

## Communication and shared decision-making after stillbirth: Results of the ShaDeS study

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### ABSTRACT

**Background:** Shared decision-making (SDM) is included in guidelines for bereavement care after a stillbirth, as it can improve women's long-term health and wellbeing. SDM within the stillbirth context is still not common, and Italy does not yet have standardised guidelines.

**Aim:** The ShaDeS (**Shared Decision-Making in Stillbirth**) study aims to investigate how Italian women with a stillbirth perceive their own centrality in decision-making processes around bereavement care and how this might impact satisfaction of care.

**Methods:** The ShaDeS study is a cross-sectional study based on a web survey consisted of four sections: socio-demographic information and medical history, communication of bad news and bereavement care, decisions about childbirth (SDM-Q-9, SHARED, and DCS), and decisions and communication about autopsy (CPS).

**Findings:** 187 women answered the survey. For the 41.1% of women that did not have an emergency childbirth, the SDM-Q-9 median score was 66.6 (0–100 range), and the SHARED median score was 3.5 (1–5 range). 29.4% of participants reached the proposed cutoff of 37.5 in the DCS (0–100 range) suggesting a difficulty in reaching decisions. Satisfaction scores were lower for those with such difficulties ( $p < 0.0001$ ). Of the 64.5% of women that discussed autopsy, 28.3% were involved in an SDM approach, despite this being associated with higher levels of satisfaction of care ( $p < 0.05$ ).

**Conclusion:** An SDM approach is only moderately widespread amongst our participants, despite it being significantly related to higher levels of satisfaction. Further studies should investigate the tools that both patients and healthcare professionals need for an SDM approach.

#### Statement of significance

##### Problem or issue

SDM experiences in Italy are limited. While SDM is highlighted as important in bereavement care guidelines, in Italy this process has not yet been explored.

#### What is already known

SDM can positively impact long-term health and wellbeing, as well as affect women's level of satisfaction of care. SDM can also minimise remorse or repentance regarding choices made.

#### What this paper adds

This paper presents a first analysis of SDM within bereavement care in Italy. It demonstrates that Italian bereaved women are more satisfied with SDM processes than with paternalistic or

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patient choice approaches.

## 1. Introduction

Worldwide, 2.6 million pregnancies end in a stillbirth each year, a number which has mostly remained unchanged since 2011 [1]. It is thus essential to work towards ending all preventable stillbirths [1]. In order to prevent adverse psychological outcomes following a stillbirth, it is equally essential to provide respectful and supportive bereavement care [2,3]. Yet, despite its importance, ensuring equitable access to high-quality care after a stillbirth is still a neglected component of bereavement care [2].

Evidence-based national practice guidelines, in addition to training of healthcare professionals, can prove successful in standardising care following a stillbirth, as proven by the cases of Australia and New Zealand, Brazil, and the United Kingdom [4–7]. Further, the absence of guidelines and training can result in increased stress and burnout in healthcare professionals, who are the main providers of respectful bereavement care [8]. The Italian healthcare system has not yet developed its own practice guidelines, and training has not been formalised, resulting in the absence of standardised care [3]. Additionally, due to a decentralised system, regions tend to perform differently in terms of health service delivery [9].

The principle of Shared Decision-Making (SDM), alongside the principles of information and communication, is highlighted as valuable in international stillbirth guidelines [4]. However, SDM does not yet receive explicit consideration within the stillbirth context, despite it being increasingly acknowledged as an essential component of high quality care [10]. SDM is an integral aspect of patient-centred care [10, 11]. It involves a discussion and ongoing conversation between healthcare providers and patients about all the different options available, considering both benefits and harms of all options [12]. Healthcare professionals and patients work together to reach the best outcomes possible, thus entailing that care should respect and prioritise the preferences, needs, and values of patients and their significant others [11, 12]. SDM requires a human connection involving kind and careful care [13]. Patients involved in an SDM process can benefit from it: shared and consciously-made decisions seem to increase adherence to therapy and minimise remorse or repentance regarding the choices they have made, especially those that have long-term repercussions [14,15].

In Italy, the importance of involving patients in decision-making processes has been highlighted in its national health plans [16]. However, experiences and clinical studies are still limited [15,17]. In some medical areas such as the oncology setting, the notion of SDM has become more widespread and practiced [17]. In other medical areas, paternalistic and patient choice approaches are instead more common [15]. Within the context of bereavement care after a stillbirth, a standardised approach to SDM is lacking in Italy, which may be linked to the absence of national practice guidelines. However, during and after a stillbirth, women and their partners have to deal with unexpected issues in the context of pregnancy, such as choosing the type of birth and discussing autopsy [10,18]. It is important that women and their partners are provided with all the information necessary to understand stillbirth and to make decisions in a conscious way and in line with their values [10,19]. SDM and communication (and not only information) can contribute to the improved long-term health and wellbeing for bereaved parents, as well as affect women's level of satisfaction of care [20,21]. Through SDM, parents might be more likely to make decisions that they will not regret later on. An evaluation of the degree of SDM in the stillbirth context could be included as a parameter in relation to a core outcome set for stillbirth care research [22].

