Cancer survivors' preference for follow-up care providers

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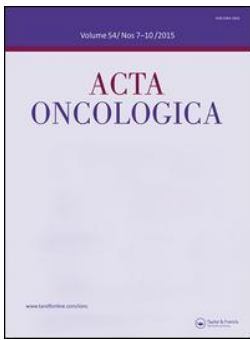
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ABSTRACT

Background: The best practice for the organization of follow-up care in oncology is under debate, due to growing numbers of cancer survivors. Understanding survivors' preferences for follow-up care is elementary for designing patient-centred care. Based on data from prostate cancer and melanoma survivors, this study aims to identify: 1) preferences for follow-up care providers, for instance the medical specialist, the oncology nurse or the general practitioner; 2) characteristics associated with these preferences and 3) the preferred care provider to discuss cancer-related problems.

Material and methods: Survivors diagnosed with prostate cancer (N = 535) and melanoma (N = 232) between 2007 and 2013 as registered in The Netherlands Cancer Registry returned a questionnaire (response rate was 71% and 69%, respectively). A latent class cluster model analysis was used to define preferences and a multinomial logistic regression analysis was used to identify survivor-related characteristics associated with these preferences.

Results: Of all survivors, 29% reported no preference, 40% reported a preference for the medical specialist, 20% reported a preference for both the medical specialist and the general practitioner and 11% reported a preference for both the medical specialist and the oncology nurse. Survivors who were older, lower/intermediate educated and women were more likely to have a preference for the medical specialist. Lower educated survivors were less likely to have a preference for both the medical specialist and the general practitioner. Overall, survivors prefer to discuss diet, physical fitness and fatigue with the general practitioner, and hereditary and recurrence with the medical specialist. Only a small minority favored to discuss cancer-related problems with the oncology nurse.

Conclusion: Survivors reported different preferences for follow-up care providers based on age, education level, gender and satisfaction with the general practitioner, showing a need for tailored follow-up care in oncology. The results indicate an urgency to educate patients about transitions in follow-up care.

Follow-up care plays an important role in detecting recurrence at an early stage, monitoring side effects, as well as in providing adequate psychosocial support [1]. Due to the growing numbers of cancer survivors, there is debate about the best organization of follow-up care in oncology to assure sufficient health staff and financial resources [2]. Cancer survivorship is accompanied by long-term functional, psychological, and physical side effects that negatively affect quality of life [3]. Both the Health Council of The Netherlands and the Dutch Cancer Society published a report about follow-up care in oncology, advocating the growing importance of oncology nurses and general practitioners in follow-up care [4,5]. These recommendations mainly resulted from financial and organizational arguments, rather than survivors' preferences and health benefits [6]. However, understanding survivors' preferences for follow-up care is elementary for designing patient-centred care, which is an important dimension of quality of care, defined by the World Health Organization.

According to a systematic review, including 10 practical guidelines and nine trials in breast, prostate, lung and colon

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cancer, there are indications that follow-up care provided by oncology nurses or general practitioners is equivalent in detecting recurrence compared to follow-up care provided by medical specialists [7]. Moreover, several reviews including trials in breast, prostate, lung, ovarian and colon cancer, suggest that psychological morbidity of cancer survivors is similar when receiving follow-up care from oncology nurses or general practitioners compared to medical specialists [8–10].

Regarding cancer survivors' preferences for follow-up care, some qualitative studies have been conducted showing conflicting results regarding cancer survivors' preferences for follow-up care provided by general practitioners or oncology nurses [11–13]. In general, it seems that cancer survivors prefer follow-up care provided by medical specialists instead of follow-up care provided by general practitioners or oncology nurses [11,13]. At the same time, cancer survivors favor the holistic approach of general practitioners, taking various aspects, such as long-term side effects and comorbid disorders, into account [12].

To our knowledge, few quantitative studies have assessed cancer survivors' preferences for follow-up care [14–17]. However, these quantitative studies neither identify survivor-related characteristics associated with survivors' preferences for follow-up care nor describe the preferred care provider to discuss cancer-related problems. To develop efficient and tailored follow-up care, insight in clinical, sociodemographic and psychosocial characteristics associated with survivors' preferences for follow-up care, is important [18]. Nevertheless, little attention has been devoted to survivor-related characteristics associated with survivors' preferences for follow-up care.

A study among breast cancer patients found that younger age and higher treatment intensity were associated with more frequent follow-up visits [18]. However, more studies on correlates of preferences for follow-up care providers are lacking. We hypothesized that age, education level, gender, number of comorbidities, cancer type, time since diagnosis, tumor stage, satisfaction with the general practitioner, physical functioning, role functioning and worry are also associated with survivors' preferences for follow-up care providers. We expected that women and those who are unsatisfied with their general practitioner prefer the oncology nurse, that survivors with worse functioning and more comorbidities prefer the general practitioner, and that younger, higher educated, and more worried survivors and survivors who are unsatisfied with their general practitioner or have more severe disease and treatment prefer the medical specialist, based on discussion with patients and care providers.

Based on data from prostate cancer and melanoma survivors, the aims of the current study are: 1) to define groups of survivors (clusters) with similar preferences for follow-up care providers (preference-profiles), for instance the medical specialist, the oncology nurse or the general practitioner; 2) to identify clinical (number of comorbidities, cancer type, time since diagnosis, tumor stage, treatment), sociodemographic (age, education level, gender) and psychosocial characteristics (satisfaction with the general practitioner, physical functioning, role functioning, worry) associated with these preference-profiles and 3) to describe the preferred care provider to discuss cancer-related problems.

