Reproductive and sexual health care in oncology: current practice and challenges

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PART II

Discussion of fertility concerns with cancer patients of reproductive age

Chapter 9

Fertility preservation counselling in Dutch Oncology Practice: Are nurses ready to assist physicians?

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INTRODUCTION

In the Netherlands, approximately one in ten cancer diagnoses concerns an adult of reproductive age (Dutch Cancer Registration 2015). Cancer survivors in this age group have reported that the effect of treatment on their fertility is one of their greatest concerns (Schover, 2005); decreased childbearing ability is a cause of long-term distress (Carter et al., 2010; Green, Galvin, & Horne, 2003; Lee et al., 2006; Partridge et al., 2004; Schover, Brey, Lichtin, Lipshultz, & Jeha, 2002). Whether impaired fertility due to gonadotoxic treatment will occur cannot be accurately predicted; it depends on a number of factors. Primary causes are alkylating agents and whole body irradiation, depending on treatment dose, sex and age, site of cancer and stage of disease (Jeruss & Woodruff, 2009; Lee et al., 2006; Wallace, Anderson, & Irvine, 2005). Pelvic surgery may also lead to damage or loss of reproductive organs. Moreover, hormonal changes (e.g. due to cranial irradiation damaging the pituitary axis) or treatments may have effects on reproductive organs (Ruddy & Partridge, 2012).

With increasing survival rates due to early detection and advances in medical treatment, quality of life becomes progressively important, including future reproductive potential. Discussing fertility should be a pressing priority for oncology health care providers immediately after diagnosis, since direct action or modification of therapy may be required. Fertility preservation (FP) is an opportunity to secure future reproductive ability, provided a patient meets the eligibility criteria. Given the number of survivors who have undergone cancer treatment before or during childbearing age, FP is considered greatly beneficial. For women, ovarian transposition and cryopreservation of embryo and oocytes are the established methods of FP (American College of Obstetricians and Gynecologists 2014; Lobo, 2005; Redig, Brannigan, Stryker, Woodruff, & Jeruss, 2011; Sonmezer & Oktay, 2004). The male option is sperm cryopreservation, with various sperm isolation procedures depending on ejaculation status (Trost & Brannigan, 2012). Other innovative possibilities are being developed: cryopreservation of ovarian tissue and cryopreservation of testicular tissue. These methods are, however, still experimental and not yet widely available (Chian et al., 2009; Practice Committee of American Society for Reproductive Medicine 2014; Yokonishi et al., 2014). In the Netherlands, the currently available methods include ovarian transposition (standard), cryopreservation of embryos (standard), ovarian tissue (experimental) and oocytes (experimental) (Garvelink, Ter Kuile, Hilders, Stiggelbout, & Louwe, 2013), and cryopreservation of sperm (standard) and testicular tissue (experimental). As yet, there are no reports of current success rates of female options in the Netherlands. Sperm cryopreservation success rates have been investigated—in a study performed in 898 Dutch men who had had cancer, 10.7% made use of their preserved sperm, with a success rate (defined as parenthood) of 77% (Muller, Oude Ophuis, Broekmans, & Lock, 2014).

Despite its wide availability, several studies have reported that FP is not addressed routinely nor in detail by oncology health care providers (Armuand et al., 2012; Bastings, Baysal, Beer-