SDM in the case of a stillbirth is very challenging: it implies that women have to make decisions for two bodies, theirs and that of their stillborn baby. Thus, women act as surrogate decision-makers for their

baby, while also seeking the best choice for themselves [10]. Parents have to make decisions that are often difficult and confronting, and which involve decisions about both birth (e.g., choosing the mode of birth) and death (e.g., decisions about post-mortem examinations) [10]. Additionally, these decisions, which are often time-bound, are also made at a time of intense grief and shock [4,10].

The ShaDeS (**Shared Decision-Making in Stillbirth**) study aims to investigate how women in Italy perceive their own centrality in decision-making processes around bereavement care and important choices (regarding birth choice and post-mortem examinations), and how their choices influence their satisfaction of care received.

## 2. Methods

The study followed a cross-sectional study design. The ShaDeS questionnaire was hosted on the Qualtrics platform provided by Florence University PeaRL laboratory and was distributed through the on-line channels of CiaoLapo Foundation, an organisation working on the promotion of perinatal health in Italy. The data were collected between 13th and 24th May 2021. Participants were deemed eligible to participate if they were women who suffered a pregnancy loss from 20 weeks of gestation until just before birth or a termination of pregnancy. However, only parents affected by stillbirth answered the survey. There was no limitation about the time which elapsed since loss. Information about the questionnaire was provided at the beginning, and consent was given by participants thereafter.

The ShaDeS questionnaire was developed based on existing scales that were consequently adapted to the context. To our knowledge, this is the first time that these scales have been used to investigate SDM in a population of women who have had a stillbirth. The ShaDeS questionnaire contained questions across several areas including: A) socio-demographic information and medical history; B) communication of bad news and bereavement care; C) decisions about childbirth (in the case of an elective childbirth), with the 9-item Shared Decision Making Questionnaire (SDM-Q-9), the SHARED questionnaire, the Decisional Conflict Scale (DCS), and associated questions related to satisfaction of care; and D) decisions and communication models regarding autopsy, with the Control Preference Scale (CPS) and questions on satisfaction of care. The questionnaire included both closed and open-ended questions. A more detailed description of the survey is reported in [Supplementary Table 1](#).

The SDM-Q-9 questionnaire is a brief 9-item survey rated on a 6-point Likert scale that assesses patients' perceived degree of involvement in decision-making processes related to their own care [23]. The tool has previously been used in various clinical settings, such as multiple sclerosis, oncology, obstetrics, and delivery of premature babies [23–25]. The Italian version of SDM-Q-9 was recently validated by de Filippis et al. with a study on psychiatric patients, but the same translation was already available for this study prior to its licensing [26]. The SHARED questionnaire is a 10-item survey rated on a 5-point Likert scale used to assess patients' experience of patient-professional discussions, including treatment options, health professional and patient preferences, and reasoning [27]. SHARED was translated by the authors for the purpose of this study, following standard back-and-forth translation procedures.

The DCS is a 16-item scale rated on a 5-point Likert scale used to measure aspects of decision-making such as feelings of uncertainty about the course of action, feelings of support, and satisfaction of the decision-making process [28]. The Italian translation of the DCS scale was validated by Esposito et al. in a study on cancer patients [29]. In order to adapt the scale to our needs, two items (11 and 15) were removed; in keeping with DCS User Manual, each item was scored from 0 to 4, a total score was obtained as the sum of all items, then the final score was normalised on a scale ranging from 0 to 100, and a score under 37.5 was used as suggesting a difficulty in reaching a decision [30].

The CPS evaluates patients' preferences in terms of medical decisions

and communication between patients and healthcare providers [31]. This tool is made of 5 vignettes which describe possible interactions between patient and physician about a clinical decision that needs to be taken (A: Patient had the final word on decision, B: Patient had the final word on decision after evaluating physician's opinion, C: Shared decision making between patient and physician, D: Patient gave the final word to physician after the latter evaluated patient's opinion, E: Patient gave the final word to physician). In this study, the CPS was slightly reworded and used instead to evaluate the mode (rather than the preference) of communication that played out between healthcare professionals and patients. The Italian version of the CPS was translated and validated by Solari et al. in a study on patients affected by multiple sclerosis [32].

A composite satisfaction index was calculated using the mean of four items of the DCS (a. I am clear about the best choice for me; b. I feel I have made an informed choice; c. My decision shows what is important to me; and d. I am satisfied with my decision) and three items of the SHARED (a. It would be OK to choose any option we talked about; b. The decision made was the best one for me; and c. The [health] professional and I agreed which option was the best for me). All items are rated on a 5-point Likert scale.

