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Perspectives and Apprehensions of Healthy Individuals toward Post-Mortem Brain Donation: A Qualitative Study Across Italy

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Abstract

Obtaining post-mortem brain tissue, particularly from healthy "control" individuals, is critical for advancing research on neurological and mental disorders, which are increasingly prevalent. Despite its importance, the perspectives of healthy individuals remain largely unexplored. This study aimed to examine the attitudes, concerns, and viewpoints of potential healthy brain donors and their relatives toward post-mortem brain donation (PMBD). The study employed a convenience sampling of the general population, including twins and their non-twin contacts. Between June 2018 and February 2019, twelve focus groups were conducted in Milan, Turin, Rome, and Naples, organized by twin and non-twin status. A qualitative content analysis was carried out using both inductive and deductive approaches, complemented by analysis of emotional interactions to validate findings. One hundred and three participants, aged 49–91 years, took part, with women representing 60% of the sample. Overall awareness of PMBD was limited. Participants' willingness to donate was shaped by emotional reactions, concerns, and misunderstandings about both donation and research. Religious and spiritual beliefs, secular perspectives, trust in research and healthcare institutions, and uncertainty surrounding brain death determination were also influential. Family emerged as a complex and pivotal factor in decision-making. Notably, prior exposure to neurodegenerative diseases appeared to increase openness to brain donation. The study offers novel insights into how healthy individuals perceive PMBD. The brain was seen as uniquely significant, and the process of establishing brain death generated debate and uncertainty. Findings underscore the need for clear, targeted communication and comprehensive information to support ethical practices in brain donation. Trust in medical professionals and researchers was highlighted as essential for fostering cooperation and informed decision-making among potential donors.

Keywords: Informed consent, Brain, Healthy individuals, Decision making, Posthumous donation

Background

The collection of brain tissue plays a critical role in expanding our understanding of neurological disorders and mental illnesses [1]. However, the optimal strategies for encouraging individuals to participate in brain tissue biobanking remain unclear [2], particularly when ethical standards regarding organ procurement and human research are considered [3]. Recruitment has been challenged by a decline in post-mortem examinations due to multiple factors [1, 4–7]. While the demand for control brain tissue to support neuroscience research is significant [8, 9], enrolling healthy "control" donors presents greater challenges compared to patients. Families of individuals with neurodegenerative conditions are generally more willing to consent to donation, often wishing to honor their relative's desire to donate their brain [10–13]. Programs specifically targeting healthy control brain donations are rare, and they often rely on medico-legal autopsies, which may

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lack comprehensive clinical histories and cognitive assessments [1].

Despite these challenges, initiatives such as the Abbiategrasso Brain Bank Protocol are noteworthy. This represents the first Italian cohort study to include both healthy and diseased brain donors, integrating rich longitudinal data across clinical, lifestyle, and biological sample dimensions [14]. As the demand for brain tissue continues to grow, there is an urgent need for structured donation programs and targeted awareness campaigns to address the shortage of high-quality brain specimens and support research on increasingly prevalent neurological disorders [15].

Understanding the perspectives of healthy individuals toward post-mortem brain donation (PMBD) remains limited. Insights into motivations and cultural beliefs that either encourage or inhibit donation are essential, given that healthy individuals may serve as both potential donors and decision-makers for deceased relatives. Factors influencing consent to PMBD appear to include contextual elements and cause of death [16–18], although multiple additional influences likely shape awareness and attitudes. Most research to date has focused on patient-donor populations in specific countries, such as Australia [19, 20] and the UK [21], using heterogeneous methodologies that limit generalizability. Studies addressing healthy populations are particularly scarce and often outdated [18, 19, 22, 23].

The recent surge in publications on brain bank development reflects growing interest in this field [24]. Evidence suggests that individuals with or without neurological disorders may equally consider PMBD, highlighting the importance of exploring donation attitudes in varied scenarios [25]. Specific subgroups, such as twins, may provide particularly valuable samples. Twin studies offer a unique opportunity to disentangle genetic (‘nature’) and environmental (‘nurture’) contributions to complex traits, including neurodegenerative disorders, with twins generally representative of the broader population in social [26] and behavioral [27] characteristics.