endonk, Braat, & Nelen, 2014; King et al., 2008; Quinn et al., 2007, 2009; Schover, Rybicki, Martin, & Bringelsen, 1999; Schover et al., 2002; Vadaparampil et al., 2007; Yee, Abrol, McDonald, Tonelli, & Liu, 2012). Patients do not recall a conversation about FP with their oncologists and report not being offered the opportunity of FP (Nakayama et al., 2009; Schover et al., 1999, 2002; Thewes et al., 2005; Zebrack, Casillas, Nohr, Adams, & Zeltzer, 2004). A recent study from a university hospital in the Netherlands by Bastings et al., 2014, reported that only 9.8% of all newly diagnosed female cancer patients aged 0–39 years were referred for FP counselling. The American Society of Clinical Oncology and the American Society for Reproductive Medicine guidelines recommend that oncologists should discuss infertility risks and FP with their cancer patients prior to commencement of cancer treatment (Ethics Committee of the American Society for Reproductive Medicine 2005; Loren et al., 2013). Similarly, the Dutch Oncology Society has developed guidelines for female (Werkgroep Oncologische Gynaecologie (WOG) 2009) and male patients (IKR-projectgroep Cryopreservatie van zaadcellen 2010), highlighting the responsibility and the importance of oncology health care providers providing adequate counselling about FP. Nonetheless, the implementation of these guidelines in clinical practice is unclear. Although FP, just like any potential treatment risk, should be discussed, there are several reasons why this is challenging for oncologists (Duffy, Allen, Dube, & Dickersin, 2012; Gilbert, Adams, Mehanna, Harrison, & Hartshorne, 2011; Louwe et al., 2013; Quinn et al., 2009). A major barrier is the often limited time to go into detail about the diagnosis and the treatment plan as related to psychosocial concerns (Adams, Hill, & Watson, 2013). Other factors which may influence whether fertility options are discussed include prognosis, the patients' age, a need for immediate therapy, hormonal receptor expression, whether the patient already has a child, the patient not having a partner, the costs, poor success rates of FP and limited knowledge about FP options (Adams et al., 2013; Arafa & Rabah, 2011; Forman, Anders, & Behera, 2010; King, Davies, Roche, Abraham, & Jones, 2012; Louwe et al., 2013).

The issue of lack of time may be addressed by involving other health care professionals in the discussion of fertility concerns (Gilbert et al., 2011), particularly oncology nurses who may serve as a link between oncologists and patients. According to a survey among 201 cancer survivors, the oncology nurse was the second-most likely person to initiate discussion on FP besides the oncology physician (Schover et al., 2002). A Dutch study with oncology nurses and oncologists found similar results (Garvelink, Ter Kuile, Louwe, Hilders, & Stiggelbout, 2012).

With the aim of ensuring that all patients receive FP information at the appropriate time, it is suggested that oncology nurses might be suitable care providers to initiate discussions about FP, provide information and facilitate the referral. The objective of this study was to explore the oncology nurses' role by investigating their knowledge about FP, how they apply this in practice, their feeling of responsibility to discussing fertility concerns with patients of reproductive age facing cancer, as well as any barriers they encounter.

METHODS

Study design

A cross-sectional, anonymous survey was performed using a newly designed questionnaire. The study sample involved Dutch oncology nurses from various departments, hospitals, specialisations and regions across the country.

Questionnaire design

As a validated questionnaire for assessing the provision of FP counselling among oncology nurses does not yet exist, a measuring instrument was designed by the author in collaboration with an expert team consisting of a urologist-sexologist, a professor of oncology, an oncology research nurse and an experienced quantitative researcher. Topics were identified from current practice and in the literature (Adams et al., 2013; Forman et al., 2010; King et al., 2008; Louwe et al., 2013). The 21-item questionnaire contains a demographic sheet and Likert-scale items (ranging from 1 = *never/rarely* to 5 = *often/always*) measuring practices and knowledge regarding FP and sexual functioning, as well as barriers to and responsibility for addressing these issues. Data concerning sexual functioning were processed separately (Krouwel et al., 2015). In a pilot study, the questionnaire was reviewed by a panel consisting of 10 randomly chosen oncology nurses (anonymous to the authors) from the Leiden University Medical Centre. The panel tested the questionnaire for its validity at face value; it was modified on the basis of their feedback.