Negative aspects of care identified by means of qualitative analysis were coded using the CLASS checklist for stillbirth care [33], based on recommendations for stillbirth management from PSANZ, Canadian Paediatric Society, Health Services Executive Ireland and WHO-UNFPA-UNICEF guidelines [4,34–36]. These were classified under the following categories:

- A - Respect for baby and parents: i.e. naming the baby, bathing and dressing the baby, providing privacy, allowing partners to spend time together, etc...
- B - Information and communication: i.e. using parent-friendly language, avoiding dehumanising terms and medical jargon, giving written information, discussing issues at most appropriate time in a quiet and private environment, etc...
- C - Birth Options: i.e. offering parents choices, offering the option of returning home, offering obstetric analgesia, avoiding sedation, etc...
- D - Hospital stay: i.e. providing privacy, allowing time with the baby, not urging parents to leave the hospital, etc...
- E - Creating Memories: i.e. allowing parents to see and hold their baby, providing mementos such as a lock of hair, footprints, ID bracelet, etc...
- F - Aftercare: i.e. informing mothers about physical and psychological consequences of perinatal loss, providing early psychological support, providing written information on support services, discussing implications for future pregnancies, etc...

### 2.1. Statistical analysis and data presentation

Survey responses were downloaded and extracted from the online survey tool, Qualtrics, and imported into Excel for data management. Incomplete records were excluded and quantitative data were imported into Stata BE 17.0 (StataCorp) for statistical analysis. Descriptive statistics were used to analyse quantitative data. Categorical data were reported as frequencies and percentages and compared using the chi-squared test, whereas continuous data were reported as mean values with standard deviations (SD) or as median [quartiles] and compared using t-test or Kruskal Wallis and Mann Whitney test. All results were considered to be statistically significant at  $p < 0.05$ . Qualitative data were analysed using MAXQDA 2018. Themes and categories were identified to classify both positive and negative aspects of clinical and care management. Responders' location, scores, and communication styles were mapped by regional areas across Italy using Tableau Desktop 2022.2 (Tableau Software, LLC).

### 2.2. Ethic statement

The survey was voluntary and anonymous, no personal data were recorded, in no way it was possible to identify the single respondents. Informed consent was obtained from all participants. Data was acquired in compliance with GDPR regulation (General Data Protection Regulation, European Union 2016/679).

## 3. Results

### 3.1. Socio-demographic information and medical history

A total of 187 women participated in this study; 95.1% of the participants were born in Italy, and all lived all over Italy (61.0% North, 16.2% Centre, 22.8% South), with 93.0% being within 50 km from a hospital. This distribution reflects that of inhabitants over Italy [37]. The average age at which the women suffered the perinatal loss was 33.0 years (SD = 4.86). For around half of the women (51.0%) the loss they described was their first perinatal loss, while the remainder had experienced one (29.9%) or two or more (19.1%) losses. The gestational age at which women had a perinatal loss was distributed homogeneously amongst gestational weeks, with 37.9% of participants suffering a loss during or before the 26th week, 31.6% between the 27th and 36th week, and 30.5% during or after the 37th week. For 23.7% of the women less than 12 months had elapsed between their stillbirth and the completion of the questionnaire, for 24.7% between 12 and 36 months had passed, and for 51.6% of women over 36 months had elapsed. At the time of the study, 97.3% of the women were married or living with the same partner as when the perinatal loss occurred. Additionally, 7.5% of participants were pregnant again at the time of the survey, 57.2% of whom at < 20 weeks gestational age.

Regarding women's mental health history, 23.3% of women had a diagnosis of anxiety and 18.4% a diagnosis of depression; 12.3% of women had both diagnoses. At the time of the study, 19.0% of women were attending individual psychotherapy, of whom 92.3% started after the loss. Of these, in 44.2% of the cases women sought support on their own initiative, in 25.0% through referral from the obstetric and gynaecology ward, while in the remainder of the cases through the recommendation from friends, support networks, or other health professionals. Only a few women were taking psychiatric drugs (e.g., anti-anxiety medications, antidepressants, and mood stabilisers), 2.5% prescribed by a psychiatrist and 1.8% prescribed by a general practitioner.

Regarding their physical health, 14.8% were suffering from hypothyroidism and 15.4% reported coagulation disorders, which are both risk factors for perinatal loss. Of the women with some physical health conditions, 19.7% were taking medications to treat their condition.

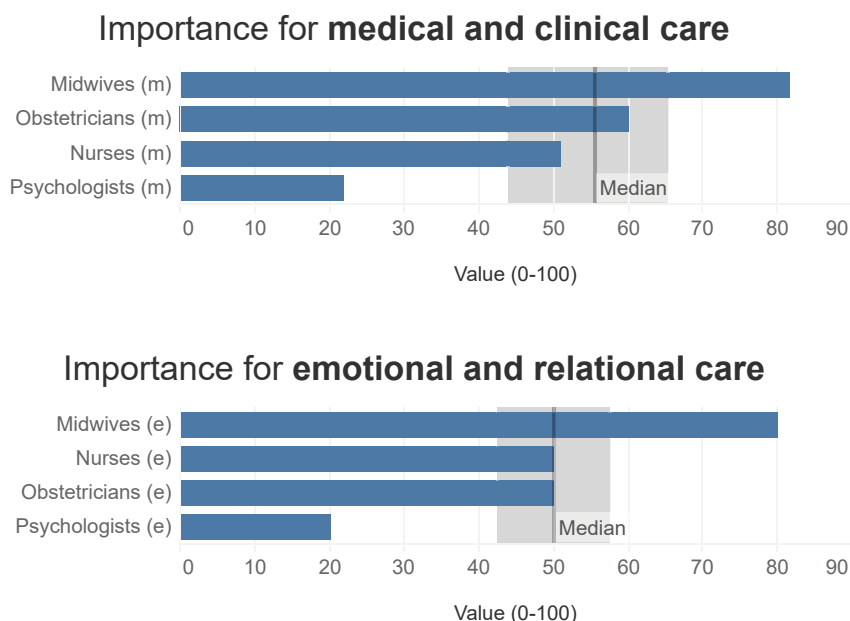
Detailed information of sample characteristics is reported in [Supplementary Table 2](#).

