



Physical and emotional health information needs and preferences of long-term prostate cancer survivors



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ARTICLE INFO

Article history:

Received 4 April 2016

Received in revised form 22 June 2016

Accepted 12 July 2016

Keywords:

Prostate cancer
Survivorship
Information needs
Treatment side effects
Sexual function
Emotional health

ABSTRACT

Objective: Many men diagnosed with prostate cancer (PC) will experience physical and psychosocial late effects of treatment. Their interest/preferences for receiving information about addressing common sequelae is not well understood. We examined long-term PC survivors' level of interest, whether this differed based upon symptomatology, and their preferred coping information source.

Methods: N=615 PC survivors (3–8 years post-diagnosis) completed a survey on physical and psychological health and their information interests and preferences related to late effects of cancer treatment.

Results: Over half of PC survivors reported interest in information about late effects of treatment or sexual health, while approximately a quarter were interested in emotional health information. Survivors preferred to receive information about late effects of treatment from their oncologists, sexual health information from their primary care providers (PCP), oncologist, or written/online resources, and emotional health information from their PCP. Information needs were more commonly reported among men with poorer domain-specific health functioning.

Conclusion: Long-term PC survivors report significant interest in receiving information about their physical, sexual, and emotional health.

Practice implications: Medical providers caring for these men should inquire about survivors' information needs and future intervention efforts should consider who delivers the information, dependent upon the type of dysfunction reported.

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1. Introduction

In 2015, over 220,000 Americans were diagnosed with prostate cancer (PC) making it the most common non-skin cancer in men. Improvements in early detection and treatment of PC have resulted in 5-year relative survival rates of almost 100% for those diagnosed with a localized disease [1]. However, curative treatments for PC (e.g., radical prostatectomy, radiation therapy, and hormonal therapy) are commonly associated with decrements to urinary,

bowel, and sexual functioning that can result in significant psychological distress [2,3].

There have been ongoing efforts to develop interventions that target the physical and psychosocial sequelae of PC that men commonly report following treatment. These programs include those seeking to improve stress management skills, relationship functioning, mood, and quality of life among other endpoints [4–8]. Researchers have tried to improve the availability of these interventions beyond the academic medical center setting by delivering these programs using telehealth, web portals, and non-doctoral level providers [8–12]. Though these attempts are well-intentioned, several recent systematic reviews of supportive care interventions for PC survivors have indicated that there is “a lack of robust evidence for supportive care interventions for men with prostate cancer” [13] due to significant limitations in study design and implementation [8,13].

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In particular, it is acknowledged that one size does not fit all when it comes to psychosocial interventions in chronic illness populations [14]. It is imperative to better understand what patients are interested in learning about, as well as how and from whom they would like to receive that information. Specifically in PC survivors, there are multiple issues that require attention as efforts are made to improve their long-term well-being. First, not all PC survivors report poor physical or emotional health [15] and recognizing those at risk can be challenging. Little is known about the degree to which PC survivors desire additional information about how to cope with the multiple individual domains of function that can be affected by treatment, such as sexual dysfunction or emotional disturbances. Secondly, despite evidence indicating that some PC survivors have unmet informational needs about coping with these side effects of treatment [16–18], it is unclear as to how these men prefer to receive this information about coping with their post-treatment sequelae. Research indicates that cancer patients are open to receiving information about their cancer-related care from a variety of sources [19,20], but there is a limited understanding of how PC survivors specifically want to receive information about their multiple needs, and from whom they wish to receive this information [21]. In the current study, we sought to improve our knowledge of the unique information needs and preferences of long-term PC survivors across three key domains (coping with the late effects of PC treatment, sexual dysfunction, and emotional health) by inquiring about their level of interest in receiving further coping information, whether their interest level was associated with their level of symptomatology, and their source of support preferences.

