

Health-related Quality of Life in Canadian Adolescents and Young Adults: Normative Data Using the SF-36

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ABSTRACT

Objectives: Normative data for the SF-36 measure of health-related quality of life (HRQOL) exist for those over 25 years of age, based on data from the population-based Canadian Multicentre Osteoporosis Study (CaMos). CaMos recently recruited a sample of young Canadians aged between 16 and 24 years. The purpose of this study was to develop normative SF-36 data for this age group.

Methods: After direct standardization to the Canadian population, means, standard deviations (SD), 95% confidence intervals and percentage at floor and ceiling were produced for the eight domain and two summary scores of the SF-36. Domains are scored from 0 (poor) to 100 (excellent). Summary scores are standardized to a mean of 50, with scores over 50 representing better than average and below 50 poorer than average function. Separate analyses were completed for men and women, and for those 16-19 years and 20-24 years.

Results: The 1,001 community-based participants consisted of 474 men and 527 women from nine CaMos centres across Canada. Mean Physical Component Summary scores were 53.9 (SD=6.9) and 53.3 (SD=5.7) for young men and women, respectively. The equivalent Mental Component Summary scores were 49.3 (SD=9.7) and 48.8 (SD=8.9). In general, men scored somewhat higher than women, and younger (16-19 years) women scored higher than older (20-24 years) women, although the differences were small.

Conclusion: HRQOL is good in this cohort of young Canadians. Both men and women scored somewhat better on physically than mentally oriented domains. In general, Canadian scores were similar to those of the US, while a comparable Swedish sample scored higher than both countries on most domains. Results underscore the importance of taking country, age and gender into consideration when using normative data.

Key words: SF-36; normative; adolescents; youth; gender; CaMos; age

La traduction du résumé se trouve à la fin de l'article.

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The Medical Outcomes Trust 36-item health survey (SF-36)^{1,2} is widely used to assess health-related quality of life (HRQOL). However, Canadian normative data exist only for adults over 25 years,³ leaving those who work with younger populations to infer either from Canadians over age 25 or from youth norms from other countries. Neither is ideal, as there is mounting evidence that younger respondents differ from older age groups.^{1,2,4} For example, while younger subjects may generally be in better physical health, those under 25 are more likely than older groups to be struggling with major decisions about relationships and career choices, which can negatively affect HRQOL. Normative data from the US and Sweden exist for younger age groups,^{1,2,4} but the differences between countries can affect the validity of using these norms for Canadian research.^{3,4}

HRQOL research has historically focused extensively on older adults to the exclusion of young adults.⁵ The need for normative data is underscored by the fact that population surveys of youth generally focus on aspects of poor health, behavioural problems or risk-taking behaviours and do not reflect the HRQOL of the majority.^{5,6} It is important to have normative data for the appropriate age and gender group if HRQOL is to be examined in adolescents and young adults.

Data from the Canadian Multicentre Osteoporosis Study (CaMos) were used to develop age- and sex-standardized norms for Canadians over 25 years.³ CaMos recently recruited a sample of young Canadians between 16 and 24 years of age. The purpose of this study was to develop normative SF-36 data for this age group.

METHODS

CaMos is an ongoing, prospective cohort study of 9,423 randomly selected men and women aged 25 years and older at baseline (1996/1997), drawn from within a 50 km radius of nine Canadian cities (St. John's, Halifax, Quebec City, Toronto, Hamilton, Kingston, Saskatoon, Calgary and Vancouver). In 2004, the CaMos cohort was supplemented by a sample of Canadians aged between 16 and 24 years, using the same methodology. Detailed descriptions of these methods are available elsewhere,^{3,7} but, in brief, households within each region were randomly selected from listed telephone numbers, and one randomly selected household mem-

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Table 1. Mean Age- and Sex-standardized SF-36 Scores for Canadian Adolescent and Young Adult Men