### 3.2. Communication of bad news and bereavement care

The place where the bad news was communicated was mainly the obstetric and gynaecology ward (57.9%), and in 77.6% of the cases the bad news was given by the attending physician. Despite the centrality of the obstetrician in the communication of the bad news, midwives played a pivotal role for women in both emotional and relational care, as well as medical and clinical care alongside obstetricians ([Fig. 1](#)). Lastly, 63.4% of women had to share a room during their stay in hospital with women who had given birth to a live baby.

### 3.3. Decision-making processes around birth choices

To discuss the decision-making processes around childbirth, the results in this section will be relative to the group of women (41.1%) that did not have an emergency childbirth, as in the latter (58.9%), the variability of the situation makes it difficult to explore decision-making



**Fig. 1.** Perceived importance of healthcare professionals for medical and clinical care (A), and for emotional and relational care (B). Midwives scored significantly higher than all other figures in both areas; \*  $p < 0.01$ .

processes.

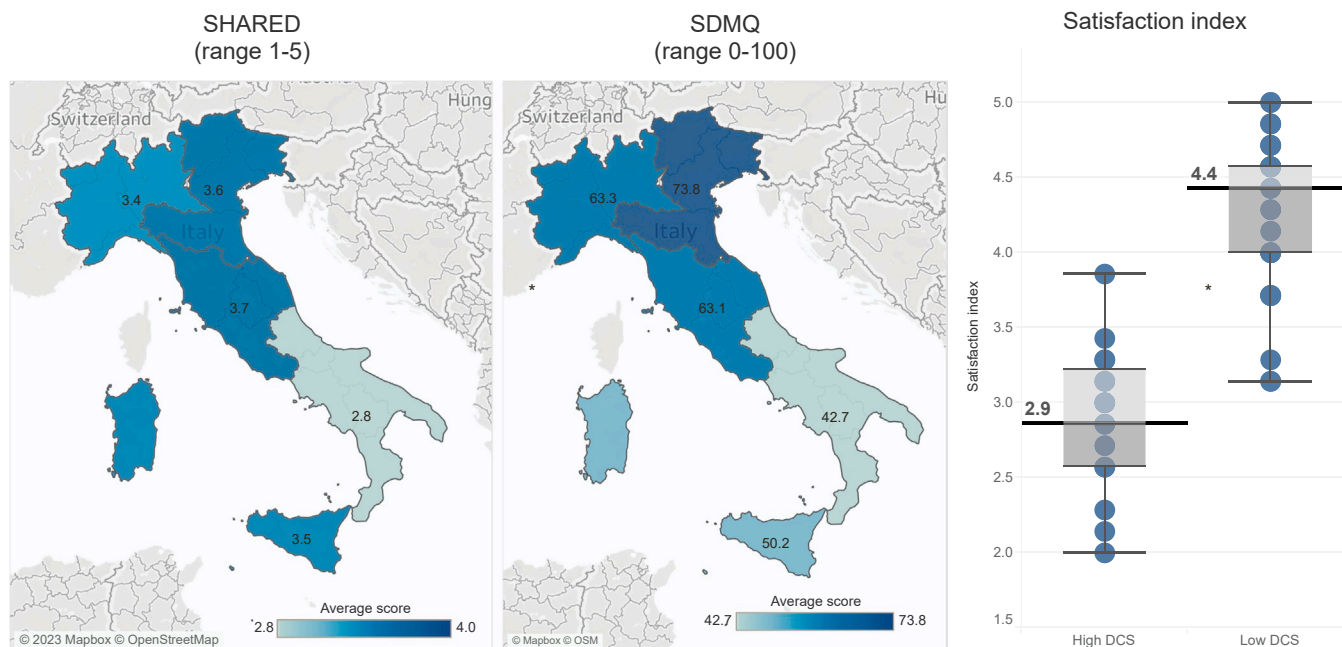
With regard to questionnaires assessing SDM processes around childbirth choices, on a national level the SDM-Q-9 median score was 66.6 [44.4; 84.4] on a 0–100 range and the SHARED median score was 3.5 [2.8; 4.0] on a 1–5 range. Nevertheless, when plotting scores on a national map, regions of the south scored significantly lower than other regions on both questionnaires (Fig. 2, panels A and B).