2. Methods

The current findings are part of a larger study querying demographics, medical history, and physical and emotional health. The survey was mailed to 979 PC survivors, 3–8 years post-diagnosis and who were seen for at least one medical visit at a comprehensive cancer center. A total of 707 men returned their survey, for a response rate of 72.2%. Our concerted efforts to achieve this level of participant response (e.g., use of Priority Mail, repeat survey mailings) are described elsewhere [22]. In the current study, we excluded participants who did not respond to items querying their information needs, resulting in a final sample of 615 PC survivors. Study responders did not significantly differ from non-responders ($p \geq 0.05$) on demographic (age, ethnicity, marital status, education, household income) or study outcome (SF-12 Physical and Emotional Quality of Life, EPIC-26 Sexual Domain) variables. Current study participants were an average of 66.9 years of age (range=47–91; SD=7.9), and 5.0 years post-diagnosis (SD=1.7). They were mostly Non-Hispanic males who were married, well-educated, and reported having a high household income. The majority of participants reported having had prostate surgery, among other treatments, and were an average of 5.0 years post-PC treatment. Some participants received PC treatment within the past 12 months (18.7%), with the majority undergoing hormonal therapy (12.3%). See Tables 1 and 2 for further information. The study protocol was approved by the cancer center's IRB. A full discussion of study recruitment and methodology has been previously reported [23,24].

Study participants provided demographic information about their age, marital status, ethnicity, education, and household income. To understand PC-related symptoms, participants responded to the EPIC-26, a 26 item questionnaire inquiring about symptoms associated with PC treatment in four domains (urinary, bowel, sexual and hormonal) [25]. Further, general health-related quality of life was assessed using the Short Form-12 (SF-12), which is a 12-item measure assessing the individuals'

Table 1
Prostate cancer survivor demographic profile.

	No.	Mean	Percent	Standard Deviation
Age (Years)	615	66.9		7.9
Ethnicity	612			
Non-Hispanic White	585		95.6%	
African-American	14		2.2%	
Other	13		2.1%	
Marital Status	614			
Married	540		87.9%	
Never Married	18		2.9%	
Divorced/Separated	35		5.7%	
Widowed	21		3.4%	
Education	614			
High school diploma or less	68		11.1%	
Some College	121		19.7%	
College Graduate	188		30.6%	
Post-Graduate	237		38.6%	
Household Income	595			
≤\$49,999	82		13.8%	
\$50,000–\$99,999	224		37.6%	
>\$100,000	289		48.6%	

Table 2
Prostate cancer survivor disease-specific and quality of life profile.

	No.	Mean	Percent	Standard Deviation
Time Since Diagnosis (Years)	615	5.0		1.7
Prostate Surgery	609			
Yes	350		57.5%	
No	259		42.5%	
Radiation Therapy	611			
Yes	294		48.1%	
No	317		51.9%	
Hormonal Therapy	610			
Yes	224		36.7%	
No	386		63.3%	
Chemotherapy	610			
Yes	51		8.4%	
No	559		91.6%	
EPIC-26 Prostate Treatment Specific				
Sexual Domain	603	31.8		28.1
Bowel Domain	604	93.4		12.6
Hormonal Domain	603	89.4		14.4
Urinary Incontinence	606	80.3		24.0
Urinary Irritative	600	90.6		11.8
SF-12 Quality of Life				
Physical	597	50.3		9.1
Emotional	597	53.2		8.7

health status in both the physical and emotional domains [26]. The SF-12 and EPIC-26 have been validated and used extensively in studies examining health outcomes for PC survivors [27] (Table 2).

Each participant's health information needs were assessed by asking them to indicate their level of interest in receiving information about 1) "Coping with side effects of prostate cancer therapy," 2) "Sexual health and function," and 3) "Emotional health (including depression, anxiety, and alcohol/drug use" with options being "Not at all," "A little bit," "Somewhat," and "Very much." They were then asked to indicate their first choice for how they would prefer to receive each type of information, with 7 options including in-person conversations with their primary care provider (PCP),

oncologist, or nurse, a written information handout, a website, or phone calls from another survivor or a professional counselor.