Survey procedure

The online questionnaire was e-mailed to all oncology nursing departments throughout the Netherlands with the request to distribute it amongst all employed oncology nurses. Furthermore, the survey was promoted at online Dutch oncology nursing platforms, including the website and newsletter of the Dutch Oncology Nursing Society, social media groups (LinkedIn and Facebook) of the Dutch Oncology Nursing Society and the website "www.nursing.nl." At the Dutch Annual Oncology Nursing Congress in November 2012, several volunteers approached the oncology nurses who were attending and asked them to complete the questionnaire. Nurses who had already participated in the online survey did not receive a copy. As a form of appreciation, books concerning cancer and sexuality were provided to each nurse who participated during the Congress. Data were collected from September 2012 to December 2012. Data from the web-based survey and the congress survey were processed together.

Statistical analysis

Analysis was performed using SPSS Release 20 (SPSS, Chicago, IL). The 10 responses from the pilot survey were added to the final analysis group, because all questions were completed by the nurses in the pilot survey and only small modifications have been made to the final instru-

ment. The sample was split by gender, age (set at median age: 44 years or under vs. over 44), experience (0–10 years vs. 11 or more) and grade (graduate nurses vs. other grades) to examine if gender, seniority and years in service had a bearing on oncology nurses' knowledge and practice patterns regarding FP. The practice patterns in discussing fertility issues were adapted for calculation; results in the response category "never/hardly ever" formed one category; the responses "in less than half of the cases," "in half of the cases" and "in more than half of the cases" were merged into one category: "in a medial number of cases," while "almost always/always" remained one category. The oncology nurses were given a list of possible barriers to discussing FP and asked to indicate the extent to which they agreed.

Descriptive statistics and frequency distribution were calculated for all variables. Chi-squared tests and Cochrane-Armitage test for trend were used to look for associations between categorical variables and demographic characteristics; $p < .05$ two-sided were considered statistically significant.

Ethics

In the Netherlands, research that does not involve either patients or interventions is not subject to formal approval from ethical boards. In previous research amongst nurses, the Medical Ethics Committee was consulted and declared that no formal ethical approval was needed (Bekker, van Driel, Pelger, Nijeholt, & Elzevier, 2011). The study was approved by the scientific committee of the Urology Department of the LUMC. Information about the study was provided to potential participants; the aims and anonymity of the survey were highlighted. Participation in the survey was completely voluntary; informed consent was obtained from all individual participants included in the study. An opt-out possibility was offered. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

RESULTS

Participants

A total of 615 oncology nurses logged in to the questionnaire or demonstrated an interest in participating at the Congress. The number who completed the questionnaire was 421: 10 were recruited for the pilot survey, 283 through the Internet and 128 at the congress. The sample consisted of Dutch nurses involved with cancer patients working in various departments in several clinical settings, as defined in Table 1.

Table 1. Demographic characteristics

Demographic characteristics (*n*=421)	***n* (%)**
Age (years)	405 (96.2)
Mean 42.6 years	
Median 44 years (range 21-62)	
Unknown	16 (3.8)
Gender	
Male	23 (5.5)
Female	385 (91.4)
Unknown	13 (3.1)
Oncology experience (years)	
<1	8 (1.9)
1–2	25 (5.9)
3-5	81 (19.2)
6-10	75 (17.8)
11-15	82 (19.5)
>15	137 (32.5)
Unknown	13 (3.1)
Employment setting	
Registered nurse [a]	71 (16.9)
Registered nurse currently in Oncology registration training	18 (4.3)
Registered nurse with Oncology certificate[b]	189 (44.9)
Clinical setting	
• In-patient	79 (18.8)
• Out-patient department	93 (22.1)
• In/out-patient	17 (4.0)
Registered nurse with graduate degree[c]	101 (24.0)
Nurse in charge of Oncology Department[d]	7 (1.7)
Research nurse	7 (1.7)
District nurse with Oncology specialism[e]	8 (1.9)
Different/unknown	20 (4.8)
Hospital type	
University hospital	148 (35.2)
District teaching hospital	124 (29.5)
District hospital	126 (29.9)
Extramural	8 (1.9)
Unknown	15 (3.6)
Area of specialization[f]	
• Single area of specialization	168 (39.9)
• Multiple areas of specialization	236 (56.1)
• Unknown	17 (4)
Breast	221 (52.5)
Colorectal	212 (50.4)
Gynaecology	166 (39.4)

