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## The unmet need for oncofertility preservation in women: Results of a survey by different oncological specialists in Lazio, Italy

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### A B S T R A C T

In recent years, we have witnessed a growing interest in the prevention of the loss of reproductive efficacy in young women as a result of cancer or its treatments. Indeed, recent studies have shown that loss of fertility impacts deeply on young women and sometimes may be even more stressful than the cancer diagnosis itself. In fact, the risk of treatment-associated infertility and premature menopause is a major concern for patients.

Nevertheless, the approach to fertility preservation in women diagnosed with cancer is far from being standardized, and counseling strategies are poorly adopted in clinical practice.

In Italy, the federal structure of public health makes it difficult to refer patients to local referral centers experienced in fertility preservation. In particular, a need exists to identify oncologists in the Lazio region

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specialized in fertility preservation and those facilities who are able to counsel patients regarding their sexuality.

For these reasons, the Lazio section of Italian Association of Medical Oncology has led an oncofertility and oncosexuality survey to assess deficiencies in the path to start fertility preservation procedures and to help patients with cancer-related sexual problems.

In total, 273 healthcare providers participated in the survey. Overall, the participants had a low interest in their patients' infertility problems, which led to a poor referral of patients to fertility preservation centers. This behavior demonstrated by healthcare providers is attributed to the necessity to rapidly start oncological treatments, the lack of knowledge of referral centers, and the little experience in tackling the subject with the patients. The interviewees also recognize communication difficulties related to lack of information on issues, absence of rehabilitations paths, and embarrassment.

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## ARTICLE INFO

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### Introduction

The reduction of cancer-related mortality remains the main aim of oncological treatments; however, with increasing cancer survival rates, quality of life also deserves attention. Indeed, in recent years, we have witnessed a growing interest in the prevention of the loss of reproductive efficacy in young women as a result of cancer itself or its treatments.<sup>1-3</sup>

Several factors are associated with an increased incidence of amenorrhea after systemic treatment for cancer, including the type of chemotherapy/radiotherapy received, fractionation scheme, irradiation field, and the ovarian reserve before treatment, as well as social and economic factors. Age has also been linked to the risk of amenorrhea after treatment, which is present in approximately 10%-50% of patients <40 years of age, and in 50%-94% in women older than 40 years of age.<sup>1,4,5</sup> Moreover, early menopause is associated with osteoporosis, cardiovascular impairment, and psychosocial distress.<sup>1</sup>

Infertility related to anticancer treatments and the deep psychological impact on the patients' quality of life have acquired increasing importance, both for the postponement of the first pregnancy and for the improvement of the pediatric and juvenile patient prognosis, leading to a large population of young survivors who are still within a child-bearing age.<sup>6</sup>

For young patients with a new cancer diagnosis who desire to preserve their fertility, every attempt should be made to refer them to fertility preservation counseling as soon as possible.<sup>7</sup>

Indeed, recent studies have shown that loss of fertility impacts deeply on young women and sometimes may be even more stressful than the cancer diagnosis itself.<sup>8,9</sup> In fact, the risk of treatment-associated infertility and premature menopause is a major concern for patients.<sup>10</sup>

Nevertheless, the approach to fertility preservation in women diagnosed with cancer is far from being standardized,<sup>11</sup> and communication strategies are poorly adopted in clinical practice for various reasons,<sup>12</sup> which include the lack of knowledge, insufficient time to discuss the issue, the need to urgently start treatment, or the perception that patients were not interested.<sup>13</sup>

In an Italian setting, data from the PREgnancy and FERtility (PREFER) study, a multicenter prospective cohort study on fertility preservation and pregnancy issues in young breast cancer patients, underlined that although 89.7% of women were interested in ovarian function and fertility preservation, only 23% of the women received fertility preservation counseling. A total of 86.2% underwent luteinizing hormone-releasing hormone (LHRH) analogue treatment during chemotherapy, but only 5.7% of the patients accepted oocyte/ovarian tissue cryopreservation following fertility counseling.<sup>14</sup> These findings outline problems of underes-

timation of fertility preservation and poor communication between healthcare providers and patients.

Unfortunately, although specific guidelines have been issued by the Italian Association of Medical Oncology (AIOM),<sup>15</sup> in Italy, the federal structure of public health makes it difficult to refer patients to local referral centers experienced in fertility preservation (including the majority of Italian oncologic centers).

