thus may not be representative of the population. Therefore, the results

should be interpreted with some caution, and the generalization of these findings requires additional studies on representative samples.

Finally, another limitation concerns the absence of long-term behavioral outcome data. Future studies may analyze whether enhanced knowledge about UCB donation and procedures may lead to an increase in donation rates.

Despite the previously acknowledged limitations, the results of the present study further sustain that Italian women are in large part not satisfied with the information about UCB donation and storage. In contrast to the findings of previous Italian studies, this study found that this information is mainly found on the Internet by the individuals themselves and that only a small proportion of individuals obtain this information from health providers. However, the findings of the present study are encouraging, as they indicate that when women obtained information on UCB from professionals, they did not need to search for additional information. Professionals in the health sector and institutions should strengthen efforts to disseminate information and promote educational campaigns on the donation and storage of UCB. Providing more precise information about UCB may result in increased satisfaction with UCB knowledge and may possibly improve expectant parents' attitudes toward cord blood donation.

Conflict of interest

The authors declare no conflicts of interest.

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This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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Abstract

Background: The use of umbilical cord blood (UCB) holds promise for the treatment of a wide spectrum of diseases. However, information on UCB donation is not widespread or accurate among expectant women. The aim of this study is to evaluate pregnant women's

knowledge of UCB donation, their main sources of information and their satisfaction with the knowledge possessed.

Material and Methods: Women (N=375) in the last semester of pregnancy completed questionnaires evaluating sociodemographics, knowledge of UCB donation, past donation, sources of information, satisfaction with the information and the desire to have received more information.

Results: Women were aware of the possibility of donating UCB (97.5%) although, on average, they reported not having enough knowledge of donation possibilities, procedures to be followed and uses of UCB (2.51, on a 5-point scale). Considering knowledge satisfaction, 28% were not at all satisfied. Only 2.8% felt fully prepared and the great majority (75,2%) would have liked to have received more information. The main source of information was the Internet (51.2%). Gynecologists and midwives were indicated by only 24.4% and 18.6% of women, respectively. Age and education were significantly correlated with UCB knowledge. Chi-square tests evidenced that those who reported professional sources of information (gynecologists, obstetricians, prenatal courses) did not need additional information. Conversely, mothers who turned to other mothers for information were more likely to desire further information.

Conclusion: Most mothers report the Internet as the main source of information. Providing accurate information through official sources may result in a more positive attitude toward donation.

Keywords

Umbilical cord blood (UCB), donation, cord blood donation, pregnant women, public cord blood banking.

Significance

There is a lack of clarity and consistency in the information on UCB donation provided to parents, and parents' knowledge of cord blood banking is poor.

Expectant mothers used the Internet as their main source of information about UCB donation. In only a few cases, information about the possibility of UCB donation was provided by health providers or within prenatal courses. In these latter cases, women did not need additional information, indicating that the information received was probably complete or that women trusted these sources more than nonprofessional sources. Providing medical health staff with trainings about UCB donation and banking may result in more accurate and satisfying information for expectant parents.

Acknowledgments

We are grateful to the pregnant women who participated in this survey.

Knowledge and Sources of Umbilical Cord Blood Donation in Pregnant Women

Objectives

The use of umbilical cord blood (UCB) as a source of transplantable hematopoietic stem cells has received much attention in the past several decades (Danzer et al., 2003) following the increase in hematologic diseases, primary immunodeficiencies, and metabolic diseases that can be treated with hematopoietic stem cells (Bhandari et al., 2017; Danzer et al., 2003; Fox et al., 2007; Katz et al., 2011). UCB is considered an important alternative source to bone marrow transplantation especially in the case of imperfect compatibility. Additionally, its recent use as a source of red blood cell transfusion in neonatology (Bianchi et al., 2018; Harris, 2009), in regenerative medicine and in clinical studies holds promise for the treatment of a wide variety of diseases (Biazar, 2014).

Two options for storing cord blood are available. Cord blood can be collected in public banks that are available to anyone who might be compatible (allogenic) or stored in private banks for potential personal (autologous) use later in life by the child or a family member. However, the main blood and marrow transplantation societies discourage this latter option, since the need for personal use rarely occurs and since scientific evidence for the use of autologous cord blood is limited (Ballen, 2010). Thus, European and US professional organization strongly advocate for the donation of UCB in public institutions (Shearer et al., 2017).

