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Gender differences in self-reported late effects, quality of life and satisfaction with clinic in survivors of lymphoma

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Abstract

Objectives: **Gender differences in perceived vulnerability to late effects and views about follow-up among cancer survivors have received little attention. As lymphoma affects both genders similarly, we compared the consequences of cancer (late effects, perceived vulnerability and quality of life (health-related quality of life (HRQoL)), and satisfaction with clinic visits between genders.**

Methods: **A cohort of 115 younger adults (18–45 years, >5 years disease-free survival), who had been treated for lymphoma participated. Questionnaires ($n = 91$) were completed before and after ($n = 62$) routine consultant-led appointments. Survivors ($n = 24$) without appointments were recruited by post. Questionnaires included HRQoL, late effects, perceived vulnerability, issues survivors wanted to discuss and reported discussing in clinic, time waiting in clinic and consultation satisfaction.**

Results: **There were no gender differences in number of self-reported late effects or perceived vulnerability. Men with more late effects reported worse psychological HRQoL ($r = 0.50$, $p < 0.001$). While men wanted to discuss more topics than they did, women were able to discuss the topics they wanted (ANOVA, $p = 0.01$). Multiple regression analyses showed a shorter wait in clinic ($r = -0.46$, $p = 0.009$) and discussing more topics ($r = 0.34$, $p = 0.06$) explained 30.6% of the variance in consultation satisfaction for men.**

Conclusions: **Issues surrounding follow-up provision are increasingly important given the length of survival in young adults following treatment for lymphoma. Men may experience poor psychological well-being due to distress about unanswered concerns. Consideration of their concerns should be prioritised, given that satisfaction and ultimately continued attendance at clinic and HRQoL may be dependent on the extent to which follow-up meets survivors' expectations.**

Keywords: lymphoma; gender differences; quality of life; late effects; delivery of healthcare

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Introduction

Hodgkin's Lymphoma (HL) and Non-Hodgkin's Lymphoma (NHL) are among the most common cancers to affect young adults aged 18–45 years [1]. Over the past 20 years, cure rates have improved rapidly, with current 5-year survival rates of approximately 80% for HL and 54–60% for NHL [2]. At the same time, a number of physical and psychological late effects have been identified, including disorders of the endocrine system, cardiac and pulmonary dysfunction, renal and hepatic impairment, secondary malignancies, neuro-cognitive impairment, psychological difficulties and gonadal dysfunction [3–9]. The increasing numbers of survivors and incidence of late effects has led to calls for long-term structured follow-up [10,11]. However, it is important to ensure follow-up meets survivors' expectations, and that they are satisfied with the care they receive.

Physical late effects may well be associated with compromised health-related quality of life (HRQoL). The availability of generic measures, such as SF-36 [12], has facilitated comparison of HRQoL of survivors relative to the general population. Compared with norms, lymphoma survivors report compromised physical HRQoL, but not necessarily compromised mental HRQoL [13]. However, such comparisons are relatively blunt and lack sensitivity to disease-specific concerns [14,15].

Previous work has shown that better HRQoL is associated with greater clinic satisfaction in patients with chronic diseases in general [16], chronic lymphocytic leukaemia [17], psoriasis [18] and Type II diabetes [19]. When aspects of the clinic visit are examined in detail, poorer satisfaction with doctor–patient communication has been associated with worse HRQoL in patients with rectal cancer [20] and coeliac disease [21]. Furthermore, these findings have implications for future healthcare. Based on a meta-analysis of 106 studies, poor physician communication was associated with a 19% higher risk of non-adherence to treatment [22].

