JMIR Public Health and Surveillance

Impact Factor (2023): 3.5
Volume 3 (2017), Issue 1   ISSN 2369-2960   Editor in Chief: Travis Sanchez, PhD, MPH

Contents

Original Papers

Rapid Surveillance Report

Original Paper

HIV Trends in the United States: Diagnoses and Estimated Incidence

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Abstract

Background: The best indicator of the impact of human immunodeficiency virus (HIV) prevention programs is the incidence of infection; however, HIV is a chronic infection and HIV diagnoses may include infections that occurred years before diagnosis. Alternative methods to estimate incidence use diagnoses, stage of disease, and laboratory assays of infection recency. Using a consistent, accurate method would allow for timely interpretation of HIV trends.

Objective: The objective of our study was to assess the recent progress toward reducing HIV infections in the United States overall and among selected population segments with available incidence estimation methods.

Methods: Data on cases of HIV infection reported to national surveillance for 2008-2013 were used to compare trends in HIV diagnoses, unadjusted and adjusted for reporting delay, and model-based incidence for the US population aged ≥13 years. Incidence was estimated using a biomarker for recency of infection (stratified extrapolation approach) and 2 back-calculation models (CD4 and Bayesian hierarchical models). HIV testing trends were determined from behavioral surveys for persons aged ≥18 years. Analyses were stratified by sex, race or ethnicity (black, Hispanic or Latino, and white), and transmission category (men who have sex with men, MSM).

Results: On average, HIV diagnoses decreased 4.0% per year from 48,309 in 2008 to 39,270 in 2013 (*P*<.001). Adjusting for reporting delays, diagnoses decreased 3.1% per year (*P*<.001). The CD4 model estimated an annual decrease in incidence of 4.6% (*P*<.001) and the Bayesian hierarchical model 2.6% (*P*<.001); the stratified extrapolation approach estimated a stable incidence. During these years, overall, the percentage of persons who ever had received an HIV test or had had a test within the past year remained stable; among MSM testing increased. For women, all 3 incidence models corroborated the decreasing trend in HIV diagnoses, and HIV diagnoses and 2 incidence models indicated decreases among blacks and whites. The CD4 and Bayesian hierarchical models, but not the stratified extrapolation approach, indicated decreases in incidence among MSM.

Conclusions: HIV diagnoses and CD4 and Bayesian hierarchical model estimates indicated decreases in HIV incidence overall, among both sexes and all race or ethnicity groups. Further progress depends on effectively reducing HIV incidence among MSM, among whom the majority of new infections occur.

(JMIR Public Health Surveill 2017;3(1):e8) doi:10.2196/publichealth.7051

KEYWORDS

HIV infections; incidence; biomarkers; United States

Introduction

Annual estimates of the number of human immunodeficiency virus (HIV) infections in the United States peaked in the mid-1980s, decreased through the early 1990s, and remained relatively stable through 2010 [1,2]. Over time, with improved diagnosis and treatment, the number of people living with HIV has steadily increased and with that has come the potential for increased HIV transmission [3-5]. But knowledge of HIV infection is associated with decreased risk behavior, and the proportion of persons with HIV in the United States who know their status is at its highest ever [3,4]. Similarly, antiretroviral treatment (ART) for HIV substantially reduces the risk of viral transmission, and decreases in incidence have been observed in populations with higher uptake of ART [6-9]. Yet, it is unclear whether HIV prevention programs and ART use have resulted in decreasing HIV incidence in recent years in the United States.

A primary goal of the National HIV/AIDS Strategy for the United States is to reduce HIV incidence [10]. However, determining progress in reducing HIV incidence is challenging as direct measures are generally not available. Some recent reports suggest that HIV diagnoses decreased in the United States during the last decade [11-13]. However, HIV diagnoses trends are affected by testing rates, diagnoses delays, and incidence rates, and should therefore be interpreted in conjunction with data on HIV testing and available incidence estimates.

To assess recent progress toward reducing HIV infections in the United States overall and in selected population segments with available incidence estimation methods, we analyzed data reported to national surveillance programs at the Centers for Disease Control and Prevention (CDC). The data presented include case counts of HIV diagnoses as well as data from new and established models to estimate HIV incidence and testing data from behavioral surveys to aid interpretation of trends. In the United States, large disparities in HIV diagnoses exist among population segments; two-thirds of persons with HIV diagnosed each year are men who have sex with men (MSM), and blacks or African Americans are 8 times and Hispanics or Latinos 3 times as likely to be diagnosed with HIV as white Americans [14]. Therefore, assessment of progress toward reaching the goal of reducing HIV incidence should include trends for the United States overall and for disproportionately affected population segments.

Methods

HIV Diagnoses and Incidence Data Sources and Methods

Data from the National HIV Surveillance System reported to the CDC through December 2015 were used to determine trends in the annual number of HIV diagnoses in the United States [15]. Data on HIV diagnoses were also used to estimate the annual number of infections (incidence) with 3 models (Table 1) using (1) additional information on a biomarker that classifies infections as recent (or not) in the stratified extrapolation approach [1,2,16-18]; (2) HIV diagnoses and the severity of disease (whether infection is classified as stage-3 AIDS, within the same calendar year as HIV diagnosis) in the back-calculation approach (Bayesian hierarchical model) to estimate HIV prevalence and the percentage of persons living with undiagnosed HIV [4,19,20]; and (3) the first CD4 count after diagnosis in a newly developed approach to derive incidence, prevalence, and the percentage undiagnosed (CD4 model) [21-23]. The biomarker data required for the stratified extrapolation approach were collected by 18 states and 3 cities participating in the incidence surveillance component of the National HIV Surveillance System. Incidence was estimated for these combined areas and then extrapolated to the remaining areas of the United States [2]. For the Bayesian hierarchical model, input data were adjusted for underreporting of HIV diagnoses in the early years of the US epidemic period before HIV reporting was implemented by all jurisdictions, whereas information on AIDS diagnoses was available for all years [19]. For the CD4 model historical data were not required and data on diagnoses and CD4 test results were directly obtained from the surveillance data.

Data are presented for 2008 through 2013; starting in 2008, all states and the District of Columbia had implemented name-based HIV reporting and these cases were reported to the National HIV Surveillance System. Diagnoses and incidence estimates were adjusted for missing risk factor information and for determining whether reporting delays may affect the interpretation of trends, we conducted analyses unadjusted and adjusted for reporting delays [14].

Data on HIV diagnoses and for derived incidence include persons aged 13 years and older at the time of diagnosis or infection, respectively. Trends in these indicators were assessed overall and by sex and race or ethnicity (blacks or African Americans, (hereafter referred to as blacks); Hispanics or Latinos; and whites), and for MSM. HIV surveillance data can be considered to represent a census of HIV diagnoses for the United States and therefore no confidence intervals (CIs) are presented. For estimates of HIV incidence, 95% CIs were calculated. To determine whether there was a significant increasing or decreasing trend in the annual numbers of diagnoses or incidence, the estimated annual percent change (EAPC) in diagnoses and incidence and associated 95% CIs were calculated, and a change in trend was considered statistically significant if *P*<.05.

Table 1. Methods for estimating HIV incidence.

Name of the model	Stratified extrapolation approach [1,16,17]	Bayesian hierarchical model [19,20]	CD4 model [23]
Method	Biomarker-based sample survey	Bayesian-based back-calculation	CD4 based back-calculation
Data requirement	Data for single or multiple years, no limit on number of years	Data for entire epidemic period	Data for recent (8+) years
	All new diagnoses	All new diagnoses	All new diagnoses
	Incidence assay result on recency of infection	AIDS classification within year of diagnosis	First CD4 after diagnosis
	Testing and treatment history		
Strengths	Annual estimates	Annual estimates	Annual estimates
	More accurate for recent years		Data for entire epidemic period not required
Weaknesses	False recent rate of incidence assay used	HIV data in earlier years incomplete as jurisdictions implemented HIV reporting over time; hence relies on accuracy of data adjustment for incomplete reporting	Relies on accuracy of CD4 depletion model
	Relies on accuracy of testing and treatment information		

HIV Testing Data Sources and Methods

Data on HIV testing among the US population are available from the National Health Interview Survey (NHIS) and the Behavioral Risk Factor Surveillance System (BRFSS), and these were used to determine trends in testing (a change in trend was considered statistically significant if $P<.05$). NHIS collects information on a broad range of health topics from a nationally representative sample of civilian, noninstitutionalized US households [24]. The annual NHIS response rate for the Sample Adult Survey ranged from 62.6% in 2008 to 60.8% in 2010 [24]. NHIS asks persons aged 18 years and above questions related to HIV testing (Have you ever been tested for HIV? In what month and year was your last test for HIV [the virus that causes AIDS]?). Differences observed in estimates of HIV testing based on NHIS 2010 and earlier and NHIS 2011 and later may be attributable to survey design changes and estimates for the percentage of persons ever tested are not comparable [25,26]. Therefore, the most recent years included in this analysis were 2008-2010. Only records for respondents aged 18-64 years were included, the age group for which CDC's recommendations encourage HIV screening, and records had to have a “Yes” or “No” response to whether the respondent had ever been tested for HIV, excluding tests for blood donations.

BRFSS is a state-based, random-digit-dialed telephone (landline and mobile) survey of the civilian, noninstitutionalized adult US population that collects information on preventive health practices and risk behaviors. In 2011, BRFSS added mobile phone numbers to the sampling frame and implemented a new weighting methodology. Differences observed in estimates of HIV testing based on 2010 and earlier BRFSS and 2011 and later BRFSS may be attributable to these design changes and estimates of the percentage of persons ever tested during the 2 periods are not comparable [26]. The median weighted survey response rates for all states were 49.7% in 2011, 45.2% in 2012, and 45.9% in 2013 [27-29]. Ever tested for HIV and tested in the last year were based on respondents who reported having ever tested for HIV and whether the most recent HIV test was within a year of their BRFSS interview date. Analyses were weighted to account for the complex survey design, nonresponse, and sociodemographic factors to provide estimates of HIV testing that are representative of the civilian, noninstitutionalized population in the United States.

Data from National HIV Behavioral Surveillance (NHBS) for 2008, 2011, and 2014 were used to determine trends in HIV testing among MSM, ever and within the past 12 months. NHBS monitors HIV-associated behaviors in 20 cities with high AIDS burden [30]. A venue-based sampling method is used for the NHBS MSM cycles [31]. First, venues frequented by MSM (eg, bars, dance clubs, gyms, restaurants, parks, street locations, and social organizations) and days and times when men frequented those venues are identified. Second, venues and corresponding day-time periods were selected randomly for recruitment events. Third, men at recruitment events were systematically approached to screen for eligibility (aged ≥18 years, lived in a participating city, and able to complete the interview in English or Spanish). An additional eligibility criterion was applied in 2011 and 2014, by which only men who reported ever having sex with another man were eligible. Consent for participation in the survey was obtained and trained interviewers used handheld computers to administer a standardized anonymous questionnaire. All analyses were conducted using SAS version 9.3 statistical software (SAS Institute Inc), except for the Bayesian hierarchical model, which used R version 3.2.2 statistical software (The R Foundation for Statistical Computing).

Results

HIV Diagnoses, Incidence, and Testing Among the US Population

Annual diagnoses decreased from 48,309 in 2008 to 39,270 in 2013, an average rate of 4.0% per year, and diagnoses adjusted for reporting delays decreased 3.1% per year from 48,938 in 2008 to 41,625 in 2013 (Table 2). In 2013, depending on the model used, an estimated 34,400 (95% CI 27,700-39,000) to 36,300 (95% CI 34,000-38,500) persons were newly infected with HIV in the United States. The CD4 model estimated an annual decrease of 4.6% in new infections from 2008 to 2013. The Bayesian hierarchical model also estimated a decrease in infections (2.6% per year) whereas the stratified extrapolation approach estimated stable numbers of new infections. During these years, the number of persons who reported ever having received an HIV test or having had a test within the past 12 months remained stable (Figure 1).

Figure 1. Percentage of persons reporting testing for HIV, United States, 2008-2014. HIV: human immunodeficiency virus; BRFSS: Behavioral Risk Factor Surveillance System; NHBS: National HIV Behavioral Surveillance; NHIS: National Health Interview Survey; MSM: men who have sex with men.

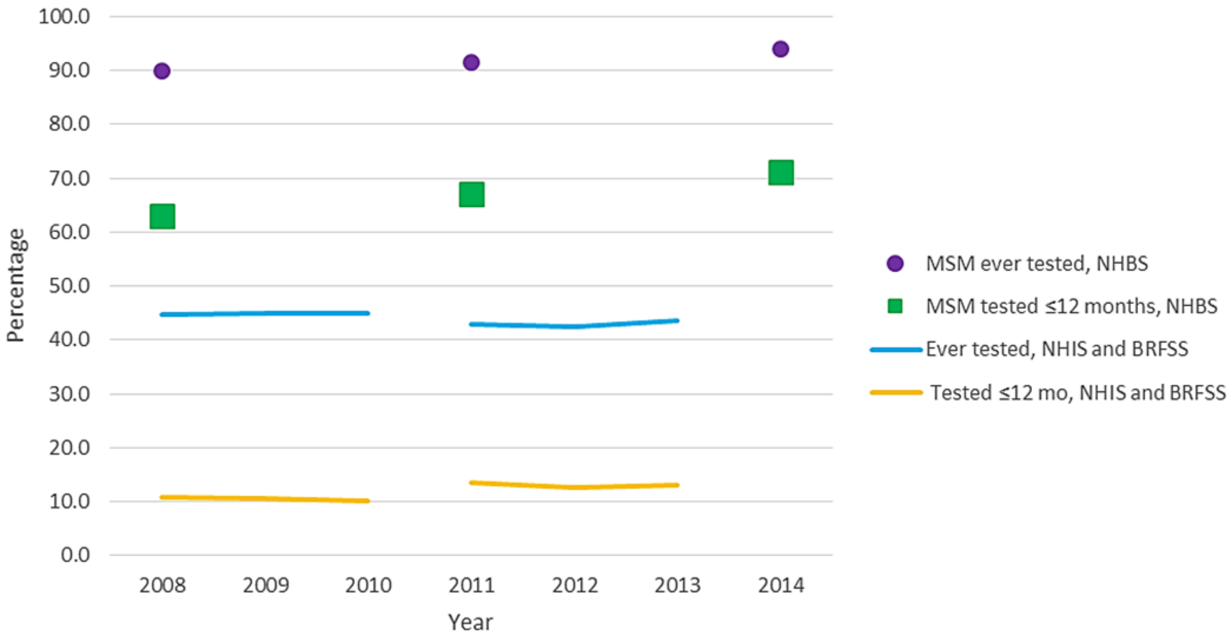


Table 2. Number of diagnoses of HIV infection and HIV incidence, by selected characteristics, United States, 2008-2013.