Age in Years	Physical Functioning	Role Physical	Bodily Pain	General Health	Vitality	Social Functioning	Role Emotional	Mental Health	PCS*	MCS*
16-19, n=243										
Mean score	93.8	87.9	77.3	79.6	63.8	86.9	84.5	74.1	53.5	49.6
SD	13.4	28.8	19.4	14.3	16.3	19.0	31.0	15.7	6.9	9.8
95% CI*	92.2-95.4	84.4-91.4	74.9-79.6	77.9-81.4	61.8-65.8	84.5-89.2	80.7-88.3	72.1-76.0	52.7-54.4	48.4-50.8
% at floor	0.7	6.2	0.3	0.3	0.1	0.1	7.1	0.4	0.1	0.1
% at ceiling	63.6	79.4	26.1	6.0	0.1	55.4	74.2	3.1	1.9	0.7
20-24, n=231										
Mean score	93.5	92.0	80.9	77.7	64.2	86.1	80.7	74.5	54.3	48.9
SD	13.3	25.0	19.4	15.0	16.7	18.5	34.5	17.5	6.8	9.7
95% CI	91.8-95.1	88.9-95.2	78.5-83.3	75.8-79.6	62.1-66.3	83.8-88.4	76.4-85.0	72.4-76.7	53.4-55.2	47.7-50.1
% at floor	0.2	4.0	0.5	0.6	0.2	2.6	10.8	2.5	0.4	0.6
% at ceiling	60.9	87.9	36.8	7.8	0.2	48.9	68.6	2.3	0.6	0.2
16-24, n=474										
Mean score	93.6	89.9	79.1	78.7	64.0	86.5	82.7	74.3	53.9	49.3
SD	13.3	27.1	19.4	14.7	16.5	18.7	32.8	16.6	6.9	9.7
95% CI	92.5-94.8	87.6-92.3	77.4-80.8	77.4-80.0	62.5-65.4	84.9-88.1	79.8-85.5	72.9-75.7	53.3-54.5	48.4-50.1
% at floor	0.1	5.1	0.2	0.1	0.1	0.02	8.9	1.2	0.02	0.02
% at ceiling	62.3	83.6	31.4	6.8	0.2	52.2	71.5	2.7	0.4	0.3

* PCS, Physical Component Summary; MCS, Mental Component Summary; SD, standard deviation; CI, confidence interval

ber of the appropriate age was asked to participate. Those who agreed to participate were sent a one-page form prior to the interview, asking them to enquire if any of their family members had any of the conditions of particular interest to CaMos, such as osteoporosis or history of fracture. Those who declined were asked to complete a short questionnaire concerning age, gender, fracture history, family history of osteoporosis, height, weight, smoking history and activity level. Ethics approval was obtained through the review boards of each participating centre.

Participation involved a detailed interview, including paper-based self-administration of the SF-36. The SF-36 measures eight aspects of HRQOL, including physical function (PF), role physical (RP), bodily pain (BP), general health (GH), vitality (VT), social function (SF), role emotional (RE) and mental health (MH). Scores range between 0 (poor) and 100 (best) HRQOL. A Physical Component Summary (PCS, primarily based on the PF, RP, BP and GH domains) and Mental Component Summary (MCS, primarily based on the VT, SF, RE and MH domains) are standardized to a mean of 50, with a score above 50 representing better than average and below 50 poorer than average function.^{1,2} Two methods were used to assess the differences among the groups. First, 5-point differences in domain scores and 2-3 point differences in summary scores were considered clinically meaningful.^{1,2} In addition, the 95% confidence intervals (CIs) of the differences were interpreted using the methodology described by Joseph and Reinhold.⁸ Comparisons that did not meet the 5-point (domain) or 2-3 point (summary scores) level were still noted if the lower or upper limits of the 95% CI were clinically interesting.⁸

After direct standardization to the Canadian population (2006 Census data), a basic descriptive analysis was completed for the eight domain and two summary scores. This included means, standard deviations (SD), 95% CIs and percentage at floor and ceiling (proportion receiving the minimum and maximum score, respectively). All analyses were done using SAS version 9.1 for Windows (Cary, NC, US). Separate analyses were completed for men and women and for two age cohorts, those between 16 and 19 years and 20 and 24 years. Participant data were also compared with those of the refusal group to evaluate possible selection bias: means and 95% CIs were compared for the continuous data and frequencies for the categorical data.

