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Adult cancer patients and parents of younger cancer patients have little information about fertility preservation: a survey of knowledge and attitude



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Abstract

Background: Impaired fertility is one of the side effects of effective cancer therapy. Saving the potential or storing the material to enable people to have biological children after cancer treatment can be of high importance to many cancer survivors. Therefore, we designed a study to determine knowledge and attitudes to fertility preservation (FP) in adult cancer patients and the parents of patients with cancer. Participants who completed this survey were a convenience sample of 384 parents of cancer patients < 18 years and cancer patients ≥ 18 years from two large referral hospitals. A 25-item self-administered questionnaire measured knowledge and attitudes to FP. Responses were yes/no, or on a 4-point Likert scale (greatly, usually, rarely, never) scored from 1 for never to 4 for greatly.

Results: Most parents and most cancer patients were unaware of the FP methods of embryo cryopreservation (96.3% and 88.4%, respectively) and sperm cryopreservation (97.5% and 89.0%, respectively). Attitudes among cancer patients and parents to use of FP options, based on a 4-point Likert scale, were determined by financial cost, lack of access and information on FP options.

Conclusion: Of concern in this sample of Iranian adult cancer patients and their parents is that knowledge of the fertility risk associated with cancer therapy and knowledge of FP treatment options was generally poor, particularly among the parents. To enable cancer patients or their parents to make the best decisions about using FP services, oncologists and fertility specialists should discuss FP options during their consultation.

Keywords: Fertility preservation, Oncofertility, Infertility, Cancer patient, Pediatric

Background

Nowadays, early detection and advances in medical treatment options, such as chemotherapy, radiation or surgery, have resulted in longer lives with greater reproductive potential for cancer survivors [1, 2]. Impaired fertility is one of the side effects of effective cancer therapy [3]. It affects the future quality of life of patients

who experience cancer prior to or during their reproductive lifespan [4–6]. Cancer patients who survive and want to have children experience more psychosocial and emotional distress because they are either uncertain about their fertility status or have been confirmed to be infertile [1, 7]. So, saving the potential or storing the material to enable cancer survivors to have biological children after cancer treatment can be of high importance and help adjustment to life after cancer therapy [8].

There are various fertility preservation (FP) techniques that aim to preserve the childbearing capacity of cancer

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patients or other patients with benign diseases [9]. The FP options currently available for pre- or post-pubertal women and men are ovarian transposition, cryopreservation of embryos, vitrification of oocytes and sperm, and cryopreservation of ovarian and testicular tissue [10].

The Ethics Committee of the American Society for Reproductive Medicine (ASRM) declared in a 2005 statement "Physicians should inform cancer patients about options for FP and future reproduction prior to treatment." [3]. However, after cancer diagnosis, it is important for the physician to minimize any possible delay in the cancer treatment of some patients [5]. Therefore, there is often only a small timeframe for cancer patients to make a cryopreservation decision [1, 11]. In order to prevent negative experiences and future regret about FP decisions, it is important to make informed decisions regarding FP [12]. The existing literature has shown that cancer patients will be able to make higher-quality decisions if they are aware and fully understand the FP issue. In that sense, cancer patients may have never seriously considered their own beliefs about their reproduction and may need enough time to build self-awareness about this issue [13]. On the other hand, there is disagreement about whether adolescents are competent to make healthcare decisions with long-term consequences. Some evidence on adolescent brain development shows that decision-making and responsibility do not mature until 19 years of age. So, younger adolescents are more likely to make emotional decisions [14–16]. In some countries, like Iran, the legal age of consent is 18 years. Accordingly, parents of patients < 18 years are responsible for making healthcare decisions for their children. The aim of this study, therefore, was to survey knowledge and attitudes to FP among adult cancer patients and parents of children with cancer, and to determine the extent to which health care providers discuss FP or recommend FP to their patients.

Methods

Patients

In this questionnaire-based study, participants were a convenience sample of cancer patients recently diagnosed (less than 6 months) or under treatment (more than 1 year) by chemotherapy, radiotherapy or surgery from two large referral hospitals in Tehran, Iran. Cancer patients less than 18 years of age were recruited from the Ali-Asghar Hospital, a specialized center for pediatric oncology, and those older than 18 years of age were recruited from the Imam-Khomeini Hospital, a cancer institute for adults. All data were gathered between November 2017 and January 2018.