Currently, the establishment of private banks is prohibited in Italy (Zeuner et al., 2013); however, since 2007, parents have the right to export and store cord blood in private banks in countries outside of Italy. This has led to an increasing number of women requiring collection for autologous use (Capone et al., 2011). Concurrently, from 2007 to 2016, the number of cord blood units donated to public banks has decreased significantly (ALLIS, 2017), despite the presence of 320 birth points through the country where it is possible to

donate (Pupella et al., 2017). This decrease has been attributed first to new regulations established in 2012, by the National Blood Center and the National Transplant Center with the agreement of the Italian Cord Blood Network and the Italian Bone Marrow Donor Registry. These regulations required that in order to be stored, the unit must contain a higher number of hematopoietic cells. Second, this decrease has been ascribed to the successful use of hematopoietic stem cells from haploidentical donors as an alternative to UCB transplantation (Pupella et al., 2017).

Studies conducted in different countries report that pregnant women do not have enough information about the donation and storage of UCB and the differences between private and public banks; furthermore, studies have shown that women do not receive accurate information from health care professionals, such as gynecologists and obstetricians. For example, a Canadian study conducted in 2003 on 650 pregnant women, found that as many as 70% did not have sufficient knowledge about the donation of UCB, even if 69% of them were willing to donate for solidarity purposes (Fernandez et al., 2003). A 2011 multicenter study of 1,785 pregnant women in five European countries (France, Germany, Italy, Spain, England) showed that the majority of respondents (79%) were willing to donate to public banks. However, at the same time, participants claimed to be poorly informed on the uses and methods of UCB donation. Major information sources for UCB donation were the media and the Internet (56%), and only 26% of women were informed by their obstetrician or their gynecologist (Bhandari et al., 2017). A recent review of the literature showed a lack of clarity and consistency in the information provided to parents and that parents' knowledge of cord blood banking is poor overall (Peberdy et al., 2018).

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ethnic backgrounds were less inclined to donate (Jordens et al., 2014). Consistently, a recent study conducted in 2016 by Bhandari and colleagues (Bhandari et al., 2017) in the USA, found that respondents with higher education were more aware of UCB collection, and the authors report lower rates of donation (58%) among women younger than 30 years of age without a college education. Finally, in the previously cited review, lower education, ethnic minority background, and age of 25 years or younger were associated with less awareness of banking and donation (Peberdy et al., 2018).

In Italy, as in other countries, knowledge among pregnant women of matters related to UCB seems to be scarce. A study conducted in 2012 (Screnci et al., 2012) showed that women had very little knowledge about UCB banking, its usefulness and the difference between private and public banks. In contrast to women in other countries, however, Italian women reported having obtained information about UCB donation primarily from gynecologists and midwives and not from the Internet, as reported in other countries (Ginori et al., 2015). However, in these studies, the women were generally recruited in the waiting areas of hospitals before the beginning of meetings specifically focused on UCB or during antenatal monitoring visits. These women might be more interested in cord blood donation and it is possible that they were more inclined to ask for information from health professionals than were pregnant women in the general population. In other cases, the studies were retrospectively conducted. Moreover, educational level and age, which previous studies reported to be associated with the knowledge that participants have on UCB, were not explored in these studies. There are no studies that target expectant mothers in the general population and that evaluate whether the desire to receive more information differs depending on the sources of information consulted.

In line with this premise, the aim of the present study is to evaluate knowledge of UCB donation among Italian pregnant women in the general population, as well as its

possible uses, the procedures to be followed for donating, and the main sources of information consulted. We also aimed to evaluate the extent to which pregnant women in the general population were satisfied with the knowledge they had about UCB donation, whether this was correlated with age and educational level and, finally, whether the desire to receive more information differed depending on the sources of information consulted. It is possible that women who obtained information about UCB donation from official sources are more satisfied and do not need further information. Knowing the main sources of information reported by women and the extent to which women are satisfied with the level of information received by these sources, may help clinicians design interventions aimed at increasing women's knowledge of UCB and the quality of the information.

Methods

Participants

The participants were 365 pregnant women in the third trimester of pregnancy (7^{th}-10^{th} month), directly and opportunistically recruited through a variety of means, including private maternity centers, schools, family associations, and cultural and sporting associations in the center of Italy. To be included in the study, women had to be in the third trimester of pregnancy and be fluent in Italian.

All participants took part on a voluntary basis and were not remunerated.