Very little work has addressed age or gender differences in cancer concern, HRQoL or views about follow-up. Indeed, the majority of research on cancer survivors has focused on either older adults or children. For young adult patients, cancer may be considered 'out of time' and potentially more stressful than for older patients as it challenges normative goals regarding work and reproduction [23]. Younger patients can expect longer survival, and thus more years living with the concerns about relapse or recurrence and the adverse consequences of late effects. Younger patients are also more vulnerable to late effects that develop as time since treatment increases, partly due to an increased post-treatment lifespan, and partly because they are likely to receive more aggressive treatment for cancer than older patients [24–26]. However, as many as 50% of survivors of cancer in young adulthood have reported unmet needs regarding information about exercise, diet and nutrition, fertility options and assistance with health insurance [27], suggesting that attention needs to be given to their survivorship concerns. These unmet needs could lead to psychosocial issues if not addressed. Although research has suggested that older patients are more vulnerable to a combination of late effects and co-morbid health conditions, and that planning and social support coping decrease with age [28,29], it has certainly been demonstrated that older and younger patients have qualitatively different concerns [24]. There have been calls for a separate cancer discipline focusing on improving outcomes in treatment and survivorship among patients diagnosed in adolescence and young adulthood [30]. Given the specific needs of younger patients following cancer, our focus in this study is on those under 45 years.

Male survivors are more likely to report that cancer adversely affects their health than female survivors [31], and male adolescent survivors report a more negative view of the future than female survivors [32]. Following HL, men report better physical [33–35] and emotional functioning [34] than women, but also more fatigue and worse HRQoL [36]. However, female survivors of childhood cancer report less satisfaction with follow-up consultations than males [37]. However, studies to date have not necessarily considered how and why the interaction between gender and age may impact on people's experiences [38]. This is important as gender is always framed in a relational context [38], and gender differences should therefore be assessed within a specific age group.

It is often not possible to evaluate age or gender differences, since many cancers are age linked oor gender linked. Thus, given that the incidence of lymphoma is relatively similar across genders, we took the opportunity to evaluate gender differences in: (i) HRQoL, late effects and perceived vulnerability in a cohort of lymphoma survivors, (ii) satisfaction with current care and (iii) expectations for the clinic visit and satisfaction with the consultation. In order to address the criticism that most past work has not been sensitive to both generic and disease-specific issues affecting survivors, we assessed both generic HRQoL [39] and aspects of survivor-specific HRQoL [40].

Methods

Participants

A cohort of younger adults treated with curative intent for lymphoma was recruited from the outpatient follow-up clinic at Weston Park Hospital, Sheffield, UK. Eligibility criteria included age (18–45 years), >5 years disease-free survival, and current registration in the clinic. Those who were undergoing palliative care, or had insufficient fluency in English to provide written informed consent or complete questionnaires were excluded. In total 144 eligible patients were identified (Figure 1). Ninety-nine eligible survivors had follow-up appointments scheduled, of these 91 completed Time 1 questionnaires and 62 returned Time 2 questionnaires. Forty-five were eligible for postal recruitment, and of these 24 returned questionnaires. In total, 115 survivors (79.9% response rate) participated in the study. The 29 survivors (15 male: (51.7%) who did not take part, did not significantly differ from participants in chronological age (37.7 vs 37.7, $t = 0.02$, $p = 0.98$) or age at diagnosis (24.8 vs 24.9, $t = 0.12$, $p = 0.91$).

Procedure

Eligible patients were identified from hospital databases and clinic lists between December 2006 and January 2008. Those attending the hospital for follow-up care were sent information about the study, a consent form and a questionnaire approximately 1 week before their appointment (T1), and asked to complete these prior to attendance. On leaving clinic, survivors were given a second questionnaire to complete at home (T2). Eligible survivors not attending follow-up during the study period were sent an information sheet, consent form and abridged questionnaire by post. All questionnaires completed at home were returned