Regarding DCS, only 29.4% of subjects reached the proposed cutoff of 37.5 (on a 0–100 range) suggesting a difficulty in reaching a decision. Parents who reported such difficulty scored significantly lower on the composite satisfaction index: 4.4 [4.0; 4.6] vs. 2.9 [2.6; 3.3],  $p < 0.0001$  (Fig. 2, panel C). Furthermore, mean scores of the last two years,

pertaining to SDM-Q-9 results of women who gave birth during the COVID-19 pandemic, were significantly higher than the years before (Fig. 3, panel A) suggesting a higher involvement in the decision making process. This difference is particularly evident in northern and central Italy, while scores in the south and islands did not improve (Fig. 3, panel B).

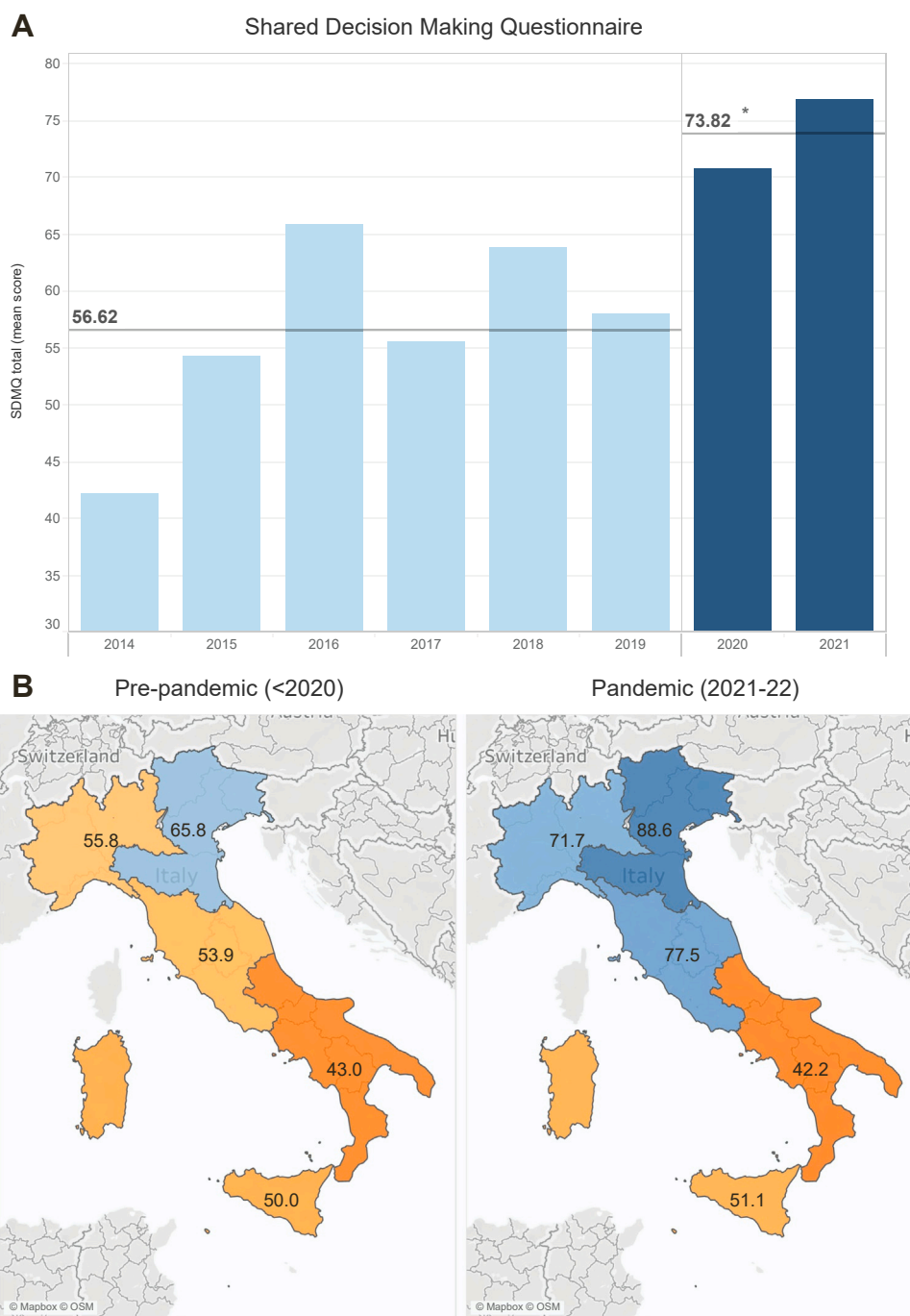
### 3.4. Decisions and communication models regarding post-mortem examination

In 64.5% of the cases, women were able to discuss with healthcare professionals whether they wanted or did not want to carry out an



**Fig. 2.** SDM-Q-9 (A) and SHARED (B) median scores in different Italian geographical zones, and satisfaction Index (C) in DCS high score (> 37) and low score (≤ 37) groups; \*  $p < 0.01$ .