RESULTS

An eligible youth resided in 4,446 of the households contacted. Of these, 2,419 (54.4%) refused to participate, 1,026 (23.1%) completed the brief refusal questionnaire, and 1,001 (22.5%, 474 men and 527 women) agreed to the complete study (questionnaires, height and weight assessment and bone mineral density measurements). For men, 243 were 16-19 years (mean 17.3, SD=1.1), and 231 were 20-24 years (mean 21.8, SD=1.3); for women, 264 were 16-19 years (mean 17.4, SD=1.1), and 263 were 20-24 years (mean 22.0, SD=1.3).

The age- and sex-standardized scores for the eight domains and two component summaries are presented in Tables 1 (men) and 2 (women). Although several domains showed a ceiling effect, there did not appear to be a floor effect. Overall, there were small differences between the men and women, but only two exceeded the five-point difference considered to be clinically relevant. The women aged 16-19 scored 5.6 points higher on the RP domain than the men of the same age. The men aged 20-24 scored 7.7 points higher than the women of the same age on BP. The 95% CIs for the differences were 1.4-9.8 and 3.9-10.9, respectively. In both cases, the upper but not the lower CI limits are of clinical interest, suggesting that these differences may be meaningful.⁸

When the two age groups were combined, the men had the higher score on 7 of 10 comparisons, although many of the differences were not large. The largest was in the domain of BP, with a mean difference of 4.7 points. Once again, although the difference fell short of the 5 points considered to be clinically relevant, the 95% CI of the difference (2.3-7.1) suggests that the upper CI limit may be of clinical interest and that the difference may be meaningful.⁸

For men, there was a relatively large difference between age groups for the RP domain, with the younger sample scoring a mean of 4.1 points lower than the older sample. Although the 95% CI of the difference (-0.8 to 8.9) includes the null value of zero, the upper CI limit may be of clinical interest.⁸ For domains other than RP, the younger and older groups of men were comparable. The scores of the two age groups of women were also comparable for most domains and both summary components. However, the younger group had higher mean scores on both the VT (6.3 points) and RE (6.8 points) domains. The 95% CIs for these differences were 3.6-9.0 and 1.5-12.1, respectively. In both cases, the upper but not the lower CI limits are of clinical interest.⁸

Table 2. Mean Age- and Sex-standardized SF-36 Scores for Canadian Adolescent and Young Adult Women