Measure			Year						EAPC[a]	*P* value
			2008	2009	2010	2011	2012	2013		
Total										
	Diagnoses of HIV infection	No.	48,309	45,688	43,637	41,793	40,872	39,270	−4.0	<.001
		estimated No.[b]	48,938	46,428	44,564	43,043	42,686	41,625	−3.1	<.001
	Stratified extrapolation approach	No.	39,000	36,100	35,300	36,900	36,700	36,200	−0.7	.22
		95% CI	33,600	31,100	30,500	31,800	31,600	31,200		
			44,400	41,000	40,200	42,000	41,800	41,300		
	Bayesian hierarchical model	No.	39,700	37,100	36,200	35,600	35,200	34,400	−2.6	<.001
		95% CI	36,900	34,700	33,500	33,300	31,300	27,700		
			42,200	39,900	39,100	37,600	38,000	39,000		
	CD4 model	No.	46,000	43,900	41,600	40,000	38,300	36,300	−4.6	<.001
		95% CI	44,800	42,600	40,100	38,300	36,400	34,000		
			47,200	45,200	43,100	41,700	40,300	38,500		
Black or African American										
	Diagnoses of HIV infection	No.	22,702	21,325	20,214	19,108	18,348	17,517	−5.0	<.001
		estimated No.[b]	23,013	21,695	20,669	19,722	19,234	18,666	−4.1	<.001
	Stratified extrapolation approach	No.	17,600	15,400	14,800	16,200	15,200	15,600	−1.5	.09
		95% CI	15,000	13,200	12,600	13,800	12,900	13,300		
			20,200	17,600	17,000	18,500	17,400	17,900		
	Bayesian hierarchical model	No.	18,700	16,700	15,900	16,100	16,100	15,900	−3.1	<.001
		95% CI	16,400	14,700	14,200	14,200	14,000	11,500		
			21,300	18,700	17,200	17,800	19,800	21,400		
	CD4 model	No.	21,600	20,700	19,300	18,300	17,000	16,100	−5.7	<.001
		95% CI	20,700	19,700	18,200	17,100	15,700	14,500		
			22,400	21,600	20,300	19,500	18,300	17,600		
Hispanic or Latino										
	Diagnoses of HIV infection	No.	9801	9466	9158	8998	8997	8788	−2.0	<.001
		estimated No.[b]	9928	9615	9351	9263	9389	9299	−1.2	<.001
	Stratified extrapolation approach	No.	7900	7600	7600	8100	8000	8100	1.0	.40
		95% CI	6600	6300	6400	6800	6700	6800		
			9200	8800	8800	9300	9200	9500		
	Bayesian hierarchical model	No.	8100	8000	8100	8300	8200	8100	0.4	.22
		95% CI	7200	6500	7000	7100	6100	5300		
			8900	8900	9100	9800	10,200	10,500		
	CD4 model	No.	9500	9200	8800	8700	8700	8600	−2.2	.05
		95% CI	8900	8600	8100	7800	7700	7400		
			10,000	9900	9500	9500	9700	9700		
White										
	Diagnoses of HIV infection	No.	13,109	12,327	11,768	11,262	11,142	10,708	−3.8	<.001
		estimated No.[b]	13,264	12,506	11,993	11,559	11,574	11,275	−3.1	<.001

Measure		Year						EAPC[a]	*P* value
		2008	2009	2010	2011	2012	2013		
Stratified extrapolation approach	No.	11,100	10,900	10,800	10,400	11,100	10,600	−0.6	.63
	95% CI	9300	9100	9100	8700	9400	8900		
		12,900	12,600	12,500	12,100	12,900	12,300		
Bayesian hierarchical model	No.	11,100	10,200	10,000	10,000	10,100	9800	−2.1	<.001
	95% CI	10,000	8300	9000	8500	7800	6500		
		12,300	11,200	10,900	12,000	12,300	12,600		
CD4 model	No.	12,400	11,500	11,100	10,700	10,400	9500	−4.7	<.001
	95% CI	11,900	10,900	10,400	9900	9500	8400		
		13,000	12,100	11,800	11,400	11,300	10,500		

[a] EAPC: estimated annual percent change.

[b] Numbers are adjusted for reporting delays.

HIV Diagnoses, Incidence, and Testing Among Population Segments

Among blacks, the number of HIV diagnoses decreased 5.0% per year from 2008 to 2013 (4.1% for diagnoses adjusted for reporting delays; Table 2). Among Hispanics or Latinos and whites, diagnoses decreased 2.0% (adjusted, 1.2%) and 3.8% (adjusted, 3.1%) per year, respectively. The CD4 model indicated decreases in incidence among blacks, Hispanics or Latinos, and whites, whereas the Bayesian hierarchical model indicated decreases among blacks and whites and the stratified extrapolation approach indicated that HIV incidence remained stable among all race or ethnicity groups.

Among males, the number of diagnoses decreased 2.8% per year from 2008 (36,614 diagnoses) to 2013 (31,578 diagnoses; decrease in adjusted diagnoses, 2.0%; Figure 2). Trends in estimated new HIV infections among males were inconsistent between the models. Incidence decreased by 3.5% (95% CI −4.6% to −2.4%) per year based on the CD4 model (2008: 35,600 infections, 95% CI 34,500-36,600; 2013: 29,600 infections, 95% CI 27,500-31,700), and by 1.5% (95% CI −1.9% to −1.2%) based on the Bayesian hierarchical model (2008: 31,500 infections, 95% CI 28,200-33,900; 2013: 28,900 infections, 95% CI 22,100-33,400). Based on the stratified extrapolation approach, HIV incidence remained stable among males (EAPC 0.9%, 95% CI −0.5% to 2.2%) from 2008 (29,400 infections, 95% CI 25,300-33,500) to 2013 (29,800 infections, 95% CI 25,700-34,000). The number of HIV diagnoses and infections among females decreased by about 30% between 2008 and 2013 using any measure, with average annual decreases in incidence from 4.2% to 8.7%.

Among men with infection attributed to male-to-male sexual contact, who accounted for 81.3% of males with HIV diagnosed in 2013, the number of HIV diagnoses decreased by 1.0% per year from 2008 (27,119 diagnoses) to 2013 (25,670 diagnoses), with no significant decrease observed in the diagnoses adjusted for reporting delays (Figure 3). During that time, the percentage of MSM who reported testing for HIV within the past 12 months increased from 63.0% in 2008 to 71.1% in 2014 ($P<.001$; Figure 1). More than 90% of MSM reported ever testing for HIV in recent years. The number of new infections among MSM increased by 2.5% per year (95% CI 1.0%-4.0%) based on the stratified extrapolation approach (2008: 22,600 infections, 95% CI 19,400-25,800; 2013: 24,700 infections, 95% CI 21,200-28,200), but the CD4 model (EAPC −1.8%, 95% CI −3.0% to −0.5%; 2008: 27,400, 95% CI 26,500-28,200; 2013: 24,600, 95% CI 22,700-26,500) and Bayesian hierarchical model (EAPC −2.5%, 95% CI −2.9% to −2.1%; 2008: 25,700 infections, 95% CI 24,000-27,700; 2013: 22,800 infections, 95% CI 19,000-26,800) both indicated a decrease in HIV incidence (Figure 3).

Figure 2. Number of diagnoses of HIV infection and estimated HIV infections, by sex, United States, 2008-2013. HIV: human immunodeficiency virus; BHM: Bayesian hierarchical model; CD4: CD4 model; SEA: stratified extrapolation approach.

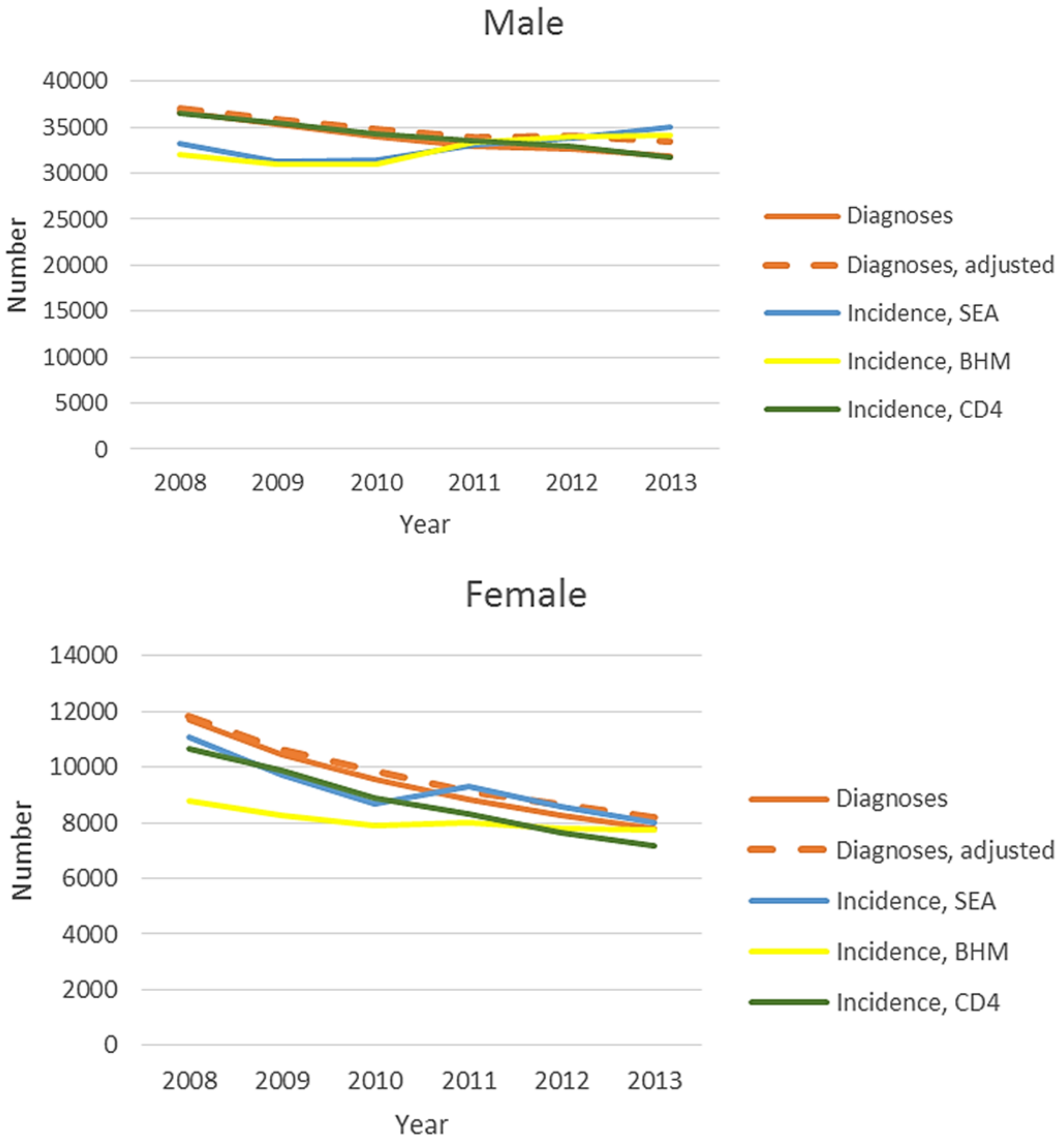
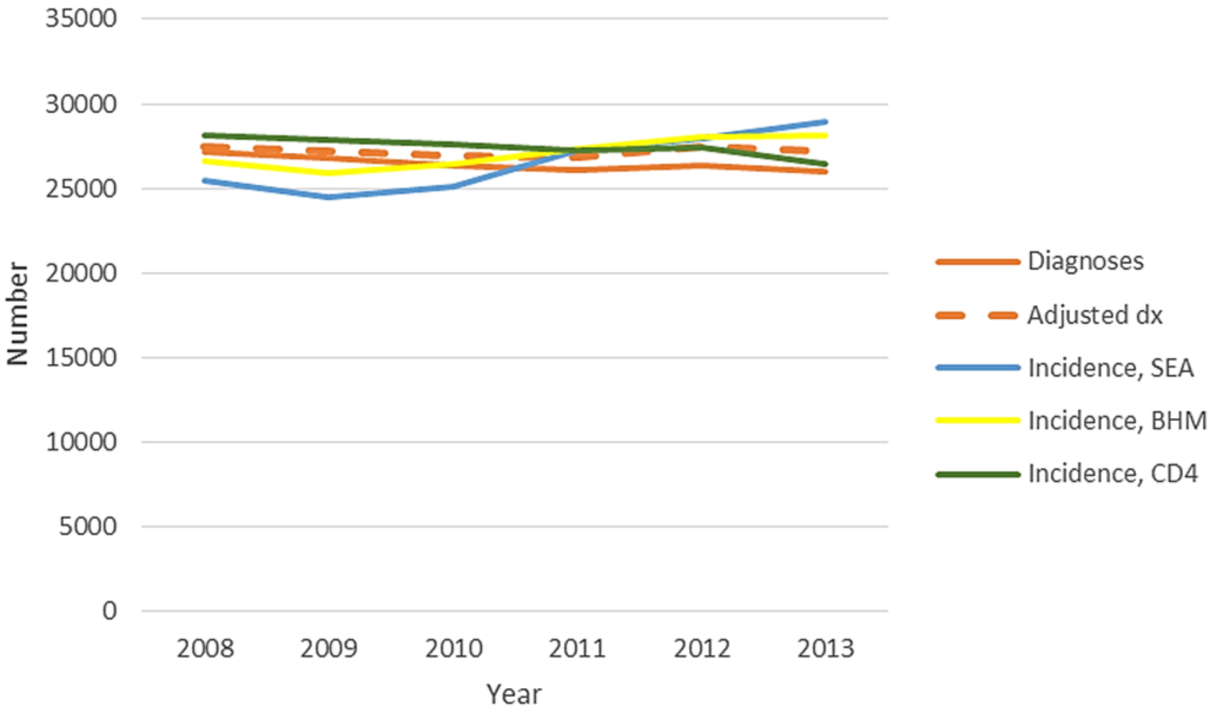


Figure 3. Number of diagnoses of HIV infection and estimated HIV infections among MSM, United States, 2008-2013. HIV: human immunodeficiency virus; BHM: Bayesian hierarchical model; CD4: CD4 model; SEA: stratified extrapolation approach; MSM: men who have sex with men.



HIV Incidence Adjusted for Reporting Delay

When analyses were repeated with data adjusted for delays in reporting of HIV diagnoses to the National HIV Surveillance System, the findings varied across models and population segments. For all 3 models, incidence estimates based on data adjusted for reporting delays did not change the interpretation of trends for blacks, whites, and females (data not shown). The Bayesian hierarchical model indicated a small increase in incidence overall (EAPC 0.8%, 95% CI 0.5%-1.1%) and among Hispanics or Latinos (EAPC 3.9%, 95% CI 3.2%-4.5%). For men with infection attributed to male-to-male sexual contact, estimates based on data adjusted for reporting delays from the CD4 (EAPC −1.0%, 95% CI −2.2% to 0.3%) and the Bayesian hierarchical models (EAPC 0.66%, 95% CI 0.31%-1.01%) no longer indicated a decrease in incidence.