In particular, a need exists to identify oncologists in the Lazio region who are specialized in fertility preservation and those facilities able to counsel patients regarding their sexuality.

For these reasons, the Lazio section of AIOM has led an oncofertility and oncosexuality survey to assess deficiencies in the path to start fertility preservation procedures and to help patients with cancer-related sexual problems.

## Methods

The main objective of the survey is to collect information about fertility preservation and sexuality services offered to patients who are diagnosed with cancer in the Lazio region, and the interest of physicians of this issue.

Institutional board review and approval was not required.

The survey consisted of 16 items (Supplementary Material): 7 were dichotomous (yes/no; question numbers: 3, 4, 7, 8, 10, 14, and 16). Seven were multiple choice questions with 1 possible response (2, 5, 6, 9, 11, 12, and 15). One (number 13) was the only open question. The opening question (number 1) had to be answered using a scale ranging from 10 to 100 to highlight the specific interest in the fertility and sexuality cancer-related issues.

The results of the analyses were reported in an electronic database and were analyzed by 2 different operators.

The survey was sent by email to different specialists (medical oncologists, radiotherapists, psychologists, and oncological gynecologists) belonging to three Italian Associations: AIOM, SIPO (Italian Association of Psycho-Oncology), and AOGOI (Italian Association of Oncological Obstetrician Gynecologists, Section Lazio). Those specialists were experienced in the treatment of a number of tumor types: mainly breast, but also gynecological tumors.

All data were analyzed by a statistician and a medical oncologist from the promoting center (Regina Elena Institute, Rome, Italy).

## Results

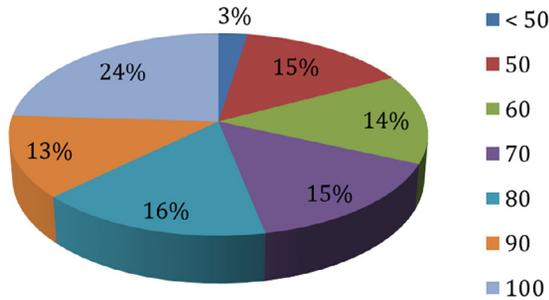
The survey was sent to 302 clinicians, and a total of 237 (78.4%) of them participated. Of these participants, 34% were male and 66% were female; 68% were 46–65 years old. A total of 45% of the clinicians specialized in gynecology, 29% specialized in oncology, 10% specialized in radiotherapy, 5% specialized in psychology, and 11% were specialized in other fields. The clinicians worked in different healthcare settings: public hospitals (67%), medical university (16%), scientific institutes (7%), and private hospitals (10%).

Most of the participants came from Rome (69%) and had 20–30 years of experience (42%).

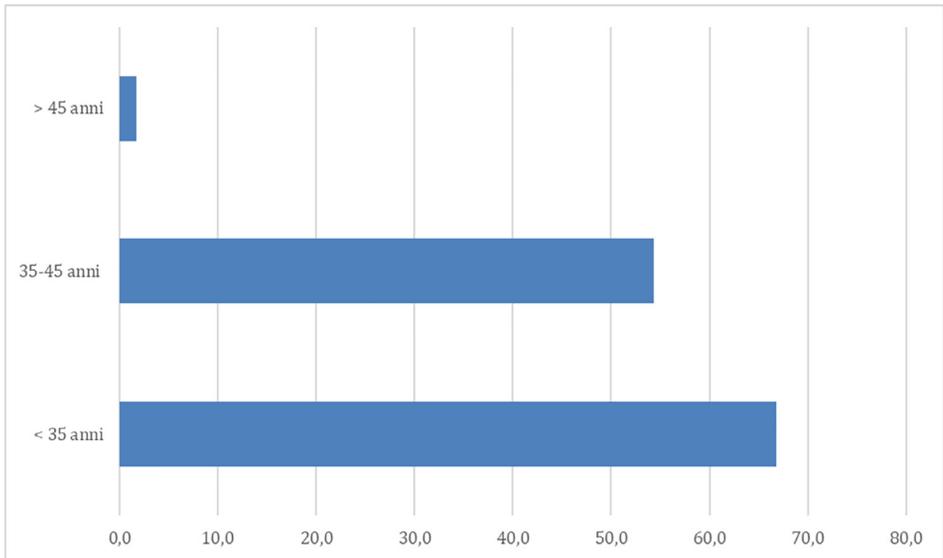
A quarter of the participants declared to be completely interested in fertility and sexual impairments (100 points on the scale), more than half were partially interested (50–90%), while 18% had other priorities (Fig 1).