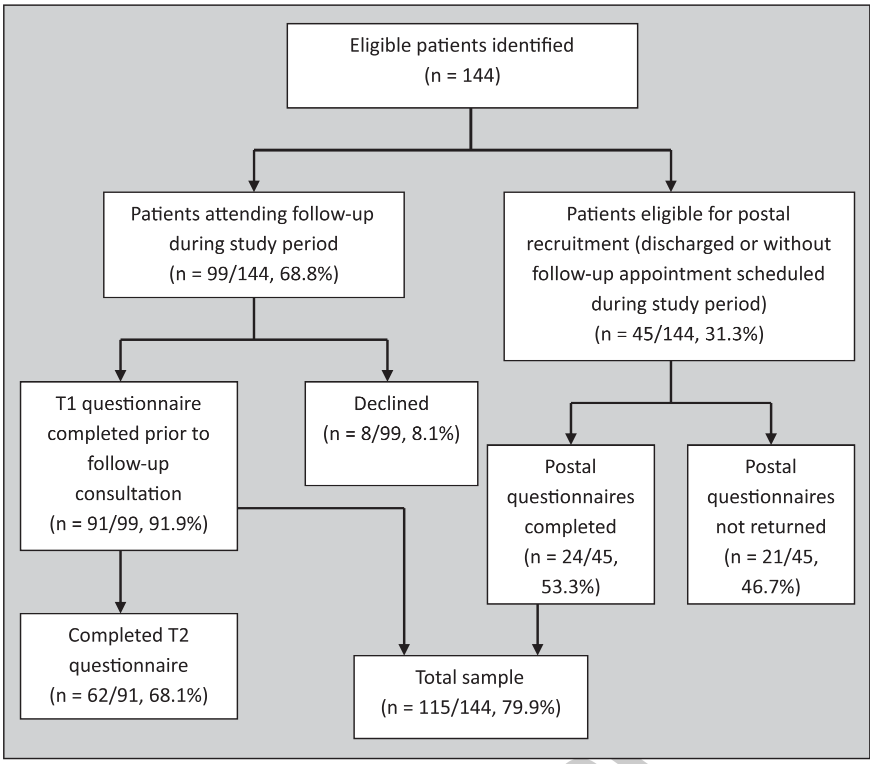

Figure 1. Participant recruitment

anonymised in freepost envelopes. At all stages, patients were reminded that participation in the study was voluntary, that declining to take part would not influence their treatment, and that they were free to withdraw from the study at any time. The study was approved by the South Sheffield Local Research Ethics Committee, and all participants provided written consent.

Measures

Time 1

- *Demographic information*
- *Issues to discuss during consultations* [37]: Ten issues were listed (e.g. current health, medication, fertility, health behaviours) and survivors were asked if they wanted to discuss each of these issues during their next follow-up consultation. The total number of issues was summed (0–10).
- *Current late effects and vulnerability* [37]: Eighteen possible cancer-related health problems were listed (e.g. infertility, fatigue, depression). Participants were asked to rate their perceived vulnerability to each late effect on a 5-point scale, from 1 (very unlikely) to 5 (very likely). A further alternative response ‘I already have this problem’, was provided. Two scores were computed: total number of late effects currently experienced (0–18) and vulnerability (range 1–5), where higher scores indicate greater perceived vulnerability.
- *HRQoL —Generic*: The SF-12v2 [38] is a 12-item measure that yields two summary scores: Physical component summary (PCS) and mental component summary (MCS). Both scales have excellent reliability and validity [39]. Age and gender matched norms are available.
- *HRQoL—Cancer-specific*: The psychological (6 items) and social well-being (8 items) scales were used from the QoL-CS [39]. Each item is scored on a 7-point Likert-type scale, where higher scores indicate worse quality of life. Good reliability and validity have been demonstrated [40].

Time 2

Following clinic appointments survivors completed measures of:

- *Issues discussed* The same 10 issues presented at T1 were presented, and survivors indicated which they discussed with clinic staff.
- *Satisfaction with the consultation*: The Princess Margaret Hospital Satisfaction with Doctor Questionnaire [41] is a 29-item measure of satisfaction with outpatient consultations which includes four subscales: information exchange, interpersonal skills, empathy and quality of time. Each item is assessed on a 4-point scale from 1 (strongly agree) to 4 (strongly disagree). There is a further alternative response ‘does not apply

to me'. Excellent reliability and validity have been demonstrated [41]. In the current study, the items were coded such that higher scores indicated greater satisfaction with the consultation. A mean score was generated for each subscale and these were summed to compute a mean overall satisfaction score.

- *Waiting time and length of consultation*: Participants were asked to estimate time waiting for the consultation once in clinic and the length of their consultation.

Survivors without scheduled follow-up appointments completed an abridged postal questionnaire that included the following described above:

- Demographic information
- Issues to discuss at their next consultation
- Current late effects and vulnerability
- Generic HRQoL [39].

Medical information

Information on diagnosis, treatment and time since end of treatment was obtained from medical records.