Discussion

Principal Findings

The study findings are that diagnoses of HIV infection and incidence estimates from 2 models indicate a reduction in HIV incidence from 2008 through 2013 overall and in subpopulations, including women, men, and MSM. Compared with earlier estimates of the number of new infections in the United States [1,2,17], HIV incidence decreased from about 50,000 infections in the 1990s through the mid-2000s to around 36,000 infections in 2013. For MSM, previously published estimates [1,2] indicate an increase in incidence from about 20,000 infections in the early 1990s to about 30,000 infections in the mid-2000s, with relatively stable incidence thereafter and, based on our analyses, about 25,000 infections in 2013. Our results from the stratified extrapolation approach for 2008-2010 are lower than the previously reported incidence estimates for these years (47,500, 45,000, and 47,000, respectively) based on the same model [2]. There is new evidence that the mean recency period (an estimate of the time between seroconversion and the time the biomarker reaches a value defined as distinguishing recent vs long-standing infection) of the BED assay is longer than previously estimated [18]. Use of a shorter recency period in the past resulted in an overestimation of incidence and therefore, a revision to modeling with the stratified extrapolation approach was required. We revised the method using the newly estimated recency period of 198 days for the BED assay (compared with 162 days used in the past) [18].

Our analyses indicated substantial reductions in HIV incidence in the United States, including among blacks and Hispanics or Latinos, who are disproportionately affected by HIV. The results also suggest modest reductions among MSM, a population with a considerably higher HIV prevalence than heterosexuals, indicating the need for greater reach of HIV prevention services to make substantial reductions in incidence. HIV testing appears to be increasing among MSM, potentially due to large-scale national efforts, with a high and increasing proportion ever tested for HIV and more MSM tested within the past 12 months. This may be reflected in previously reported increases in HIV diagnoses among young MSM who are most likely to have undiagnosed HIV, and the overall increase in awareness of HIV infection among MSM [4,11]. Annual testing is recommended for sexually active MSM and more frequent testing may be indicated for those at highest risk for HIV infection to detect HIV infection early, which allows risk counseling and initiation of treatment and is cost effective [32-34]. Additional assessments are needed to determine whether testing is not reaching certain subpopulations of MSM at high risk for HIV infection.

More work needs to be done to alleviate the possible reasons that HIV transmission continues at high rates among MSM, including a proportion of MSM with viral suppression well short of national goals [4,10], increases in risk behavior [35], and lack of substantial uptake of pre-exposure prophylaxis (PrEP) to date [36]. The overall high proportion of undiagnosed HIV (51% in 2013) among young persons may contribute to higher HIV transmission [4]. In addition, the proportion with a suppressed viral load is lower among younger compared with older MSM [37]. With MSM accounting for the majority of transmissions of HIV in the United States [14,38], it is crucial that prevention efforts reach all MSM.

Blacks and Hispanics or Latinos remain disproportionately affected by HIV compared with whites. In 2013, about 44% of persons who were infected with HIV were black and about 24% Hispanic or Latino, compared with them comprising 12% and 17% of the US population, respectively. The decreasing trends in diagnoses and incidence among women are encouraging and, as previously reported, are mirrored by decreasing diagnoses among black, Hispanic or Latino, and white women [39]. Data on HIV testing in the United States for women overall do not indicate that decreases in diagnoses among women would be due to decreases in testing [40]. However, some data indicate that testing among young women, including black and white young women, has decreased from 2011 to 2013 [41], whereas data for women at increased risk for HIV infection from NHBS indicate an increase in testing [42,43]. To achieve the goal of the National HIV/AIDS Strategy of reducing disparities in HIV, there is a need to strengthen treatment for persons living with HIV to improve their health and prevent transmission, as well as primary prevention efforts [10]. Lower percentages of blacks and Hispanics or Latinos living with HIV have their infection diagnosed or are promptly linked to care after diagnosis [4]. Disparities by race or ethnicity also exist in receipt of treatment and viral suppression overall as well as among women and MSM [4,37,39].

Limitations

There are some limitations to each of the measures available to estimate trends in HIV incidence. Diagnoses represent a census of events for the United States. However, trends in diagnoses depend on testing rates and are subject to diagnosis delays, with an estimated median delay between HIV infection and HIV diagnosis of 3.6 years (mean 5.6 years) for 2011 [21]. Back-calculation models to estimate incidence rely on valid input data on diagnoses and the time from infection to late stage disease (Table 1). An advantage to the CD4 model is that historical data are not required. The Bayesian hierarchical model, on the other hand, requires input data for the entire epidemic period and hence additional uncertainty is introduced because of the need to estimate HIV cases for the early years when HIV testing was not available and when few jurisdictions had HIV reporting even after HIV testing became available. Another advantage of the CD4 model is that HIV surveillance requires the reporting of the first CD4 count after HIV diagnosis in all jurisdictions, and CD4 reporting completeness is expected to increase as laboratory reporting improves [4]. Collection of biomarker data for the stratified extrapolation approach is limited to the 18 states and 3 cities participating in incidence surveillance, requiring extrapolation to the remaining areas of the United States [2]. The stratified extrapolation approach is also subject to incidence assay and testing history inaccuracies [44]. In addition, stratified extrapolation approach estimates rely on a correctly calculated mean recency period for the incidence assay used. We applied the updated mean recency period of 198 days for the BED assay (compared with 162 days used in the past) [18], which resulted in lower incidence estimates compared with earlier estimates. These limitations may also explain why the incidence estimates from the stratified extrapolation approach were at times inconsistent with the other 2 methods. Back-calculation models have greater uncertainty in later years reflected in wider CIs, and hence more uncertainty in determining trends. Estimating incidence by age with back-calculation models is more complex as age at HIV infection must also be estimated but could be included in future work. Reporting of HIV diagnoses is subject to reporting delays and duplicate reporting of cases, which primarily affect the reporting of data for the most recent years. Therefore, adjustment for reporting delays may overestimate diagnoses when duplicate cases have not been removed from the data. Finally, long-term trend data on testing rates to compare with diagnosis trends are not available for the general population or the entire population of MSM. The NHBS System relies on venue-based, time-space sampling of MSM in 20 large urban areas and therefore may not be representative of the entire MSM population. Testing data are also subject to accuracy of recall and possibly response influenced by social desirability.

Conclusions

In summary, incidence models estimated that about 36,000 people were infected with HIV in the United States in 2013. From 2008 to 2013, HIV diagnoses decreased overall, among both sexes and all race or ethnicity groups, and similar to earlier estimates of HIV incidence [45,46], the CD4 and Bayesian hierarchical models indicated decreases in incidence. The overall decrease in incidence reflects a substantial decrease among women, heterosexual men, and as previously reported, among persons who inject drugs [1,2]. However, further progress is dependent on effectively reducing HIV incidence among MSM, among whom the majority of new infections occur. To do so, the nation will need to accelerate access to testing, antiretroviral therapy, and prevention advances, including PrEP, to reduce HIV infections by the targeted 25% of the National HIV/AIDS Strategy [10,47,48].

Acknowledgments

The findings and conclusions in this study are those of the authors and do not necessarily represent the views of the CDC.

Conflicts of Interest

None declared.

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Abbreviations

ART: antiretroviral treatment
BRFSS: Behavioral Risk Factor Surveillance System
EAPC: estimated annual percent change
HIV: human immunodeficiency virus
MSM: men who have sex with men
NHIS: National Health Interview Survey
NHBS: National HIV Behavioral Surveillance

Edited by T Sanchez; submitted 25.11.16; peer-reviewed by R Valdiserri, E Mokotoff, D Holtgrave, E Rosenberg; comments to author 22.12.16; revised version received 30.12.16; accepted 18.01.17; published 03.02.17.

Please cite as:
Hall HI, Song R, Tang T, An Q, Prejean J, Dietz P, Hernandez AL, Green T, Harris N, McCray E, Mermin J
HIV Trends in the United States: Diagnoses and Estimated Incidence
JMIR Public Health Surveill 2017;3(1):e8
URL: http://publichealth.jmir.org/2017/1/e8/
doi:10.2196/publichealth.7051
PMID:28159730

Original Paper

Using Administrative Data to Ascertain True Cases of Muscular Dystrophy: Rare Disease Surveillance

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Abstract

Background: Administrative records from insurance and hospital discharge data sources are important public health tools to conduct passive surveillance of disease in populations. Identifying rare but catastrophic conditions is a challenge since approaches for maximizing valid case detection are not firmly established.

Objective: The purpose of our study was to explore a number of algorithms in which International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes and other administrative variables could be used to identify cases of muscular dystrophy (MD).

Methods: We used active surveillance to identify possible cases of MD in medical practices in neurology, genetics, and orthopedics in 5 urban South Carolina counties and to identify the cases that had diagnostic support (ie, true cases). We then developed an algorithm to identify cases based on a combination of ICD-9-CM codes and administrative variables from a public (Medicaid) and private insurer claims-based system and a statewide hospital discharge dataset (passive surveillance). Cases of all types of MD and those with Duchenne or Becker MD (DBMD) that were common to both surveillance systems were examined to identify the most specific administrative variables for ascertainment of true cases.

Results: Passive statewide surveillance identified 3235 possible cases with MD in the state, and active surveillance identified 2057 possible cases in 5 actively surveilled counties that included 2 large metropolitan areas where many people seek medical care. There were 537 common cases found in both the active and passive systems, and 260 (48.4%) were confirmed by active surveillance to be true cases. Of the 260 confirmed cases, 70 (26.9%) were recorded as DBMD.

Conclusions: Accuracy of finding a true case in a passive surveillance system was improved substantially when specific diagnosis codes, number of times a code was used, age of the patient, and specialty provider variables were used.

(JMIR Public Health Surveill 2017;3(1):e2) doi:10.2196/publichealth.6720

KEYWORDS

muscular dystrophy; algorithm; administrative records

Introduction

Administrative records that include insurance claims, hospital discharge datasets, and vital records have become important public health tools to understand prevalence of disease in populations [1-4]. Some studies have explored algorithms that can identify incident cases [5,6], while others used algorithms to identify prevalent conditions [2,7]. The special case of identifying rare but catastrophic conditions has emerged as a challenge since understanding the effects of these conditions on populations is important for medical, public health, insurance, and advocacy groups [8-10]. Active approaches to case finding can be effective in identifying and describing cases [11] but are time intensive and expensive. With the growing availability of administrative data sources for researchers and public health practitioners, prospects of conducting surveillance more efficiently using such data sources are intriguing. However, approaches for maximizing the validity of case detection using such data sources are not yet established.

Muscular dystrophy (MD) is a particularly challenging condition for surveillance because there are 9 types with different presentations and all types are rare. There are 2 relatively common types, Becker MD and Duchenne MD (DMD), which have childhood or young adulthood onset and are more common in males. DMD is characterized by onset of symptoms by age 4 years, followed by substantial muscle weakness in childhood and progression to loss of mobility by adolescence and high risk of mortality from respiratory and cardiac failure in young adulthood. Becker MD typically is associated with an older age of onset and slower progression of muscle weakness than DMD [12]. The prevalence of Duchenne/Becker MD (DBMD) in US males aged 5 through 24 years old, using active surveillance, is estimated to be 1.38 per 10,000 [11]. The International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) code for identification of DBMD is 359.1. However, this code includes other hereditary progressive muscular dystrophies (eg, limb-girdle), so the prevalence of DBMD cannot be isolated when using passive surveillance methods. Similarly, the International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) code used to identify DBMD, G71.0, includes other hereditary progressive muscular dystrophies.

This study was designed to explore the value added using a number of algorithms to identify cases that had diagnostic support for MD (henceforth referred to as true cases) from administrative data sources, including insurance claims and hospital discharge uniform billing datasets. The feasibility of distinguishing between DBMD and other muscular dystrophies was also investigated.

Methods

Overview

The 2 methods of data collection used for this project are (1) a passive surveillance system whereby data about cases of MD were ascertained through the linkage of a private and public (Medicaid) insurance program and an all-payer hospital discharge data system and (2) an active surveillance system whereby data about cases of MD were abstracted directly from medical records from medical practices that serve individuals with this condition. The passive system included all 46 counties in South Carolina, and the active surveillance was conducted in 5 target counties (combined population 1.4 million), which included 2 metropolitan centers with large university- affiliated hospital systems. The active and passive systems were independently conducted.

The active system's data collection was completed by the Maternal and Child Health Bureau at the South Carolina Department of Health and Environmental Control (DHEC), and the passive system's data analysis was completed by the Health and Demographics Section of the South Carolina Revenue and Fiscal Affairs (RFA) Office. DHEC is the state health department, and RFA serves as a central repository for health and human service data in South Carolina. Data usage approvals for the passive system were obtained from participating organizations from which the data originated and the South Carolina Data Oversight Council. Active data collection was conducted in accordance with established ethical principles and approved by the DHEC Institutional Review Board. Upon completion of the 2 systems, the datasets were linked at RFA. Analyses were then performed at RFA, and aggregate results were provided to investigators.

Passive Surveillance

The passive surveillance system relied on identification of ICD-9-CM codes from insurers and hospital discharge data. People with MD do not necessarily receive care in their county of residence, so the entire state was included in the passive system. We used ICD-9-CM codes 359.0 (congenital hereditary muscular dystrophy), 359.1 (hereditary progressive muscular dystrophy), and 359.21 (myotonic muscular dystrophy) to flag cases from administrative health databases from 1998-2012 in the passive system. The linked insurance and hospital discharge data included the following variables: MD ICD-9-CM codes, sex (male, female), age (18 years and younger, over 18 years), race (white, African American, other), other neurologic code (an ICD-9-CM code for diseases of the nervous system other than MD), setting of care (inpatient, outpatient, clinic), specialty of provider noted on the claim (neurology, cardiology, genetics, orthopedics, other), and prescription for corticosteroid (yes, no). The current standard of care for DBMD includes the prescription of steroid medication; thus, this information was included to test its utility in identifying DBMD cases.

Active Surveillance

The active system relied on record reviews in specialty physician offices in the 5 selected counties that are served by 2 large medical centers. Medical practices for physicians in neurology, genetics, and orthopedics were identified through state licensure data and a nurse from the health department with public health surveillance authority scheduled a visit to these practices to abstract medical records with an MD ICD-9-CM code. The nurse was given 2067 records, in total, with an ICD-9-CM code for MD, without consideration of the year of service. Of these 2067 records, 384 (18.58%) were confirmed as true cases after medical record review. It should be also noted that that 1530 (74.02%) of the actively reviewed records were not in the passive system and that 124 of those individuals were determined to be true cases. Likely reasons for being omitted from the passive system were that these individuals were insured by Medicare or by a private insurer that was not in the passive system and they did not have a hospitalization within the state during the study period. The nurse abstracted information from medical records to determine instances of true cases, where there was positive clinical or genetic diagnostic support for an MD diagnosis. Active unconfirmed cases included those that had a negative clinical or genetic test result for MD and/or a diagnosis of another condition (not MD).

Cases of MD

The 537 cases that were found in both systems were used to investigate whether passively collected variables, in addition to ICD-9-CM codes, could aid in the detection of true cases of MD without active surveillance.

Statistical Approach

Logistic regression models and knowledge of coding practices and disease course were used to determine which passively collected variables could be useful for predicting which individuals identified in the administrative data would be confirmed as true cases by active surveillance. Models were estimated only for the subset of individuals who were identified as potential cases in both the active and passive surveillance approaches. We report coefficients and *P* values for the variables instead of odds ratios because we are using logistic regression to predict MD status and not to examine the association of this status with individual variables or to report the relative odds of having confirmed cases of MD. We considered a *P* value less than or equal to .05 to be statistically significant. Variables selected for the algorithms included (1) provider specialty (neurology, cardiology, orthopedics, genetics, or other), (2) location of service (inpatient, outpatient, or clinic), (3) number of times a code was identified on claims during the study period, (4) other neurological and muscular disease codes carried forward after an initial MD code was registered, (5) age at first coded claim, (8) sex, and (9) race. The accuracy rate was defined as the number of true cases divided by the total number of cases (true positives / true positives + false positives) and was used to assess the value of the algorithms. Textbox 1 displays the MD ICD-9-CM codes and types of MD associated with each code. First, we noted if 1 of the 3 MD codes identified any type of MD. Then, we determined if a code identified the correct type of MD. Finally, we determined how accurately code 359.1 identified cases of DBMD.