Material and methods

Study design

For this cross-sectional study, a population-based sample was selected of survivors diagnosed with prostate cancer and melanoma between September 2007 and April 2013 as registered in The Netherlands Cancer Registry of the southern region of The Netherlands, as part of the Patient Reported Outcomes Following Initial treatment and Long-term Evaluation of Survivorship registry (PROFILES). Data were obtained from the questionnaires and The Netherlands Cancer Registry.

Participants

Prostate cancer and melanoma survivors were included, as the study was part of a broader guideline development and implementation project. The project focused on these survivor groups because the cancer types were meaningful model groups.

Prostate cancer survivors receive follow-up appointments six weeks, and three, six and 12 months after treatment [19]. Further, they receive follow-up appointments every six months during three years and every year during 5–10 years [19]. Survivors with stage 0, stage I or stage IA melanoma receive just one follow-up appointment one month after treatment, while survivors with stage IB or higher receive at least nine follow-up appointments during at least five years after diagnosis, according to the current Dutch guideline [20].

Survivors with stage 1–4 prostate cancer or survivors with all stages of melanoma were eligible, but excluding those with a diagnosis of prostate cancer during surgery for bladder cancer as these survivors may not always have been aware of prostate cancer. Other inclusion criteria were: having been diagnosed between September 2007 and April 2013, being between 18 and 85 years of age at time of survey, and being able to read the Dutch language.

Procedure and ethical considerations

By returning the informed consent form and the questionnaire, survivors agreed to participate in the study. Data-collection took place in 2014–2015 with use of the PROFILES-registry. PROFILES is a registry for the study of the physical and psychosocial impact of cancer and its treatment from a dynamic, growing population-based cohort of cancer survivors. Data obtained from PROFILES was linked directly to data from The Netherlands Cancer Registry to obtain clinical and sociodemographic characteristics. Non-respondents were sent a reminder letter and a questionnaire within two months. The procedures followed were in accordance with the ethical standards of the responsible committee on

human experimentation and with the Helsinki Declaration of 1975, as revised in 1983.

Measures

Clinical and sociodemographic characteristics

Clinical and sociodemographic characteristics, including time since diagnosis, tumor stage, Gleason-score (prostate cancer), treatment, age and gender were obtained from The Netherlands Cancer Registry. Education level and marital status were obtained from the questionnaires. Number of comorbidities was a continuous variable measured by the validated Self-Administered Comorbidity Questionnaire (SCQ) [21]. It consists of 15 questions regarding comorbid disorders.

Psychosocial characteristics

Satisfaction with the general practitioner was assessed by asking: 'How satisfied were you/are you with the general practitioner during your illness?' The answer categories were rated on a five-point Likert-scale ranging from 'very satisfied' to 'very unsatisfied'.

Physical functioning and role functioning during last week at time of survey, were measured by the validated EORTC-QLQ-C30 version 3.0 questionnaire [22]. The answer categories were rated on a four-point Likert-scale ranging from 'not at all' to 'very much'. Responses were transformed to a 0–100 linear scale, with higher scores indicating a higher level of functioning.

Social support was measured by the validated Multidimensional Scale of Perceived Social Support (MSPSS) questionnaire [23]. It consists of 12 statements, such as: 'There is a special person who is around when I am in need'. The answer categories were rated on a seven-point Likert-scale ranging from 'entirely disagree' to 'entirely agree'. The score for social support was obtained by calculating the mean score of the 12 questions.

Worry was assessed with the 'worry' scale of the Impact of Cancer version 2.0 (IOCv2) questionnaire [24]. The 'worry' scale consists of seven statements, such as: 'I worry about my health' [24]. The answer categories were rated on a five-point Likert-scale ranging from 'strongly disagree' to 'strongly agree'. The score for worry was obtained by calculating the mean score of the seven questions.

Perceived competence of care providers to provide follow-up care

The perceived competence of care providers to provide follow-up care was a continuous variable assessed using three self-developed statements: 'Follow-up care in oncology could be provided by the medical specialist', 'Follow-up care in oncology could be provided by the oncology nurse' and 'Follow-up care in oncology could be provided by the general practitioner'. The answer categories were rated on a five-point Likert-scale ranging from 'strongly agree' to 'strongly disagree'. The statements were discussed with two groups of six patients and cognitive walkthroughs with five individual patients. Prior to the study, survivors were not specifically informed about the competence of care providers to provide follow-up care.

Preferred care provider to discuss cancer-related problems

The preferred care provider to discuss cancer-related problems, such as weight and sexuality was assessed using 17 self-developed statements. The preferred care provider was assessed by asking: 'If you were confronted with the following cancer-related problem, which care provider do you prefer to discuss the cancer-related problem?' The answer categories were: medical specialist; oncology nurse; general practitioner; other (i.e. patient organization and other as answering category) and not applicable. More than one mark was acceptable. The statements were discussed with two groups of six patients and cognitive walkthroughs with five individual patients.

Statistical analyses

Statistical analyses were conducted using Statistical Analysis System (SAS) version 9.4 (SAS Institute, Cary, NC, USA, 1999). p-Values of <0.05 were considered statistically significant and p-values were from two-sided tests. Differences in characteristics between survivors with prostate cancer and survivors with melanoma were compared using an independent t-test, a Pearson's χ^2-test or a Fisher's exact test. Missing values in the statements regarding perceived competence of care providers to provide follow-up care were mean imputed if one or two statements consisted of missing values. If three statements consisted of missing values, the survivor was excluded from statistical analyses.