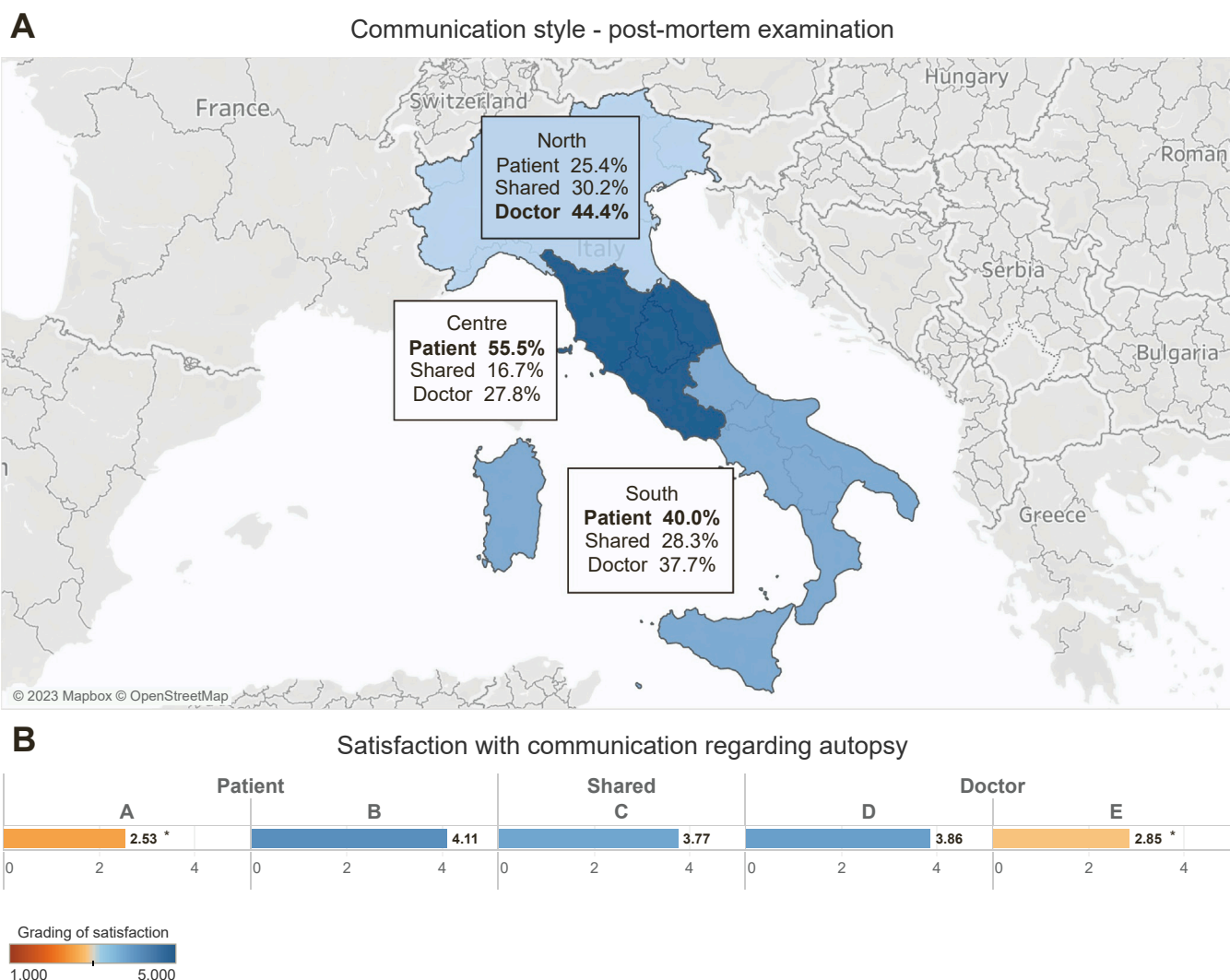
**Fig. 3.** Mean SDM-Q-9 scores since 2014–2021 as a whole (A) and in different Italian zones (B); \* $p < 0.01$  vs pre-pandemic period.

autopsy or histological examination. Of these women, based on the CPS, 34.0% were the main decision-makers (patient choice approach), 28.3% shared the decision equally with their healthcare professional (SDM approach), while in 37.7% of cases, women were not involved in decision-making processes (paternalistic approach). Doctor-centred communication was dominant in northern Italy, while patient choice communication was dominant in central and southern Italy (Fig. 4, panel A). Nonetheless, when one of the two actors (either the doctor or the patient) had a prevailing role in the communication the satisfaction was lower than when the communication was shared, at least to some extent. In particular, Fig. 4, panel B shows that Patient-centred (A) and Doctor-centred (E) communication style were significantly associated with lower satisfaction (\* $p < 0.01$ ) with respect to SDM approach (C) or mixed approaches (B and D).

Consistently with what was observed for birth choices, SDM regarding post-mortem examination also seems to have been increasing in the last years. In particular, during the last 12 months, 50% of respondents shared the decision equally with professionals, vs. 22% of the previous period, and both patient choice and doctor-centred approaches significantly decreased (Table 1).