Textbox 1. ICD-9-CM codes for muscular dystrophy and types of muscular dystrophy associated with codes.

359.0 Congenital hereditary muscular dystrophy:

- Benign congenital myopathy
- Central core disease
- Centronuclear myopathy
- Myotubular myopathy
- Nemaline body disease

359.1 Hereditary progressive muscular dystrophy:

- Becker
- Distal
- Duchenne
- Erb’s
- Fascioscapulohumeral
- Gower’s
- Landouzy-Dejerine
- Limb-girdle
- Ocular
- Oculopharyngeal

359.21 Myotonic muscular dystrophy:

- Dystrophia myotonica
- Myotonia atrophica
- Myotonic dystrophy
- Proximal myotonic myopathy
- Steinert’s disease

Results

Overall, there were 2698 potential MD cases identified through the passive data system only, 1530 potential MD cases through the active data system only, and 537 potential cases identified by both the active and passive data systems. Among these, 260 were determined to be true cases of which 70 were diagnosed as DBMD.

Table 1 displays results from logistic regression models of the cases identified through both active and passive surveillance, stratified by whether the first MD code was identified on or before 18 years of age. To predict the true cases for those under age 18 years, the variables that were statistically significant were number of times the MD code was recorded during the study period, having MD identified by an inpatient claim or at least 2 outpatient claims 30 days apart, and being male. Having a visit with a specialist other than a neurologist during the study interval was the only other marginally significant predictor (*P*=.054). To predict the true cases for those identified after age 18 years, we had the following statistically significant predictors: number of times the MD case was recorded during the study period, having MD identified by an inpatient claim or at least 2 outpatient claims 30 days apart, being white, and having another neurologic syndrome coded after the first code of MD in the record. For those over 18 years, being male was only marginally significant (*P*=.054).

Table 1. Determining variables important in muscular dystrophy algorithm development using data from 5 South Carolina counties, 1998-2012.

		Age group ≤18 years		Age group >18 years	
Parameter	Referent group	Estimate/coefficient	*P* value	Estimate/coefficient	*P* value
Number of MD[a] codes recorded	Number of encounters with MD codes—continuous variable	0.0065	.014	0.0211	.035
MD identified by inpatient claim or 2 outpatient claims at least 30 days apart	MD code used for only 1 outpatient claim or 2 claims less than 30 days apart	1.3687	.001	1.0676	.001
Sex (male)	Female	1.1856	.001	0.5080	.054
Race (African American)	White	−0.4621	.242	−0.8774	.004
Race (other)	White	−0.7188	.120	−2.3076	<.001
Neurologist coded MD	No neurology specialist coded MD	−0.4945	.203	−0.0871	.796
Other specialist coded MD	No other specialty physician coded MD	0.6661	.054	−0.2619	.368
Other neurological syndrome coded after MD	No other neurology syndrome coded	0.1290	.838	−1.1373	.004
Patient age	In years—continuous variable	0.0449	.120	0.0158	.081

[a] MD: muscular dystrophy.

See Multimedia Appendix 1 for the number of MD cases identified in both active and passive data systems by confirmation status along with the percentage of true cases for a variety of variable combinations from the passive data. Overall, 537 cases were identified in both the passive and active systems. It should be noted that, of the 260 actively confirmed true cases, about 25% were of unknown MD type. Passively collected data with at least one 1 of any of the MD codes (359.0, 359.1, or 359.21) did not accurately predict true MD cases in general (accuracy rate 260/537, 48.4%) or true DBMD in particular (accuracy rate 136/537, 25.3%). However, 1 of the codes (359.21 for myotonic MD) did have a high probability for accurately predicting any MD (accuracy rate 88%) and for predicting myotonic MD in particular (accuracy rate 46/58, 79.3%). Restricting to data with at least 1 inpatient hospitalization code or 2 other medical claim codes marginally improved the accuracy for any MD code collected passively (accuracy rate 224/378, 59.3%, for any confirmed MD; accuracy rate 118/378, 31.2%, for confirmed DBMD). When restricting to only cases coded with the 359.1 (hereditary progressive MD) ICD-9-CM code, which is the most appropriate code for DBMD, and males less than 18 years of age at first recorded 359.1 code and 1 inpatient code or at least 2 outpatient codes, a diagnosis of a case of any type of MD was a true case 82.8% (77/93) of the time, and a diagnosis of DBMD was a true case 63.8% (51/80) of the time. If a neurologist or other specialist coded 359.1, this was indicative of a true case of any MD type 83.1% (49/59) and 82.8% (77/93) of the time, respectively, and was indicative of a true case of DBMD 66% (33/50) of the time for neurology claims and 64% (51/80) of time for other specialist. If a prescription for prednisone or prednisolone was recorded in the claims system, this was indicative of a true case of any MD type 80% of the time and was indicative of a true case of DBMD 62.9% (22/35) of the time. As more visits with the 359.1 code were identified, accuracy increased for any MD type from 78.1% (82/105) for 1 visit to 86.2% (75/87) for 3 or more visits and to 96% for 10 or more visits. Furthermore, accuracy increased for identifying a true case of DBMD from 60.0% (54/90) for 1 visit to 66.2% (49/74) for 3 or more visits and to 82% for 10 or more visits.

Discussion

Principal Findings

This study demonstrates the potential to improve the validity of case identification for MD in administrative (billing) data with simple measures. We found that while accuracy of linked administrative data was low when using a straightforward criterion of a single diagnosis with MD, it improved substantially when additional factors were included in the algorithm. Consideration of specific diagnosis codes and number of diagnoses present in the data appeared to have the greatest impact. The diagnosis code for congenital hereditary MD (359.0) was consistently less predictive than codes for hereditary progressive MD (359.1) and myotonic MD (359.21). Based on these findings, health services researchers need to be well versed about the limitations of using ICD-9-CM codes; for rare conditions, they need to be confident that the population from which the study group is identified is large enough to produce meaningful results. Accuracy increased substantially with the number of times a diagnosis of MD occurred, with the bulk of the improvement occurring between 1 and 8 diagnoses. These results were similar to a study by Kaye et al [13], which found that using (1) the specific code for amyotrophic lateral sclerosis (ALS) versus other motor neuron disease ICD-9-CM codes, (2) the code for ALS recorded on multiple visits, and (3) the ALS code from a neurology specialty claim all increased the ability to identify true cases of ALS from administrative data. The similarity of these algorithms is encouraging in that it suggests that this process may be generalizable to other rare neurological conditions.

Limitations

This research has a number of important limitations. First, we only included data from South Carolina, a state with a population of 4.8 million residents in the southeastern United States. Replication in other geographic locations would be helpful for assuring generalizability. Second, the study was conducted using ICD-9-CM codes, and as of October 1, 2015, health providers have converted to ICD-10-CM codes; thus, our study provides insight into the identification of cases prior to 2015. It may not be appropriate to extrapolate the findings of this study to research using ICD-10-CM data. However, research on rare conditions using administrative data will continue to rely on ICD-9-CM coding for some time, given the limited sample sizes that will be available in ICD-10-CM coded records for several years.

Third, the cases in the passive system were identified if the individual received a service during the period 1998-2012, but the active surveillance was not limited by service date. This probably contributed to a number of cases that were identified by the active system. Fourth, the study would have been improved if we could have done active surveillance throughout the state, but this was not feasible due to financial limitations. We believe there were cases found in the passive system that were not identified through active surveillance because they received care in other counties. Finally, small cell sizes impaired our ability to conduct some analyses, particularly for myotonic MD. Additional research using data from multiple geographic regions may be necessary to establish the validity of billing data to identify individuals with myotonic MD.

The passive system included all provider specialty types, other professional claims, and coded facility claims from all counties within the state whereas the active system only included selected specialty practices in 5 counties. Therefore, it was anticipated that a number of cases would be present in the passive system but not found in the active one. Likewise, the active system identified cases from some payer sources that were not available in the passive system.

There are important potential advantages to using administrative data to study health care utilization and health outcomes for individuals with MD. First, the low prevalence of MD means that identifying affected individuals for enrollment in primary research studies can be very time consuming and expensive. Second, the range of data available from billing records is excellent for answering research questions related to receipt of services, number and causes of emergency department visits and hospitalizations, and health care expenditures. In some states, including South Carolina, linkable data warehouses exist, facilitating linkage to other data sources such as vital records, which enables research investigating risk of death and specific causes of mortality. Another benefit of research using secondary data is that it is not subject to limitations in recall on the part of study participants, family members, or health care providers since billing is conducted prospectively at the time of care delivery.

In applying algorithms to improve accuracy of billing data for identifying cases of MD, it is important to keep in mind the ultimate goals of the research. If the goal is to identify potential demand for resources, it may be preferable to maximize sensitivity to avoid insufficient resource allocation. On the other hand, if the goal is to evaluate the receipt and potential benefits of specific health care services for individuals with MD, using algorithms to maximize specificity and accuracy is likely to be preferable. For other types of research questions, it may be that conducting sensitivity analyses over a range of assumptions is the best approach. In every case, it is important to keep in mind the balance of sensitivity and specificity, as increasing one reduces the other.

Conclusion

Administrative records have become important public health tools to understand prevalence of disease in populations. We explored the identification of a rare but catastrophic condition, muscular dystrophy, to maximize the validity of case detection using such data sources. Accuracy was low when using a straightforward criterion of a single code for MD; however, it improved substantially when additional administrative variables were included in the algorithm. Consideration of specific diagnosis codes, number of times a code was used, and demographic variables appeared to have the greatest impact on accuracy.

Acknowledgments

This research was funded by the Centers for Disease Control and Prevention (cooperative agreement 1U01DD000927). Information contained in this report is from records of the RFA Office, Health and Demographics, South Carolina. The Data Oversight Council authorization to release this information does not imply endorsement of this study. The findings and conclusions of this report are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention, South Carolina Department of Health and Environmental Control, South Carolina RFA Office, South Carolina Department of Health and Human Services, South Carolina Public Employee Benefit Authority, or South Carolina Data Oversight Council.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Variables for algorithm development from the passive data system to identify cases of muscular dystrophy in 5 South Carolina counties, 1998-2012.

[PDF File (Adobe PDF File), 52KB - publichealth_v3i1e2_app1.pdf]

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Abbreviations

ALS: amyotrophic lateral sclerosis

DBMD: Duchenne/Becker muscular dystrophy
DHEC: Department of Health and Environmental Control
DMD: Duchenne muscular dystrophy
ICD-9-CM: International Classification of Diseases, Ninth Revision, Clinical Modification
ICD-10-CM: International Classification of Diseases, Tenth Revision, Clinical Modification
MD: muscular dystrophy
RFA: Revenue and Fiscal Affairs

Edited by T Sanchez; submitted 02.10.16; peer-reviewed by N Sathe, J Bolen; comments to author 01.11.16; revised version received 29.11.16; accepted 19.12.16; published 12.01.17.

Please cite as:
Smith MG, Royer J, Mann JR, McDermott S
Using Administrative Data to Ascertain True Cases of Muscular Dystrophy: Rare Disease Surveillance
JMIR Public Health Surveill 2017;3(1):e2
URL: http://publichealth.jmir.org/2017/1/e2/
doi:10.2196/publichealth.6720
PMID:28082256

Original Paper

The Readability of Electronic Cigarette Health Information and Advice: A Quantitative Analysis of Web-Based Information

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Abstract

Background: The popularity and use of electronic cigarettes (e-cigarettes) has increased across all demographic groups in recent years. However, little is currently known about the readability of health information and advice aimed at the general public regarding the use of e-cigarettes.

Objective: The objective of our study was to examine the readability of publicly available health information as well as advice on e-cigarettes. We compared information and advice available from US government agencies, nongovernment organizations, English speaking government agencies outside the United States, and for-profit entities.

Methods: A systematic search for health information and advice on e-cigarettes was conducted using search engines. We manually verified search results and converted to plain text for analysis. We then assessed readability of the collected documents using 4 readability metrics followed by pairwise comparisons of groups with adjustment for multiple comparisons.

Results: A total of 54 documents were collected for this study. All 4 readability metrics indicate that all information and advice on e-cigarette use is written at a level higher than that recommended for the general public by National Institutes of Health (NIH) communication guidelines. However, health information and advice written by for-profit entities, many of which were promoting e-cigarettes, were significantly easier to read.

Conclusions: A substantial proportion of potential and current e-cigarette users are likely to have difficulty in fully comprehending Web-based health information regarding e-cigarettes, potentially hindering effective health-seeking behaviors. To comply with NIH communication guidelines, government entities and nongovernment organizations would benefit from improving the readability of e-cigarettes information and advice.

(JMIR Public Health Surveill 2017;3(1):e1) doi:10.2196/publichealth.6687

KEYWORDS

electronic cigarettes; tobacco use cessation products; health services; consumer health information; health education

Introduction

The popularity and use of electronic cigarettes (e-cigarettes) has rapidly increased across all demographic groups in recent years [1]. In fact, there is a continuing increase in not only Web-based promotional messages for e-cigarette brands and flavors [2], but also the use of e-cigarettes by non or former-smokers[1] and youth [3]. Despite inconclusive and contested evidence regarding their safety and effectiveness in helping smoking cessation [4,5], many e-cigarette users believe that they have better health, including improved breathing, less coughing, and lesser chance of getting a sore throat when compared with combustible cigarette users [3]. Thus, analyzing readability (ie, how difficult a text is to understand) of easily accessible e-cigarette related health information and advice (EHIA) is a much needed step toward understanding available

EHIA and identifying opportunities to enhance health advice practices for specific target populations.

The Internet has become a prominent source of text-based health information for consumers [6]. Meanwhile, health information is only productive if it is understood by its audience. The average American adults' reading level is estimated to be at the 8th grade [7]. Thus, the US Department of Health and Human Services (HHS) [8] and the National Institutes of Health (NIH) [9] recommend health information to be written at 6th to 7th grade level, which is the expected reading level for age 10 to 13 years in the US education system. These recommendations are made to ensure the understandability of health information and reduce health information deficits in the general population.

A number of studies have investigated the readability of health-related content on the Internet. Across these studies, researchers consistently found empirical evidence that text-based consumer health information resources were too complex for the recommended 6th to 7th grade reading level [8,9]. For instance, smoking education materials [10], warnings on alcohol and tobacco products [11], Web-based patient education materials [12-14], informed consent documents used in clinical trial research [15], government endorsed written action-plan handouts [16], and commercially available health information [17] were found to require higher literacy levels than that recommended by the NIH and HHS. Moreover, health information available from commercially funded sources was significantly more difficult to read than information available from government-funded sources [18]. This complexity often led to comprehension errors [19,20] for average Americans. We believe that this study is the first study that examines the readability of EHIA available on the Internet.