Latent class cluster model analysis

To define groups of survivors (clusters) with similar preferences for follow-up care providers (preference-profiles) to provide follow-up care, a latent class cluster model analysis was conducted. Statements regarding perceived competence of care providers to provide follow-up care were used for latent class cluster model analysis. Latent class modeling is a data-driven approach, which aims to obtain the smallest number of groups of survivors (clusters) who responded similarly to the three statements regarding perceived competence of care providers to provide follow-up care [25]. This result in each cluster resembling a preference-profile that could be distinguished within the data. The optimal number of clusters is derived based on goodness-of-fit statistics [25]. The five-cluster model was selected as best fitting. Statistical analyses were conducted with Latent GOLD version 5.1.0 (Statistical Innovations Inc., Belmont, MA, USA). Details of the selection procedure are described in the Appendix.

Multinomial logistic regression analysis

To identify clinical, sociodemographic and psychosocial characteristics associated with these preference-profiles, a multinomial logistic regression analysis was conducted. These

preference-profiles were obtained from the latent class cluster model analysis and were dependent variables. A priori, a selection was made of independent variables which may be included in the multinomial logistic regression analysis. According to univariate logistic regression analyses, age, education level, gender, cancer type, satisfaction with the general practitioner, physical functioning and role functioning were significantly associated with preference-profiles, while number of comorbidities, time since diagnosis, tumor stage, treatment and worry were not significantly associated with preference-profiles. Number of comorbidities and worry were kept as we had strongly hypothesized their association with survivors' preferences for follow-up care. Interaction terms with cancer type were created for all independent variables to assess whether the association between independent variables and the preference-profile was different in prostate cancer and melanoma survivors.

Results

Survivor-related characteristics

Response rate was 557 (71%) and 245 (69%) (N prostate cancer = 787; N melanoma = 367) (Figure 1). Most survivors were educated at intermediate level (39%), had a partner (84%)

and had two or more comorbidities (45%). Of all prostate cancer survivors, 28% were under active surveillance or watchful waiting policy. Compared to survivors with prostate cancer, survivors with melanoma were younger, had a higher level of physical functioning and role functioning, perceived more social support and were less worried (Table 1).

Perceived competence of care providers to provide follow-up care

The perceived competence of care providers to provide follow-up care is higher for medical specialists (M = 1.3; SD = 0.7) than for oncology nurses (M = 2.7; SD = 1.3) and general practitioners (M = 3.1; SD = 1.3) (Table 2).

Develop preference-profiles using latent class cluster model analysis

A five-cluster model had the best possible fit of the data (Appendix 1). Of all survivors, 29% reported no preference, 40% reported a preference for the medical specialist, 20% reported a preference for both the medical specialist and the general practitioner and 11% reported a preference