On the other hand, one-third of physicians never refer young patients to fertility preservation center and a half only do it sometimes, but almost all of them asked for a sensitization campaign (99%). In addition, two-thirds of participants think that the number of fertility centers present in the Lazio region is insufficient, even though 76% of physicians send the patients to Lazio centers.

In the last 2 years, a mean of only 18 patients per center (out of a mean of 36 patients with fertility potential seen per year) have been referred to fertility centers. The main limiting reason was the necessity to rapidly start oncological treatments (68.9%; time to first visit, range: from



**Fig. 1.** Participants' interest in patients' fertility and sexuality impairments during oncological treatments. A value of 100 means 'completely interested'.



**Fig. 2.** Age with most evident need for fertility preservation.

<7 days [40%] to >30 days [13%]). Other limiting factors include: the lack of knowledge of the center of reference (23%) and little experience in tackling the subject with the patients (13.9%). In fact, only one-third of those participants who were interviewed discuss fertility problems during a therapeutic path or in the follow-up phase (25%) with their patients.

The principal communication problems are due to the lack of information (49.1%) or absence of rehabilitations paths (47.7%) and embarrassment (11.1%), since 78% of participants referred a lack of experienced psychologists in their centers.

Almost all the participants (97%) thought the presence of a psychologist during the fertility preservation's process was mandatory, and recognize that the preservation need is greater in the younger patient (Fig 2), since the menopausal symptoms interfere a lot (57%) or enough (36%) with the patients' sexuality and completely (13%) or at least in part (69%) with treatment adherence.

Oocyte cryopreservation is the most requested method of fertility preservation by patients (73.8%), followed by ovarian tissue cryopreservation and implantation (22.4%), embryo cryopreservation (16.9%), and LHRH analogue injection (11%).

The first is actually the most practiced by patients (57.8%), followed by LHRH analogue injection (16.5%), ovarian tissue cryopreservation and implantation (16%), and embryo cryopreservation (13.5%).

## Conclusions

There is a need to refer patients for fertility counseling services and fertility preservation, as they now appear to offer a significant chance to improve oncological treatment adherence and the quality of life post-treatments.

Overall, the results of the survey underline that participants had a low interest in their patients' infertility problems, which led to a poor referral of patients to fertility preservation centers. This behavior is attributed to the necessity to rapidly start oncological treatments, the lack of knowledge of the center of reference, and the little experience in tackling the subject with the patients. The interviewees also recognize communication difficulties related to lack of information on issues, to absence of rehabilitations paths and embarrassment. Almost all the participants outline the necessity of the presence of a psychologist throughout the fertility preservation process to facilitate doctor-patient communication and to ensure an adequate management of psychological issues for young patients. While this may not be immediately possible due to organizational and economic issues, we feel that the implementation of dedicated meetings with a psychologist should be considered in order to optimize outcomes.

The Lazio specialists recognize the real and deep difficulties to create a link between the specialties of oncofertility even if there is the awareness that preservation, surveillance, and restoration of fertility should be integral parts of care for cancer patients. Larger surveys all over the Italian territory and including different specialist are required to further investigate the issue of physicians' approach to sexuality preservation. Moreover, a larger analysis would also allow to correlate the interest in fertility with given specialties.

There is a need to train the healthcare professionals to an adequate knowledge of the problem and provide them with the relational and communicative skills in order to be able to offer the young cancer patients with adequate fertility counseling. We feel that the results of our survey, albeit limited, can prompt the definition of multidisciplinary rehabilitative pathways, with a trained psycho-oncologist inside, to integrate them within the oncological care pathways, immediately after the diagnosis, and to activate a network system with the medically assisted procreation centers for an early management of young cancer (<40 years) patients.

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## Supplementary material

Supplementary material associated with this article can be found, in the online version, at doi:[10.1016/j.currprobcancer.2019.05.002](https://doi.org/10.1016/j.currprobcancer.2019.05.002).

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