Analysis

Analyses were conducted using SPSS version 15. All measures were scored according to information in manuals or original articles. Cronbach αs were computed to assess internal reliability. As appropriate, Chi-square and *t*-tests were used to assess gender differences in demographic variables, treatment regimens, HRQoL, late effects, topics survivors wanted to discuss and topics discussed. Pearson correlations were used to identify associations between HRQoL, late effects and satisfaction with the consultation. McNemar's tests were used to compare the proportion of survivors intending to raise each issue during the consultation with issues that were discussed, by gender. A mixed ANOVA was used to assess the interaction between gender and number of topics (wanted to discuss and discussed). Multiple regressions were conducted to determine predictors of satisfaction separately for men and women.

Results

Demographic and clinical information

Demographic and clinical information about the sample is described in Table 1, and details of chemotherapy and radiotherapy regimens in Table 2. The modal dosage of radiotherapy was 3500 Gy (62/85 patients, 72.9%) in 20 fractions (66/85 patients, 77.6%).

Table 1. Means (SD) for demographic and clinical information by gender

	Male (*n* = 57)	**Female (*n* = 58)**	**Overall (*N* = 115)**
Demographics			
Age	37.5 (5.8)	37.9 (5.6)	37.7 (5.6)
Years since end of treatment	11.4 (4.5)	12.0 (5.3)	11.7 (4.9)
Time since diagnosis	12.4 (4.6)	13.1 (5.5)	12.8 (5.0)
Diagnosis (N, %)			
Hodgkin lymphoma	46 (80.7%)	51 (87.9%)	97 (84.3%)
Non-Hodgkin lymphoma	11 (19.3%)	7 (12.1%)	18 (15.7%)
Treatment (N, %)			
Surgery	50 (87.7%)	56 (96.6%)	107 (93%)
Chemotherapy	49 (86%)	51 (87.9%)	100 (87%)
Radiotherapy	39 (68.4%)	46 (79.3%)	85 (73.9%)
Employment status (N, %)			
Full-time	46 (80.7%)	31 (53.4%)	77 (67%)[a]
Part-time	1 (1.8%)	20 (34.5%)	21 (18.3%)[b]
Sick leave	1 (1.8%)	1 (1.7%)	2 (1.7%)
Student	1 (1.8%)	2 (3.4%)	3 (2.6%)
Homemaker	1 (1.8%)	2 (3.4%)	3 (2.6%)
Retired	1 (1.8%)	0	1 (0.9%)
Unemployed	3 (5.3%)	2 (3.4%)	5 (4.3%)
Marital status (N, %)			
Single	13 (22.8%)	9 (15.5%)	22 (19.1%)
Married/living with partner	41 (71.9%)	44 (75.9%)	85 (73.9%)
Divorced/separated	3 (5.3%)	5 (8.6%)	8 (7%)

[a] Men were more likely to be working full-time (χ^2 (1) = 13.1, $p<0.001$).
[b] Women were more likely to be working part-time (χ^2 (1) = 19.5, $p<0.001$).

Table 2. Chemotherapy regimens (*N*, %) by gender

Regimen	**Male**	**Female**	**Overall**
ABVD	5/49 (10.2%)	8/51 (15.7%)	13/100 (13%)
ChLVPP (alone/in combination)	16/49 (32.7%)	16/51 (31.4%)	32/100 (32%)
CHOP (alone/in combination)	7/49 (14.3%)	5/51 (9.8%)	12/100 (12%)
LOPP (alone/in combination)	7/49 (14.3%)	11/51 (21.6%)	18/100 (18%)
Other	14/49 (28.6%)	11/51 (21.6%)	25/100 (25%)
Radiotherapy—mantle/mediastinum/neck	28/39 (71.8%)	42/46 (91.3%)	70/85 (82.3%)[a]
Radiotherapy–other part of body	11/39 (28.2%)	4/46 (8.7%)	15/85 (17.6%)

ABVD, Adriamycin, bleomycin, vinblastine, dacarbazine; ChLVPP, Chlorambucil, vinblastine, procarbazine, prednisone; CHOP, Cyclophosphamide, Adriamycin, Vincristine, Prednisone; LOPP, Chlorambucil, vincristine, procarbazine, prednisone.
[a] More women than men had received mantle field radiotherapy: 91 vs 72%; (χ^2 (1) = 5.53, p = 0.02).