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┌─────────────────────────────┐        ┌─────────────────────────────┐
│ 10158 survivors were        │        │ In case both tumours were   │
│ registered with prostate    │        │ diagnosed, the most recent  │
│ cancer (7581) or melanoma   │───────▶│ tumour was selected:        │
│ (2577) between September    │        │ - 11 survivors had prostate │
│ 1st 2007 and April 1st 2013.│        │   cancer first (excluded for│
│                             │        │   prostate cancer)          │
│                             │        │ - 9 survivors had melanoma  │
│                             │        │   first (excluded for       │
│                             │        │   melanoma)                 │
└─────────────────────────────┘        └─────────────────────────────┘
              │
              ▼
┌─────────────────────────────┐        ┌─────────────────────────────┐
│ 10138 survivors selected:   │        │ 1742 survivors deceased:    │
│ - 7570 prostate cancer      │───────▶│ - 1364 prostate cancer      │
│ - 2568 melanoma             │        │ - 378 melanoma              │
└─────────────────────────────┘        └─────────────────────────────┘
              │
              ▼
┌─────────────────────────────┐        ┌─────────────────────────────┐
│ 8396 survivors were still   │        │ - 3 hospitals declined      │
│ alive in April 2013 (6206   │        │   (N=273) for melanoma      │
│ prostate cancer; 2190       │        │ - Excluded: 132 prostate    │
│ melanoma). A random         │───────▶│   cancer (28 no consent     │
│ selection was made selecting│        │   doctor, 36 deceased, 68   │
│ 1615 survivors (919 prostate│        │   other reasons); 56        │
│ cancer; 696 melanoma).      │        │   melanoma (11 no consent   │
│                             │        │   doctor, 15 deceased, 30   │
│                             │        │   other reasons)            │
└─────────────────────────────┘        └─────────────────────────────┘
              │
              ▼
┌─────────────────────────────┐        ┌─────────────────────────────┐
│ A questionnaire was sent to │        │ 352 non-completion          │
│ 1154 survivors:             │        │ survivors:                  │
│ - 787 prostate cancer       │───────▶│ - 230 prostate cancer       │
│ - 367 melanoma              │        │ - 122 melanoma              │
└─────────────────────────────┘        └─────────────────────────────┘
              │
              ▼
┌─────────────────────────────┐        ┌─────────────────────────────┐
│ Survivors included in the   │        │ 35 survivors excluded (they │
│ study:                      │        │ did not fill in questions   │
│ - Prostate cancer: 557 (71%)│───────▶│ about the care providers):  │
│ - Melanoma: 245 (67%)       │        │ - 22 prostate cancer        │
│                             │        │ - 13 melanoma               │
└─────────────────────────────┘        └─────────────────────────────┘
              │
              ▼
┌─────────────────────────────┐
│ 767 survivors remained for  │
│ analyses:                   │
│ - 535 prostate cancer       │
│ - 232 melanoma              │
└─────────────────────────────┘
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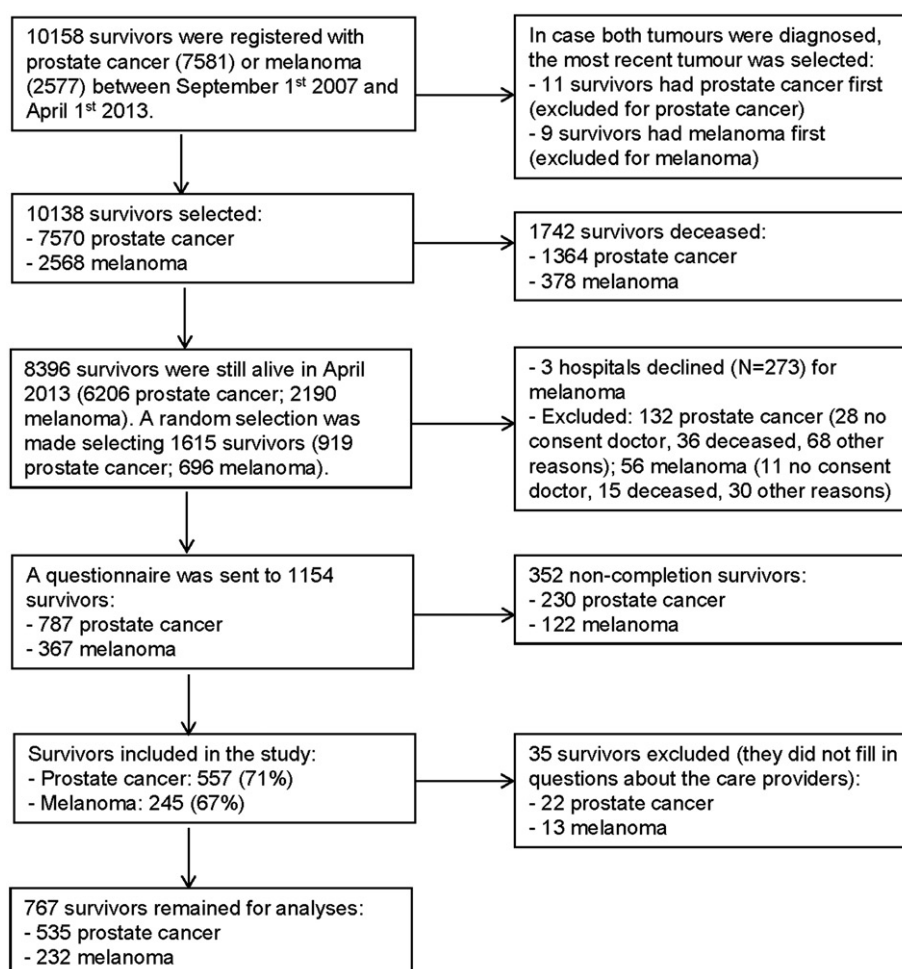
Figure 1. Flow-chart of the data-collection process. Results from the PROFILES follow-up care study among melanoma and prostate cancer survivors in 2014–2015 in The Netherlands.

for both the medical specialist and the oncology nurse (Table 3).

Characteristics associated with preference-profiles

Survivors who were older were significantly more likely to have a preference solely or mostly for the medical specialist compared to having no preference [cluster 2 vs. 1, OR 1.03 (CI 1.001;1.05); cluster 4 vs. 1, OR 1.11 (CI 1.07;1.14)].

Lower educated survivors compared to higher educated survivors were significantly less likely to have a preference for both the medical specialist and the general practitioner compared to having no preference [cluster 3 vs. 1, OR 0.38 (CI 0.21;0.69)]. Lower educated survivors and intermediate educated survivors compared to higher educated survivors were significantly more likely to have a preference mostly for the medical specialist compared to having no preference [cluster 4 vs. 1, OR 4.49 (CI 1.98;10.16); OR 2.73 (CI 1.18;6.29)].

Table 1. Clinical, sociodemographic and psychosocial characteristics of the study population according to cancer type. Results from the PROFILES follow-up care study among melanoma and prostate cancer survivors in 2014–2015 in The Netherlands.

	Total N = 767	Prostate cancer N = 535	Melanoma N = 232	p-Value*
Age (M, SD)	68.1 (11.1)	71.7 (7.5)	59.9 (13.4)	<0.01
Education level (N, %)				0.03
Low	243 (32)	185 (36)	58 (25)	
Intermediate	291 (39)	193 (37)	98 (43)	
High	215 (29)	143 (27)	72 (32)	
Marital status (N, %)				0.27
Partner	640 (84)	452 (85)	188 (82)	
No partner	119 (16)	78 (15)	41 (18)	
Gender (N, %)				
Male	640 (83)	535 (100)	105 (45)	
Female	127 (17)		127 (55)	
Number of comorbidities (N, %)				0.01
No comorbidities	187 (25)	114 (21)	73 (31)	
1 comorbidity	229 (30)	166 (31)	63 (27)	
$\geq$2 comorbidities	347 (45)	251 (47)	96 (41)	
Years since diagnosis				0.22
Median, range	4.3 (1.8–8.1)	4.3 (1.8–8.1)	4.3 (2.0–7.9)	
<2 years (N, %)	17 (2)	15 (3)	2 (1)	
2–5 years (N, %)	481 (63)	331 (62)	150 (65)	
>5 years (N, %)	269 (35)	189 (35)	80 (34)	
Tumor stage (N, %)				<0.01
T_1	337 (45)	158 (30)	179 (79)	
T_2	259 (34)	225 (42)	34 (15)	
T_3	108 (14)	97 (18)	11 (5)	
$T_4/N_+/M_+$	53 (7)	51 (10)	2 (1)	
Gleason-score (N, %)				
$\leq$5		25 (5)		
6		240 (45)		
7		168 (31)		
$\geq$8		102 (19)		
Treatment (N, %)				
Surgery		168 (31)	232 (100)	
Radiotherapy		71 (13)		
Hormonal therapy		51 (10)		
Radiotherapy + hormonal therapy		89 (17)		
Unknown		8 (2)		
No therapy		148 (28)		
Active surveillance		136 (92)		
Watchful waiting		9 (6)		
Unknown		3 (2)		
Satisfaction with the GP (N, %)				0.79
Satisfied	636 (84)	445 (84)	191 (83)	
Unsatisfied	125 (16)	86 (16)	39 (17)	
HRQoL (0–100) (M, SD)				
Physical functioning[a]	86.8 (18.8)	84.8 (19.6)	91.2 (15.9)	<0.01
Role functioning[a]	84.9 (25.2)	83.0 (26.4)	89.0 (21.6)	<0.01
Social support (1–7)[b] (M, SD)	5.4 (1.4)	5.3 (1.4)	5.6 (1.2)	<0.01
Worry (1–5)[b] (M, SD)	2.4 (1.0)	2.4 (1.1)	2.3 (1.0)	0.03