This research forms part of a large, peer-reviewed Italian project led by the University of Milan: “Role of LSD1 in Aging-Dependent epigenetic drift leading to FrAilty-associated mood disoRders (RADAR)”. One component of this project involved a sensitization initiative aimed at increasing public awareness about PMBD in the context of Frailty [28] and Mental Health research.

The primary objective of this study was to examine attitudes and awareness regarding PMBD among healthy potential donors and/or their relatives, focusing on: (i) knowledge of PMBD and its procedures, including potential misconceptions; (ii) opinions, beliefs, and concerns about PMBD; and (iii) strategies to ethically promote PMBD among citizens.

Methods

This study employed a qualitative design using focus groups (FGs), a method well-suited for investigating attitudes, beliefs, and emerging perspectives on complex topics [29]. Given the sensitive nature of post-mortem brain donation (PMBD) and the general lack of public knowledge, in-person FG discussions led by a moderator and observed by a co-facilitator were considered the most effective approach to identify and clarify misconceptions.

A directed content analysis approach was used to examine and expand understanding of participants’ perspectives [30]. Emotional interactions during discussions were also incorporated into the analysis to enrich interpretation of the data. The study design was developed by VT and MAS. VT (principal investigator) and CC (co-investigator) created the interview guide (see Additional file 1) based on existing literature, composed of open-ended questions aligned with the objectives of the FGs, accompanied by guidelines to facilitate productive discussions. The guide was pilot-tested in an initial FG in Rome to ensure questions effectively stimulated dialogue on all targeted topics.

A structured approach to moderation and observation during each session allowed the team to provide participants with answers to their questions at the conclusion of each FG. The sampling strategy included a convenience sample of twins, followed by a purposeful recruitment of their non-twin contacts (friends, relatives, or colleagues). The sampling aimed to: (1) represent the main geographic macro-areas of Italy, recognizing that cultural, historical, and social contexts might influence opinions, beliefs, and concerns regarding PMBD, and (2) maximize participation among healthy individuals, given the limited recruitment observed during the pilot FG. Recruitment was greatly facilitated by the Italian National Twin Registry (ITR), a research infrastructure of the Italian Public Health Institute (ISS) [31]. Twin participants helped recruit most non-twin individuals, with each twin acting as an index participant to identify a non-twin friend or acquaintance, ideally of similar age and sex. To minimize potential bias related to twins' generally favorable attitudes toward scientific research [32], FGs were conducted separately for twin and non-twin participants.

FGs were organized across four Italian cities representing different geographic regions: Milan and Turin in the North, Rome in the Centre, and Naples in the South. A total of 12 FGs were conducted, stratified according to twin and non-twin status.

Recruitment

Recruitment was carried out by AA, MS, and SL. A list of potential twin participants, aged 50 years and older, both male and female, residing in Italy, was obtained from the ITR database. Twins were initially invited via email and enrolled progressively, with participation assigned according to their city of residence. To avoid influencing participants' prior knowledge or causing emotional distress, no detailed information regarding PMBD procedures or significance was provided during initial contact.

By early 2019, recruitment in certain regions required reinforcement. Consequently, the ITR Facebook page was used to promote FGs in Milan and Naples through targeted posts to enhance enrollment.

Ethical Issues and Personal Data Protection

The study received approval from the ISS Ethics Board on June 6, 2018 (Prot. N. PRE.BIO.CE.20580). Participation in the FGs, as well as the use of audio recordings and questionnaires, followed informed consent procedures in line with the ethical standards for human research outlined in the Helsinki Declaration [3]. Prior to the FGs, participants were informed about confidentiality measures and procedures for handling personal data.

At the start of each FG, participants were provided with a detailed information sheet and gave written consent. Personal data were pseudonymized and stored separately from audio recordings and questionnaires, in accordance with EU Regulation n. 679/2016 (GDPR), ensuring data quality control and allowing participants to receive follow-up information. Audio recordings were securely stored, and all names or identifiers were removed from transcripts and debriefing notes. Only aggregated, anonymized findings were presented in the project report and in this study.