Study questionnaire

Based on earlier published data on the issue of FP in adult cancer patients [17] and in parents of pediatric

patients with cancer [18], and on the basis of 8 in-depth interviews conducted with a panel of embryologists, gynecologists, and oncologists familiar with FP options in patients with cancer, a 25-item self-administered questionnaire was developed to measure self-reported knowledge and attitudes to FP in parents of cancer patients < 18 years and in cancer patients ≥ 18 years. Feasibility of the self-completed questionnaire was confirmed by a number of obstetricians and gynecologists, embryologists, and oncologists. In addition, non-physician staff reviewed the questions for clarity. Both the mother and father of cancer patients < 18 years were asked to fill out the questionnaire together. When this was not possible, the relationship between the person(s) who filled out the questionnaire and the patient < 18 years was noted. Adult cancer patients ≥ 18 years responded to the questions themselves. The first part of the questionnaire asked subjects to provide demographic information (sex, age, occupational status, marital status, number of children), duration of suffering from cancer and any infertility history before cancer diagnosis. Parents of cancer patients < 18 years completed the questions on demographic and clinical characteristics of their children.

The second part of the questionnaire firstly included 7 items (yes/no responses) on the subject's knowledge of FP options, such as cryopreservation of ovarian tissue, oocyte, sperm and testicular tissue, embryo cryopreservation, pre-treatment with Gonadotropin-releasing hormone (GnRH), and ovarian transposition. Secondly, it included three awareness questions (yes/no responses) on the availability of clinics providing FP services in Iran, effects of cancer treatment on fertility, and the possibility of genetic transmission of their cancer to the next generations. Thirdly, the practice behavior of the oncologists treating the cancer patients studied was examined using the question "Have you been referred to reproductive specialists for preserving your fertility (your child's fertility) by your physician?" (yes/no responses). Fourthly, the cancer patients were asked to respond to questions on attitudes towards FP. The questions were as follows: "How important is preserving fertility in cancer patients?"; "How important is use of FP options in cancer patients?"; and "What is the success rate of FP options in cancer patients?" Response options for these three questions were 4-point Likert scales (greatly, usually, rarely, never) scored from 1 for never to 4 for greatly. The next question was on the priority to be given to cancer treatment and starting FP after cancer diagnosis. Participants were allowed to choose an option from therapeutic measures, FP, and no idea. Another question was "If you (your child) become(s) infertile after cancer treatment and you were not aware of possible FP options before starting treatment, who is responsible for the problem?" Participants were asked to

select one option from cancer patient, patient's family, physician, and fate. The last question asked about characteristics and clinical conditions of the cancer patients that might influence the use of FP. These included the risk of recurrence of the cancer in the future, lack of access to FP services, lack of information on FP options in cancer patients, financial cost, and disappointment with the treatment process and prognosis. Responses were on a 4-point Likert scale (greatly, usually, rarely, never), with scores ranging from 1 for never to 4 for greatly.

Statistical analysis

Frequencies were summarized for categorical variables. Continuous variables were expressed as mean \pm standard deviation (SD) and 95% confidence intervals (CIs). Chi² tests of independence were used to assess relationships between categorical variables derived from answers to yes/no questions. Attitude questions with responses on a 4-point Likert scale were compared using the independent samples t test. The means of these scores indicate the attitude of the population studied. Heeren and D'Agostino, in 1987, demonstrated that this t test is robust for ordinal scaled data [19]. All analyses were carried out using STATA (version 12.0; Stata Corp. LP, College Station, TX). P values of less than 0.05 were considered to indicate statistical significance.

Results

A total of 397 participants were given a questionnaire, of whom 384 (96.72%) responded and participated in the study. Among these, 303 participants (78.9%) were \geq 18 years and 81 participants were < 18 years. The mean age of the respondents was 39.94 \pm 10.38 years in adult patients \geq 18 years and 7.93 \pm 3.94 in patients < 18 years. Most cancer patients < 18 years (95.1%) and \geq 18 years (78.6%) were receiving active cancer treatment. The demographic and clinical characteristics of the respondents are presented in Table 1.