Table 1. Demographic characteristics (*continued*)

Demographic characteristics (*n*=421)	***n* (%)**
Lung	149 (35.4)
Haematology	149 (35.4)
Nephro- and urology	140 (33.3)
Lymphoma	123 (29.2)
Head and neck	90 (21.4)
Skin	76 (18.1)
Sarcoma	64 (15.2)
Neuro-endocrine	48 (11.4)
Unknown	17 (4)

[a] Vocational trained nurses as well as bachelor's degree nurses with no registered specialism but currently employed in an Oncology Department.
[b] Nurses with official Oncology registration (acknowledged by the Dutch board of Hospital Education) following 1 year official Oncology training.
[c] Nurses with a Master's degree from a University or Higher Education College, usually involved with in- and outpatient departments.
[d] Clinical setting undefined.
[e] Nurses caring for cancer patients at home.
[f] Multiple areas of specialisation possible.

Practice behaviour

In response to the question "How often do you discuss fertility issues with patients of reproductive age?," answers ranged from: "never/hardly ever" (27.7%), "in less than half of the cases" (21.2%), "in half of the cases" (8.4%), "in more than half of the cases" (10.5%) to "almost always/always" (32.2%) (n = 419). The frequency of discussing fertility issues was associated with having a Master degree, experience, knowledge related to FP and some specialisations (Table 2).

Perceived knowledge of FP

When it comes to knowledge of FP options, 31.1% of the nurses reported having "sufficient" or "a lot" of knowledge. Others declared having "some" (39.7%), "not so much" (23.3%) and "no" knowledge (5.2%) about FP (n = 418). Calculated associations with age, gender, experience in the field of oncology nursing, Master's grade and specialisation in relation to perceived knowledge are presented in Table 3.

Table 2. Demographic factors and specialisations in relation to the frequency of discussing FP

Demographic item	FP never / hardly ever discussed	FP discussed in moderate number of cases	FP almost always / always discussed	*P*[a]
	n (%)	*n* (%)	*n* (%)	
Total	116 (27.7)	168 (40.1)	135 (32.2)	
Gender				
Male	9 (39.1)	7 (30.2)	7 (30.4)	NS
Female	104 (27.2)	156 (40.7)	123 (32.1)	
Age				
44 years and under	56 (27.6)	85 (41.9)	62 (30.5)	NS
Over 44 years	60 (28)	83 (38.8)	71 (33.2)	
Master's grade				
Master's degree	22 (22)	30 (30)	48 (48)	.001
Non-academic training	91 (29.7)	133 (43.5)	82 (26.8)	
Oncology experience				
≤10 years of experience	71 (37.6)	70 (37)	48 (25.4)	<.001
>11years of experience	42 (19.4)	93 (42.9)	82 (37.8)	
Hospital setting				
University hospital	26 (17.6)	62 (41.9)	60 (40.5)	<.001
Non-academic hospital	86 (33.7)	99 (38.8)	70 (27.5)	
Perceived knowledge about FP				
Sufficient knowledge	6 (4.6)	41 (31.5)	83 (63.8)	<.001
Insufficient knowledge	110 (38.2)	126 (43.8)	52 (18.1)	
Area of specialization[b]				
Breast +	53 (24)	95 (43)	73 (33)	NS
Breast -	59 (32.6)	66 (36.5)	56 (30.9)	
Colorectal +	63 (29.7)	95 (44.8)	54 (25.5)	.020
Colorectal -	49 (25.8)	66 (34.7)	75 (39.5)	
Haematology +	32 (21.5)	60 (40.3)	57 (38.3)	.013
Haematology -	80 (31.6)	101 (39.9)	72 (28.5)	
Lymphoma +	25 (20.3)	53 (43.1)	45 (36.6)	.039
Lymphoma -	87 (31.2)	108 (38.7)	84 (30.1)	
Lung +	49 (33.1)	63 (42.6)	36 (24.3)	.010
Lung -	63 (24.8)	98 (38.6)	93 (36.6)	
Urology +	32 (23.2)	69 (50)	37 (26.8)	NS
Urology -	80 (30.3)	92 (34.8)	92 (34.8)	
Gynaecology +	40 (24.2)	82 (49.7)	43 (26.1)	NS
Gynaecology -	72 (30.4)	79 (33.3)	86 (36.3)	
Dermatology +	21 (28)	38 (50.7)	16 (21.3)	NS
Dermatology -	91 (27.8)	123 (37.6)	113 (34.6)	