Methods

A systematic search of EHIA was conducted using 3 search engines (ie, Google, Yahoo, and Bing) in January of 2016. We simulated the behavior of general consumers using various combinations of search terms: *advice*, *cig*, *cigarette*, *e*, *electronic*, *health*, and *information*. Then for comparison purposes, we specifically searched for EHIA from various US public health agencies (eg, HHS), other English speaking nations' public health agencies (United Kingdom, Australia, New Zealand, Canada), popular consumer health information sites (eg, WebMD), as well as nongovernment organizations (eg, Wikipedia).

In this study, data was only gathered from the first page of search results for each search engine, as most users rarely investigate past the first page of search results [21], and so our focus with this work is the analysis of the most frequently accessed EHIA, rather than a comprehensive study of all EHIA. We manually verified search results and retained those webpages that included any EHIA. We excluded articles published in peer-reviewed journals since general consumers are unlikely to read them. Any figures, such as pictorial descriptions, were removed and the webpages were converted to plain text for analysis.

Organization types were determined by the affiliations, funding sources, and available classification information for each organization. Several websites had no explicit indication of their affiliations or funding sources. We assumed that they were for-profit entities due to their informational advertising style content. Moreover, several documents formed part of a bigger document (eg, Wikipedia), in which case we only included sections on EHIA in this study (see Multimedia Appendix 1).

To assess readability (ie, the estimated US grade level that is required to comprehend a text), we used *Flesch-Kincaid grade level* [22], *Simple Measure Of Gobbledygook (SMOG) Index* [23], *Coleman and Liau Index* [24], and *automated readability index* [25], which are widely used metrics in previously mentioned readability studies [10-16,18]. To perform the automated readability analysis, we used the open-source Python *textstat* package [26]. In order to increase the reliability of our readability metrics, and given that different readability metrics can generate a range of results, our analysis was based on the mean of the 4 readability metrics. We then conducted pairwise independent sample *t* tests to compare readability scores among different groups (ie, for-profit entities, nongovernment organizations, non-US government entities, the US government, the US government entities written for teens) followed by *P* value adjustments using the prespecified Hommel procedure [27] to adjust for multiple comparison. The research reported in this study was exempted from review by the University of Utah Institutional Review Board (ethics committee) (IRB_00076188).

Results

We collected a total of 54 documents for this study including materials from 27 US government entities (eg, HHS), 10 for-profit entities (eg, Consumer Affair), 7 non-US government entities (eg, Ministry of Health New Zealand), 7 nongovernment organizations (eg, Mayo Clinic), and 3 documents that were specifically written for teens by US government entities (eg, National Institute on Drug Abuse).

Complete readability scores for each document are presented in Multimedia Appendix 1. On average, the following grade reading levels (standard error) were required to understand the materials from these organizations (see Multimedia Appendix 2):

- for-profit entities: 10.46 (0.55)
- nongovernment organizations: 14.30 (0.86)
- non-US government entities: 14.44 (0.58)
- the US government: 13.48 (0.33)
- the US government entities written for teens: 10.71 (1.15)

The overall comparisons of different groups are shown in Table 1, and the details of comparison results using individual metrics are available in Multimedia Appendices 3-6. Content from for-profit entities was found to be significantly easier to read when compared with materials from all other entities except for materials written for teens by the US government. The differences among all other groups were not found to be significant (Table 1).

Table 1. Pairwise *t* test using average scores of 4 metrics.

Organization Type	Organization Type	*t* value	*P* value	Adjusted *P* value (Hommel)
Versus for-profit entities	Nongovernment organizations	−3.97	.001	.01
	Non-US government entities	−4.90	<.001	.002
	US government	−4.76	<.001	<.001
	US government (teen)	−0.21	.84	.89
Versus nongovernment organizations	Non-US government entities	−0.14	.84	.89
	US government	1.07	.29	.88
	US government (teen)	2.36	.05	.23
Versus non-US government entities	US government	1.36	.18	.59
	US government (teen)	3.27	.01	.07
Versus US government	US government (teen)	2.64	.01	.08

Discussion

Principal Findings

In this study, we used 4 different readability metrics to evaluate the readability of EHIA from 54 sources gathered on the Internet. All 4 metrics indicate that all located EHIA are written at a higher level than the recommended level for the general public. Moreover, EHIA written by for-profit entities, many of whom were advocating e-cigarettes, were significantly easier to read than materials written by nongovernment organizations, non-US government entities, and the US government. Our results contrast with the results of a previous readability study comparing health information written by commercially funded sources and government-funded sources [18]. However, both studies found that the readability of health information was generally too difficult for the public. One encouraging finding in this study is that materials written specifically for teens by US government entities were easier to read than other materials generated by US government entities aimed at the general population, although the difference was found significant for only 1 metric— *Coleman and Liau Index* (see Multimedia Appendix 5).

Limitations

We recognize various limitations of this study. First, individuals accessing EHIA on the Web may not be representative of the general population. However, given that the Internet has become an increasingly popular resource for gathering health information in recent years [6,28], it is likely that a substantial proportion of those potential and current e-cigarettes users seeking EHIA on the Web would have experienced difficulties in fully comprehending “official” health advice, potentially hindering effective health-seeking behaviors. Second, we acknowledge that readability measures alone may not be a perfect representation of reading level [29]. For instance, EHIA could contain pictorial information, which has been shown to be more effective than text-only messages in conveying health warnings on tobacco packages [30]. In this study, we focused on textual information as text remains the primary medium for health communication and information dissemination on the Internet [31]. Third, we used general purpose readability metrics that measure rudimentary lexical features of text. Although these metrics may not be able to accurately assess the complexity of a text [32], a recent study shows lexical features are more important in estimating readability than the complexity of sentences [33]. Finally, our analysis, although systematic, is not exhaustive. A large number of EHIA exist that were not included in our study. Moreover, we limited our search to English language materials. However, we evaluated materials from key official websites that are easily accessible via widely used search engines.

Conclusions

The results of this study suggest that EHIA generated by the for-profit sector is easier to read than EHIA generated by government entities. In order to comply with communication guidelines of the NIH and HHS, government entities and nongovernment organizations would benefit from improving the readability of EHIA.

Acknowledgments

Dr Park was funded by the National Institute for Health-National Library of Medicine T15 LM007124. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

The authors would like to thank Mr Gregory Stoddard at the University of Utah for his advice and comments during the preparation of this article.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Individual scores.

[PDF File (Adobe PDF File), 85KB - publichealth_v3i1e1_app1.pdf]

Multimedia Appendix 2

Mean (SE) of each organization type.

[PDF File (Adobe PDF File), 23KB - publichealth_v3i1e1_app2.pdf]

Multimedia Appendix 3

Pairwise *t* test of Flesch Kincaid Grade.

[PDF File (Adobe PDF File), 15KB - publichealth_v3i1e1_app3.pdf]

Multimedia Appendix 4

Pairwise *t* test of SMOG Index.

[PDF File (Adobe PDF File), 15KB - publichealth_v3i1e1_app4.pdf]

Multimedia Appendix 5

Pairwise *t* test of Coleman Liau Index.

[PDF File (Adobe PDF File), 15KB - publichealth_v3i1e1_app5.pdf]

Multimedia Appendix 6

Pairwise *t* test of Automated Readability Index.

[PDF File (Adobe PDF File), 15KB - publichealth_v3i1e1_app6.pdf]

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Abbreviations

e-cigarettes: electronic cigarettes
EHIA:: e-cigarette related health information and advice
HHS: US Department of Health and Human Services
NIH: National Institutes of Health
SMOG: Simple Measure of Gobbledygook

Edited by G Eysenbach; submitted 23.09.16; peer-reviewed by A Lazard, A Wilson, A Keselman; comments to author 03.11.16; revised version received 22.11.16; accepted 08.12.16; published 06.01.17.

Please cite as:
Park A, Zhu SH, Conway M
The Readability of Electronic Cigarette Health Information and Advice: A Quantitative Analysis of Web-Based Information
JMIR Public Health Surveill 2017;3(1):e1
URL: http://publichealth.jmir.org/2017/1/e1/
doi:10.2196/publichealth.6687
PMID:28062390

Original Paper

SmartMom Text Messaging for Prenatal Education: A Qualitative Focus Group Study to Explore Canadian Women's Perceptions

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Abstract

Background: We engaged Canadian women in the development of a prenatal education program delivered via one-way text messaging called SmartMom. SmartMom is the first peer-reviewed, evidence-based mHealth program for prenatal education in Canada and the first to be endorsed by the Society of Obstetricians and Gynaecologists of Canada.

Objective: To explore women's preferences for a prenatal education program by text messaging.

Methods: We conducted a qualitative focus group study in three Canadian communities in the Northern Health Authority. Women completed a demographic questionnaire, participated in a guided discussion about their pregnancy information-seeking behavior, reviewed a printed copy of the SmartMom text messages, and then engaged in a moderated discussion about their perceptions of the usability of the SmartMom program. Open-ended questions explored women's perceptions regarding the message content, acceptability of receiving information by text message, positive health behaviors they might engage in after receiving a message, modifiable program factors, and intention to use the program. Thematic analysis of transcribed audio recordings was undertaken and modifications were made to the SmartMom program based on these findings.

Results: A total of 40 women participated in seven focus groups in three rural northern communities. The vast majority had a mobile phone (39/40, 98%), used text messages "all the time" (28/40, 70%), and surfed the Internet on their phone (37/40, 93%). Participants perceived SmartMom to be highly acceptable and relevant. The text message modality reflected how participants currently sought pregnancy-related information and provided them with local information tailored to their gestational age, which they had not received through other pregnancy resources. Women recommended adding the opportunity to receive supplemental streams of messages tailored to their individual needs, for example, depression, pregnancy after previous cesarean, >35 years of age, new immigrants, and harm reduction for smoking and alcohol.

Conclusions: This formative qualitative evaluation provides evidence that a prenatal education program by text messaging, SmartMom, is acceptable to the end users. These findings support the usability of the SmartMom program at a population level and the development of an evaluation program exploring the effects of the text messages on adoption of health-promoting behaviors and maternal-child health outcomes.

(JMIR Public Health Surveill 2017;3(1):e7) doi:10.2196/publichealth.6949

KEYWORDS

pregnancy; text messaging; prenatal education; health behavior

Introduction

Prenatal education is designed to teach women and their support persons about the physiologic and psychological changes of pregnancy; what to expect during prenatal care; and how to prepare for labor, birth, and newborn care [1]. A Cochrane systematic review conducted by Gagnon and Sandall in 2007 [2], currently being updated by Brixval et al [3], investigated the effect of structured individual or group antenatal education and concluded that the effect of general antenatal education on both health and psychosocial outcomes is unclear. A more recent systematic review of the international literature investigating the effect of antenatal education on labor and birth found that positive effects might include fewer false labor admissions, less anxiety, and more partner involvement [4]. In Canada, the first national study of women’s childbirth experiences reported that 65.6% of Canadian women attended prenatal classes in their first pregnancies [5]. However, women living in a household at or below the low-income cutoff were less likely to attend classes (24.1%, 95% CI 21.6-26.7) than women living in a household above the low-income cutoff (34.7%, 95% CI 33.5-35.9) [5]. In Canadian rural and remote settings, access is a significant issue and prenatal classes may be offered as infrequently as once per year and require travel to other communities [6].

Internationally, women have significant gaps in understanding the determinants of healthy pregnancy outcomes, such as the role of healthy weight gain [7] and nutrition [8]. In Canada, an Ontario population-based survey with a 94% response rate indicated that only 25% of respondents had been told by their caregiver that there were risks associated with inappropriate weight gain [9]. A 2009 study in Toronto reported that 80% of pregnant women believed that an influenza vaccine given during pregnancy caused birth defects [10]. Typically, prenatal appointments with family doctors and obstetricians last only 10-15 minutes and thus physicians tend to focus on biomedical issues rather than on health promotion and education [11]. Consequently, there is a need for resources in an accessible and acceptable format that provide pregnant women and families with the information and skills to engage in healthy behaviors during pregnancy, labor, and birth.

An emerging body of evidence supports the utility of text messaging in provoking attitudinal and behavior change in the areas of smoking cessation, alcohol consumption, and disease management [12-14]. Short message service (SMS) text messaging interventions combine the reach and scalability of mass media with the personalization of health communication through the tailoring of messages to individuals’ health needs and preferences [15,16]. Mobile phone messaging is also useful in accessing remote or hard-to-reach populations and in providing patients with timely health information and education [15].

In the United States, the Text4baby program was launched in 2010 to provide prenatal education via text message to reduce the rate of premature birth and infant death, particularly among low-income and minority groups. As of December 2016, the service had enrolled over 1,077,628 English- and Spanish-speaking women since launching [16,17]. A randomized controlled trial of the Text4baby program among female military health beneficiaries in 2013 found that high exposure to Text4baby had a significant effect on self-reported alcohol consumption postpartum (odds ratio [OR] 0.212, 95% CI 0.046-0.973) [14]. Exposure to at least one message on prenatal health vitamins was associated with increased agreement with belief in the importance of taking vitamins (OR 1.91, 95% CI 1.08-3.34) [18].

While there is evidence on the impact of mobile phone messaging on health behavior change, little is known about the characteristics of effective programs and how to successfully implement such programs at a population level. In a 2010-2011 study, an evaluation of Text4baby assessing enrollment and usage among a prospective cohort of Atlanta, Georgia, women observed that despite high interest in the program, women who were younger (<26 years), less educated, and had lower literacy were more likely to have interrupted messages [19]. These findings indicate the importance of understanding patient perspectives on the feasibility of delivering SMS text message health promotion in underserved populations. Further, involving end users in all stages of text messaging program development, including piloting, implementation, and evaluation, allows developers to identify and address potential barriers to enrollment and use of the program [20]. This includes ensuring that the language used is lay friendly, culturally appropriate, and trauma informed to meet the needs of a broad target audience, including women experiencing conditions that contribute to vulnerability such as substance use and violence [9,21]. A 2015 Cochrane Review of the effects of mobile phone messaging interventions in health observed that pilot testing can assist in tailoring the messages to the preferences and needs of the target population [2].

In Canada, the use of mobile devices continues to increase [22] and creates an opportunity to reach a broad population base with health information. The vast majority of Canadian households (84.9%) subscribe to mobile phones and more Canadian households with incomes lower than average (<Can $51,804) are mobile phone-only households, suggesting that access and affordability drive Canadians’ communication usage [22]. A Pew Research Center survey conducted in 2015 with 1003 adult Canadians found that 63% of women of all ages and 94% of men and women aged 18-34 owned an advanced-feature mobile phone [23]. To ensure the relevancy and acceptability of using this mobile platform for prenatal education, we engaged Canadian women in the development of a prenatal education program delivered via one-way text message called SmartMom. We developed a prototype version of SmartMom, initially based

on the delivery of Text4baby, which sends three evidence-informed messages per week to enrolled American women, timed to be relevant to their gestational age. The objective of this study was to explore women's perceptions of the SmartMom program, paying particular attention to their perceptions about the message content, acceptability of receiving information by text message, positive health behaviors they might engage in after receiving a message, modifiable program factors, and intention to use the program.