Descriptive statistics describing the PC survivors' demographic, medical, and health variables were calculated. Their level of interest and source preference for receiving further information about their treatment-related, sexual, and emotional health was tabulated. Confidence intervals were calculated to provide further information regarding the proportion of individuals reporting interest and preferences for different sources of information. To further clarify their interest in receiving health information, we conducted chi-square tests to determine whether men who reported a higher level of symptomatology also reported greater interest in receiving information, and who they wished to receive that information from. To categorize high versus low levels of functioning, we completed a median split for the SF-12 Physical Quality of Life (for information related to side effects of prostate cancer therapy), EPIC-26 Sexual Function Domain (for information related to sexual health and function), and the SF-12 Emotional Quality of Life (for information related to emotional health). For

this analysis, we dichotomized interest level into Low Interest (including "Not at all" and "A little bit") versus High Interest (including "Somewhat" and "Very much"). Finally, we examined the relationships between the PC survivor's level of function with their interest in receiving information by completing Pearson correlation analyses with the continuous data for these same items.

3. Results

PC survivors endorsed interest in receiving more information about all facets of their health and well-being, though their desired sources of information varied. A total of 52.2% of the long-term PC survivors in our sample reported being "Somewhat" or "Very Much" interested in receiving information about coping with the late effects of their PC treatment, 64.1% were "Somewhat" or "Very Much" interested in information about dealing with their sexual health, and 27.2% were "Somewhat" or "Very Much" interested in further information about their emotional health (Table 3).

Table 3
Information interest and preferences for prostate cancer survivors.

	No.	Percent	95% Confidence Interval
Interest in receiving information about "Coping with side effects of prostate cancer therapy"	615		
Not at all	173	28.1%	24.7–31.8%
A little bit	121	19.7%	16.7–23.0%
Somewhat	168	27.3%	24.0–31.0%
Very much	153	24.9%	21.6–28.5%
First choice for source of information about "Coping with side effects of prostate cancer therapy"	595		
Conversation with primary care provider	113	19.0%	16.0–22.3%
Conversation with oncologist	180	30.3%	26.7–34.1%
Conversation with nurse	1	0.2%	0.0–0.2%
Written information sheet	128	21.5%	18.4–25.0%
Website	136	22.9%	19.7–26.4%
Phone call from another survivor	9	1.5%	1.0–2.9%
Phone call from professional counselor	28	4.7%	3.3–6.7%
Interest in receiving information about "Sexual health and function"	615		
Not at all	111	18.1%	15.2–21.3%
A little bit	110	17.9%	15.1–21.1%
Somewhat	159	25.9%	22.6–29.5%
Very much	235	38.2%	24.5–42.1%
First choice for source of information about "Sexual health and function"	615		
Conversation with primary care provider	135	22.0%	18.9–25.4%
Conversation with oncologist	134	21.8%	18.7–25.2%
Conversation with nurse	1	0.2%	0.0–0.2%
Written information sheet	155	25.2%	21.9–28.8%
Website	139	22.6%	19.5–26.1%
Phone call from another survivor	14	2.3%	1.4–3.8%
Phone call from professional counselor	37	6.0%	4.4–8.2%
Interest in receiving information about "Emotional health"	613		
Not at all	335	54.5%	50.7–58.6%
A little bit	111	18.0%	15.3–21.4%
Somewhat	99	16.1%	13.5–19.3%
Very much	68	11.1%	8.8–13.8%
First choice for source of information about "Emotional health"	572		
Conversation with primary care provider	188	32.9%	29.2–36.8%
Conversation with oncologist	46	8.0%	6.1–10.6%
Conversation with nurse	3	0.5%	0.2–1.5%
Written information sheet	138	24.3%	20.8–27.8%
Website	141	24.7%	21.3–28.3%
Phone call from another survivor	7	1.2%	0.6–2.5%
Phone call from professional counselor	49	8.6%	6.5–11.2%

With respect to coping with the late effects of prostate cancer treatment, participants in our sample reported a preference to receive their information from their oncologist (30%). Alternatively, a second tier of information sources (PCP, written information sheet, website) was preferred by between 19 and 23% of survivors. In terms of learning more about their sexual health and function, the men in the current study expressed similar levels of interest (22–25% of survivors) in receiving information from 4 different sources: PCP, oncologist, written information sheet, or website. Finally, the men in our sample had a preference to receive information about their emotional health from their PCP (33%), with a second tier of resources (written information sheet or website; 24–25%). In contrast with their desired information source for physical late effects, PC survivors did not desire to speak with their oncologist about their emotional function (<10.0%). Few survivors reported a preference for receiving information about their physical, sexual, or emotional health from a nurse, or a phone call from another survivor or a professional counselor (all <10.0%). Refer to Table 3 for further details.