Internal reliabilities of the scales

Where considered appropriate, Cronbach's α's were computed to assess internal reliability. For the CS-QoL [40], Cronbach's α was 0.88 for the psychological well-being scale and 0.74 for the social well-being scale, indicating acceptable reliability. The α for the psychological well-being scale is equivalent to that in the validation study, but that of the social well-being scale is lower than that of 0.81 demonstrated in the validation study [40]. In order to determine that the scale was gender appropriate (the original sample included 80% women), we ran Cronbach αs separately by gender. This showed the α for the social well-being scale was higher for men (0.77) than for women (0.67). There were no major differences in the psychological well-being scale. For the Satisfaction with Doctor Questionnaire, Cronbach's α for the overall scale was 0.96, indicating excellent reliability. αs for the subscales were comparable in the validation and current studies, respectively: interpersonal skills: 0.89 vs 0.90, information exchange: 0.89 vs 0.92, quality of time: 0.92 vs 0.88, and empathy: 0.93 vs 0.88, indicating excellent reliability [41]. Again, when broken down by gender, overall αs were similar for men (0.97) and women (0.96), indicating excellent reliability.

(i) HRQoL, late effects and perceived vulnerability.

HRQoL scores are shown in Table 3. Survivors compared favourably with age- and gender-matched norms on both the PCS and MCS [32]. There were no gender differences on PCS or MCS or for psychological and social HRQoL on the CS-QoL [40].

Seventy two (62.6%) survivors reported one or more late effects (mean = 2.0), including fertility (27%), thyroid dysfunction (22.6%), chronic fatigue (17.4%) and mood swings (17.4%) (Table 4).

Late effects differed by gender: the most common for women were thyroid dysfunction (32.8%), fertility (29.3%) and chronic fatigue (20.7%), whereas the most common for men were fertility (24.6%), mood swings (17.5%) and weight gain (15.8%). Higher perceived vulnerability to late effects was associated with worse MCS scores (SF-12) in men ($r = -0.41$, $p = 0.003$), but not women. Based on the QoL-CS, men who reported more late effects also reported worse psychological ($r = 0.50$, $p < 0.001$), and social ($r = 0.40$, $p = 0.007$) quality of life. Men who reported greater perceived vulnerability to late effects also reported worse social quality of life ($r = 0.38$, $p = 0.01$).

More reported late effects ($r = -0.35$, $p < 0.001$) and higher perceived vulnerability to late effects ($r = -0.24$, $p = 0.01$) were associated with worse PCS scores. Based on the QoL-CS, worse psychological quality of life was associated with more reported late effects ($r = 0.26$, $p = 0.01$), and greater perceived vulnerability to late effects ($r = 0.44$, $p < 0.001$).

Table 3. HRQoL [Mean (SD)] by gender

Scale	Men	Men norm	Women	Women norm	Overall
SF-12					
MCS	50.2(7.9)	50.1 (0.2)	47.6 (10.4)	47.5 (0.7)	48.9 (9.3)
PCS	52.1 (8.0)	53.0 (0.6)	52.8 (9.3)	51.5 (0.9)	52.4 (8.7)
QoL-CS					
Psychological	2.5 (1.5)		2.2 (1.5)		2.4 (1.5)
Social	1.8 (1.1)		1.5 (0.9)		1.6 (1.0)

(ii) Satisfaction with current care

T2 questionnaires were completed by 62 of the 115 survivors. There were no differences between responders and non-responders, except that time since diagnosis was shorter for responders (11.9 vs 13.8 years, t (113) = 2.00, $p < 0.05$).

Overall satisfaction was high (mean = 3.5, SD = 0.5). There were no differences between genders in satisfaction on the overall scale or on individual subscales measuring information exchange, interpersonal skills, empathy and quality of time. Length of wait and length of consultation are reported in Table 5. The modal length of wait was 0–20 min, and the modal length of consultation was 6–10 min.

(iii) Expectations for the clinic visit and satisfaction with the consultation.

Percentages of survivors who wanted to discuss and discussed particular topics are reported in Table 6.