### 3.5. Care satisfaction: a qualitative analysis

We asked mothers to identify positive and negative aspects of care. The major positive aspects (51 respondents) were: healthcare professionals' support (23.5%), healthcare professionals' empathy (19.6%), having a private room (11.8%), and partner inclusion during hospital stay (7.8%). Six respondents said that there were no positive aspects.



**Fig. 4.** Communication style regarding post-mortem examination. Panel A shows % of the different styles in Northern, Central or Southern Italy measured by CPS; panel B shows the mean of satisfaction index with different communication styles (measured by CPS) graded on a scale from 1 to 5, grouped in Patient prevailing (A and B), Shared (C) and Doctor prevailing (D and E); \*p < 0.01 vs B, C, and D.

**Table 1**  
Shared decision making regarding post-mortem examination according to time elapsed.

Control Preference Scale	Time elapsed since loss				Total		χ <sup>2</sup>	p
	< 12		> 12					
	No.	%	No.	%	No.	%		
Patient	5	20.8%	31	37.8%	36	34.0%	7.339	0.025
Shared	12	50.0%	18	22.0%	30	28.3%		
Doctor	7	29.2%	33	40.2%	40	37.7%		

Concerning negative aspects (62 respondents), the sample described bad communication and no SDM (14.5%), lack of healthcare professionals’ support (14.5%), lack of information (11.3%), and inadequate psychological support (8%) as the most problematic issues. Ten respondents said there were no negative aspects.

Negative themes emerging from the qualitative analysis are reported in Table 2, classified according to the CLASS checklist [33]: “B - Information and communication” was the most affected area (38.3% of cases), followed by “A - Respect for baby and parents” (18.3%), “C - Birth Options” (18.3%), “F - Aftercare” (18.3%), “E - Creating Memories” (15.0%) and “D - Hospital stay” (8.3%). Subthemes emerged for each category are reported in Table 2.

#### 4. Discussion

In summary, regarding the possibility of discussing birth choices, women reported being moderately involved in decision-making processes, with women from southern regions deeming themselves significantly less involved in decisions. Over the last two years there has been a significant shift, especially in northern and central Italy, towards SDM. This improvement could be the result of the growing awareness and knowledge about the importance of shared decision making between healthcare professionals. We have already shown that Italian perinatal HCPs have been actively in search of training in bereavement care in recent years [33], and this is much more relevant for professionals

Table 2 Negative themes and subthemes emerging from the qualitative analysis, classified according to the CLASS checklist.

	n (tot 60)	%
<b>A - Respect</b>	11	<b>18.33</b>
Aa - Baby	2	3.33
Ab - Parents	9	15.00
<b>B - Information and Communication</b>	23	<b>38.33</b>
Ba - Timing	3	5.00
Bb - Delivery of information	18	30.00
Bc - Mode of information	4	6.67
Bd - Terminology	4	6.67
Be - Burial and funeral services	4	6.67
Bf - Post-mortem examination	4	6.67
<b>C - Birth options</b>	11	<b>18.33</b>
Ca - Timing	6	10.00
Cb - Mode of birth	5	8.33
<b>D - Hospital stay</b>	5	<b>8.33</b>
Da - Environment	5	8.33
Db - After-birth care	5	8.33
<b>E - Creating memories</b>	9	<b>15.00</b>
Ea - Spending time with baby	7	11.67
Eb - Parenting	3	5.00
Ec - Mementos	5	8.33
<b>F - Aftercare</b>	11	<b>18.33</b>
Fa - Spiritual / religious needs	3	5.00
Fb - Maternal changes	3	5.00
Fc - Support services	8	13.33
Fd - Follow-up	1	1.67

working in Northern and Central Italy than colleagues working in the South [38]. The fact that such an improvement was particularly observed in Northern and Central Italy suggests that the effect is not specifically correlated with the pandemic, as Southern Italy was also affected, but rather may be a coincidental timing. Importantly, our results showed that difficulties in reaching a decision about birth led to lower levels of satisfaction. With regard to discussing post-mortem examinations, overall we observed that the SDM approach was the least common compared to the paternalistic (most common in northern Italy) and patient choice models (most common in central and southern Italy). On the other hand, approaches that were closer to an SDM approach (full shared decision making but also partial shared decision making) were significantly correlated with higher degrees of perceived satisfaction of care. On a positive note, SDM in the context of post-mortem examination discussions seems to have been increasing over the last years. Overall, while SDM may not yet be the norm in the context of stillbirths in Italy, there have been some improvements over the years.

The Australian and New Zealand guidelines place SDM as one of the core principles for respectful and supportive care after perinatal loss [10]. Not adopting an SDM approach throughout bereavement care may thus result in disrespectful and non-supportive care. The value of SDM for women and, as one woman wrote, of ‘feeling like a fundamental part of all phases’ is highlighted clearly in this study, both with regard to decisions about birth choice, as well as to communication and discussions about post-mortem examinations. Even women who suffered a stillbirth many months before filling in the ShaDeS questionnaire remember the form of decision-making that their healthcare professional involved them in, as well as whether or not they were satisfied with the care received [39]. Both positive and negative memories remained engrained; for example, one woman wrote: ‘They remained close to us all the time and I still remember everything’. Not involving women in decision-making processes may lead to women mistrusting their healthcare provider, in turn leading to worsened psychological outcomes [40,41].