The numbers will not always add up to 100, because percentages have been rounded off to whole numbers.
Education level included low = primary education or less, or secondary education; intermediate = intermediate vocational level; high- = higher vocational level or university.
Marital status included partner = married or living together; no partner = divorced, widowed or never married.
Satisfaction with the GP included satisfied = very satisfied or satisfied; unsatisfied = neither satisfied nor unsatisfied, unsatisfied or very unsatisfied.
*Independent t-tests and χ^2-tests;
[a]A higher score represents a higher level of functioning;
[b]A higher score represents a stronger endorsement of that content area.
GP: general practitioner; HRQoL: health-related quality of life.

Table 2. Perceived competence of care providers to provide follow-up care according to the study population. Results from the PROFILES follow-up care study among melanoma and prostate cancer survivors in 2014–2015 in The Netherlands.

	Strongly agree (N, %)	Agree (N, %)	Neither agree nor disagree (N, %)	Disagree (N, %)	Strongly disagree (N, %)	(M, SD)
Medical specialist	572 (76)	146 (19)	21 (3)	11 (1)	4 (1)	1.3 (0.7)
Oncology nurse	119 (19)	177 (29)	154 (25)	102 (17)	66 (11)	2.7 (1.3)
General practitioner	85 (14)	123 (20)	158 (25)	161 (26)	99 (16)	3.1 (1.3)

Table 3. Mean scores for cluster models. Results from the PROFILES follow-up care study among melanoma and prostate cancer survivors in 2014–2015 in The Netherlands.

	Cluster 1 'no preference' N = 225; 29%	Cluster 2 'preference solely for medical specialist' N = 175; 23%	Cluster 3 'preference for both medical specialist and GP' N = 153; 20%	Cluster 4 'preference mostly for medical specialist' N = 128; 17%	Cluster 5 'preference for both medical specialist and oncology nurse' N = 86; 11%
Medical specialist $(1-5)^a$	1.36	1.22	1.58	1.12	1.20
Oncology nurse $(1-5)^a$	1.65	4.08	3.28	2.69	1.67
General practitioner $(1-5)^a$	2.14	4.40	2.36	3.09	4.32

[a]A higher score represents a higher level of disagreement.

Women were significantly more likely to have a preference solely for the medical specialist compared to having no preference [cluster 2 vs. 1, OR 2.17 (CI 1.01;4.68)].

Survivors being unsatisfied with the general practitioner compared to survivors being satisfied with the general practitioner were significantly more likely to have a preference solely for the medical specialist [cluster 2 vs. 1, OR 2.71 (CI 1.52;4.83)], for both the medical specialist and the general practitioner [cluster 3 vs. 1, OR 2.01 (CI 1.07;3.75)] and for both the medical specialist and the oncology nurse [cluster 5 vs. 1, OR 2.87 (CI 1.45;5.68)] compared to having no preference (Table 4). Interaction terms with cancer type for all independent variables were not statistically significant.

Preferred care provider to discuss cancer-related problems

Most survivors prefer to discuss diet, weight, physical fitness, fatigue, relationship with children, relationship difficulties and sexuality with the general practitioner (41–66%). The majority prefer to discuss hereditary and recurrence with the medical specialist (64–76%). Only a small minority (<10%) favored to discuss cancer-related problems with the oncology nurse. The results for sexuality, erectile dysfunction or menopausal symptoms, return to work and inability to work were statistically significant different between prostate cancer survivors and melanoma survivors (Table 5).

Discussion

In this study among prostate cancer and melanoma survivors, five preference-profiles were defined. Of all survivors, 29% reported no preference, 40% reported a preference for the medical specialist, 20% reported a preference for both the medical specialist and the general practitioner and 11% reported a preference for both the medical specialist and the oncology nurse. Survivors who were older, lower or intermediate educated and women were more likely to have a preference for the medical specialist, whereas lower educated

survivors were less likely to have a preference for both the medical specialist and the general practitioner. Survivors being unsatisfied with the general practitioner were most likely to have a preference for the medical specialist and for both the medical specialist and the oncology nurse. Surprisingly, they were also likely to have a preference for both the medical specialist and the general practitioner. Results also showed that survivors prefer to discuss psychosocial cancer-related problems with the general practitioner, and hereditary and recurrence with the medical specialist. Only a small minority favored to discuss cancer-related problems with the oncology nurse.