Table 4. Self reported late effects by gender (*N*, %)

Late effect	Men (*n* = 57)	Women (*n* = 58)	Overall (*N* = 115)
Fertility	14 (24.6%)	17 (29.3%)	31 (27%)
Thyroid dysfunction	7 (12.3%)	19 (32.8%)	26 (22.6%)
Chronic fatigue	8 (14%)	12 (20.7%)	20 (17.4%)
Mood swings	10 (17.5%)	10 (17.2%)	20 (17.4%)
Depression	8 (14%)	7 (12.1%)	15 (13%)
Damage to testes/ovaries	6 (10.5%)	9 (15.5%)	15 (13%)
Weight gain	9 (15.8%)	6 (10.3%)	15 (13%)
Lung	5 (8.8%)	8 (13.8%)	13 (11.3%)
Lymphoedema	6 (10.5%)	4 (6.9%)	10 (8.7%)
Sight	7 (12.3%)	3 (5.2%)	10 (8.7%)
Memory	6 (10.5%)	4 (6.9%)	10 (8.7%)
Sexual functioning	3 (5.3%)	4 (6.9%)	7 (6.1%)
Hearing	5 (8.8%)	1 (1.7%)	6 (5.2%)
Osteoporosis	1 (1.8%)	2 (3.4%)	3 (2.6%)
Second cancer	1 (1.8%)	1 (1.7%)	2 (1.7%)
Diabetes	1 (1.8%)	0	1 (0.9%)
Heart	0	0	0
Liver	0	0	0
1+problem reported	32 (56.1%)	40 (69%)	72 (62.6%)
Mean number of late effects (SD)	1.7 (2.0)	1.8 (1.9)	1.8 (2.0)
Mean perceived vulnerability (SD)	2.6 (0.6)	2.8 (0.7)	2.7 (0.6)

Table 5. Length of wait before consultation and length of the consultation (*N*, %)

Variable	Minutes	Male ($n = 31$)	Female ($n = 31$)	Overall ($N = 62$)
Length of wait	0–20	19 (61.3%)	17 (54.8%)	36 (58.1%)
	21–30	3 (9.7%)	8 (25.8%)	11 (17.7%)
	31–60	8 (25.8%)	5 (16.1%)	13 (18.3%)
	61–90	1 (3.2%)	1 (3.2%)	2 (3.2%)
Length of consultation	0–5	9 (29.0%)	3 (9.7%)	12 (19.4%)
	6–10	13 (41.9%)	15 (48.4%)	28 (45.2%)
	11–20	6 (19.4%)	13 (41.9%)	19 (30.6%)
	21–30	3 (9.7%)	0	3 (4.8%)

Table 6. Discrepancy between topics survivors wanted to discuss and topics discussed, by gender (*N*, %)

Topic	Men			Women		
	Wanted to discuss	Discussed	McNemar Test (exact sig)	Wanted to discuss	Discussed	McNemar Test (exact sig)
Current health	27 (87.1%)	28 (90.3%)	1	23 (74.2%)	28 (90.3%)	0.13
LE of treatment	25 (80.6%)	9 (29.0%)	<0.001**	25 (80.6%)	15 (48.4%)	0.002*
Medication	9 (29.0%)	8 (25.8%)	1	5 (16.1%)	12 (38.7%)	0.07
Current health behaviours	21 (67.7%)	12 (38.7%)	0.04*	10 (32.3%)	7 (22.6%)	0.73
Fertility	10 (32.3%)	4 (12.9%)	0.07	10 (32.3%)	4 (12.9%)	0.07
Work/education	5 (16.1%)	5 (16.1%)	1	3 (9.7%)	4 (12.9%)	1
Contraception	3 (9.7%)	0	0.25	1 (3.2%)	0	1
Sexual problems	4 (12.9%)	2 (6.5%)	0.50	1 (3.2%)	0	1
Insurance	10 (32.3%)	0	0.01*	6 (19.4%)	0	0.06
Overall number of topics to discuss	3.7	2.3	$t\ (30) = 3.0,\ p = 0.005$	2.6	2.7	$t\ (30) = -0.11\ p = 0.91$