Knowledge of FP

Table 2 lists the knowledge questions on existing FP options used in cancer patients with 7 items covering cryopreservation of ovarian tissue, oocyte, sperm and testicular tissue, embryo cryopreservation, pre-treatment with Gonadotropin-releasing hormone (GnRH), and ovarian transposition (yes/no). Of concern is that the majority of participants were not aware of available FP treatment options, even established FP methods like sperm, oocyte, and embryo cryopreservation. Most parents of cancer patients < 18 years (96.3%) and cancer patients \geq 18 years (88.4%) did not know about IVF with embryo cryopreservation. There was a statistically significant difference in knowledge between parents of cancer patients \geq 18 years and cancer patients \geq 18 years (p

Table 1 Demographic and clinical characteristics of 384 cancer patients

		< 18 years N(%)	≥ 18 years <i>N</i> (%)
Sex	Male	49 (60.5)	45(14.9)
	Female	32(39.5)	258 (85.1)
Occupation status	Housewife	=	195(68.9)
	Employee	=	34 (12)
	Worker	-	9 (3.2)
	Student	47(58)	29 (10.2)
	Self-employed	=	16 (5.7)
Marital status	Single	81 (100)	49 (16.2)
	Married	=	254 (83.8)
Has child/children	Yes	=	230 (76.2)
	No	81 (100)	72 (23.8)
Education level	Under diploma	80 (98.8)	137 (46.8)
	Diploma	=	98 (33.4)
	academic	=	58 (19.8)
^a Receiving cancer treatment	Yes	77 (95.1)	232 (78.6)
	No	4 (4.9)	63 (21.4)
Diagnosis of infertility before the start of cancer treatment	Yes	1 (1.2)	21 (7.2)
	No	80 (98.8)	271 (92.8)

The answer "yes" means cancer patients were being treated (more than 1 year)

^aThe answer "no" means cancer patients were recently diagnosed (less than 6 months)

Table 2 Comparison of participants' knowledge of FP options, awareness of fertility centers providing fertility preservation services, and adverse effects of cancer and cancer treatment by age group (< 18, respondent = parents; ≥ 18 respondent = patient)

FP options Embryo cryopreservation		ears	≥ 18 years n (%)	Sig ^a
		3(3.7)	35 (11.6)	0.03*
	No	78(96.3)	268 (88.4)	
Ovarian tissue cryopreservation	Yes	4 (4.9)	30 (9.9)	0.19
	No	77 (95.1)	272 (90.1)	
Oocyte cryopreservation	Yes	4 (4.9)	34 (11.3)	0.09
	No	77 (95.1)	268 (88.7)	
Ovarian transposition	Yes	3 (3.7)	30 (10)	0.07
	No	78 (96.3)	271 (90)	
gonadotropin releasing hormones (GnRH)	Yes	1 (1.2)	17 (5.7)	0.13
	No	80 (98.8)	282 (94.3)	
Sperm cryopreservation	Yes	2 (2.5)	33 (11)	0.01*
	No	79 (97.5)	268 (89)	
Testicular tissue cryopreservation	Yes	2 (2.5)	22 (7.3)	0.12
	No	79 (97.5)	278 (92.7)	
Awareness				
Side effects of cancer treatments on fertility	Yes	21 (26.3)	41 (14.1)	0.01*
	No	59 (73.8)	250 (85.9)	
The possibility of transferring genes and traits attributed to cancer to the next generation	Yes	25 (30.9)	116 (39.3)	0.16
	No	56 (69.1)	179 (60.7)	
Fertility clinics providing fertility preservation services	Yes	8 (9.9)	70 (23.3)	0.008*
	No	73 (90.1)	231(76.7)	

^{*}P < 0.05 was statistically significant

= 0.03). In addition, more than 90% of parents of cancer patients < 18 years and almost 89% of adult cancer patients ≥ 18 years were not aware of sperm and oocyte cryopreservation. There was a statistically significant difference in knowledge between parents of cancer patients < 18 years and cancer patients \geq 18 years (p = 0.01). Table 2 also shows participants' awareness of fertility centers providing FP services, and information on adverse effects of their disease and cancer treatment. Only 21 parents of cancer patients < 18 years (26.3%) and 41 cancer patients \geq 18 years (14.1%) were already aware of the fertility risks associated with cancer therapy before the start of cancer treatment. There was a statistically significant difference in knowledge between parents of cancer patients < 18 years and cancer patients ≥ 18 years (p = 0.01). The majority of parents of cancer patients < 18 years and cancer patients ≥ 18 years did not know about centers providing FP services. Again, there was a statistically significant difference in knowledge between parents of cancer patients < 18 years and cancer patients \geq 18 years (p = 0.008). Fewer than half of the participants were aware of the possibility of transferring genes and traits attributed to cancer to the next generation.