To honor ethical obligations toward participants, a summary of the overall study and its general findings was sent to participants via email in June 2021. This report was specifically designed to be accessible to non-specialists, adapting scientific and technical language for lay understanding. To encourage participation in the FGs, a lottery was held at the end of each session, awarding two participants per FG with subscriptions to museums or art exhibitions. All attendees also received a USB drive as a token of appreciation.

Data collection

FGs were conducted between June 2018 and February 2019. Prior to the sessions, participants completed a self-administered socio-demographic questionnaire collecting information on age, education, offspring, spirituality, and religious beliefs. At the beginning of each FG, participants were given thorough explanations about the study objectives and procedures, and at the conclusion, they received an informational brochure on brain banking for research purposes.

An experienced researcher (CC) facilitated the FGs, while an observer (VT) recorded detailed notes capturing group dynamics, participant engagement, emotional responses, and non-verbal communication. The observer ensured that all discussion topics were addressed and recorded participants' questions, which were answered at the end of each session. Discussions encouraged participants to share any concerns, opinions, or questions regarding PMBD, fostering an informal environment that promoted openness. Each FG lasted approximately 1.5–2 hours, was audio-recorded, transcribed by SL, and subsequently checked by CC and VT for accuracy and to resolve any potential misunderstandings.

Data analysis

A directed content analysis was applied to identify themes and sub-themes from the collected data. Following the study design, themes were developed using a dual approach: deductively, drawing from existing literature, and inductively, allowing new themes and interpretative categories to emerge from the discussions. This combined strategy aimed to maximize the insights gained from the data [33] and to explore potential issues related to the sensitive topic of PMBD, which remains under-researched. FG transcripts were organized separately for twin and non-twin participants.

CC and VT created an initial coding framework, which they independently applied to the full set of transcripts to categorize data into primary themes and corresponding sub-themes. In line with the inductive approach, coding remained flexible, allowing modifications as the analysis progressed, and unique perspectives provided by individual participants were also considered. The overall analysis was supported by examining interactions within discussions, and a few categories related to emotional interactions were identified.

GG and IU independently reviewed the coding, and discrepancies in interpreting key patterns were discussed in three in-person meetings with all four researchers (CC, VT, GG, IU) until consensus was reached. Subsequently, all themes and sub-themes were refined, redundancies resolved, and final interpretations and systematization of the results were completed. SL then selected representative verbatim excerpts from the FG transcripts to illustrate the findings, which were reviewed by IU. Data management and coding were facilitated using NVivo software [34]. A 32-item checklist outlining the study procedures is provided in Additional file 2 [35].

Results

The study included 70 twins and 33 non-twin participants, aged 49 to 91 years, across 12 FGs (two participants—one in Rome, one in Naples—dropped out without providing reasons). Females represented 60% of the sample. Among participants, the proportion with a university degree ranged from 40% to 100%.

Table 1 presents the socio-demographic characteristics of each FG sub-sample, along with the percentages of participants' views regarding the significance of religion and spirituality in their lives.

Table 1. The Focus Groups plan; socio-demographic characteristics of participants and reported importance of religion and spirituality

City of Religion	Participants	Women	Men	Age Range	University degree	Offspring						
FG TWINS	N.	N.	N.	Yrs.	%	%	Yes %	No %	I don't know %	Yes %	No %	I don't know %
Rome 1	16	8	8	50–69	56	69	25	69	6	44	50	6
Rome 2	8	6	2	60–77	50	87	25	50	25	50	25	25
Milan 1	9	6	3	49–72	44	78	67	11	22	100	---	---
Naples 1	10	5	5	51–69	40	70	50	40	10	60	20	20
Naples 2	4	2	2	50–66	50	75	25	25	50	50	25	25
Turin 1 ^	11	8	3	51–90	45	54	55	36		91		
Turin 2	12	5	7	54–75	42	58	58	17	25	67	16.5	16.5
	70	40	30									
FG NON-TWINS Rome 3 §§	4	3	1	53–68	75	75	--	--	--	--	--	--
Rome 4^^	10	8	2	50–85	60	80			10	70	20	10
Milan 2	4	4	---	50–59	100	75	50	50	---	75	25	---
Naples 3^^^	6	3	3	55–69	100	83	33	50		50	17	

Turin 3	9	4	5	52–91	44	78	56	22	22	56	33	11
	33	22	11									
Tot. 12 FG	103	62	41									