Chi-square analyses revealed that 77.6% of participants reporting poor physical quality of life (SF-12; Table 4) reported interest in receiving further information about coping with the side effects of PC therapy, compared with 68.5% of men reporting good physical quality of life ($p=0.02$). Similarly, 77.4% of men reporting poor sexual function (EPIC-26) indicated interest in receiving information about sexual health and function compared with 66.8% of men reporting good sexual function ($p=0.004$). Finally, 62.8% of men reporting poor emotional quality of life (SF-12) reported interest in receiving information about their emotional health compared with 27.5% of men who reported high emotional quality of life ($p < .001$). Correlation analyses demonstrated similar statistically significant relationships when these variables were treated as continuous variables. Physical quality of life was associated with interest in information about coping with the side effects of PC therapy ($r=-0.09$; $p=0.03$), sexual function was associated with interest in receiving information about sexual health and function ($r=-0.13$; $p \leq 0.01$), and emotional quality of life was associated with interest in receiving information about emotional health ($r=-0.39$; $p \leq 0.001$).

4. Discussion and conclusion

Men treated for prostate cancer (PC) experience a variety of physical and psychosocial late effects of their treatment that can result in long-term decrements to their health and quality of life. Unfortunately, these men do not always discuss these late effects with their medical providers, including regarding key issues such

as sexual health [28] and, as a result, report ongoing informational needs about how they can cope with their health issues years after active treatment has ended. In the current study, we sought to improve our understanding of the specific information needs and preferences of long-term PC survivors in hopes that this can potentially guide improvements to intervention efforts for this population.

In our study, PC survivors report being interested in receiving further information about how to deal with post-cancer life, especially when it comes to coping with the physical late effects of their cancer therapy, such as sexual dysfunction. Over 50% of our sample wanted to learn more about these issues and, consistent with prior reports [17,18,29], suggests that there is a deficit with respect to how effectively these long-term survivorship needs are being met [30]. It is notable that these men are open to receiving this information, though they expressed a clear preference for a different source of information depending on their needs. When it comes to coping with late effects of their PC therapy, men understandably report interest in learning more information from their oncologists. In contrast, when it came to their sexual health, survivors were interested in receiving information both from their oncologist and their PCP. It is also encouraging that the men are open to using written or web-based resources in order to learn more about all of their physical sequelae, including sexual dysfunction, despite concerns that fewer older adults use the Internet [31]. The use of written/web-based resources may be appealing for survivors who may be concerned about embarrassing their medical providers during a discussion about sensitive topics, such as their sexual health [32], and is an excellent opportunity to consider ways in which we can improve our use of the Internet to better communicate with patients [33]. Surprisingly, PC survivors did not report having a desire to speak with a nurse, another survivor, or a professional counselor. There has been evidence demonstrating that nurse-led follow up care and interventions [34,35] and peer support groups [36,37] are effective at improving PC survivors' adjustment. This may indicate that these men have not had sufficient exposure to programs with demonstrated efficacy, and would benefit from additional resources dedicated to educating them about the role of alternative support sources in meeting the PC survivor's ongoing needs.

With respect to emotional health, PC survivors report enthusiasm for further information, with roughly 25% indicating interest. Consistent with literature suggesting that PC survivors may struggle to express their emotional needs [38,39], this highlights an issue for programs designed to improve emotional health outcomes in PC populations. It is possible that though these men may be experiencing poor emotional health functioning, their

Table 4
Interest in receiving information categorized by high versus low functioning.