As shown in Table 6, both men and women most wanted to address late effects of treatment, current health and current health behaviours in the consultation. The most common topics discussed were current health, late effects of treatment and current health behaviours for men, and current health, late effects of treatment and medication for women. Both men and women wanted to discuss late effects of treatment significantly more than they did (Men: 80.6 vs 29%, $p < 0.001$; Women: 80.6 vs 48.4%, $p = 0.002$). Men also wanted to discuss insurance and current health behaviours significantly more than they did (Insurance: 32.3% vs 0, $p = 0.01$; Current health behaviours: 67.7 vs 38.7%, $p = 0.04$). More men than women wanted to discuss current health behaviours (67.7 vs 32.2%; $\chi^2 = 7.81$, $p = 0.005$). Women who wanted to discuss more topics reported that more topics were discussed in the consultation ($r = 0.50$, $p = 0.004$) and also perceived greater vulnerability to late effects ($r = 0.41$, $p = 0.006$). There were no similar results for men.

A mixed ANOVA with number of topics (wanted to discuss, discussed) as the within subjects factor and gender as the between subjects factor revealed (i) a significant main effect of number of topics ($F(1,\ 60) = 6.22$, $p = 0.015$), indicating that survivors wanted to discuss more topics (Mean = 3.3) than they did (Mean = 2.5), and (ii) a significant gender by number of topics interaction ($F(1,\ 60) = 6.83$, $p = 0.01$), indicating that while men wanted to discuss more topics than they discussed, women were able to discuss the topics they wanted.

Correlations between satisfaction with the consultation and a variety of other variables were run for the overall sample and by gender. For the overall sample, survivors who reported being more satisfied with their consultation had waited a shorter time ($r = -0.32$, $p = 0.01$). No correlates of satisfaction were identified for women. For men, the only correlates of satisfaction were waiting time (men who were more satisfied reported waiting a shorter time once in the waiting room: $r = -0.46$, $p = 0.009$) and number of topics discussed (men who were more satisfied tended to have discussed more topics in the consultation: $r = 0.34$, $p = 0.06$). Importantly, there was no relation between working full-time and satisfaction with the consultation. In a multiple regression carried out on men only, number of topics discussed and waiting time were entered as independent variables and explained 30.6% of the variance in satisfaction with the consultation ($F(2,\ 28) = 6.17$, $p = 0.006$).

Discussion

The young adult lymphoma survivors in this study reported MCS and PCS comparable to age-and gender-matched norms, even though approximately two-thirds reported one or more late effects of their

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cancer. Apart from thyroid problems, an established consequence of mantle field radiation, [42], men and women reported similar numbers of late effects. Not surprisingly, those who *self*-reported more late effects, and rated themselves as more vulnerable to late effects also reported worse physical HRQoL, as measured by a generic scale. Good reliability and validity had previously been reported for all scales, and good to excellent reliability (Cronbach's α) was demonstrated in the current study, both for the overall sample, and when the results were broken down by gender. These findings suggest that the measures used were appropriate for the population in question. The only area of concern is that for women, the social well-being scale of the QoL-CS demonstrated slightly below adequate reliability, and thus future studies should consider the removal of specific items as appropriate.

Overall, high levels of satisfaction with the consultation were reported (mean 3.5 out of 4). Despite this, survivors wanted to discuss a range of issues, such as current health, advice on health behaviours, late effects of treatment, and insurance, which tended to be addressed less frequently than was wanted. Both men and women wanted to discuss late effects of treatment significantly more than they did, and men wanted more advice on current health behaviours and insurance, and to discuss significantly more topics overall than they did. Although the questionnaires were returned anonymously and patients were expressly informed that participation would not influence their treatment, it is possible (though unlikely) they might have had concerns that negative evaluation would jeopardise their follow-up.

Notwithstanding time constraints in clinic, our study suggests that survivors want to discuss late effects. There have also been recommendations for discussions to address the need for a healthy lifestyle to reduce morbidity and mortality in cancer survivors [43], particularly men, who are less likely to engage in good health practices than women [44]. It is also important to address fertility concerns, and patients (especially men) should be advised of recent advances in assisted conception and availability of fertility testing [45]. Leaflets advising patients on insurance would also be helpful, even if there is no time to discuss this in the consultation. Appropriate leaflets giving advice about late effects, similar to those developed by the Children's Cancer and Leukaemia Group (CCLG) might be helpful: (http://www.cclg.org.uk/index.php).