Table 2. Demographic factors and specialisations in relation to the frequency of discussing FP (*continued*)

Demographic item	FP never / hardly ever discussed	FP discussed in moderate number of cases	FP almost always / always discussed	*P*[a]
	n (%)	*n* (%)	*n* (%)	
Total	116 (27.7)	168 (40.1)	135 (32.2)	
Head- and neck +	29 (32.6)	40 (44.9)	20 (22.5)	.048
Head- and neck -	83 (26.5)	121 (38.7)	109 (34.8)	
Neuro-endocrine +	11 (23.4)	26 (55.3)	10 (21.3)	NS
Neuro-endocrine -	101 (28.5)	135 (38)	119 (33.5)	
Sarcoma +	14 (22.2)	34 (54)	15 (23.8)	NS
Sarcoma -	98 (28.9)	127 (37.5)	114 (33.6)	
Multiple specialties	64 (27.1)	103 (43.6)	69 (29.2)	NS
Single specialty	48 (28.9)	58 (34.9)	60 (36.1)	

Abbreviation: NS, not significant. NA, not applicable.

a) P value of linear-by-linear association between frequency of discussing FP and demographic items.

b) Many nurses reported multiple specializations, as shown in Table 1. Plus (+) indicates that this group reported the area as a speciality; minus (-) indicates they did not report this area as a specialty.

Table 3. Demographic factors and specialisations in relation to the perceived knowledge about FP

Demographic item	Sufficient perceived knowledge	Limited perceived knowledge	*P*[a]
	n (%)	*n* (%)	
Total:	127 (31.4)	278 (68.6)	
Gender			
Male	6 (26.1)	17 (73.9)	NS
Female	121 (31.7)	261 (68.3)	
Age			
44 years and under	58 (28.7)	144 (71.3)	NS
Over 44 years	73 (34.1)	141 (65.9)	
Master's grade			
Master's degree	51 (51.0)	49 (49.0)	<.001
Non-graduate	76 (24.9)	229 (75.1)	
Oncology experience			
≤10 years of experience	39 (20.7)	149 (79.3)	<.001
>11years of experience	88 (40.6)	129 (59.4)	
Hospital setting			
University hospital	54 (36.5)	94 (63.5)	NS
Non-academic hospital	72 (28.3)	182 (71.7)	
Area of specialization[b]			
Breast +	73 (33.2)	147 (66.8)	NS
Breast -	53 (29.3)	128 (70.7)	

Table 3. Demographic factors and specialisations in relation to the perceived knowledge about FP (*continued*)

Demographic item	Sufficient perceived knowledge	Limited perceived knowledge	*P*[a]
	n (%)	*n* (%)	
Total:	127 (31.4)	278 (68.6)	
Colorectal +	53 (25.1)	158 (74.9)	.004
Colorectal -	73 (38.4)	117 (61.6)	
Haematology +	52 (35.1)	96 (64.9)	NS
Haematology -	74 (29.2)	179 (70.8)	
Lymphoma +	45 (36.6)	78 (63.4)	NS
Lymphoma -	81 (29.1)	197 (70.9)	
Lung +	38 (25.7)	110 (74.3)	NS
Lung -	88 (34.8)	165 (65.2)	
Urology +	42 (30.2)	97 (69.8)	NS
Urology -	84 (32.1)	178 (67.9)	
Gynaecology +	49 (29.7)	116 (70.3)	NS
Gynaecology -	77 (32.6)	159 (67.4)	
Dermatology +	20 (26.7)	55 (73.3)	NS
Dermatology -	106 (32.5)	220 (67.5)	
Head- and neck +	20 (22.2)	70 (77.8)	.033
Head- and neck -	106 (34.1)	205 (65.9)	
Neuro-endocrine +	16 (33.3)	32 (66.7)	NS
Neuro-endocrine -	110 (31.2)	243 (68.8)	
Sarcoma +	18 (28.1)	46 (71.9)	NS
Sarcoma -	108 (32.0)	229 (68.0)	