Level of Function	Low Interest % (n)	High Interest	p value
<i>"Coping with side effects of prostate cancer therapy"</i>			
SF-12 Physical Quality of Life			0.02
Low Function	22.4% (49)	77.6% (170)	
High Function	31.5% (119)	68.5% (259)	
<i>"Sexual health and function"</i>			
EPIC-26 Sexual Domain			0.004
Low Function	22.6% (67)	77.4% (229)	
High Function	33.2% (102)	66.8% (205)	
<i>"Emotional health"</i>			
SF-12 Emotional Quality of Life			<0.001
Low Function	37.2% (113)	62.8% (191)	
High Function	72.5% (211)	27.5% (80)	

relative disinterest may mean that intervention efforts targeting emotional health must be careful to first identify survivors with genuine interest in improving this specific health domain. We found a strong preference for PC survivors to receive any emotional health information from their PCP, as this preference was more than four times greater than their preference for getting such information from their oncologists. This suggests that these men may not directly associate their current emotional health status with the physical consequences of their PC treatment, and do not view their oncology team as the best resource for addressing these issues. These findings are consistent with literature indicating that breast cancer survivors strongly endorse the idea of receiving psychosocial support from their PCP [40]. As cancer survivorship care shifts into the long-term phase, men often meet with their PCPs more frequently than their oncologists. The relationship with the PCP is also critical because it can be challenging for providers to identify PC survivors struggling to deal with health decrements following treatment [41]. It is crucial that primary care clinicians assess the men's needs and provide them with resources during the clinical encounter. This is particularly important since our data show an association between the survivor's information needs and their health status, and provides a clear example that the men who report need are likely to be the ones who would benefit from additional services.

Several limitations of our novel findings regarding long-term PC survivor's needs and preferences for information must be acknowledged. First, this sample is relatively affluent, well-educated and predominantly non-Hispanic white group seen at a single comprehensive cancer center in New England. Thus, these findings may not be generalizable to all PC survivors across the United States, and these demographic gaps require further investigation in lower SES and ethnic minority groups. Next, we understand that there is a potential gap between what our sample reported and their uptake of these services in practice. Therefore, it is possible that though our participants reported a high level of interest in further information about coping with PC sequelae, they may decline such an opportunity if presented one in the clinic. Finally, our data regarding PC treatment was collected via self-report, rather than medical record abstraction. Thus, it will be important in future research to determine the unique role that differing PC therapies may have on the information needs and preferences of survivors. Despite these limitations, our findings are consistent with those conducted in other settings and populations and therefore provide valuable information regarding the needs and preferences for specific domains of information relevant to the health of PC survivors who are several years past the end of treatment.

4.1. Practice implications

It will be important to consider these findings as future efforts are designed to improve the biopsychosocial health of PC survivors, with particular consideration for targeting individuals who are interested in learning how to cope with specific areas of dysfunction, as well as the source of that information. For clinicians providing survivorship care for PC survivors, there are a number of resources that can be considered. Evidence demonstrates that individual and group-based psychotherapeutic and psycho-educational interventions are effective at improving emotional health and general quality of life [42], which is important given how frequently PC survivors experience extreme distress in the form of suicidal ideation [23]. Patients who are experiencing poor physical function may benefit from targeted physical activity trials, with compelling research demonstrating efficacy at improving upper/lower body strength, fatigue, functional quality of life, and mood [43]. Finally, there has been a

successful trial to deliver a sexual health focused intervention for PC survivor [44]. The efforts to improve emotional, physical and/or sexual health are not mutually exclusive. Researchers have delivered interventions which address two, or even all three, of these potential challenges that PC survivors face [8,45–47]. There exist general guides to assist clinicians in understanding and assessing biopsychosocial health in cancer survivors [48], as well as more specific strategies [49,50]. The National Comprehensive Cancer Network has published guidelines for thorough survivorship care [51], and the American Cancer Society specifically describes care guidelines for prostate cancer survivorship [52]. We note that a sizeable minority of our sample reported low interest in receiving further coping-related information while simultaneously reporting poor physical, sexual and/or emotional health functioning. This means that a large number of PC survivors will likely fall through the cracks and not benefit from evidence-based therapies that can help resolve their late effects. The comprehensive care of cancer survivors is complex, and requires careful attention not only to content, but to matching need with the correct resource. There are key clinically actionable implications of these findings that identify unique roles for medical providers, and for the development of patient-focused resources that can be effectively disseminated for adjustment-related challenges.