Age in Years	Physical Functioning	Role Physical	Bodily Pain	General Health	Vitality	Social Functioning	Role Emotional	Mental Health	PCS*	MCS*
16-19, n=264										
Mean score	94.5	93.5	75.6	75.3	65.6	89.1	82.9	74.8	53.5	49.9
SD*	10.7	19.0	18.6	15.2	14.9	13.8	28.0	13.5	5.6	7.7
95% CI*	93.2-95.8	91.1-95.8	73.2-77.9	73.4-77.2	63.8-67.5	87.4-90.9	79.4-86.4	73.1-76.5	52.7-54.2	48.9-50.9
% at floor	0.5	2.9	0.03	0.3	0.03	0.03	4.9	0.03	0.27	0.03
% at ceiling	55.9	85.2	23.5	3.4	0.1	51.3	68.7	1.9	0.16	0.1
20-24, n=263										
Mean score	93.1	92.7	73.2	74.1	59.3	86.6	76.1	72.8	53.2	47.7
SD	10.8	21.0	20.1	15.5	16.4	17.3	33.9	14.8	5.8	9.9
95% CI	91.7-94.5	90.1-95.3	70.7-75.8	72.2-76.1	57.2-61.3	84.4-88.8	71.9-80.4	71.0-74.7	52.5-54.0	46.5-49.0
% at floor	0.1	3.4	0.1	0.1	0.04	0.4	11.7	0.04	0.1	0.4
% at ceiling	50.2	86.7	22.4	2.0	0.1	51.2	62.0	0.1	0.8	0.2
16-24, n=527										
Mean score	93.8	93.1	74.4	74.7	62.5	87.9	79.5	73.8	53.3	48.8
SD	10.8	20.0	19.4	15.4	15.9	15.7	31.2	14.2	5.7	8.9
95% CI	92.9-94.8	91.3-94.9	72.7-76.1	73.3-76.1	61.0-64.9	86.5-89.3	76.8-82.3	72.6-75.1	52.8-53.8	48.0-49.6
% at floor	0.2	3.2	0.03	0.1	0.04	0.2	8.3	0.04	0.1	0.2
% at ceiling	53.1	85.9	23.0	2.7	0.1	51.3	65.4	1.0	0.4	0.1

* PCS, Physical Component Summary; MCS, Mental Component Summary; SD, standard deviation; CI, confidence interval

When participant and refusal questionnaire data were compared, there were differences in mean weight for women aged 16-19 (62.0 and 57.8 kg for participants and refusals, respectively), but height was similar (164.0 and 164.4 cm), suggesting that participants had a somewhat higher body mass index. These differences may, in reality, be smaller given that the refusal questionnaire data were based on self-reported weight (often underestimated), whereas the participants' weight was measured. In addition, participating women were more likely to engage in regular physical activity (64.9% versus 57.9%).

Participating men were more likely than refusals to have fractured a bone (44.5% versus 37.5%) and to have a family history of osteoporosis (29.0% versus 19.5%). Similarly, participating women were more likely to have fractured a bone (31.1% versus 21.8%) and to have a family history of osteoporosis (30.5% versus 18.7%). This may be because they were asked to complete an information sheet regarding family medical history before being interviewed, whereas those who only completed the refusal questionnaire may have had less knowledge of their family history.

DISCUSSION

The HRQOL of Canadian youth is good, on average. However, both young men and women scored somewhat better on the physically oriented domains, such as PF and RP, than on the mentally oriented domains, such as VT and MH. The exception is the SF domain, one of the mentally oriented domains, which was quite high for both men and women. The overall pattern is similar to published normative data for those aged 25-34 years,³ although the younger men scored 2.4 points lower on the MCS than the adjacent age group. The relatively high physically oriented scores but somewhat lower mentally oriented scores suggest that while these younger groups are in good physical health, they are more likely than older groups to be struggling with major decisions about relationships and career choices, which can negatively affect mental aspects of HRQOL. In general, men tended to score somewhat higher than women, and younger (15-19 years) women tended to score somewhat higher than older (20-24 years) women.

Normative data for adolescents and young adults also exist for the US^{1,2} and Sweden.⁴ Comparisons are somewhat imprecise, as the age groups, methodology and response rates differ. For example, Sweden assessed those aged 13-23 years, the US sample was

18-24 years, and the CaMos sample was 16-24 years. The US sample used a combined mail survey and telephone survey and had a response rate of 77.1%. The Swedish study randomly assigned participants to a telephone interview or a postal questionnaire and reported response rates of 76.7% and 63.5%, respectively. CaMos had a response rate of 22.5%, and participants completed the SF-36 on their own in an interview setting.

Swedish SF-36 scores for the telephone-administered and mailed sample were combined for comparison with the CaMos and US data. For men, Canadian and US means were all within five points of each other. However, mean scores for the Swedish sample were considerably better than Canadian and US scores for four domains, i.e., BP, GH, VT and SF. In addition, Swedish scores were also more than five points higher than the RE and MH domains of the Canadian sample. For all six domains on which the Swedish sample outscored the Canadian sample, the Swedish mean fell well above the 95% CI of the Canadian sample. However, the PCS and MCS were within two points of each other for the three countries.