Despite improvements towards an SDM approach over the last couple of years, it is clear that there might still be some barriers to the integration of an SDM approach within bereavement care. Firstly, as mentioned, the Italian health system has not yet developed national guidelines for respectful bereavement care. Such guidelines, aside from being culturally specific, should explicitly state the importance and the

benefits of SDM, and should be useful, but also usable [42]. For the development of such guidelines, lessons can be learned from neonatal and paediatric critical care, where for the last two decades practices have been adapted to support parents in making decisions together with health professionals [43,44]. Critical care services for children are a prime example of the effectiveness of SDM in a very challenging circumstance [43].

However, the establishment of guidelines which include SDM as a core aspect of respectful bereavement care may not be enough if, in actual fact, both patients and healthcare professionals do not possess the tools to reach decisions in a shared manner. From a patient perspective, women should be empowered and educated about their rights and about the role that they play in the decision-making processes [11]. Women thus need to possess the awareness, motivation, and tools to be involved in SDM prior to the decision-making process itself. A model that could be used also in this setting is the ASK (AskShareKnow) patient-clinician communication model, whereby women during a clinical encounter are encouraged to use the questions 1) What are my options?; 2) What are the possible benefits and harms of these options?; and 3) How likely are each of these benefits and harms to happen to me?. [45] These questions can facilitate patient involvement and they are the starting point of most healthcare discussions. Also other intervention could be considered, including decision aids and specific tools to support the decision making process [46].

As a part of the process to empower them, women should receive both physical and emotional support needed to express their own preferences and values, without being afraid of the health professionals’ reaction [11,47]. In the open questions of our study, women valued the ‘humanity and the availability of the health personnel’, as well as receiving ‘all the necessary support and information needed to choose the most suitable solution’. Importantly, the timing of the SDM process is fundamental, and healthcare professionals should choose the most appropriate moment. For example, one woman wrote that, because she was completely disoriented by the stillbirth, she ‘got carried away without really deciding anything’. Similarly, another woman was asked whether she wanted to see her baby immediately after she had just woken up from anaesthesia, which could have influenced her decision of not wanting to at the time [48].

At the same time, healthcare professionals need to give up their role of sole decision-makers, thus moving away from the paternalistic model that they might be used to, and establishing instead an equal relationship with their patients [11]. To be able to do so, it is essential that they receive training to learn how to ask the right questions to initiate a conversation and discussion, as well as how to use terminology that can be understood by patients [10,47]. Additionally, clinicians should not make assumptions about their patients’ needs and wants, for example with regard to birth choice and post-mortem examinations, and over-generalisations should not be made [10]. Ultimately, healthcare professionals need to respect the final decision made by their patients (who have received all the necessary information to make a decision), even if it goes against what they believe might be the best option.

#### 4.1. Strength and limitations

To our knowledge, this is the first time that SDM is investigated amongst women who have suffered a perinatal loss. The scales used in this study had therefore not been used in this context prior to this study. Further studies are thus needed to understand the validity of the scales, in particular when, like in the context of a stillbirth, decisions are not only made about oneself, but also about another body (the stillborn baby).

Another limitation is that only a small number of mothers responded to the open-ended questions regarding positive and negative aspects of care. Therefore, the findings of the qualitative analysis do not fully capture the experiences of the entire sample.

For some women, many months had passed between their stillbirth

and the completion of the questionnaire. This may have affected their memory and the answers they gave. However, their answers seem to be consistent with the other participants.

## 5. Conclusion

Results from the ShaDeS study show that SDM is only moderately perceived amongst women living in Italy in the context of bereavement care after a stillbirth, despite some recent improvements. Instead, paternalistic and patient choice communication models are more widespread. However, an SDM approach is significantly correlated to higher levels of satisfaction of care in women, both with regard to choosing the birth method and to discussing post-mortem examinations. Further studies should investigate whether SDM also results in better psychological outcomes for women. Additionally, we have speculated on possible barriers to an SDM approach within a stillbirth context in Italy, but further culturally specific studies should be carried out to be able to identify the tools that both patients and healthcare professionals are lacking to reach decisions in a shared manner.

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## Author contributions

CR, AV, LL and TG led this research including proposal write up and designed the instrument. CR, AV, CM, LL and TG collected the data; AV, CR and LM analyzed the data; CR, CM, LM, FR, LL, AV and TG discussed data and wrote the manuscript. All authors read and approved the final manuscript.

## Ethical Statement

The study was approved on 19.04.2021 by the Ethics Committee for Psychological Research (area 17) of the University of Padua (protocol n. 4091).

## Conflict of interest

None to declare.

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## Appendix A. Supplementary material

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.wombi.2023.04.001](https://doi.org/10.1016/j.wombi.2023.04.001).

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