Acknowledgements

This research was generously funded by a research grant from the American Foundation for Suicide Prevention (PRG-1-10-156) awarded to Christopher J. Recklitis, PhD, MPH.

References

- [1] American Cancer Society. Cancer facts and figures. 2015.
- [2] I.J. Korfage, M.L. Essink-Bot, G.J. Borsboom, et al., Five-year follow-up of health-related quality of life after primary treatment of localized prostate cancer, *Int. J. Cancer* 116 (2005) 291–296.
- [3] D.T. Eton, S.J. Lepore, Prostate cancer and health-related quality of life: a review of the literature, *Psycho-Oncol.* 11 (2002) 307–326.
- [4] F.J. Penedo, I. Molton, J.R. Dahn, et al., A randomized clinical trial of group-based cognitive-behavioral stress management in localized prostate cancer: development of stress management skills improves quality of life and benefit finding, *Ann. Behav. Med.* 31 (2006) 261–270.
- [5] F.J. Penedo, C. Benedict, E.S. Zhou, et al., Association of stress management skills and perceived stress with physical and emotional well-being among advanced prostate cancer survivors following androgen deprivation treatment, *J. Clin. Psychol. Med. Settings* 20 (1) (2012) 25–32.
- [6] B.A. Weber, B.L. Roberts, M. Resnick, et al., The effect of dyadic intervention on self-efficacy, social support, and depression for men with prostate cancer, *Psycho-Oncol.* 13 (2004) 47–60.
- [7] L.L. Northouse, D.W. Mood, A. Schafenacker, et al., Randomized clinical trial of a family intervention for prostate cancer patients and their spouses, *Cancer* 110 (2007) 2809–2818.
- [8] K. Parahoo, S. McDonough, E. McCaughan, et al., Psychosocial interventions for men with prostate cancer: a Cochrane systematic review, *BJU Int.* 116 (2015) 174–183.
- [9] S.O. Agboola, W. Ju, A. Elfiky, J.C. Kvedar, K. Jethwani, The effect of technology-based interventions on pain, depression, and quality of life in patients with cancer: a systematic review of randomized controlled trials, *J. Med. Internet Res.* 17 (2015) e65.
- [10] S.K. Chambers, S. Occhipinti, L. Schover, et al., A randomised controlled trial of a couples-based sexuality intervention for men with localised prostate cancer and their female partners, *Psycho-Oncol.* 24 (7) (2015) 748–756.
- [11] G. Bouma, J.M. Admiraal, E.G. de Vries, C.P. Schröder, A.M. Walenkamp, A.K. Reyners, Internet-based support programs to alleviate psychosocial and physical symptoms in cancer patients: a literature analysis, *Crit. Rev. Oncol. Hematol.* 95 (1) (2015) 26–37.
- [12] H. McAlpine, L. Joubert, F. Martin-Sanchez, M. Merolli, K.J. Drummond, A systematic review of types and efficacy of online interventions for cancer patients, *Patient Educ. Couns.* 98 (2015) 283–295.
- [13] T.H.M. Moore, A.J.L. King, M. Evans, D. Sharp, R. Persad, A.L. Huntley, Supportive care for men with prostate cancer: why are the trials not working? A systematic review and recommendations for future trials, *Cancer Med.* 4 (8) (2015) 1240–1251.
- [14] J. Trappenburg, N. Jonkman, T. Jaarsma, et al., Self-management: one size does not fit all, *Patient Educ. Couns.* 92 (2013) 134–137.