Attitudes toward FP

A 4-point Likert scale was used for questions on attitudes toward FP with response options 1 = never; 2 = rarely, 3 = usually, and 4 = greatly. The median score on this scale is 2.5. Attitudes among cancer patients and parents to use of FP options by cancer patients were determined by financial cost and lack of access and information on FP options. Compared to parents of cancer patients < 18 years, cancer patients ≥ 18 years were more influenced by an increased risk of recurrence in the future [2.58 (CI 95% 1.29-3.87) vs. 2.09 (CI 95% 0.83–3.35), p = 0.002], and disappointment about the result of treatment and cancer prognosis in relation to using FP options [2.37 (CI 95% 1.1-3.64) vs. 1.91 (CI 95% 0.63-3.19), p = 0.005] (Table 3). As displayed in Table 3, the importance of preserving fertility, and the success rate and use of FP options by age group hardly differed between the parents of cancer patients < 18 years and cancer patients ≥ 18 years. Most respondents felt preserving fertility by using FP options was important, with scores of 3.97 (CI 95% 3.64–4.3) for parents of cancer patients < 18 years and 2.32 (CI 95% 0.93-3.71) for adult

^aP value is obtained by chi² test

Table 3 Comparison of participants' attitudes toward factors influencing participants' reasons for enjoying fertility preservation options, importance of preserving fertility, and success rate and use of fertility preservation options by age group

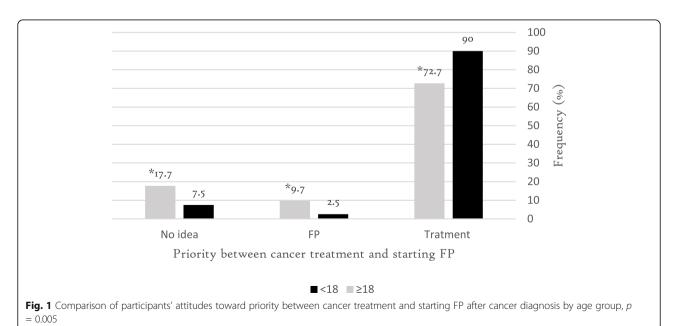
Influencing factors	< 18 years Mean ± SD	\geq 18 years Mean \pm SD	Sig ^a
An increased risk of recurrence in the future	2.09 ± 1.26	2.58 ± 1.29	0.002*
Lack of access to fertility preservation services	3.44 ± 1.05	3.00 ± 1.19	0.003*
Lack of information on fertility preservation options	3.75 ± 0.68	3.17 ± 1.16	< 0.001*
Cost of fertility preservation options	3.32 ± 1.15	3.04 ± 1.19	0.064*
Disappointment in the treatment result	1.91 ± 1.28	2.37 ± 1.27	0.005*
Importance of FP			
Importance of preserving fertility in cancer patients	3.96 ± 0.33	2.25 ± 1.4	< 0.0001*
Importance of using fertility preservation options in cancer patients	3.97 ± 0.33	2.32 ± 1.39	< 0.0001*
The success rate of fertility preservation options in cancer patients	1.15 ± 0.62	2.31 ± 1.18	< 0.0001*