§ % of participants in the FG with at least 1 child

§§ Pilot FG in which the items regarding the importance of religion and spirituality were not administered

^ 1 Missing response for Religion and Spirituality importance

^^ 9 Missing responses for Religion importance

^^^ 1 Missing response for Religion importance and 2 Missing responses for Spirituality importance

The analysis highlighted several key topics and associated themes, reinforced by participants' frequent expressions of sincerity and mutual support, particularly regarding the "role of the family" in PMBD. Additionally, group interactions revealed instances of avoidance and reluctance that emerged during discussions, especially concerning the "brain and identity" theme and the sub-theme of "the thought of death" **(Table 2)**.

Table 2. Themes and Sub-themes from Focus Group Analysis with Corresponding Key Quotes

Themes	Sub-Themes	Verbatim
Understanding of PMBD	Targeted Conditions	"I believe it's about researching growing health issues like Alzheimer's, Parkinson's, and other neurodegenerative disorders." "Supporting this research is crucial because brain diseases are deeply painful, preserving the body while stripping away one's sense of self."
	Advancement of Science	"The goal is to drive scientific progress, enhance knowledge, and ultimately improve people's quality of life." "It's about boosting research efforts, making them easier, and contributing to scientific breakthroughs."
	Organ Donation vs. PMBD	"At this stage, I see no distinction—donating for transplants saves lives now, while PMBD could save lives in the future through research." "To me, donating organs like the heart or liver feels like directly saving a life, but the brain doesn't seem to have that immediate impact."
Information Requirements	Determining Brain Death	"People often say 'brain death' marks the end, but I'm unsure if what's reported as brain death is truly final." "Is organ donation performed during an irreversible coma or only after confirmed brain death?"
	Surgical Procedures and Brain Preservation	"Taking brain tissue too late might render it useless; I'm not sure about the technical details." "I assume brain tissue needs to be preserved without damage to avoid skewed research results, but that's just my guess."
	Donor Characteristics	"I thought organs could be donated, but I assumed they needed to come from healthy people—would anyone use an 80-year-old's heart? Maybe it's not usable." "Why not donate the brain if it can help? But I wonder how useful it is if donated at an older age."
Perceptions and Concerns	Brain as a Transplant Organ	"I wouldn't agree to donating my brain for transplantation into someone else—it feels wrong; everyone should live and die with their own brain." "My tissue should only be used to treat specific diseases, not to transfer my memories or identity to another person—that's where I draw the line."
	Brain Tissue Removal While Alive	"This might sound ignorant, but could tiny amounts of brain tissue be taken from living people?"
Brain and Personal Identity	Brain as the Core of Self	"The brain is who we are—our thoughts, our essence. Can we really talk about giving away a piece of it? It's me." "The brain holds our soul, our identity—it feels even more significant than the heart."
Spirituality and Religious Beliefs	Preserving Bodily Integrity Post-Death	"Some people, due to religious beliefs, insist the body must remain whole for burial." "Does donating brain tissue affect the body's wholeness? I'm not sure."
	Questions About the Afterlife	"The real issue is: what happens after we die? That's a fundamental question."
	Evolving Religious Perspectives	"Since cremation is now accepted, religious objections to donation are less of an issue." "From a religious standpoint, the soul isn't tied to the brain, so there's no problem."