- [15] D.T. Eton, S.J. Lepore, Prostate cancer and health-related quality of life: a review of the literature, *Psycho-Oncol.* 11 (2002) 307–326.
- [16] J. Dale, W. Jatsch, N. Hughes, A. Pearce, C. Meystre, Information needs and prostate cancer: the development of a systematic means of identification, *BJU Int.* 94 (2004) 63–69.
- [17] R. O'Brien, P. Rose, C. Campbell, et al., I wish I'd told them: a qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment, *Patient Educ. Couns.* 84 (2011) 200–207.
- [18] E.W. Boberg, D.H. Gustafson, R.P. Hawkins, et al., Assessing the unmet information, support and care delivery needs of men with prostate cancer, *Patient Educ. Couns.* 49 (2003) 233–242.
- [19] L.J.F. Rutten, A.A. Agunwamba, P. Wilson, et al., Cancer-related information seeking among cancer survivors: trends over a decade (2003–2013), *J. Cancer Educ.* (2015) 1–10.
- [20] M.C. Walsh, A. Trentham-Dietz, T.A. Schroepfer, et al., Cancer information sources used by patients to inform and influence treatment decisions, *J. Health Commun.* 15 (2010) 445–463.
- [21] L.J.F. Rutten, N.K. Arora, A.D. Bakos, N. Aziz, J. Rowland, Information needs and sources of information among cancer patients: a systematic review of research (1980–2003), *Patient Educ. Couns.* 57 (2005) 250–261.
- [22] J. Bakan, B. Chen, C. Medeiros-Nancarrow, J.C. Hu, P.W. Kantoff, C.J. Recklitis, Effects of a gift certificate incentive and specialized delivery on prostate cancer survivors' response rate to a mailed survey: a randomized-controlled trial, *J. Geriatr. Oncol.* 5 (2014) 127–132.
- [23] C.J. Recklitis, E.S. Zhou, E.K. Zwemer, J.C. Hu, P.W. Kantoff, Suicidal ideation in prostate cancer survivors: understanding the role of physical and psychological health outcomes, *Cancer* 120 (21) (2014) 3393–3400.
- [24] E.S. Zhou, J.C. Hu, P.W. Kantoff, C.J. Recklitis, Identifying suicidal symptoms in prostate cancer survivors using brief self-report, *J. Cancer Survivorsh.* 9 (2015) 59–67.
- [25] J.T. Wei, R.L. Dunn, M.S. Litwin, H.M. Sandler, M.G. Sanda, Development and validation of the expanded prostate cancer index composite (EPIC) for comprehensive assessment of health-related quality of life in men with prostate cancer, *Urology* 56 (2000) 899–905.
- [26] J. Ware Jr., M. Kosinski, S.D. Keller, A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity, *Med. Care* 34 (1996) 220–233.
- [27] M.G. Sanda, R.L. Dunn, J. Michalski, et al., Quality of life and satisfaction with outcome among prostate-cancer survivors, *N. Engl. J. Med.* 358 (2008) 1250–1261.
- [28] E.R. Park, S.L. Bober, E.G. Campbell, C.J. Recklitis, J.S. Kutner, L. Diller, General internist communication about sexual function with cancer survivors, *J. Gen. Intern. Med.* 24 (Suppl. 2) (2009) S407–11.
- [29] L.E. Neese, L.R. Schover, E.A. Klein, C. Zippe, P.A. Kupelian, Finding help for sexual problems after prostate cancer treatment: a phone survey of men's and women's perspectives, *Psycho-Oncol.* 12 (2003) 463–473.
- [30] A.L. Stanton, What happens now? Psychosocial care for cancer survivors after medical treatment completion, *J. Clin. Oncol.* 30 (2012) 1215–1220.
- [31] Pew Research Center. Older adults and technology use. 2014 at <http://www.pewinternet.org/2014/04/03/older-adults-and-technology-use/>.
- [32] E.R. Park, R.L. Norris, S.L. Bober, Sexual health communication during cancer care: barriers and recommendations, *Cancer J.* 15 (2009) 74–77.
- [33] E. Beckjord, L.F. Rutten, L. Squiers, et al., Use of the internet to communicate with health care providers in the United States: estimates from the 2003 and 2005 Health Information National Trends Surveys (HINTS), *J. Med. Internet Res.* 9 (2007) e20.