Methods

The Intervention

A multidisciplinary group of researchers, clinicians, and allied health professionals initially adapted the message content from existing recognized public health resources, including British Columbia's Baby's Best Chance handbook [24], the Healthy Families BC website [25], and the British Columbia Maternity Care Pathway, a guideline for best practice for routine prenatal care in the province [26]. The experts engaged in multiple, iterative rounds of reviewing, revising, and weighting the messages. Research team members (SM, AH) edited the prototype messages for plain language and to ensure that each included an evidence-based behavior change strategy (ie, a physical activity message was supported by a goal-setting exercise). Messages were reviewed and endorsed by the Society of Obstetricians and Gynaecologists of Canada. The prototype SmartMom program consisted of 109 brief SMS text messages that focused on encouraging positive health behaviors, including increasing pregnancy- and childbirth-related knowledge, accessing routine antenatal assessments and recommended screenings, and adopting lifestyle behaviors to support healthy pregnancy and physiologic birth.

We propose that women who enroll in SmartMom will receive three SMS text messages per week, keyed to their gestational age beginning as early as 5 weeks gestation until their delivery. The communication will be one way and all women will receive the same messages for their region. Women and providers referring women to the program will have access to all messages on the program website [27]. Messages will be tailored to women's gestational age and local region. Figure 1 presents the home page for the website. While the SmartMom program will be provided free of charge to women, data charges for browsing websites will not be covered. See Figure 2 for a sample of the messages.

Figure 1. Home page for the SmartMom website.

SmartMom is a free text messaging program that sends you information timed to your stage of pregnancy to help you achieve healthy pregnancy and birth.

SmartMom is also your local and online guide to services and programs available to support you.

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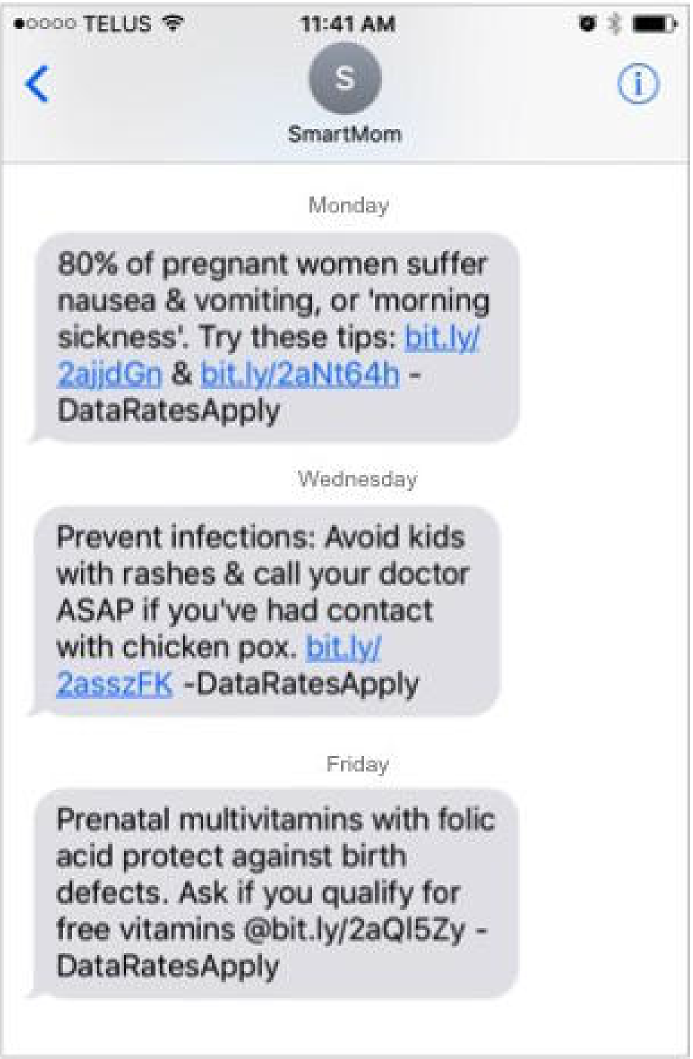
Figure 2. Example health promotion messages provided through the SmartMom program.



80% of pregnant women suffer nausea & vomiting, or 'morning sickness'. Try these tips: bit.ly/2ajjdGn & bit.ly/2aNt64h - DataRatesApply

Prevent infections: Avoid kids with rashes & call your doctor ASAP if you've had contact with chicken pox. bit.ly/2asszFK -DataRatesApply

Prenatal multivitamins with folic acid protect against birth defects. Ask if you qualify for free vitamins @bit.ly/2aQl5Zy - DataRatesApply

Settings and Participants

We conducted seven focus groups in three British Columbia communities in the Northern Health Authority (NHA), the region where the SmartMom pilot testing would take place. The NHA is the largest health region in the province, covering over two-thirds of British Columbia, and has on average 3500 births per year [28]. The behavioral research ethics boards of the University of British Columbia and the NHA provided ethical approval for the focus groups.

Participants were recruited through a range of methods: (1) third-party recruitment by public health nurses; (2) passive recruitment using study posters in community settings frequented by pregnant women and new mothers; and (3) passive recruitment through posting of study posters to Facebook groups involving childbirth, parenting, and community events for each study community. Recruitment via Facebook provided the greatest number of potential participants.

After contacting the research team, interested participants received an information letter outlining the purpose of the study and what their involvement would entail. Participants were then screened for eligibility; at the outset of each focus group, participants read and signed a study consent form that reflected the information letter. To participate, participants had to be English speaking, reside in the NHA, and be pregnant or have given birth in the past 12 months.

To minimize any barriers to participation for new mothers and women living in rural and remote communities, reimbursement was made available for childcare costs and travel expenses. Data collection was conducted in local settings that were convenient and familiar to new mothers, including public health units and family outreach centers. These settings had play spaces for children while their mothers participated in the focus group sessions. Participants received a Can $25 honorarium for their participation.

Data Collection

In the first segment of the focus group, participants completed a demographic questionnaire, including four questions on mobile phone usage. Then a research team member (SM, AH) with experience in qualitative data collection guided a discussion on the women’s current information-seeking behavior. In the second segment, participants reviewed a printed copy of the SmartMom text messages and participated in a second moderated discussion, in this case on perceptions of the usability of the text message program. Open-ended questions explored participants' perceptions about the message content, receiving information by text message, behavior they might engage in after receiving a message, modifiable program factors, and intention to use the program. Each focus group discussion was audiotaped and later transcribed verbatim for analysis.

Data Analysis

Following thematic analysis [29] techniques, two members of the research team (SM, AH) first read and reread the focus group transcripts and then collaboratively developed an initial codebook of preliminary themes related to women's perceptions of SmartMom's strengths, weaknesses, and usability. Codes that expressed similar perceptions were grouped into categories. Constant comparison of emerging categories between transcripts helped to identify patterns and relationships in focus group discussions. The evolving codebook was refined into core categories and then tested for fit and relevance by two members of the research team (EG, NT). Using this focused codebook, the two coders (EG, NT) independently coded a sample of focus group transcripts. There were minimal disagreements in their interpretation of the transcripts. Discrepancies in interpretation were resolved through discussion with a third member of the research team (SM), who then entered the transcripts into NVivo for Mac version 10.1.3 (QSR International) qualitative data management software for organization. The thematic findings were then written into an explanatory narrative while two team members (AH, PAJ) led modifications to the SmartMom program based on the focus group feedback.

Results

Overview

Table 1 summarizes the demographic characteristics of the 40 women who participated in six focus groups in three rural northern communities. Among participants who had given birth, the rate of primary cesarean section was 19% (7/36). The majority of multiparous participants had received antenatal care from a family doctor (22/36, 61%), while the remainder received obstetrician (6/36, 17%) or midwifery (7/36, 19%) care, and one reported no birth attendant.

Table 2 describes the participants' mobile phone usage. The vast majority of participants reported using a mobile phone (39/40, 98%), using text messages "all the time" (28/40, 70%), and surfing the Internet on their phone (37/40, 93%).

Table 1. Characteristics of participants (N=40).

Characteristic		n (%)
Maternal place of birth		
	Canada	37 (93)
	Mexico	1 (3)
	The United States	2 (5)
Maternal age in years		
	<20	3 (8)
	20-29	19 (48)
	30-39	18 (45)
Lives with a partner		
	Yes	32 (80)
	No	8 (20)
Number of children given birth to		
	0	3 (8)
	1	17 (43)
	2	12 (30)
	3	3 (8)
	4	3 (8)
	5	1 (3)
Household annual revenue (Can $)		
	<$35,000	14 (35)
	$35,000-$75,000	6 (15)
	>$75,000	15 (38)
	Prefer not to answer	5 (13)
Highest level of education completed		
	Primary school	1 (3)
	Graduated high school	11 (28)
	College or technical/trade program	13 (33)
	University degree	15 (38)

Table 2. Mobile phone usage survey (N=40).

Question from survey		n (%)
Do you use a mobile phone?		
	Yes	39 (98)
	No	1 (3)
Do you use text messages?		
	Yes	38 (95)
	No	2 (5)
How often do you text people?		
	All the time	28 (70)
	Occasionally	10 (25)
	Never	2 (5)
Do you surf the Internet on your phone?		
	Yes	37 (93)
	No	3 (8)

Characteristics of the SmartMom Program

Enhances Knowledge of Options

Participants believed that the SmartMom messages enhanced their knowledge of pregnancy health-promotion strategies, particularly for first-time mothers. They also expressed how SmartMom gave them strategies to be active participants in their care:

> *I think that a lot of women, especially marginalized women, don't really know that they have a choice. They don't know what's coming up at the appointments and [SmartMom] might give them a heads up to ask those questions, when otherwise they wouldn't know about it.* [Focus Group (FG) 1]

Participants believed that SmartMom would provide particular support to women in rural and remote communities where there are shortages of physicians, as the program would inform women of "different resources and other options" like public health programs (FG7).

Provides Knowledge in a Convenient and Timely Manner

A text message alert was perceived to be convenient for its immediacy and for being a free service:

> *I just like having the resource in my hands. You know, like right there connecting to a hyperlink.* [FG7]

Receiving messages three times per week and timed to gestational age was considered more ideal than the frequency of messages from existing apps or email newsletters. However, a number of participants described the transience of text message notifications as a potential barrier to use:

> *It's a link buried in my text messages that I will never look at again.* [FG6]

Reflects How Women Access Information

Participants described text messaging as a ubiquitous mode of communication—"everyone texts" (FG5)—that reflects how women of their generation currently access pregnancy-related information via mobile phone data and the Internet. Participants indicated that having a text message was like a "bookmark," and they could access a hyperlink later using free Wi-Fi (FG7). Only one participant in the sample had a phone without Internet access and was unable to access the hyperlinks.

Provides Support and Encouragement

The positive tone of the text messages was perceived to be "encouraging" and relatable and increased women's interest to subscribe to the program. Participants expressed that harm reduction messages for drug and alcohol use (eg, encouraging women to reduce the negative effects of use) were confidence boosting and "not fear based" or "shaming" as some had found with prenatal resources. The overall tone of the messages was perceived to be "straightforward" and not "sugar coated." One woman described SmartMom as a character:

> *She's not your girlfriend. You wouldn't go out for coffee...I don't think she'd be, like, my friend, but I think she's credible.* [FG5]

Reflects Local Knowledge and Resources

Participants expressed appreciation that SmartMom provided local, not national or international, information tailored to their region. Local content enhanced the credibility of the program and would increase participants' likelihood of using SmartMom:

> *[SmartMom] is a reliable source and you can trust that. When you go to Google, you can find anything. It [the Internet] is very scary sometimes. But if you have a reputable text and you know where it's coming from and you trust the source, then you're more likely to go to that resource and believe it and seek it out.* [FG3]

Stimulates Behavior Change

The primary action that participants might take after reading a message would be to discuss it with their care provider or prepare a list of questions to ask:

> *I like that the one text was about making a list [of questions]. Because when you do have your prenatal appointments you maybe would feel a bit more prepared with some questions, things that had been brought up in the text messages. As opposed to trying to think of all the things that you want to ask your doctor at your one appointment. Because it's not easy to just go in and ask a question, right?* [FG6]

A number of participants expressed that they may forget to bring up a topic because of the time gap between receiving a message and going to an antenatal visit. As one noted, "You get a text message, two or three weeks go by, you might not still be thinking about it at your appointment" (FG6).

Participants indicated the hyperlinks were the strongest feature of the SmartMom program:

> *I just like the links leading you to one of the articles or something. I was like "Oh I'd love to read that," even open [the webpage] and even go back to it.* [FG1]

Phone numbers, in contrast, were perceived to be less useful than hyperlinks because they would not be saved in the same manner:

> *I would click on the link rather than call somebody. It's just boom, and then you're done. You just click it...I've got kids at home and they yell and scream.* [FG1]

SmartMom also includes interactive components intended to stimulate behavior change, such as knowledge quizzes, nutrition calculators, and links to interactive maps of local health services. Although participants did not have an opportunity to test these individual components, they welcomed the idea and felt these interactive components would help them stay engaged in the program.

Modifiable Characteristics

To improve the SmartMom program further, participants also identified a range of modifiable characteristics.

Frequency and Timing

Certain topics were considered very important for the first weeks of pregnancy, particularly regarding accessing services:

> *Some of those moms are 14, 15, 16 years old and those are the ones that don't have great information or even the knowledge how to access information. So getting it early to them would be good.* [FG6]

Some participants suggested receiving a "bundle" of messages upon enrollment related to prenatal classes, doula care and midwifery, and morning sickness triggers. Participants also wished to access the text messages outside of their SMS program to help them remember what to discuss with their care provider and what hyperlinked articles to read again. In response, we modified the program to include key messages earlier in pregnancy and provided a full list of the messages on the SmartMom website. At the participants' suggestion, we also removed any repetition of messages related to drugs and alcohol.

Relevance

Some messages were perceived to be relevant for some women and not for others. Some participants suggested that they would disenroll from SmartMom if the harm reduction messages were repetitive, irrelevant, or countered their beliefs:

> *Could you have like a questionnaire in the beginning where you're like, "I'm not wanting information on this, this, and this"?... If I was being shown information that I didn't need, I wouldn't want to be a part of [SmartMom].* [FG4]

To address this concern, we changed the program to provide women with one message on each topic (eg, smoking), which will be accompanied by an option to receive more messages on that topic. We also developed *supplemental streams* of messages tailored to individual pregnancy needs: (1) smoking, (2) alcohol, (3) depression, (4) pregnancy after previous cesarean, (5) obesity, (6) pregnancy loss, (7) new immigrants, (8) >35 years of age, and (9) exposure to violence. Women can opt in to receive these streams at the time of enrollment.

Support and Affirmations

Participants felt that the SmartMom prototype did not meet their needs for social and emotional support and support from peers:

> *It would be so cool if there could be like a [local] forum for women. Like if you're connected by your postal code then there would be an actual online community of women in your area that you could actually meet up with.* [FG1]

We consequently added hyperlinks that listed local pregnancy and parenting groups for users to have face-to-face interaction with other women. We also enhanced the supportive language and tone of the messages by adding more encouraging messages or *affirmations* —"You're doing great!"—which participants believed would keep them motivated, maintain their interest in receiving future texts, and enhance their confidence in making healthy choices.