Abbreviation: NS, not significant. NA, not applicable.

a) P value of chi-squared test between level of knowledge about FP and demographic items

b) Many nurses reported multiple specializations, as shown in Table 1. Plus (+) indicates that this group reported the area as a speciality; minus (-) indicates they did not report this area as specialty.

Barriers

The most important reasons for not discussing FP options were a "lack of knowledge" (25.2%), "a poor prognosis" (16.4%) and "lack of time during a consultation" (10.5%). All barriers and the percentages of nurses agreeing and disagreeing are presented in Table 4.

Table 4. Barriers to discussing fertility preservation

I would tend not to discuss fertility preservation with a patient because:	(Strongly) Agree	Neither agree nor disagree	(Strongly) Disagree
	n (%)	*n* (%)	*n* (%)
of lack of knowledge about FP	104 (25.2)	111 (26.9)	198 (47.9)
the patient has a poor prognosis	67 (16.4)	116 (28.4)	225 (55.2)
of lack of time during a consultation	43 (10.5)	81 (19.8)	286 (69.6)
the patient does not ask about it	29 (7.1)	74 (18.0)	307 (74.9)
the patient is 40 years of age or older	29 (7.0)	61 (14.8)	322 (78.2)
it might raise concerns for the patient and their family or spouse	26 (6.3)	72 (17.5)	313 (76.2)
curing has a greater priority	23 (5.6)	67 (16.3)	320 (78.1)
the patient is currently not in a relationship	20 (4.9)	62 (15.0)	330 (80.1)
I do not know where to refer the patient to	20 (4.9)	59 (14.4)	331 (80.7)
the patient already has children	9 (2.2)	44 (10.7)	358 (87.1)

Responsibility

Almost all nurses considered the oncologists to be responsible for discussing FP (94.5%). A majority felt the oncology nurses be responsible (72.8%), 13.1% did not know if they should feel responsible and 14.1% did not feel responsible for discussing FP. The level of agreement from the responders on responsibility of the oncology nurses vs. the oncologists is illustrated in Figure 1.

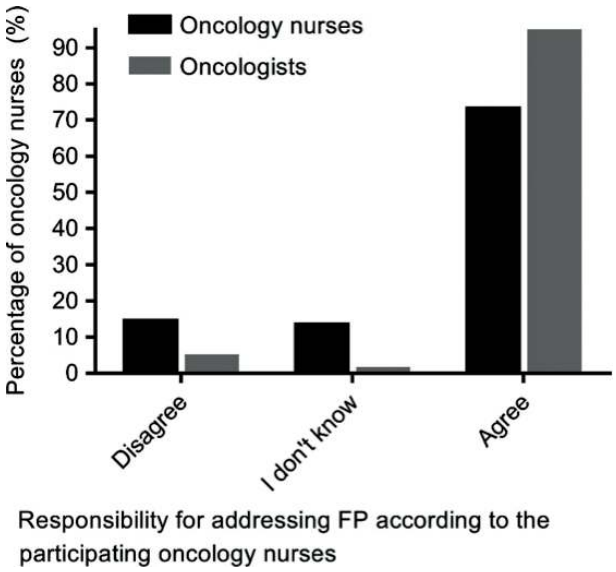

Fig 1. Answers to the questions: "Should the oncologist carry responsibility for addressing fertility preservation?" and "Should the oncology nurse carry responsibility for addressing fertility preservation?" (*n* = 419)

DISCUSSION

Summary

This study reports on the attitudes, knowledge and feeling of responsibility of oncology nurses with regard to discussing FP. Graduate nurses and experienced nurses reported having more knowledge of the subject, and, together with nurses working in a university hospital, were more likely to discuss the issue with the patient. In general, an optimistic picture emerges for the role of oncology nurses in assisting with the discussion of FP, as the majority of them feel responsible for addressing the issue. This role could be enhanced if their level of knowledge about the subject is improved and attention is paid to the importance of ensuring that information about FP options is routinely provided to patients.