- [34] M. Tarnhuvud, C. Wandel, A. Willman, Nursing interventions to improve the health of men with prostate cancer undergoing radiotherapy: a review, *Eur. J. Oncol. Nurs.* 11 (2007) 328–339.
- [35] B. Anderson, The benefits to nurse-led telephone follow-up for prostate cancer, *Br. J. Nurs.* 19 (17) (2010) 1085–1090.
- [36] J. Ussher, L. Kirsten, P. Butow, M. Sandoval, What do cancer support groups provide which other supportive relationships do not: the experience of peer support groups for people with cancer, *Soc. Sci. Med.* 62 (2006) 2565–2576.
- [37] H.S. Campbell, M.R. Phaneuf, K. Deane, Cancer peer support programs—do they work, *Patient Educ. Couns.* 55 (2004) 3–15.
- [38] R.J. Gooden, H.R. Winefield, Breast and prostate cancer online discussion boards: a thematic analysis of gender differences and similarities, *J. Health Psychol.* 12 (2007) 103–114.
- [39] S.G. Zakowski, C. Harris, N. Krueger, et al., Social barriers to emotional expression and their relations to distress in male and female cancer patients, *Br. J. Health Psychol.* 8 (2003) 271–286.
- [40] J.J. Mao, M.A. Bowman, C.T. Stricker, et al., Delivery of survivorship care by primary care physicians: the perspective of Breast cancer patients, *J. Clin. Oncol.* 27 (6) (2009) 933–938.
- [41] G.A. Sonn, N. Sadetsky, J.C. Presti, M.S. Litwin, Differing perceptions of quality of life in patients with prostate cancer and their doctors, *J. Urol.* 189 (2013) S59–S65 (discussion S65).
- [42] H. Faller, M. Schuler, M. Richard, U. Heckl, J. Weis, R. Küffner, Effects of psycho-oncologic interventions on emotional distress and quality of life in adult patients with cancer: systematic review and meta-analysis, *J. Clin. Oncol.* 31 (6) (2013) 782–793.
- [43] R.M. Speck, K.S. Courneya, L.C. Mäse, S. Duval, K.H. Schmitz, An update of controlled physical activity trials in cancer survivors: a systematic review and meta-analysis, *J. Cancer Survivorsh.* 4 (2010) 87–100.
- [44] S.K. Chambers, L. Schover, K. Halford, et al., ProsCan for couples: randomised controlled trial of a couples-based sexuality intervention for men with localised prostate cancer who receive radical prostatectomy, *BMC Cancer* 8 (2008) 226.
- [45] P. Cormie, S.K. Chambers, R.U. Newton, et al., Improving sexual health in men with prostate cancer: randomised controlled trial of exercise and psychosexual therapies, *BMC Cancer* 14 (2014) 1.
- [46] F.J. Penedo, J.R. Dahn, I. Molton, et al., Cognitive-behavioral stress management improves stress-management skills and quality of life in men recovering from treatment of prostate carcinoma, *Cancer* 100 (2004) 192–200.
- [47] S.J. Lepore, V.S. Helgeson, D.T. Eton, R. Schulz, Improving quality of life in men with prostate cancer: a randomized controlled trial of group education interventions, *Health Psychol.* 22 (2003) 443–452.
- [48] M. Feuerstein, Springer, Handbook of cancer survivorship, 2007.
- [49] P.B. Jacobsen, Clinical practice guidelines for the psychosocial care of cancer survivors, *Cancer* 115 (2009) 4419–4429.
- [50] E.S. Zhou, L. Nekhlyudov, S.L. Bober, The primary health care physician and the cancer patient: tips and strategies for managing sexual health, *Transl. Androl. Urol.* 4 (2015) 218–231.
- [51] J.A. Ligibel, C.S. Denlinger, New guidelines for survivorship care, *J. Nat. Compr. Canc. Netw.* 11 (2013) 640–644.
- [52] T.A. Skolarus, A. Wolf, N.L. Erb, et al., American Cancer Society prostate cancer survivorship care guidelines, *CA Cancer J.* 64 (2014) 225–249.