Attitudes Toward PMBD	PMBD as an Act of Generosity	“You could say, ‘I’m doing this for others’—it’s an act of love, whether donating organs for transplants or tissue for research.” “Promoting a culture of helping others, even after we’re gone, improves the lives of future generations.”
	Practical Perspective	“We benefit daily from past contributions, so if we can support research that helps in ways we can’t yet predict, we should.” “We should all feel a duty to contribute to research that benefits others, even if the exact outcomes are unclear.”
	Positive Support for PMBD	“Donating brain tissue shows you’re a compassionate, supportive person driven by solidarity.” “Knowing my final act could serve science feels incredibly meaningful and positive.”
	Brain Use vs. Waste	“After I’m gone, my brain is useless unless I donate it to contribute to a worthy cause.” “Instead of discarding organs like the brain, they can be used to help others, just like any other organ.”
Negative Emotional Triggers	Uncertainty Around Brain Death	“Honestly, the idea of dying scares me, especially the fear of being declared dead when I’m not—it’s terrifying.” “When assessing brain death, I’ve heard families worry, ‘What if the machines aren’t accurate?’”
	Perceived Harshness of Surgery	“The thought of my head being cut open makes me want to say no immediately.” “It’s shocking to think they’d actually cut you up and distribute your parts—it’s unsettling.”
	Confronting Mortality	“Talking about death is overwhelming, like staring at the sun too long—you have to look away.” “The brain evokes strong emotions, and when families face donation decisions, they often avoid it to not think about death.”
	Stigma Around Mental Illness	“The brain is unique, and people hesitate to discuss mental illnesses, so PMBD brings up those associations.”
Family Perspectives	Respecting the Deceased’s Wishes	“If my loved one expressed their wishes, I’d honor them completely, even if I disagreed.” “Without clear consent or refusal, deciding for someone else is tough—I wouldn’t know what to do.”
	Emotional Strain and Grief	“When my mom passed, I was so overwhelmed with grief and anger, I would’ve refused donation.” “When a loved one is dying, you just want to focus on saving them—anything else feels intrusive.”
	Need for Family Consensus	“All family members should agree on donation; if one says yes but others say no, it’s complicated.” “I support PMBD and plan to consent to cremation, but I’d need to talk it over with my family, who might struggle with it.”
	Decision by Close Relatives Only	“Only a spouse, parent, sibling, or child should make this decision.” “It’s incredibly hard to consent when it’s your own child dying—those who do are remarkably brave.”
	Distrust in the Process	“Even if I consent, someone could override my wishes later on.” “I want my decision documented clearly so no one—neither my family nor doctors—can change it.”
	Influence of Neurodegenerative Disease Experience	“My father had Alzheimer’s, so I’d be more likely to consent to brain donation to advance research.” “Having dealt with Parkinson’s personally makes me pay close attention—it shapes my perspective.”
Trust in the Process	Confidence in Research Validity	“People have reservations about brain donation because it feels different from other organs, so the research purpose must be verified.” “The goals of the research need to be crystal clear.”
	Transparency in Research	“Generally, research might involve unclear methods to achieve certain aims.” “There have been questionable cases in research history, so I’m just raising a concern.”
	Reputation of Institutions	“Since this request came from a reputable institution, I wasn’t concerned, but with all the misinformation today, clarity is essential.”
	Ethical Considerations	“History shows research can cross dangerous lines, making it hard to regulate.” “A barrier is the fear that research might not benefit everyone and could be manipulated.”

Knowledge and information needs

Participants generally demonstrated limited familiarity with PMBD and expressed a clear desire for more detailed understanding of its purpose and procedures. When reflecting on the goals of PMBD, participants suggested a variety of possibilities, including studying brain structure and function, genetic research, investigating neurodegenerative diseases, and exploring links between brain anatomy, functionality, and pathological outcomes. A broader notion of "scientific progress" was mentioned, particularly among twin participants.

A recurring theme across all FGs was confusion between organ donation for transplantation (OD) and PMBD. Participants frequently raised questions that revealed basic uncertainties regarding both OD and PMBD, such as surgical methods, organizational procedures for brain procurement, and storage duration of tissue. Many assumed that only part of the brain would be donated, with only a few recognizing that the entire organ could be involved.

The discussions highlighted a strong need for clear explanations on these topics, particularly regarding the determination of brain death. Participants were also interested in the intended research use of donated tissue and expressed curiosity about receiving feedback from the studies. Questions about the "donor profile" for PMBD frequently arose, reflecting interest in whether donated brains should come from healthy or diseased individuals. Some participants questioned whether a brain from a deceased person could still serve a research purpose, illustrating persistent confusion between OD and PMBD. This type of reasoning appeared consistently in all FGs.

Conceptualization of the "Brain"

In several FGs, especially in Rome, participants imagined that donated brains might be transplanted into another individual. Misunderstandings also emerged about the timing of brain donation, with some assuming it could occur before death.