^{*}P < 0.05 was statistically significant

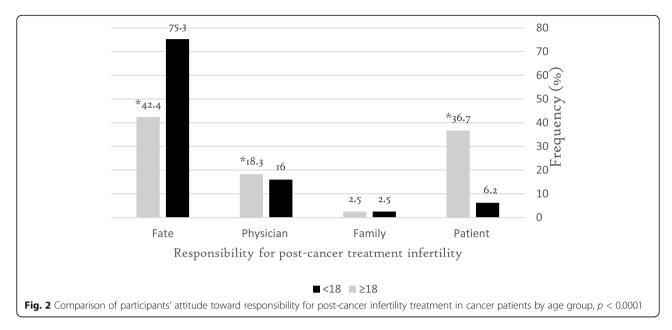
cancer patients \geq 18 years (p < 0.0001), and though the low success rate of FP options in cancer patients; scores 1.15 (CI 95% 0.53-1.77) in parents of cancer patients < 18 years and 2.31 (CI 95% 1.13-3.49) in cancer patients \geq 18 years (p < 0.0001). As seen in Fig. 1, 90% of cancer patients \geq 18 years and 72.7% of parents of cancer patients < 18 years preferred cancer treatment to starting FP after cancer diagnosis (p = 0.005). Only 16% of adult cancer patients ≥ 18 years and 18.3% of parents of cancer patients < 18 years believed that the physician is responsible for infertility after cancer treatment through not making cancer patients aware of FP options before starting treatment (p < 0.0001) (Fig. 2). The vast majority of respondents declared that the oncologists who were treating the cancer patients did not refer them to a reproductive specialist for preserving fertility, although, again, there was an evidence of an age group difference (p = 0.01) (Fig. 3).

Discussion

The most important finding of the present study was that the majority of cancer patients \geq 18 years and parents of cancer patients < 18 years had limited knowledge of FP options and were not aware of the adverse effect on fertility of cancer treatment. This finding is in contrast with what has been reported in some studies. Balthazar et al. provided a quantitative assessment of female patients' knowledge about fertility and FP treatment options before the initial FP consultation, and revealed that the mean knowledge score for 41 women aged 18 to 41 years was 5.9 \pm 2.7, out of a maximum



^aP value is obtained by independent sample test



possible score of 13. Many patients were also aware that different cancer treatments have varying effects on fertility [20]. A cross-sectional online survey conducted by Urech et al. in 155 young female cancer patients from English- and German-speaking countries assessed knowledge about and attitudes towards FP. In this study, approximately two-thirds of participants knew about techniques like freezing embryos or freezing egg cells. Other FP techniques, such as hormonal protection of the ovaries, freezing ovarian tissue, organ-preserving surgery, freezing immature eggs or in vitro maturation of eggs were less known [21]. A survey on attitudes of female adolescent cancer patients (ACPs) aged 15–21

years and their parents toward FP techniques in the case of infertility from cancer treatment showed that a total of 69% of ACPs were aware of the problem of infertility. However, only 31% recalled being spoken to about treatment effects on fertility [22]. Shnorhavorian et al., conducted a study of 459 adolescent and young adult (AYA) cancer patients diagnosed between 2007 and 2008 and recruited through seven US population-based cancer registries. The authors found that 80% of males and 74% of females knew that cancer therapy might affect fertility. However, 29% of the males and 56.3% of females reported not discussing FP prior to starting cancer treatment [17]. A retrospective cohort study included the

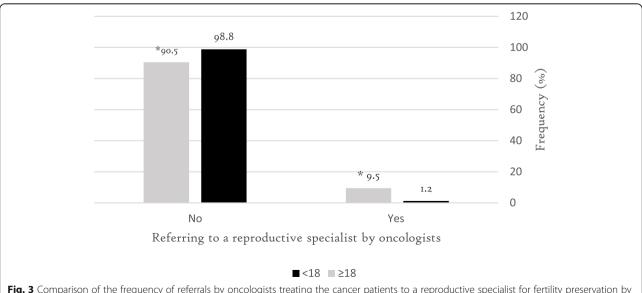


Fig. 3 Comparison of the frequency of referrals by oncologists treating the cancer patients to a reproductive specialist for fertility preservation by age group (*ρ* for difference, 0.01)

parents of all boys who were diagnosed with cancer from December 1990 to December 2009 at the Mahak Institute in Tehran, Iran, and their children who were still alive. Only 22% of all parents reported that they knew about the effect of cancer treatment on fertility before they received this questionnaire. Of those parents who were aware of the effects of cancer treatment on fertility before they received the questionnaire, only one-third had been informed about this by the treating physician [18]. Consequently, awareness of fertility impairment or loss related to cancer therapy in those suffering from cancer steadily improve with increasing oncologists' awareness of the importance of FP issues [23]. The American Society for Clinical Oncology (ASCO) outlines how cancer treatment regimens, multi-agent therapy, and cumulative treatment may affect fertility. The authors of these recommendations confirmed that "oncologists should address the possibility of infertility with patients treated during their reproductive years and be prepared to discuss possible FP options or refer appropriate and interested patients to reproductive specialists". Therefore, the potential risk should be discussed with all pubertal or post-pubertal patients at the time of diagnosis. It has been suggested that the discussion should include an explanation of potential methods of FP [24]. Findings of the current survey suggest that the vast majority of respondents declared that the oncologists who were treating the cancer patients did not refer them to a reproductive specialist for preserving fertility. Possible reasons for this may be one of 3 causes, including lack of national guidelines, advanced stage cancer at the time of diagnosis, pre-pubertal diagnosis of cancer.