Procedures

To recruit participants, two master's level students went to different centers attended by pregnant women. After explaining the aims of the research, they asked the women to sign an informed consent form. Each woman received an information sheet explaining the general aims of the study. They were required to provide an e-mail address and a phone number for

further contact. In a second phase, and within a week from the first contact, an email with more complete information about the study and the link to a questionnaire was sent to them. At the same time, a personal code was sent to their mobile phone. Only through this code did women have access to the online questionnaire. The study was approved by the Institutional Review Board of the Psychology Department, Sapienza University of Rome.

Materials

To explore women's knowledge of the donation and storage of UCB, a questionnaire was specifically developed for this study. The construction of the questionnaire was based on previous meetings conducted with expectant mothers and on the analysis of the literature. To ensure understandability of the questionnaire, a pilot version of the questionnaire was administered to 30 expectant mothers who were not asked to complete the final questionnaire later. Following the pilot version, small changes in the phrasing of two questions were made.

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Knowledge of UCB donation and storage was evaluated through 3 items that specifically captured women's awareness of the possibility of donating, their knowledge of the procedures to be followed for donating, and their knowledge on the possible uses of UCB. An example item was "Do you think you have enough information about the possible uses of

UCB in the medical and research fields?" Answers were reported on a 5-point scale ranging from (1) "not at all" to (5) "completely". The alpha coefficient for these three items was 0.92.

The degree of satisfaction regarding the level of knowledge possessed was assessed with the following item: "In general, are you satisfied with your knowledge regarding the donation and storage of UCB?" The 5-point response scale range from (1) "not at all" to (5) "completely". Participants were asked if they would have liked to receive more information regarding UCB donation and storage. These questions were answered on a dichotomous scale (yes/no).

Finally, sources of information were evaluated through one item: "Which of the following were your sources of information?" Women were given the possibility of indicating more than one option from a list of different sources of information (e.g.. gynecologist, obstetrician, friends, Internet, prenatal course, informative material, etc.). The questionnaire is presented in Appendix 1.

Statistical Analyses

Prior to the analysis, 11 participants with pathologies that precluded the donation of UCB were eliminated from the analysis, which left a final sample of 365 participants. Analyses of the frequencies and Pearson's correlations were calculated. Chi-square tests were conducted to evaluate whether there were differences in the desire to have additional information depending on the source of information used. Analyses were run with the statistical software IBM Statistics SPSS version 25. Tests were considered statistically significant if $p<.05$.

Results

Age, parity, months of gestation, current relationship, and education of the expectant mother and father are reported in Table 1. The vast majority of respondents were of Italian nationality (96.1%), followed by Romanian (1.4%), and other nationalities (2.5%).

Almost all the women reported being aware of the possibility of donating or conserving UCB (97.5%) and only 2.8% had previously donated UCB.

Although the percentage of women stating that they were aware of the possibility of donating UCB was very high, when women were asked more specifically about the knowledge they had of the possibility of donating, the procedures to be followed for donating, and the possible uses of UCB in the medical and research fields, the results showed a mean of 2.51 (SD=0.88) on a scale of 5 points, indicating a low level of knowledge of donation, procedures and possible uses of UCB. Indeed, as shown in Table 2, the degree of women's satisfaction with the level of knowledge possessed was quite low, with 28% of them reporting no satisfaction at all and with only 2.8% of women considering themselves completely prepared for UCB donation. In line with these results, the great majority (75,2%) of women reported that they would have liked to receive more information about UCB donation and storage.

Sources of information are reported in Table 3. More than half of the sample (51.2%) indicated that the Internet was a source of information, followed by prenatal classes (32.3%) and informational materials (30.7%). Gynecologists and midwives were indicated as sources of information only by 24.4% and 18.6% of women, respectively. Other mothers and family/friends were indicated in 14% and 11.2% of the cases, respectively.

Correlations among the variables considered are reported in Table 4. Age ($r=0.15$, $p=0.005$) and years of education ($r=0.15$, $p= 0.004$) of the mothers were positively correlated with their knowledge of the possibility of donating, the procedures to be followed for

donating, and their knowledge of the possible uses of UCB. Partial correlations were also calculated with adjustments made for previous children. The results remain substantially identical (age r=0.15, p=0.002; years of education r=0.15, p< 0.001).

Considering the role of past donations (only for those who had other children; N=145), years of education of the mother (r=0.19, p=0.020) and of the father (r=0.17, p=0.042) were positively correlated with having donated UCB in the past.

Knowledge of the possibility of donating, the procedures and the possible uses of UCB were highly correlated with satisfaction with the level of knowledge (r=0.88, p=0.001), with no desire to have received additional information about UCB donation (r=0.49, p=0.001) and with having donated UCB in the past (r=0.30, p=0.001). Satisfaction with the level of knowledge was positively correlated with having no desire to receive additional information (r=0.54, p=0.001), and with having donated UCB in the past (r=0.31, p=0.001).