Enrollment

In our original protocol for the implementation of SmartMom, we proposed that potential users would enroll via an existing, trusted information source (eg, doctor, public health nurse, or British Columbia Ministry of Health website). However, participants noted that women in their region commonly do not attend their first prenatal appointment until their second trimester. They reflected that, instead, women would be easiest to reach in early pregnancy via social media:

> *I think here social media campaigning is a great way to get the word out. There seems to be huge groups on Facebook that have thousands of women in them. That would be a great way to get it out, at least in this town.* [FG6]

To address this, we expanded our enrollment plan to advertise SmartMom via Facebook, other social media platforms, and in the pregnancy test section of pharmacies.

Postpartum

Participants strongly recommended extending the SmartMom program of messages for the postpartum period and first year of newborn life. They expressed that there were few timely, evidence-based resources readily available to meet their postpartum needs, as stated by a participant in one group:

> *At the end of pregnancy and after you've had your baby, resources for that as well. If there's a way to say at the end, "I've had my baby, now start sending me the other one." Because those first few weeks are very crucial, very hard. Very, very hard.* [FG1]

In response, we developed prototype SmartMom messages for birth to age one, which will be evaluated in a separate study.

Discussion

Principal Findings

The results of our thematic analysis indicate that participants perceived SmartMom to be highly acceptable and relevant for childbearing Canadian women. Our findings suggest that SmartMom will enhance women's knowledge of health promotion strategies in a convenient and timely manner, provide support, and encourage women to engage in new behavior, such as discussing the text message topics with their care provider at the appropriate gestational age. The text message modality reflected how participants currently sought pregnancy-related information and provided them with local information tailored to their gestational age, which they had not received through other pregnancy resources. Eliciting the perspectives of potential SmartMom users early in the design process resulted in the identification of factors that allowed us to modify and tailor the program to address the perceived needs of childbearing women in the study region. Key modifications included creating supplemental streams of messages for subgroups of women (ie, smoking and pregnancy after previous cesarean). We also added the entire suite of messages to the SmartMom website and provided hyperlinks to local programs that provide peer-to-peer social support in pregnancy.

The SmartMom program is novel in that it is tailored to offer the right prenatal health message at the right time to the right woman. Text messages serve as a cue to action with salient information for pregnant women, essentially providing just-in-time, locally relevant tips and resources to help women make healthy prenatal and postpartum health choices based on their individual needs [30]. To our knowledge, SmartMom is the first peer-reviewed, evidence-based mHealth program for prenatal education in Canada and the first to be endorsed by the Society of Obstetricians and Gynaecologists of Canada, the professional organization that establishes evidence-based standards of maternity care in Canada. Previous tools have been developed for the US context and women in this study cited using them. O'Donnell and colleagues compared the content of two free mobile phone apps for US women, Text4baby and BabyCenter's *My Pregnancy Today*, and determined that <20% of the messages delivered by either program contained information that explicitly addressed recommended prenatal care content [31]. The health care product company Johnson & Johnson owns BabyCenter, which also provides *My Pregnancy Today* to Canadian populations, but no studies have been published on the development of that app. In contrast, we explicitly sought to develop SmartMom based on information from existing peer-reviewed, evidence-based Canadian resources [24-26].

The Text4baby program underwent iterative cycles of user testing with childbearing women prior to its launch in 2010 [16]. In a commentary on the Text4baby development, Whitaker et al indicated that the testing included the following: (1) informal discussion groups with women from community health centers in six cities across the United States regarding the message topics and frequency; (2) health literacy testing of the messages with 100 pregnant African American, low-income women in the Women, Infants, and Children program waiting room at a large city hospital in Atlanta, Georgia; and (3) beta testing of the program with a sample of 10 childbearing women [16]. However, it is unclear what demographics of women were involved, what methods were used for data collection and analysis, and what findings emerged from the user testing.

Recent qualitative studies on women's views of mHealth pregnancy interventions conducted in Argentina and Australia found, similar to our study, that exposure would enhance women's perceived access to high-quality, pregnancy-related information [32], but would not meet women's needs for two-way interaction [33]. To address this gap, we included hyperlinks to local pregnancy and parenting groups for women to interact with peers and health care professionals. Future iterations of the program may benefit from further interactive components.

In our study, we conducted a qualitative investigation with childbearing women to ensure that SmartMom "will reflect an understanding of context, of the users, of the functionality of the system (and thus the users' needs), and of the software development process" [34]. We used feedback from women to modify the program before conducting pilot testing on a larger scale. This aimed to ensure that the program will be usable and acceptable and to avoid any program errors that would threaten our stakeholder partners' investment in the program. Findings from our analysis may be transferable to prospective SmartMom user populations of childbearing women in similar geographic and health service settings in Canada.

Limitations

It is possible that the perspectives of some end users may not have been captured in this study. Participants were recruited primarily via Facebook and, consequently, perspectives may be overrepresented by women who have Internet and/or mobile phone access. We did not purposefully sample for Aboriginal and First Nations women or report separately on the unique perspectives of this population group. In addition, we did not purposefully recruit women from communities with no mobile phone coverage or women with no local maternity services. The perspectives of these women will be elicited through focus groups during the next phase of the SmartMom development—pilot usability testing—which will include summative evaluation through user surveys and further focus groups.

Strengths

This study was strengthened by the diverse sample of childbearing women. This provided a rich understanding of women's perceptions of the SmartMom program and the context in which they will use it. Our inductive, team-based analysis enhanced the rigor and credibility of findings. A final strength of the study was our testing of a prototype *wireframe* version of the SmartMom program prior to developing the text message software and investing in an expensive technology platform. The usability and acceptability findings from this study will inform the next phase of the research process, which includes testing the messages in a real-world pilot feasibility study where rural pregnant women enroll in the SmartMom program and interact with the messages and website in real time.

Conclusions

This formative qualitative evaluation provides evidence that SmartMom is acceptable to end users. Exploring the perspectives of childbearing women in British Columbia resulted in the tailoring and modification of the program to their specific needs, which we anticipate will enhance SmartMom's usability. These findings support the initiation of a pilot study to investigate the usability of the SmartMom program at a population level and explore the effects of the messages on adoption of health-promoting behaviors and maternal-child health outcomes.

Acknowledgments

This community-based participatory study was conducted in partnership with prenatal programs affiliated with the British Columbia Association of Pregnancy Outreach Programs. Leadership was provided by researchers at the University of British Columbia and health-service decision makers with British Columbia Ministry of Health, British Columbia First Nations Health Authority, and the NHA. Guidance on the message development was provided by those organizations as well as Child Health BC, Perinatal Services BC, and the Canada Fetal Alcohol Spectrum Disorder Research Network. The BC Children's Hospital Research Institute, the Peter Wall Institute for Advanced Studies, and the Alva Foundation provided financial support for the study.

Conflicts of Interest

None declared.

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Abbreviations

FG: focus group
NHA: Northern Health Authority
OR: odds ratio
SMS: short message service

Edited by M Focsa; submitted 07.11.16; peer-reviewed by I Graetz, J Willcox; comments to author 23.11.16; revised version received 16.12.16; accepted 09.01.17; published 07.02.17.

Please cite as:
Munro S, Hui A, Salmons V, Solomon C, Gemmell E, Torabi N, Janssen PA
SmartMom Text Messaging for Prenatal Education: A Qualitative Focus Group Study to Explore Canadian Women's Perceptions
JMIR Public Health Surveill 2017;3(1):e7
URL: http://publichealth.jmir.org/2017/1/e7/
doi:10.2196/publichealth.6949
PMID:28174149

Original Paper

Investigating Subjective Experience and the Influence of Weather Among Individuals With Fibromyalgia: A Content Analysis of Twitter

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Abstract

Background: Little is understood about the determinants of symptom expression in individuals with fibromyalgia syndrome (FMS). While individuals with FMS often report environmental influences, including weather events, on their symptom severity, a consistent effect of specific weather conditions on FMS symptoms has yet to be demonstrated. Content analysis of a large number of messages by individuals with FMS on Twitter can provide valuable insights into variation in the fibromyalgia experience from a first-person perspective.

Objective: The objective of our study was to use content analysis of tweets to investigate the association between weather conditions and fibromyalgia symptoms among individuals who tweet about fibromyalgia. Our second objective was to gain insight into how Twitter is used as a form of communication and expression by individuals with fibromyalgia and to explore and uncover thematic clusters and communities related to weather.

Methods: Computerized sentiment analysis was performed to measure the association between negative sentiment scores (indicative of severe symptoms such as pain) and coincident environmental variables. Date, time, and location data for each individual tweet were used to identify corresponding climate data (such as temperature). We used graph analysis to investigate the frequency and distribution of domain-related terms exchanged in Twitter and their association strengths. A community detection algorithm was applied to partition the graph and detect different communities.

Results: We analyzed 140,432 tweets related to fibromyalgia from 2008 to 2014. There was a very weak positive correlation between humidity and negative sentiment scores (r=.009, P=.001). There was no significant correlation between other environmental variables and negative sentiment scores. The graph analysis showed that “pain” and “chronicpain” were the most frequently used terms. The Louvain method identified 6 communities. Community 1 was related to feelings and symptoms at the time (subjective experience). It also included a list of weather-related terms such as “weather,” “cold,” and “rain.”

Conclusions: According to our results, a uniform causal effect of weather variation on fibromyalgia symptoms at the group level remains unlikely. Any impact of weather on fibromyalgia symptoms may vary geographically or at an individual level. Future work will further explore geographic variation and interactions focusing on individual pain trajectories over time.

(JMIR Public Health Surveill 2017;3(1):e4) doi:10.2196/publichealth.6344

KEYWORDS

fibromyalgia; Twitter messaging; social networks; pain; weather; sentiment analysis; infodemiology

Introduction

Fibromyalgia syndrome (FMS) is a chronic rheumatic syndrome of unknown etiology, characterized by persistent widespread musculoskeletal pain and stiffness and a variety of other symptoms including fatigue, poor sleep quality, altered cognition, and affective dysfunction [1]. Fibromyalgia symptoms can worsen or flare up over time. Individuals with FMS frequently attribute variation in their symptoms to environmental factors, including the weather [2-8]. Investigating the relationship between weather and FMS symptoms can be considered a key step toward a systematic study of flare-ups [3]. Such studies will allow the development of theories about the causes and possible approaches to treatment of FMS symptoms that can be tested empirically in future. A good understanding of the influence that weather conditions could have on FMS symptoms will provide clinicians with valuable insights into the context in which pain occurs and the association of these environmental factors (eg, temperature and humidity) with pain. The results can potentially provide the basis for developing more effective treatment methods, contributing to improving the quality of life of large numbers of patients.

Although existing studies have suggested an influence of weather on the pain experienced in FMS and related conditions [2-7], no consistent effect of a particular weather condition on FMS symptoms has been demonstrated. Such inconsistency may reflect individual sensitivity to weather conditions [2] or the complex interplay of other mediating factors such as low mood and lack of sleep or exercise [9]. Alternatively, the limitations of traditional data collection techniques such as questionnaires [2], diaries [5], and open-ended questions [3] may have led to a failure to detect a relationship between weather and symptoms in FMS. Such limitations may affect both internal validity (eg, response bias [2], small sample size [5]) and external validity (eg, sampling in particular geographic locations [3]).

Social networking sites introduce an unprecedented opportunity to collect first-person data from a very large population across diverse locations [10]. They provide a rich source of real-time data that can be collected and analyzed for health research including infodemiology and infoveillance [11,12]. Among existing sites, Twitter has been the most popular platform for accessing and analyzing infodemiology data [13,14]. Twitter provides an easier access to real-time and historical data through Twitter application program interfaces (APIs) and third-party tools, compared with the other platforms such as Facebook. Moreover, extensive studies have been conducted using Twitter that provide useful guidance.

In recent years, Twitter has been widely used as a platform to disseminate and share health-related information [15-20]. “Crowdsourced” data have been shown to be as reliable and viable as traditional survey data [21]. Sentiment analysis of a large number of messages can provide valuable insights into crowd mood [22] and health status [16,19]. Individuals with FMS are known to be active Internet users [23]. However, to date there has been relatively little research regarding the ways in which this community interacts via Twitter. Analysis of patterns of use within the FMS community may allow a deeper understanding of the subjective experience of this common pain syndrome and may inform future attempts to utilize social media as a therapeutic tool. We consider this form of analysis complementary to other forms of epidemiological inquiry.

In this infodemiology study, we used computerized content analysis of tweets to investigate the subjective experience of FMS in a large, widely distributed population and any association with coincident environmental factors. To better understand the environmental context around an individual’s symptoms and pain events, we were also interested to explore and uncover thematic clusters and communities. We hypothesized that detected communities identify specific contexts including environmental context such as weather. Toward this aim, we also performed graph analysis on tweets to understand the existence of specific topics associated with symptom severity and applied community detection to partition the graph and detect different communities. To the best of our knowledge, this is the first research attempt to study environmental associations of fibromyalgia pain using Twitter content analysis in a large sample of individuals with fibromyalgia.

Methods

Sample

We collected tweets from January 2008 to November 2014. The search used the keywords #fibromyalgia, #fibro, and #spoonie. The term “spoonie” is commonly used in tweets referring to the experience of chronic illnesses with prominent fatigue, particularly FMS but also illnesses such as chronic fatigue syndrome and systemic lupus erythematosus (SLE), and arises from the use of spoons as a metaphor for an individual’s ability to carry out daily tasks (“the spoon theory” [24]).

Tweets were collected during numerous search cycles programmatically using the Python language. Each cycle queried tweets for a 30-day period. The process involved a total of 84 cycles to retrieve the historical data over 7 years (2008-2014). Each cycle had multiple iterations to collect all the tweets because the API had a call limit of 100 tweets per request. We collected the data between November 11 and 24, 2014. The search was filtered for English-language tweets.

The date and time of posting of each tweet along with the location were also collected. This allowed us to collect the climate data for each tweet from the public Web APIs. Because of the large number of tweets, we wrote a Python program to collect the weather data. There was a limit on the number of calls per day (ie, a total of 1000 calls per day); therefore, it took November 2014 to February 2015 to collect the weather data for all the tweets. It is noteworthy that most of the location information collected was relative location such as city, state, or country. We excluded tweets that did not have any location data. The weather variables that we retrieved included temperature, humidity, wind speed, feels like, heat index, wind chill, and dew point. Because the date and time in our collected tweets from different locations were expressed in Greenwich Mean Time (GMT) or Coordinated Universal Time (UTC), we could directly use it in the weather API queries, which also support GMT and UTC.

Ethics

Monash University's Ethics Committee approved this study.

Sentiment Analysis and Correlation Tests

To perform sentiment analysis, we incorporated the Stanford CoreNLP [25] libraries. The Stanford CoreNLP works by initiating the properties object and defining annotators [26]. The annotation object executes a number of predefined annotators such as tokenization, sentence splitting, POS (part-of-speech) tagging, and named entity recognition (NER) on text and retrieves an annotated document that can train the sentiment analyzer [26]. The Stanford CoreNLP also includes a sentiment tool and it can be used to analyze the text by adding "sentiment" to the list of annotators [26]. The classifier in CoreNLP is trained using a deep learning algorithm. In our analysis, the classifier assigned a positive score and a negative score between 0 and 100 to each tweet. The 2 assigned scores for each tweet added up to 100.