For women, the results were less consistent. Canadian women had mean scores exceeding 5 points higher than the US women on the RP and SF domains but scored more than 5 points lower on the BP domain. Swedish means were substantially higher than US means for PF and SF. Canadian women scored higher than the Swedish sample on RP and the MCS but scored 7.4 points lower on the BP domain, so although there were differences, no clear pattern emerged.

A number of limitations of these data need to be considered. First, although participants were randomly selected, not all who were invited to do so participated, which may affect the representativeness of the sample. In addition, the differences between participants and non-participants as measured on the refusal questionnaire suggest that participants had higher fracture rates, and a higher percentage had a family history of osteoporosis. However, this may in part be explained by the fact that the participants were asked to complete an information sheet regarding family medical history before being interviewed. Finally, although the 50 km radius around each CaMos centre often included rural areas, our data do not allow us to fully differentiate between rural and urban regions.

Nevertheless, the strengths of the study, including the random selection of subjects invited to participate, use of a validated ques-

tionnaire and representation from nine centres across Canada, support our belief that the HRQOL of Canadian youth is generally good and that these data provide good estimates of the HRQOL of Canadian youth. The differences among age groups, gender and country underscore the importance of taking these factors into consideration when using normative data.

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RÉSUMÉ

Objectifs : Des données normatives sur la qualité de vie liée à la santé (QVLS) dans le questionnaire sur l'état de santé SF-36 existent déjà pour les personnes de plus de 25 ans grâce aux données représentatives de l'Étude canadienne multicentrique sur l'ostéoporose (CaMos). La CaMos a recruté récemment un échantillon de jeunes Canadiens âgés de 16 à 24 ans. Le but de notre étude était d'élaborer des données normatives SF-36 pour ce groupe d'âge.

Méthode : Après avoir effectué une standardisation directe à partir de la population canadienne, nous avons calculé les moyennes, les écarts-types (ET), les intervalles de confiance de 95 % et le pourcentage minimum et maximum pour les huit domaines et les deux notes globales du SF-36. Les domaines sont notés de 0 (mauvais) à 100 (excellent). Les notes globales sont standardisées selon une moyenne de 50, les notes de plus de 50 indiquant des fonctions supérieures à la moyenne, et les notes de moins de 50, des fonctions inférieures à la moyenne. Nous avons analysé séparément les hommes des femmes, et le groupe des 16 à 19 ans de celui des 20 à 24 ans.

Résultats : Les 1 001 participants sélectionnés dans la communauté comprenaient 474 hommes et 527 femmes des neuf centres CaMos du Canada. Les notes globales moyennes pour la composante santé physique étaient de 53,9 (ET=6,9) et de 53,3 (ET=5,7) pour les jeunes hommes et les jeunes femmes, respectivement. Les notes équivalentes pour la composante santé mentale étaient de 49,3 (ET=9,7) et de 48,8 (ET=8,9). En général, les hommes ont obtenu des notes un peu meilleures que celles des femmes, et les femmes plus jeunes (16 à 19 ans), de meilleures notes que leurs aînées (20 à 24 ans), mais ces différences étaient faibles.

Conclusion : La QVLS est bonne dans cette cohorte de jeunes Canadiens. Tant les hommes que les femmes ont obtenu des notes un peu meilleures pour la santé physique que pour la santé mentale. En général, les notes canadiennes étaient semblables à celles des États-Unis, mais un échantillon suédois comparable a obtenu des notes plus élevées que ces deux pays dans la plupart des domaines. Ces résultats soulignent l'importance de tenir compte du pays, de l'âge et du sexe lorsqu'on utilise des données normatives.

Mots clés : SF-36; normatif; adolescent; jeune; sexospécificité; CaMos; âge