Considering each source of information, chi-square tests were performed comparing those who reported having searched information through a specific source to those who reported not needing more information. The results of all chi-square tests are reported in Table 5. The findings showed that expectant mothers who acknowledged gynecologists as a source of information were more likely to report that they did not desire additional information [X^2 =16.24, p <.01]. Similar results were obtained for those who acknowledged the obstetricians [X^2=12.08, p =.001] and the prenatal courses [X^2=13.86, p <.01] as sources of information. Conversely, expectant mothers who acknowledged other mothers as a source were more likely to desire more information [X^2=6,82 p =.009]. No other significant differences emerged for the other sources of information (Internet, information material, friends/family, mass media).

Discussion

The aim of the present study was to evaluate the knowledge that pregnant women reported of UCB donation, the procedures to be followed for donating, the possible uses of UCB in the medical and research fields, and their level of satisfaction with this information. We were interested in evaluating whether women's knowledge was correlated with their educational level and age. Finally, the study aimed to evaluate the information sources most frequently consulted and how the level of satisfaction changes based on the type of source consulted.

The findings from the present study show that the majority of women were aware of the possibility of UCB donation; however, when asked about the knowledge they possessed, the procedures to be followed for donating, and the possible uses of UCB in the medical and research fields, they reported, on average, not having enough knowledge, with the great majority of them stating that they would have liked to have received more information about UCB donation and storage. Similarly, the study by Jordens et al. (2014) conducted in Australia, found that despite being aware of the existence of the UCB banks, 70.7% of pregnant women did not possess specific knowledge of the potential uses of cord blood, with the great majority of them (93.1%) expressing the desire to be informed about UCB banking (Jordens et al., 2014). Overall, these findings seem consistent with the review of Peberdy, in which awareness of cord blood banking was found to be higher than knowledge (Peberdy et al., 2018).

It has been previously observed that a lack of knowledge can lead to negative emotional states and fears regarding potential unethical or nonlegitimate uses of UCB, which, in turn, may hinder choices related to donation (Danzer et al., 2003). Conversely, a small amount of basic information may lead women who are undecided to become more likely to donate. Indeed, in the previously mentioned study on Australian women, the percentage of

women willing to donate doubled, going from 30% to 67.7%, after they were informed by hospital maternity staff about the importance of the donation of UCB (Jordens et al., 2014). Further studies are necessary regarding the potential utility of giving this information to mothers.

Our findings are also consistent with those of other studies previously conducted in Italy reporting similar percentages of pregnant women who were not satisfied with the information they had on the donation and storage of UCB (69%) (Screnci et al., 2012). However, in contrast to these Italian studies, women in our study stated that the information on UCB they possessed was largely obtained from the Internet and rarely from health providers or prenatal courses. This may be due to the different samples in those studies. In fact, it is possible that women recruited in hospitals before participating in meetings specifically focused on UCB or during antenatal monitoring may be more prone to say that they would seek information on UCB from health professionals than would women recruited outside medical settings, as is the case in our sample. Another possible explanation is that the use of the Internet has become more widespread in recent years, leading more women to search for information through this resource.

However, information obtained through the Internet may be incomplete, unclear, and not always independent. Interestingly, the chi-square statistics in our study evidenced that the few expectant mothers who referred to gynecologists, obstetricians and prenatal courses to obtain information about UCB were more likely to state that they did not need additional information, indicating that the information received was probably complete or that they trusted these sources more than the others examined in the present study. Conversely, those who referred to other mothers were more likely to state that they wished to have received more information. It is also possible that parents do not turn to professional sources for answers about UCB when they do not receive adequate information from their health

providers. Indeed, a study conducted in the USA, has recently shown that pediatric providers rarely inform parents about UCB donation and storage, and may themselves benefit from further education on this matter (Armstrong et al., 2018). Providing medical health staff with more training about UCB donation and storage may also result in more accurate and satisfying information for expectant parents. As suggested by Peberdy's study, information on cord blood banking and donation should be incorporated as a regular intervention in antenatal care and education (Peberdy et al., 2018).