The brain was often viewed as the locus of the self or Ego, with many participants attributing to it a unique significance compared to other organs. These perceptions triggered strong emotions and fears about losing such a central organ. Some participants equated donating the brain with giving one's mind or personal thoughts. Others noted a cultural hesitancy toward mental health treatments: "we do not have a culture of this things" [NdA: of treating brain pathologies] (FG Naples), reflecting the belief that "the brain is not the heart or the liver…" (FG Rome).

Religion, spirituality, and solidarity

A subset of participants cited religious principles emphasizing the body's inviolability and expressed uncertainty about what occurs after death: "one never knows what may happen after death." Some worried that the removal of the brain could conflict with beliefs about the afterlife. Moral conflicts between PMBD or OD and burial/cremation practices were also discussed, summarized by statements like: "should I donate to help others or refrain out of respect for my faith and bodily integrity?"

At the same time, some participants observed that religion—particularly Catholicism—has adopted more progressive positions regarding therapeutic restraint, which may facilitate more favorable attitudes toward PMBD and OD. Across all FGs, a secular perspective also emerged among participants who supported PMBD, emphasizing that after death "nothing really has value anymore." Both OD and PMBD were often framed as civic duties: "a part of myself can be useful, and I can embrace a civil view of donation." Participants also described PMBD as giving "meaning to life," acting as a "gift," or representing "a form of active contribution."

Issues eliciting negative emotions

Across all FGs, participants consistently reported difficulty coping with topics related to "death" and "disease." Some reflected that people in the past may have been better equipped psychologically to handle such events. A primary concern centered on the ascertainment of brain death, which generated considerable worry and fear, sometimes even anxiety.

Several participants imagined that contemplating the removal of the brain could provoke negative emotions, as it evoked images of the "cruelty" of surgical procedures. In particular, discussions in Turin emphasized the need to mentally "process" and "accept" the idea of brain explantation in advance, acknowledging that the surgery itself inherently involves a certain degree of unavoidable violence.

Reluctance also emerged when considering mental illness in relation to PMBD. In Milan, a few participants highlighted the value of FGs for discussing mental disorders, noting that such dialogue could facilitate emotional acceptance. Additionally, most participants across all FGs felt that donating a portion of the brain, rather than the entire organ, was far less distressing and emotionally easier to accept.

The role of family

The importance of the "family" was particularly pronounced in Naples, though family emerged as a critical factor in PMBD decision-making across all FGs, often in a complex or controversial manner. Therefore, the "role of family" warranted detailed exploration.

Participants generally agreed that the decision made by the individual during their lifetime was essential. Only when a person had not clearly expressed their wishes regarding PMBD were next of kin permitted to provide consent. Recurrent comments emphasized the significant responsibility family members bear in making such decisions, as well as the challenges they face when the dying person is a loved one. In Naples, bereavement grief was highlighted as a major barrier to family consent for PMBD. Some participants who intended to donate their brain felt it necessary to inform their general practitioner or hospital staff, believing that only official procedures could ensure their wishes were respected.

The importance of considering each family member's opinion and respecting their sensitivities when making PMBD decisions was also emphasized. A few participants expressed a preference to leave the choice to their children at the time of death. In Turin, one participant expressed deep concern that family members would inevitably encounter moral, psychological, and emotional challenges in consenting to PMBD on their behalf. In Rome, participants stated that consent should be limited to close relatives (spouses, children, siblings), and some explicitly noted that they would consent to PMBD for a dying relative. A family history of neurodegenerative or neurological disease was commonly cited as a strong facilitating factor for choosing PMBD.

Attitudes towards organ donation and PMBD

From cultural and social perspectives, participants often drew parallels between OD and PMBD. OD was seen as directly life-saving, whereas PMBD was viewed as advancing research that could ultimately save lives in the future. Some participants emphasized the potential to "prolong life" and give purpose to the dying individual's life through PMBD. Others considered the practical utility of using the brain for research despite its inevitable deterioration.

Many opinions aligned with an "altruism and solidarity" framework, reflecting a sense of social responsibility and a commitment to biomedical progress. Within this context, a "utilitarian" perspective also emerged, with participants weighing the benefits gained from prior biomedical research against the act of PMBD today to advance future medical knowledge.