It is worth noting that the existing gaps in oncologists' knowledge of FP options and their referral behavior are of reasons for not making FP arrangements. In this regard, other barriers to FP reported by US male and female AYAs included being unaware of options, cost issues, the physician or patient not wanting to delay treatment, the effect of cancer on future offspring, and not wanting biological children. Findings from the current survey are in line with some of the reasons mentioned by US AYAs, such as cost and lack of information on and access to FP services [17]. It is notable that the differences are inevitable because the cultural context in which the surveys took place is widely different.

Burns et al. investigated whether female adolescents with a diagnosis of cancer and their parents were interested in trying to preserve fertility. They found that adolescents and parents were interested in preserving fertility, but not willing to postpone cancer therapy [25]. In accordance with this study, most cancer patients \geq 18 years and parents of cancer patients < 18 years in the current survey had strongly positive attitude toward prioritizing their cancer treatment to starting FP after they

had been diagnosed with cancer. However, many parents of cancer patients < 18 agreed with the importance of preserving childbearing capacity and the use of FP options in cancer patients.

Although ASCO and ASRM guidelines highlight that oncologists have a responsibility to inform patients that cancer treatment may affect fertility [6], in the current survey a minority of cancer patients \geq 18 years and parents of cancer patients < 18 years felt that it is the physician who is responsible for infertility after cancer treatment through not providing information on FP options before starting treatment.

Study limitations

There are several limitations to the current survey. First, there is the possibility of selection bias in our study population, with the findings open to the influence of non-clustered sampling and heterogeneity due to age, type of malignancy, and type and number of chemotherapeutic agents. They may, thus not be representative of the entire population of oncological patients in Iran or further afield. Second, there is the possibility of reporting bias: the questionnaire was not validated quantitatively. The self-reported nature of the survey may also have led to an under estimation of FP behavior of oncologists and so may not be representative of actual practice. However, few objective measures of FP knowledge and attitudes among cancer patients ≥ 18 years and parents of cancer patients < 18 years are available from routine data so this is an unavoidable limitation.

Conclusion

The current survey provides concerning evidence that knowledge at diagnosis about FP treatment options and adverse effects of cancer treatment in a sample of Iranian adult cancer patients ≥ 18 years and Iranian parents of cancer patients < 18 years is generally poor. To facilitate the best decisions about use of FP services by cancer patients, oncologists and fertility specialists should introduce information about FP options during their consultation, focusing particularly on parents of patients under the age of 18. The data indicate that uptake of FP among cancer patients and parents is influenced most by financial cost, lack of access to FP options, and information on FP options. Better awareness and understanding of these issues will enhance patients' decision-making about FP options and help improve quality of care. The current study provides good insight into future initiatives to improve FP care.

Abbreviations

FP: Fertility preservation; ASRM: American Society for Reproductive Medicine; GnRH: Gonadotropin-releasing hormone; SD: Standard deviation; Cls: Confidence intervals; ASCO: American Society for Clinical Oncology

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s43043-021-00072-5.

Additional file 1.

Acknowledgements

We would like to thank Dr. R. Safaei (head of an oncology and hematology ward in Imam Hospital) for her assistance with all aspects of study design and implementation.

Authors' contributions

ROS: study design, approved the final version, and agreed to be accountable for the work. BN: data acquisition. MM: statistical analysis. ZNA: data acquisition. KA: study design and data acquisition. SV: data acquisition, drafting of manuscript, and manuscript revision. All authors have read and approved the manuscript.

Funding

Not applicable

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from the Ethics Committee of the Royan Institute (IR.ACER.ROYAN.REC.1394.158). The aims of the study were clearly explained to all participants prior to the investigation, and confidentiality and anonymity was assured. Voluntary completion of the questionnaire was considered as written consent.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Received: 25 March 2021 Accepted: 5 August 2021 Published online: 14 August 2021

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