Age and years of education of the mother were positively correlated with knowledge of the possibility of donating, the procedures to be followed for donating, and information on the possible uses of UCB, even after adjustments were made for the presence of previous children. This is consistent with previous findings reporting that undecided women and those who were unaware of UCB donation were younger and less educated (Jordens et al., 2014; Peberdy et al., 2018). Similarly, other studies have found that the level of education was positively correlated with the degree of knowledge of UCB (Ozturk et al., 2017). Future interventions may specifically target young and less educated expectant mothers.

Finally, some limitations of the study need to be acknowledged. First, only expectant mothers were surveyed about UCB knowledge and satisfaction. It would also be of interest to survey expectant fathers since decisions on UCB donation are generally made by the parental couple. In our study, we only asked mothers to report on sociodemographic data of their partners. We also found that father's education was related to having donated in the past, thus supporting the idea that the role of both parents needs to be investigated.

Second, expectant mothers in the present sample volunteered to participate. Participants in a convenience sample may have a different opinion from individuals who are not available and thus may not be representative of the population. Therefore, the results

should be interpreted with some caution, and the generalization of these findings requires additional studies on representative samples.

Finally, another limitation concerns the absence of long-term behavioral outcome data. Future studies may analyze whether enhanced knowledge about UCB donation and procedures may lead to an increase in donation rates.

Despite the previously acknowledged limitations, the results of the present study further sustain that Italian women are in large part not satisfied with the information about UCB donation and storage. In contrast to the findings of previous Italian studies, this study found that this information is mainly found on the Internet by the individuals themselves and that only a small proportion of individuals obtain this information from health providers. However, the findings of the present study are encouraging, as they indicate that when women obtained information on UCB from professionals, they did not need to search for additional information. Professionals in the health sector and institutions should strengthen efforts to disseminate information and promote educational campaigns on the donation and storage of UCB. Providing more precise information about UCB may result in increased satisfaction with UCB knowledge and may possibly improve expectant parents' attitudes toward cord blood donation.

Conflict of interest

The authors declare no conflicts of interest.

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Table 1. Sociodemographic characteristics

	N=365
Age (years): Mean (SD)	33.22 (4.19)
Education (years): Mean (SD)	
Mother	14.2 (3.58)
Father	13.0 (3.71)
Parity (%)	
Nulliparous	75.6
Primiparous/multiparous	24.4
Months of gestation (%)	
Seventh	28.2
Eighth	39.2
Ninth	31.8
Tenth	0.8
Current relationship (%)	
Married	55.1
Cohabitant	40.8
Have a partner (not cohabitant)	4.1

Table 2. Degree of women's satisfaction with the level of knowledge about UCB donation

	N=365
Level of satisfaction (%)	
Not at all	28.0
Slightly	31.6
Moderately	31.0
Very	6.6
Completely	2.8
Previous donations (%)	
Yes	2.8
No	97.2

Table 3. Sources of information about UCB donation

Percentages* N=365	
Internet	51.2
Prenatal course	32.3
Information material	30.7
Gynecologist	24.4
Midwife	18.6
Other mothers	14.0
Friends/family	11.2
Mass-media	10.4
Nobody	2.5
Partner	1.9
Other sources	4.12

*Women could indicate more than one source

Table 4. Correlations among all the variables considered

	1	2	3	4	5	6	7
1. Age	-						
2. Years of education	.33**	-					
3. Partners' years of education	.28**	.43**	-				
4. Knowledge of the donation	.15**	.15**	.05	-			
5. Satisfaction with the knowledge	.07	.10*	.04	.88**	-		
6. Desired more information	-.01	-.071	-.10	.49**	.54**	-	
7. Past donations (N†=)145	.05	.19*	.17*	.30**	.31**	.11	-

**. The correlation is significant at 0,01 level

*. The correlation is significant at the 0,05 level

† Correlations were not calculated for nulliparous women

Table 5. Desire to have more info: Comparisons between the number of participants who reported a specific source and the number of those who did not.

	Gynecologist		Obstetrician		Prenatal course		Other mothers	
Desire to have more info	Yes	No	Yes	No	Yes	No	Yes	No
Yes								
	52	218	40	230	73	197	45	225
Standardized residuals	(-1.7)	(1.0)	(-1.6)	(0.8)	(-1.5)	(1.1)	(1.2)	(-.5)
No								
	36	53	28	61	43	46	5	84
Standardized residuals	(3.0)	(-1.7)	(2.7)	(-1.3)	(2.7)	(-1.8)	(-2.1)	(0.8)
	X^2 =16.24, p <.01		X^2 =12.08, p <.001		X^2 =13.86, p <.01		X^2 =13.86, p <.01	

*Chi-square tests are significant at p<.05