In line with previous research, the highest proportion of the survivors reported a preference for the medical specialist [14–17]. Previous research shows that survivors rate follow-up care provided by oncology nurses higher than follow-up care provided by general practitioners [16,17]. However, the current study found that preference for the oncology nurse was less mentioned compared to preference for the general practitioner. Differences might be explained by the fact that survivors were not specifically informed about the competence of care providers to provide follow-up care. Systematic reviews showed that cancer survivors were satisfied with follow-up care provided by oncology nurses and general practitioners [9,10]. This indicates that unfamiliarity with oncology nurses and general practitioners lead to lower perceived competence of the respective care providers. Differences in results might be explained by variation in healthcare systems. In The Netherlands, follow-up care is provided by medical specialists and oncology nurses in hospitals, and generally not by general practitioners in general practices [6]. Every individual has its own general practitioner who can be assessed free of charge in the individuals' own community. Further, general practitioners in The Netherlands are gate keepers for secondary care. At time of study, oncology nurses were generally not involved in daily clinical practice of prostate cancer and melanoma survivors in The Netherlands.

To our knowledge, the current study is the first study which identifies characteristics associated with preference-

Table 4. Descriptive statistics of clinical, sociodemographic and psychosocial characteristics by preference-profile and the result of the multinomial logistic regression analysis evaluating the association between preference-profiles and clinical, sociodemographic and psychosocial characteristics. Results from the PROFILES follow-up care study among melanoma and prostate cancer survivors in 2014 − 2015 in The Netherlands.

	Cluster 1 'no preference'	Cluster 2 'preference solely for medical specialist'	Cluster 3 'preference for both medical specialist and GP'	Cluster 4 'preference mostly for medical specialist'	Cluster 5 'preference for both medical specialist and oncology nurse'	Cluster 2 versus cluster 1 OR ±95% CI	Cluster 3 versus cluster 1 OR ±95% CI	Cluster 4 versus cluster 1 OR ±95% CI	Cluster 5 versus cluster 1 OR ±95% CI
Age (M, SD)	66.7 (11.2)	66.7 (11.2)	66.8 (11.0)	75.2 (6.9)	66.4 (11.8)	**1.03 (1.001;1.05)***	1.02 (0.996;1.05)	**1.11 (1.07;1.14)***	1.01 (0.98;1.04)
Education level (N, %)									
Low	73 (33)	48 (27)	27 (18)	66 (56)	29 (34)	0.71 (0.41;1.23)	**0.38 (0.21;0.69)***	**4.49 (1.98;10.16)***	1.01 (0.51;2.02)
Intermediate	88 (40)	69 (39)	61 (41)	40 (34)	33 (38)	0.83 (0.50;1.37)	0.74 (0.45;1.22)	**2.73 (1.18;6.29)***	0.97 (0.51;1.87)
High	61 (27)	58 (33)	60 (41)	12 (10)	24 (28)	Ref	Ref	Ref	Ref
Gender (N, %)									
Male	198 (88)	135 (77)	129 (84)	110 (86)	68 (79)	Ref	Ref	Ref	Ref
Female	27 (12)	40 (23)	24 (16)	18 (14)	18 (21)	**2.17 (1.01;4.68)***	0.91 (0.40;2.04)	2.58 (0.85;7.83)	2.76 (0.997;7.64)
Number of comorbidities (M, SD)	1.6 (1.5)	1.7 (1.5)	1.5 (1.5)	2.0 (1.6)	1.6 (1.5)	1.11 (0.94;1.30)	0.92 (0.77;1.09)	1.02 (0.85;1.23)	1.06 (0.87;1.29)
Cancer type (N, %)									
Melanoma	59 (26)	66 (38)	54 (35)	27 (21)	26 (30)	Ref	Ref	Ref	Ref
Prostate cancer	166 (74)	109 (62)	99 (65)	101 (79)	60 (70)	0.72 (0.38;1.36)	0.53 (0.28;1.000)	0.79 (0.32;1.95)	1.19 (0.48;2.92)
Satisfaction with the GP (N, %)									
Satisfied	200 (89)	131 (76)	126 (82)	115 (93)	64 (74)	Ref	Ref	Ref	Ref
Unsatisfied	25 (11)	42 (24)	27 (18)	9 (7)	22 (26)	**2.71 (1.52;4.83)***	**2.01 (1.07;3.75)***	0.79 (0.33;1.89)	**2.87 (1.45;5.68)***
HRQoL (0–100) (M, SD)									
Physical functioning[a]	86.5 (19.6)	90.3 (14.9)	87.3 (19.8)	80.7 (20.0)	88.0 (18.2)	1.02 (0.997;1.03)	0.99 (0.97;1.01)	1.01 (0.99;1.03)	1.004 (0.98;1.03)
Role functioning[a]	83.4 (26.3)	88.2 (21.1)	87.4 (23.5)	78.3 (28.4)	86.6 (26.2)	1.004 (0.99;1.02)	1.01 (0.997;1.02)	0.995 (0.98;1.01)	1.01 (0.99;1.02)
Worry (1–5)[b] (M, SD)	2.3 (1.1)	2.4 (0.9)	2.4 (1.0)	2.5 (1.0)	2.4 (1.2)	1.12 (0.90;1.40)	1.10 (0.88;1.38)	1.18 (0.90;1.54)	1.06 (0.81;1.40)

The numbers will not always add up to 100, because percentages have been rounded off to whole numbers.
Satisfaction with the GP included satisfied = very satisfied or satisfied; unsatisfied = neither satisfied nor unsatisfied, unsatisfied or very unsatisfied.
*p < 0.05;
[a]A higher score represents a higher level of functioning;
[b]A higher score represents a stronger endorsement of that content area.
GP: general practitioner; HRQoL: health-related quality of life.
All significant findings are indicated with an asterisk.