Trust

Trust emerged repeatedly as a central element in the discussions. Participants highlighted aspects such as the reliability of research, the reputation of institutions and investigators, and, more broadly, transparency in scientific practices. Concerns were raised about the potential for unjustified experiments or manipulations, as well as the risk of brain tissue being removed before brain death is confirmed. Some participants also mentioned the possibility of biological specimens being used for commercial purposes without authorization. In contrast, a few participants expressed high levels of confidence and a relaxed attitude toward donation, noting sentiments such as: "…Once I have donated, I forget it."

How to promote PMBD

Many participants considered families of individuals affected by mental or neurodegenerative diseases to be the most appropriate "micro environment" for receiving information about PMBD. They emphasized that open dialogue between health professionals and family members is essential to raise awareness.

Education was viewed as a key strategy. Participants suggested that schools and community settings could play a pivotal role in fostering a sense of responsible solidarity among young people. In terms of content, participants highlighted the importance of addressing "mental health and neurodegenerative diseases," particularly those affecting the elderly. They also stressed the need to clearly communicate the "aim and objectives of the research" using donated brain tissue and to differentiate, while also comparing, PMBD and OD for therapeutic purposes.

Health professionals, especially general practitioners, were identified as key actors in promoting awareness and providing information about PMBD. Participants proposed specific tools for formalizing individual informed consent, such as living wills or registrations on personal cards, similar to the legally required OD declaration on the Italian Identity Card. Additionally, many participants suggested the establishment of new standards to regulate PMBD. Themes and sub-themes derived from the analysis, accompanied by illustrative participant quotes, are presented in **Table 2**.

Discussion

The findings indicated that PMBD was largely a novel concept for most participants. Although twin participants showed slightly higher enthusiasm for scientific research during discussions, no significant differences were observed between twin and non-twin groups regarding knowledge, attitudes, or concerns about PMBD.

Participants frequently expressed opinions in relation to what “others” (e.g., family members) or “society” might think about PMBD. The multifaceted and sometimes conflicting role of family members emerged as a distinctive finding of this study. While previous research has often identified single themes related to the role of family [10, 11, 18], our study revealed a wide spectrum of themes regarding family influence, opinions, and participation in the decision-making process for PMBD. Collectively, these findings underscore the significance of family as an emotional and cultural context that is central to PMBD. A “family-centered” approach to decision-making was particularly evident in the FGs conducted in Naples. Considering cultural and historical variations across Italian regions, this may reflect the stronger influence of family in certain social and cultural settings, especially when addressing sensitive decisions [36].

Family-related sub-themes often showed conflicting perspectives, ranging from valuing family involvement in the PMBD decision-making process to concerns that family members might disregard the deceased’s wishes. A potentially influential family role in PMBD has been previously recognized [10, 11, 37], and our findings reinforce this observation. Participants anticipated strong emotional responses and concerns among family members, including a heightened sense of responsibility, profound grief over the loss of a loved one, and uncertainty regarding whether the deceased’s will would be respected.

Several factors contributed to these concerns. Hesitation could arise from a lack of clear expression of the dying individual’s wishes during life. Participants also expressed empathic anxiety about the possibility that their own families might refuse PMBD, and worries about the intensity of grief and stress family members could experience when asked to give consent. This dynamic has been highlighted in previous studies [25].

In contrast to healthy individuals, motivations for PMBD are more readily observed among patients with neurological or neurodegenerative diseases and their families, as the presence of disease strongly influences willingness to donate [25, 37]. Nonetheless, understanding the factors that shape PMBD decisions among healthy populations remains a recognized need [10]. A recent systematic review [38] emphasized that conceptual understanding, family context, and personal experience are key determinants influencing PMBD decisions, all of which were indirectly reflected in our study. For healthy participants, personal experience was often limited, and opinions were primarily shaped by intellectual reasoning.

The extensive information needs expressed by participants concerning the aims, procedures, and mechanisms of PMBD indirectly highlight the role of health literacy in facilitating acceptance [10, 11, 37]. Our study documented limited knowledge among individuals, along with a recurring confusion between OD and PMBD, consistent with earlier research [10, 11, 37, 39]. This misunderstanding was frequently intertwined with imagination and fantasy, alongside other influential factors, such as identification of the “brain” with the “Self,” negative emotions elicited by thoughts of “death,” and uncertainty regarding the definition and ascertainment of brain death.