Comparison with existing literature

Considering the number of studies on the attitude of oncologists (Duffy et al., 2012; Forman et al., 2010; Quinn et al., 2009), the role of oncology nurses in the discussion of FP is relatively unexplored. There has been an American qualitative pilot-study (King et al., 2008), and a survey from the United States focusing on oncology nurses' knowledge of survivorship, which found that less than 25% of their sample reported having knowledge of fertility issues (Lester, Wessels, & Jung, 2014). Australian nurses reported being least confident about discussing fertility with patients. Consequently, this was one of the least-performed interventions during survivorship care (Wallace et al., 2015). A survey focusing on the discussion of sexuality by oncology nurses reported that 60% of their sample had perceived knowledge on fertility and 67% felt comfortable discussing fertility with patients (Moore, Higgins, & Sharek, 2013). There are also, several studies on practice patterns of paediatric nurses (Clayton et al., 2008; Vadaparampil et al., 2007).

The qualitative, single-centre survey performed in the United States, addressed oncology nurses' knowledge and attitudes to discussing FP with non-paediatric patients (King et al., 2008). Outcomes are comparable to those of our survey with only half of the nurses actually discussing FP methods with their patients, although most believed this to be part of their role (King et al., 2008). Similar to our findings, level of knowledge, time constraints and patient characteristics were mentioned as barriers. Some nurses participating in King et al.'s survey believed that the physician should initiate the FP discussion and let the nurse provide the follow-up care.

This study results indicate that the vast majority of the nurses consider addressing FP to be their task; practically all nurses consider it a task for the oncologists. The division of tasks might, however, be more subtle, as suggested by Garvelink et al. (2012). There is a difference between bringing up the subject and actually discussing FP options; a different individual could be responsible for each task. Every eligible patient should at least receive some informa-

tion about FP shortly after diagnosis. This could be provided by an oncology nurse, followed later by detailed information from a fertility expert.

In the Netherlands, the majority of FP clinics for female cancer patients are located in university hospitals, an interesting fact considering the difference in frequency of discussing FP between academic and non-academic nurses, especially as no difference in knowledge was reported. Apparently, the possibility of being able to refer a patient to a local fertility specialist increases the comfort in discussing fertility concerns. This phenomenon was also shown by a physician survey: the oncologists reported that the offer of FP was influenced by its local availability (Louwe et al., 2013). On the contrary, in the UK, 63% of the surveyed oncologists reported that the availability of fertility services is not a factor (Adams et al., 2013).

A complementary research topic is whether nurses' moral considerations can legitimately exert an influence when offering or withholding the discussion of FP. Such issues should not prevent patients from protecting their future ability to have a biological child, a view confirmed by a consensus among Dutch clinicians: personal opinions of clinicians as well as the hospital's general view should not influence the provision of information about FP (Garvelink et al., 2012). Every patient—whatever their condition, prognosis, family status or age—should at least be informed about the consequences of the treatment with regard to fertility impairment. Moral considerations due, for example, to religious or other beliefs, might, however, mean that not every healthcare provider is able to discuss this delicate subject. Possible reasons for withholding discussion on fertility issues and referral for FP are a delay in starting treatment, which in certain situations would not be advisable, and a poor prognosis. However, as the posthumous use of preserved material is legally accepted in the Netherlands, a poor prognosis should not be a reason for withholding information (Kalkman-Bogerd, Hendriks, & Egberts, 2006).