Table 5. Preferred care provider to discuss cancer-related problems according to the study population. Results from the PROFILES follow-up care study among melanoma and prostate cancer survivors in 2014–2015 in The Netherlands.

	Care provider (N, %)				
	Medical specialist	Oncology nurse	General practitioner	Other*	Not applicable (N, %)
Diet	193 (37)	52 (10)	240 (46)	32 (6)	188 (27)
Weight	154 (31)	26 (5)	297 (59)	23 (5)	198 (28)
Physical fitness	136 (32)	18 (4)	239 (56)	31 (7)	273 (39)
Physical activity	170 (45)	10 (3)	191 (50)	10 (3)	320 (46)
Fatigue	249 (46)	9 (2)	281 (52)	6 (1)	152 (22)
Relationship with children	59 (18)	11 (3)	179 (55)	76 (23)	371 (53)
Relationship difficulties	79 (20)	7 (2)	218 (56)	87 (22)	312 (44)
Sexuality					
Prostate cancer	171 (48)	5 (1)	145 (41)	32 (9)	129 (27)
Melanoma	22 (18)		79 (66)	19 (16)	95 (44)
Erectile dysfunction or menopausal symptoms					
Prostate cancer	235 (64)	8 (2)	111 (30)	14 (4)	113 (23)
Melanoma	40 (35)	1 (1)	69 (61)	4 (4)	104 (48)
Return to work					
Prostate cancer	33 (37)	5 (6)	39 (43)	13 (14)	392 (81)
Melanoma	15 (21)		37 (51)	21 (29)	144 (66)
Inability to work					
Prostate cancer	41 (41)	2 (3)	45 (45)	13 (13)	381 (79)
Melanoma	23 (29)		34 (43)	20 (25)	139 (64)
Hereditary	296 (64)	3 (1)	155 (33)	9 (2)	233 (33)
Recurrence	440 (76)	6 (1)	132 (23)	3 (1)	126 (18)
Coping with anxiety	99 (23)	11 (3)	271 (62)	56 (13)	269 (38)
Religion/spirituality	25 (12)	4 (2)	67 (33)	109 (53)	495 (71)
Alternative medicine	55 (22)	6 (2)	120 (48)	67 (27)	453 (65)

The numbers will not always add up to 100, because percentages have been rounded off to whole numbers. Other includes patient's organization and other as answering option.
The results were stratified if the results were statistically significant different between prostate cancer survivors and melanoma survivors.

profiles among cancer survivors. However, a systematic review on patient characteristics as predictors of primary healthcare preferences outside oncology has been conducted among all types of patients [26]. This review showed that older patients preferred the general practitioner rather than the medical specialist [26]. Besides, women preferred nurses opposed to doctors for consultation [26]. Differences between our findings and the review findings may be explained by the assumption that cancer survivors treated by the medical specialist are familiar with the medical specialist and therefore less likely to prefer the oncology nurse or the general practitioner. In line with our results, the review showed that lower educated survivors preferred a traditional care provider and were less involved in information seeking processes [26]. Surprisingly, in our study, survivors being unsatisfied with the general practitioner were more likely to have a preference for both the medical specialist and the general practitioner rather than a preference mostly for the medical specialist. This may be caused by the dichotomization of the variable 'satisfaction with the general practitioner', which originally held five answer categories. 'Neither satisfied nor unsatisfied' was dichotomized into 'unsatisfied'. However, these survivors may have less negative evaluations regarding the general practitioner than the unsatisfied group or might have mixed experiences.

To our knowledge, the current study is the first study which describes the preferred care provider to discuss cancer-related problems. However, studies among adolescent cancer survivors on preferences for follow-up care showed that medical aspects, such as recurrence were perceived as more important than general aspects, such as sexuality [14,17]. These outcomes confirm the reported preference for the medical specialist to provide follow-up care. A study on primary healthcare utilization among women with a history of breast cancer showed that during the first year of follow-up more patients than controls had face-to-face contacts for psychological reasons with the general practitioner [27]. These outcomes confirm that survivors prefer to discuss psychosocial cancer-related problems with the general practitioner.

Despite the growing importance of oncology nurses in follow-up care in oncology, only a small minority favored to discuss cancer-related problems with the oncology nurse. This may be due to the low number of oncology nurses involved in follow-up care for survivors with prostate cancer and melanoma. Currently, oncology nurses are increasingly involved in daily clinical practice, which might change patients' perceptions regarding perceived competence of oncology nurses to provide follow-up care.

A limitation of the current study is that the perceived competence of care providers to provide follow-up care, may be biased by whom the survivors' follow-up care was provided. Second, immunotherapy (ipilimumab) and targeted therapy (vemurafenib) were not registered. Noticeably, none of the survivors received chemotherapy (dacarbazine) in our study population. Third, selection bias may occur as a result of non-participation and illiteracy of a part of the Dutch population which could influence the validity of the results. Further, due to the variety of time since diagnosis, it is possible that survivors answered the statements based on experiences or based on expectations which could have led to variation in answers. Also, results regarding gender may be less valuable because women were a minority in the study population and only represented among melanoma survivors.