Those who were more satisfied with their consultations reported shorter waiting times. This was the case even though those who had waited longer tended to report longer consultations. There was no association between perceived length of consultation and number of topics discussed, implying that time constraints are not necessarily a barrier to effective consultations.

A number of gender differences were identified. First, men, but not women, who reported greater perceived vulnerability to late effects reported poorer MCS. In addition, men who reported more late effects also reported worse psychological and social quality of life based on the survivor-specific QoL-CS. Despite this, men discussed significantly fewer issues than they wished, while women discussed the same number of topics as they wanted. Thus, men may experience poor psychological well-being as a consequence of distress about unanswered concerns. In support of this explanation, a qualitative study of men newly diagnosed with cancer revealed high levels of unmet information needs [46]. Men themselves may be more reluctant or lack confidence to raise concerns in clinic compared with women. A potential explanation for this result is the 'fixed role' hypothesis of gender and health [47], which suggests that women are socialised to seek medical help, whereas men are taught early in their lives to manifest stoicism [48]. It is also possible that doctors are less likely to address men's concerns in depth. Physicians generally provide more information, support and reassurance when patients ask questions, offer opinions and express concerns [49], which are more commonly assumed to be feminine characteristics [49]. Either way, it may be important to address gender-based stereotypes suggesting that men are more stoic, self sufficient or simply do not need to discuss issues to a similar extent as women [49–54], particularly as masculine characteristics, such as inexpressiveness, have been shown to be a significant predictor of poor health in men [50]. Only by addressing such stereotypes will it be possible to address men's concerns about their illness or provide opportunities for health promotion and lifestyle change.

Second, women, but not men who reported greater vulnerability to late effects wanted to discuss more topics, suggesting that they view the consultation as an opportunity for reassurance. Third, the relation between greater satisfaction with the consultation and shorter waiting time held only for men. Men who are newly diagnosed with cancer also report feeling uncomfortable in the hospital setting and wanting their consultation to finish as quickly as possible [46]. This again fits with recent theorising about gender, which suggests that men traditionally refuse to admit weakness, which creates gender role conflict in situations of vulnerability [55]. As some waiting times are inevitable in busy oncology units, research is needed to explore how to help men feel more relaxed in the hospital. Fourth, men who were more satisfied with their consultation tended to have discussed more topics. This finding is of special significance in that men discussed significantly fewer issues than they wanted.

The strengths of this study include recruitment across a relatively narrow age group, who are likely to have similar issues of concern [24], a consequence of their young age at diagnosis, and associated disruption of life goals. The majority experienced similar treatment (almost all had surgery and chemotherapy), with the likelihood of common late effects. Different results may be found for those from different age groups.

Inevitably there were a number of limitations with this study. First, details of late effects and topics discussed during consultations were obtained from survivors' reports only, and not confirmed in medical records. Significant differences between survivor reported late effects and those in medical notes have been reported [56] as well as considerable discrepancies between doctor and patient recollection of medical consultations [57]. Second, the sample was relatively small and recruited from a single cancer centre, and thus may not be representative of all patients with lymphoma. Third, details of the consulting clinician (e.g. gender, experience) were not recorded, which meant differences in consultation style could not be examined. It is also possible that clinician gender may affect male patients' willingness to discuss issues. Previous work suggests that both male and female patients tend to talk more and ask more questions when interacting with female health-care professionals [49].

Given increasing number of survivors, length of survival and prevalence of late effects, questions about appropriate follow-up are highly topical. Our results suggest that survivors' satisfaction is related to practical issues including waiting time, but also aspects of the consultation, especially opportunities to ask questions. Men seem especially intolerant of lengthy waiting times, and less likely than women to ask questions. More qualitative studies are needed to determine the dynamics between doctors and patients in clinic consultations in order to clarify if men are reluctant to initiate discussions about their concerns, or whether doctors provide fewer opportunities for men. Improved understanding of any gender differences could lead to better management of late effects and approaches to health promotion among cancer survivors. As with survivors of other cancers, the wide range of follow-up needs in lymphoma survivors challenges provision of follow-up.

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