Strengths and limitations

As the recruitment procedure used a web-based survey and a personal approach during an oncology nursing congress, a response rate cannot be calculated. The results might represent an underestimation of practices due to a non-response bias, as oncology nurses with no affinity with the subject of FP may not have been motivated to participate. On the other hand, the survey method relies on self-report, which may have led to an overestimation of practices. Self-perceived knowledge rather than objective knowledge was measured. Although no validated instrument exists for assessing the discussion of FP by oncology nurses, serious attempts were made to develop an adequate, pilot-tested measuring instrument in the form of this questionnaire. The sample was restricted to a national Dutch setting. Although differences in culture and medical guidelines could affect the provision of FP counselling by oncology nurses, the comparative findings derived in a qualitative study from the US suggest that the results may be applicable in other Western countries (King et al., 2008).

The importance of FP counselling

Future parenthood is of considerable importance to survivors of cancer (Yee et al., 2012; Zebrack et al., 2004). Generally, 75% of patients of reproductive age diagnosed with cancer wish to have a biological child in the future (Schover et al., 1999) and according to Schover et al. (2002), 24% of childless men felt that having cancer had increased their wish to have children.

Currently, it is estimated that a reproductive specialist sees only 9.8%–61% of young women before they undergo cancer treatment (Bastings et al., 2014; Letourneau et al., 2012). About one-third of a group of young female cancer patients indicated that the discussion of fertility concerns was initiated by themselves, their friends or family rather than their health care providers (Yee et al., 2012). In Partridge's et al. (2004) paper, 29% of women reported that the fear of becoming infertile influenced their treatment decisions. As for young male patients, 51% had been offered sperm banking and 60% recalled being informed about infertility as a side-effect of cancer treatment (Schover et al., 2002). Evidence suggests that patients who were not informed about FP at the time of treatment initiation, might be angry and disappointed (Zebrack et al., 2004). It is, therefore, important to consider the effect of any proposed therapy, as well as which strategies exist to protect or restore fertility in later life.

The Dutch guideline on FP for male cancer patients specifically describes the role of the oncology nurse: if the medical history does not report a discussion on FP, the nurse is supposed to bring this to the attention of the physician (IKR-projectgroep Cryopreservatie van zaadcellen 2010). The practice of oncology nursing encompasses the roles of direct caregiver, educator and consultant and as oncology nurses interact more directly with patients and their families, they are in an excellent position to discuss FP and guide them to finding more information.

Implications for clinical practice

In the United States, an "onco-fertility" consortium is making significant attempts to overcome the lack of interface between clinicians in the field of oncology and fertility. In the Netherlands, there is a similar network on FP (Nederlands Netwerk Fertiliteitspreservatie). Collaboration within this type of network can facilitate education, improvement of guidelines and referral lists. A coordinated approach and more systematic infrastructures contribute to enhancement of availability of FP for all young cancer patients. Until there is an infrastructure for referral for FP which can be implemented in young oncology patients, we recommend that every oncology team appoints an individual who is confident to discuss these matters of responsibility for coordinating fertility counselling. A nurse or a nurse specialist is in a suitable position to take this responsibility and to check whether or not an FP discussion has taken place. Documenting the status of fertility discussions could reinforce the cooperation and interaction between doctors and nurses. Specific nursing guidelines concerning FP could be developed, clarifying how to deal with this issue and providing background information about FP options. Information sources for patients should become more widespread, referral lists easy to access, and should include contact information for both female and male patients.

In conclusion, less than half of oncology nurses are comfortable discussing fertility issues. The vast majority report limited knowledge about FP options, but do feel responsible for addressing FP, in cooperation with the oncologist. There is room for enhancing the practical role of oncology nurses in assisting with FP discussions and documentation; also, education aimed at facilitating FP discussions by nurses with patients should be extended or incorporated. Clinical practice guidelines could be accentuated, specifying the role of the nurse and the need to document discussions about referral for FP. Future studies should focus on the division of tasks within oncology departments and on the implementation of structured programmes ensuring FP issues are addressed at all times.

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