However, women were represented in all preference-profiles. Moreover, according to the number of cases in the smallest preference-profile (N = 86) and the rule of thumb of 10 cases per independent variable, a maximum of eight independent variables was allowed in the multinomial logistic regression analysis [28]. We chose to include 10 independent variables because recent literature on this topic suggests that 5–9 events per independent variable may be sufficient. Finally, from cross-sectional studies, we cannot conclude about any changes in outcomes and associations over time.

A strength of the current study is the high response rate of both survivors with prostate cancer and survivors with melanoma. Further, the current study has a large population-based study sample which supports extrapolating the findings to the target population. Finally, the latent class cluster model analysis provides the opportunity to define different clusters of survivors with preferences, rather than assessing overall preferences in a population.

Differences in survivor-related characteristics associated with preference-profiles emphasize the need for developing tailored follow-up care. As we considered the low perceived competence of oncology nurses being related to unfamiliarity, urologists and dermatologists working in oncology should make cancer survivors familiar with the expertise of oncology nurses. A patient-centred follow-up care system in which survivors can make informed decisions may be desirable. In that case, additional education of general practitioners and oncology nurses might be required.

Further research is needed to compare the findings in cancer types familiar with oncology nurses. In addition, a prospective cohort study on patient satisfaction and quality of follow-up care provided by medical specialists, oncology nurses and general practitioners would be valuable. Further, the reason why cancer survivors have little trust in the oncology nurse and in the general practitioner requires further investigation.

In conclusion, the majority of medium- to long-term prostate cancer and melanoma survivors neither reported a preference for a specific care provider nor reported a preference for the medical specialist for follow-up care. These preferences vary according to survivors' sociodemographic characteristics and satisfaction with the general practitioner. It depends on the cancer-related problem which care provider patients prefer, showing the need for developing tailored follow-up care in oncology. The results indicate an urgency to educate patients about transitions in follow-up care.

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Appendix

Latent class cluster model analysis

To define groups of survivors (clusters) with similar preferences for follow-up care providers (preference-profiles) to provide follow-up care, a latent class cluster model analysis was conducted. Statements regarding perceived competence of care providers to provide follow-up care were used for latent class cluster model analysis. Latent class modeling is a data-driven approach, which aims to obtain the smallest number of groups of survivors (clusters) who responded similarly to the three statements regarding perceived competence of care providers to provide follow-up care [25]. This result in each cluster resembling a preference-profile that could be distinguished within the data. The optimal number of clusters is derived based on goodness-of-fit statistics [25]. The likelihood ratio χ^2 statistic (L^2), the Akaike's Information Criterion (AIC), the Bayes' Information Criterion (BIC) and the Consistent Akaike's Criterion (CAIC) are statistics that can be used to assess how well the model fits the data [25]. The AIC, BIC and CAIC were obtained from the L^2. The L^2 was available because the outcome variables used for latent class cluster model analysis were measured on an ordinal scale. The larger the L^2, the AIC, the BIC and the CAIC, the poorer the model fits the data [25]. In addition, reduction in the L^2 compared to a one-cluster model was obtained. If the reduction is substantially higher compared to the reduction of the cluster model with one cluster less, the latent class cluster model has added value. The standard R-squared (R^2) is a classification statistic [25]. The closer the value is to one, the better predictions. The L^2, AIC, BIC, CAIC, the reduction in L^2 compared to a one-cluster model and the R^2 were used to obtain the optimal number of clusters. Statistical analyses were conducted with Latent GOLD version 5.1.0 (Statistical Innovations Inc., Belmont, MA, USA). Looking to the reduction in L^2 compared to a one-cluster model, a five-cluster model had a substantially higher decrease in the L^2 statistic compared to a four-cluster model. This indicates a substantial added value compared to a four-cluster model. Also, the standard R^2 of a five-cluster model was relatively high, 0.99. This indicates a low level of residual values. By taking into account all these conditions, the five-cluster model was selected as best fitting. Cluster analyses of prostate cancer and melanoma survivors separately showed a similar structure for prostate cancer survivors but a two cluster solution for melanoma survivors. As these two clusters of melanoma survivors were very similar as the first two clusters of prostate cancer survivors and because tumor type was not a significant predictor in the multinomial logistic regression analyses we decided to analyze both cancer types together to have a higher sample size which increased the possibilities in the regression analyses.

Goodness-of-fit statistics for cluster models.

Model	L^2 statistic	Reduction in L^2 compared to one-cluster model	Standard R^2	AIC*$_{LL}$	BIC*$_{LL}$	CAIC*$_{LL}$
One cluster	1370.287		1.0	6950.571	7034.135	7052.135
Two cluster	1220.436	10.9	0.68	6808.719	6910.854	6932.854
Three cluster	1155.919	15.6	0.69	6752.202	6872.907	6898.907
Four cluster	1117.509	18.4	0.84	6721.792	6861.067	6891.067
Five cluster	**729.799**	**46.7**	**0.99**	**6342.082**	**6499.927**	**6533.927**
Six cluster	708.359	48.3	0.94	6328.643	6505.057	6543.057
Seven cluster	695.967	49.2	0.90	6324.250	6519.235	6561.235
Eight cluster	609.538	55.5	0.94	6245.821	6459.376	6505.376
Nine cluster	467.427	65.9	0.92	6111.711	6343.835	6393.835
Ten cluster	428.288	68.7	0.93	6080.572	6331.266	6385.266

*AIC: Akaike's Information Criterion; BIC: Bayes' Information Criterion; CAIC: Consistent Akaike's Information Criterion; LL: log-likelihood.
Bold indicates the finding with the optimal fit.