self-reported indirect costs are underestimated in a canadian cohort of patients with SLE

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Background Indirect costs (IDC) of SLE reflect lost productivity in work force (WF) and non-WF activities and can be expressed as: 1) patient self-report of lost productivity or 2) the difference between productivity of an age-and-sex matched general population and the patients stated productivity. We assess IDC calculated by both methods in a Canadian-wide cohort and compare IDC, stratified by damage, across methods.

Methods Patients fulfilling the ACR or SLICC Classification Criteria from 6 centres were enrolled. Participants completed a validated questionnaire on lost productivity. Lost productivity was calculated as: 1) the difference between the time patients reported they expected they would engage in WF and non-WF activities if not ill versus the time they reported working and 2) the difference between the time worked by an age-and-sex matched general population in WF and non-WF activities versus the time patients reported working. IDC were valued using age-and-sex-specific wages from the Statistics Canada General Social Survey. IDC from non-WF activities were valued using opportunity costs (i.e., expected WF earnings, rather than expected earning of service workers). Annual IDC (2017 Canadian dollars) associated with damage measured on the SLICC/ACR Damage Index (SDI) were obtained from multiple regressions adjusting for age, race/ethnicity, and disease duration.

Results 1368 patients participated, 90.4% female, 70.9% Caucasian, mean age at diagnosis 33.0 years (SD 13.5), mean SLE duration 16.8 years (SD 11.6), mean SLE Disease Activity Index (SLEDAI-2K) 2.15 (SD 3.07), and mean SDI 1.54 (SD 2.61). IDC by method #1 versus #2, stratified by SDI, are shown in table 1. Although at SDI=0, mean predicted IDC did not differ between methods, for SDI=1 through SDI 5, IDC by method #2 were greater. Conclusions IDC by method #2 were greater for SDIs 1 through 5 and the difference between methods increased significantly between lower and higher SDIs (<2 versus 5). Our results suggest that IDC calculated by comparing the patients actual productivity to their self-report of expected productivity versus the productivity of an age-and-sex-matched general population leads to underestimation, which is not associated with damage. Patients expectations of productivity appear to plateau with increasing damage and do not reflect their likely productivity if they were not ill. Hence, IDC should not only rely on patients self-report of lost productivity, but should also incorporate a comparison of the patients productivity with the actual productivity of a matched general population.

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