The ascertainment of brain death emerged as a potential barrier to PMBD. Many participants expressed emotional non-acceptance of “death” and “illness,” which likely play a substantial role in personal decision-making. They reported ambiguity around brain death determination and sometimes held hope that a dying individual “might recover.” However, evidence on this issue is mixed: while higher knowledge of brain death correlates with increased PMBD rates, accurate understanding of brain death alone does not consistently drive willingness to donate [40]. Other studies report only a moderate association between knowledge of life-prolonging medical procedures and willingness to participate in PMBD [16].

The debate over the definition of brain death remains unresolved [41], and empirical research shows significant non-acceptance of brain death among the public [42]. Consequently, concerns among potential donors are unsurprising. Our findings suggest that addressing the perceived uncertainty around brain death ascertainment is critical. To reduce misunderstandings and emotional distress, it is essential to clarify that only individuals who have suffered cardiac death are eligible for brain donation, as cardiac death is unambiguous and more quickly ascertained. The key practical challenge lies in minimizing the post-mortem interval for brain explantation, ideally keeping it under 24–30 hours [14].

Religion and spirituality played a fundamental underlying role in shaping perceptions and decisions regarding death and PMBD, consistent with prior research. Some studies reported that religious beliefs could positively influence donation decisions [11, 21], while others highlighted that religious concerns often acted as barriers [10, 25, 37]. In our study, contrasting contributions were observed. On one hand, participants expressed the desire to preserve bodily integrity, reflecting an indirect rejection of brain removal due to concerns about "body disfigurement." On the other hand, participants also exhibited a sensitive and altruistic stance toward PMBD, recognizing its potential benefits for others, often guided by religious principles. This altruistic view was sometimes linked to a more progressive contemporary interpretation of religion.

Expressions such as, "A part of me, of my body, may be useful, therefore I may help others this way," highlighted a sense of solidarity. Many participants regarded PMBD as a "good act" or a "gift," contributing to potential research advancements that could help others. A few participants framed the decision in utilitarian terms, emphasizing a balance between the benefits derived from past biomedical research and the opportunity—or even duty—to contribute to future generations. Overall, the role of solidarity, whether grounded in utilitarianism, religion, or spirituality, was consistently evident in participants' support for PMBD.

Trust in research

The topic of societal trust toward research and its actors also emerged as a key factor. Concerns about inappropriate procedures, unclear research objectives, and the resulting lack of confidence in researchers and physicians were highlighted as crucial influences on the willingness of healthy individuals to engage in PMBD [39].

Legal context

From a legal perspective, recent developments in Italy have emphasized the importance of an individual's deliberate choice and free will to donate their body for research purposes [43]. However, the law enacted in 2020 [44] does not specifically address PMBD or its procedural details, leaving a significant legislative gap.

Study Limitations

The qualitative methodology was essential for a thorough exploration of opinions and concerns about a relatively unfamiliar topic such as PMBD. Nevertheless, as with all qualitative research, limitations exist. Future studies should include quantitative approaches with larger, representative samples from the general population to evaluate the impact of the identified factors on PMBD. Furthermore, this study explored participants' theoretical perspectives; additional research is needed to observe actual behaviors when individuals are offered the opportunity to join a PMBD program. High refusal rates were observed in Southern Italy (including the islands), warranting further investigation into this phenomenon.

Conclusions

The study highlighted the complex processes involved in PMBD decision-making. Our findings reinforce the importance of public initiatives aimed at promoting PMBD, as noted by prior scholars [21, 37]. Particular attention should be given to evaluating the capacity of medical professionals to communicate the significance of PMBD and to address concerns of potential donors and their families. Establishing a territorial or institutional network of well-trained, empathetic medical professionals—including specialists and general practitioners—may be necessary to foster awareness [14].

At the same time, promoting PMBD outside the clinical context requires acknowledging the societal and personal conceptualization of the brain. Cultural initiatives are also needed to support broader acceptance of "death" and "disease" and to stimulate ethical debates on balancing the value of scientific and healthcare advancements with individuals' inner needs.

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