Sentiment analysis commonly uses a dictionary of opinion words (the "opinion lexicon") to identify and determine sentiment orientation (positive, negative, or neutral). In the opinion rule examples [27], "pain" was considered a "negative" word in the opinion lexicon. The negative sentiment scores can therefore be used to represent severe symptoms such as the pain severity in an individual. In our research, we make the assumption that the severity of negative symptoms (particularly pain) in individuals with FMS can be estimated based on the negative and positive scores assigned to the tweets (a value between 0 and 100).

This means that a high negative sentiment score (and a low positive score) of a tweet will be interpreted as representing more severe pain and unpleasant physical sensations (eg, "too tired to write, too tired to function, just too tired. i ache all over. damn #fibromyalgia. maybe epsom salt bath..." with a negative score of 99.24 and a positive score of 0.76). On the other hand, a low negative score and a high positive score will imply a low severity of pain and related symptoms (eg, "Celebrating the very fact that I am up at 9:30 p.m. I lived through Saturday!#fibro" with a negative score of 0.07 and a positive score of 99.93).

In the second step, we used the Pearson correlation test to investigate the association between negative sentiment scores (as a measure of symptom severity) and climatic variables. We started with a null hypothesis that there is no correlation between FMS symptom severity and weather conditions. The correlation test was first conducted for all the tweets posted from all over the world. Considering that the weather conditions can vary considerably in different geographic locations (and climate zones), and individuals' feelings and adaptation to the weather conditions may also vary by location, we also performed correlation tests for locations that had a total number of users greater than 1000. Statistical analysis was performed using IBM SPSS Statistics 23.0 (IBM Corporation).

Graph Analysis and Community Identification

In addition to the correlation tests, we performed graph analysis on the tweet corpus to gain further insight into the common terms that are used by individuals with FMS and how these terms are associated with each other. The graph analysis identifies the most relevant and commonly used terms and their relationships to the domain. More specifically, our aim was to explore and use the following 4 measures.

Measure 1

The occurrence frequency distribution of terms relevant to the corpus.

Measure 2

The degree centrality (or local connectivity) of each of these terms measured by calculating the number of relations that the term has regardless of whether it is an in-relation or out-relation within the corpus. In addition, we also considered the betweenness centrality of terms in the graph. This metric measures all the shortest paths between every pair of terms in the graph and then counts how many times a term is on a shortest path between two others. In our context, it can detect the dominant terms that occupy a set of intermediate terms observed between two other terms.

Measure 3

The association strengths among the terms that are measured by calculating how frequently particular terms are associated together based on their co-occurrences within the corpus.

Measure 4

The community structures that determine the level of dissemination of content within the domain corpus.

The first measure was determined by counting the total occurrence frequency of each of the terms extracted from our corpus. The second and third measures were achieved using graph analysis. For this, we constructed a term-term association graph. The association strength between 2 terms was measured by how often they co-occur within the corpus.

The last measure was done by decomposing the term-term association graph into subgroups or communities, which are sets of highly interconnected terms. We used the Louvain method [28] as a community detection algorithm implemented in Gephi [29]. This method is simple and efficient and one of the most widely used methods for identifying communities in a large network [17]. The Louvain method is an iterative algorithm that scans step by step the density of connections between the nodes in the graph. The nodes that are more densely connected to one another are included in the same community. This allows the potential detection of a priori unknown communities of highly associated terms in the FMS domain.

Preprocessing Steps

We first split each tweet in the corpus at whitespace characters to obtain individual terms [17]. We converted these terms to lowercase and removed stopwords (eg, common terms such as “the” and “is”), tweet-specific meta terms (eg, terms using “via” prefixes), symbols (eg, “@”), punctuation, and numbers. We then constructed a term-document matrix, where a row represents a tweet identifier and a column represents an individual term extracted from the corpus. By counting all the frequencies under each term within the matrix, we produced the frequency distribution of the terms. In order to restrict the size of the term-document matrix, we removed those terms whose sparse rates were greater than.999, that is, those terms that had a 99.9 sparse percentage of empty elements. A sparse percentage of 0.999 was chosen to ignore very infrequent terms and to retain only the terms whose document frequencies were greater than “N×(1−.999),” where N is the total number of tweets considered.

To measure the degree centrality of the terms and association strengths among the terms, we constructed a term-term graph. To build this graph, we created a term-term matrix, where rows and columns represent unique terms and a cell represents how many times a certain term co-occurs with another term.

Results

Correlation Tests

A total of 157,377 tweets were collected. After excluding the retweets, and tweets that contained a URL or did not have any location data, a total of 140,432 tweets were available for analysis. There was a very weak positive correlation between humidity and negative sentiment scores (*r*=.009, *P*=.001). There was no significant association between negative sentiment scores and other environmental variables (ie, temperature, wind speed, feels like, heat index, wind chill, and dew point).

There were 8 locations that had at least 1000 users, all of which were US states (California, Colorado, Florida, Georgia, Minnesota, New York, Ohio, and Texas). California had the highest number of tweets (5149) among all the locations.

There was no significant correlation between negative sentiment scores and any of the weather variables in Colorado, Florida, Georgia, Minnesota, Ohio, and Texas. However, the correlation tests for California and New York showed significant but weak relationships between negative sentiment scores and climatic variables (see Table 1). In California, there was a weak positive relationship between negative sentiment scores and humidity and a weak negative correlation between negative sentiment scores with temperature, feels like, heat index, and wind chill. In New York, there was only a weak positive relationship between negative sentiment scores and wind speed.

Table 1. Correlation between environmental variables and negative tweet sentiment, by US state.

Location	Temperature	Humidity	Wind speed	Feels like	Heat index	Wind chill	Dew point
California (n=5149)							
Pearson *r*	−.062	.050	−.030	−.057	−.059	−.060	.005
P value[a]	<.001	<.001	.03	<.001	<.001	<.001	.71
Direction of relationship	Negative	Positive	Negative	Negative	Negative	Negative	Positive
New York (n=2058)							
Pearson *r*	−.035	−.023	.078	−.039	−.036	−.037	−.055
P value[a]	.11	.28	<.001	.07	.10	.09	.01
Direction of relationship	Negative	Negative	Positive	Negative	Negative	Negative	Negative

[a] Statistical significance was defined as *P*<.001.

Graph Analysis

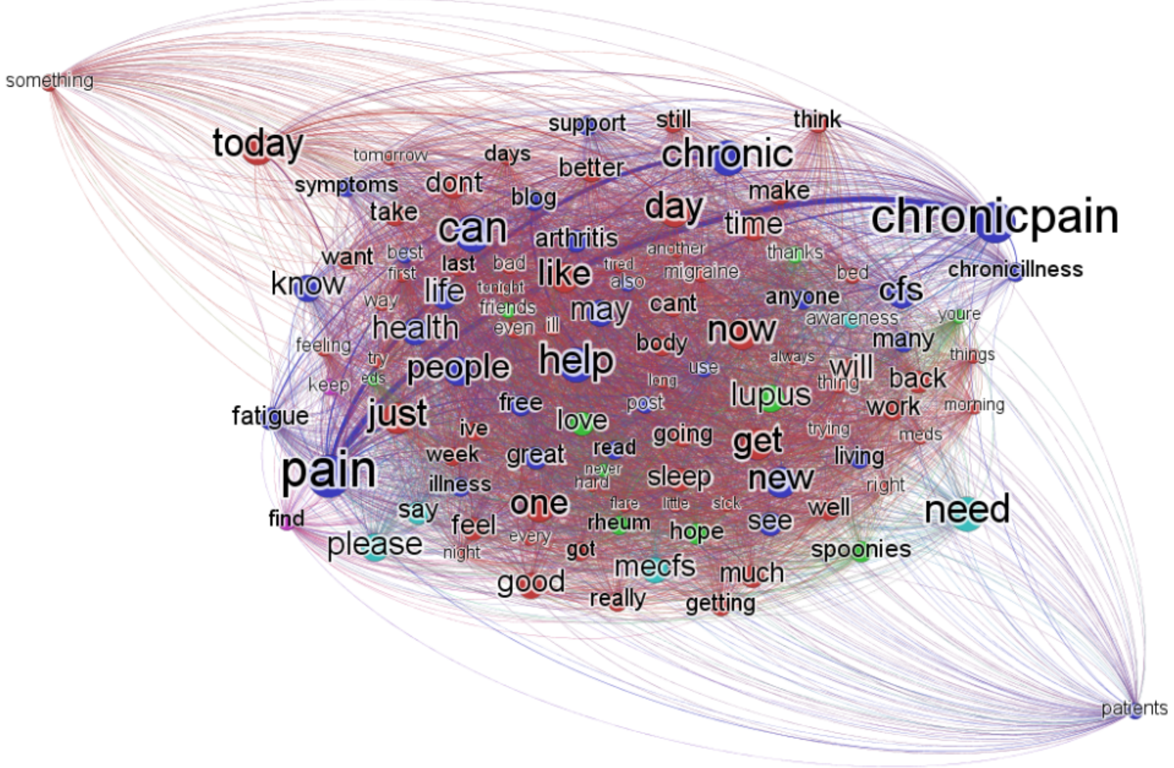
From the 140,432 tweets in the corpus, we extracted 61,469 terms after taking the preprocessing steps. After removing the sparse terms, 1170 terms were finally used to create a term-term matrix.

The occurrence frequency distribution results showed that the 2 most frequent terms were “pain” (appearing 24,323 times) and “chronicpain” (19,523 times). Among the top 25 terms (Multimedia Appendix 1), 2 broad groupings of terms may be identified: those that relate to medical conditions or states (eg, “chronic,” rank=5; lupus, rank=8; sleep, rank=19) are mixed with nonphysical terms (eg, day, rank=3, and today, rank=6).

The degree centrality scores of the top 2 terms “pain” and “chronicpain” were 1073 and 1070, respectively (Multimedia Appendix 1). These data indicate that these pain-related terms are the most highly associated with other terms. The mean degree centrality of the 1170 terms was 549, meaning that each term co-occurred with 549 terms in the corpus, on average.

Figure 1 shows the term-term graph constructed based on betweenness centrality. Betweenness centrality measures the number of shortest paths from all nodes in a graph to all others that pass through that term, and it may be considered an indicator of the importance of a term. The more important terms are denoted in larger term labels according to betweenness centrality. We used the top 10% terms, chosen by the degree centrality scores, to make the graph more readable and highlight the terms with higher scores. Degree centrality of a term counts how many links the term has with other terms within the fibromyalgia tweet corpus. We observed that the top 10 terms according to betweenness centrality were “pain,” “chronicpain,” “can,” “chronic,” “help,” “need,” “today,” “day,” “now,” and “just.” The association strength between 2 terms “pain” and “chronicpain” was the highest, co-occurring 5385 times (Multimedia Appendix 1).

Figure 1. The term-term graph built based on betweenness centrality.



Community Identification

Results of community detection using the Louvain method [28] showed that 2 communities (communities 1 and 3) had the highest number of terms (Multimedia Appendix 1). This may indicate that Web-based communications about fibromyalgia form a limited dissemination of the content mostly covered by 2 communities.

To investigate the term associations within the 2 largest communities, we generated associations of terms within each of these communities. Tables 2 and 3 show the top 15 associations of terms. In Tables 2 and 3, the “weight” indicates the number of co-occurrences of a pair of terms.

We also examined these communities for weather-related terms. Table 4 lists the weather-related terms identified in community 1. The weight of each term represents the number of associated terms (co-occurred terms) with a given term.

Table 2. The top 15 associations of terms within community 1.

Rank	Term 1	Term 2	Weight
1	Like	Feel	1133
2	Today	Day	1048
3	Just	Day	869
4	Raw	Healed	747
5	Little	Day	694
6	Good	Day	678
7	Day	Bad	551
8	Right	Now	550
9	Night	Last	500
10	One	Day	479
11	Sleep	Night	464
12	Feel	Better	463
13	Get	Day	462
14	Like	Day	429
15	Like	Just	426

Table 3. The top 15 associations of terms within community 3.

Rank	Term 1	Term 2	Weight
1	Pain	Chronicpain	5385
2	Pain	Chronic	4116
3	Post	Blog	2428
4	Day	Awareness	1498
5	Pain	Can	1456
6	Pain	Free	1348
7	Pain	Day	1311
8	Illness	Chronic	1304
9	Fatigue	Chronic	1249
10	Chronicpain	Can	1228
11	Keep	Fit	1190
12	Free	Chronicpain	1144
13	Like	Feel	1133
14	Pain	Back	1130
15	Today	Pain	1051

Table 4. The weather-related terms within community 1.

Terms	Weight
Weather	772
Cold	749
Hot	668
Rain	584
Warm	509
Sun	443
Winter	397
Summer	359

Discussion

Principal Findings

The main findings of this study add to the existing evidence base that suggests that there is no single weather condition that has a uniform effect on symptom expression in individuals with FMS at the group level. Although a statistical correlation between humidity and symptom severity was found in the tweets posted worldwide, the strength of the correlation was of negligible explanatory value.

Only several US states provided enough tweets (ie, >1000) for analysis within discrete geographic areas. Although there is some global variation in FMS prevalence [30], it is likely that this finding reflects a higher proportion of active Twitter users in the United States. However, this requires further investigation.

The interpretation of significant correlation test results in Table 1 (although very weak) could be that, in California, when the temperature, feels like, or heat index increases, the symptom severity (pain) decreases; however, an increase in humidity induces an increase in symptom severity (pain). This result agrees with the study by Macfarlane et al [9] that suggests patients believe warmer and drier climates improve their symptoms. Yet, Table 1 shows a different result for New York. In New York, when the wind speed increases the symptom severity (pain) increases. This underlines the fact that any impact of weather variables such as temperature, humidity, and wind speed on fibromyalgia symptoms (if true) may vary by geographic location.

Each state represented a distinct climate condition that was important in our tests. Correlation patterns in these states varied. A clear association between weather variables and FMS symptoms also did not emerge from these data. This large dataset is further evidence that any associations between climatic variables and pain symptoms seen in single locations are unlikely to reliably represent causal influences and would not be expected to be replicated in larger samples.

We did not test for the influence of interactions between weather variables on FMS symptoms in this study, although a clinically significant effect of any such interaction would be unlikely. Furthermore, these data do not exclude an effect of weather on the FMS experience at the individual level, and it remains plausible that particular weather states (or changes in weather states) have different effects between individuals with FMS or within individuals over time.

The graph and community detection analyses revealed several distinct patterns of communication in the FMS community. Analysis of the top 25 term associations shows that the term “pain” is associated with 5 other terms, which creates a combination of pain-related concepts (ie, “pain,” “chronicpain,” “chronic”) and non–pain-related terms (ie, “can,” “free,” “day,” “back,” “today,” and “new”; Multimedia Appendix 1). The term “chronic” is also associated with other symptom-related terms (“pain,” “illness,” “fatigue,” and “syndrome”).

The term-term graph built based on betweenness centrality (Figure 1) showed that the top 10 terms according to betweenness centrality included a number of words that are used to describe time (eg, “today,” “day,” “just,” and “now”). This may reflect the use of Twitter as a description of recent or immediate events or subjective states. This can be considered as a reassuring finding that Twitter provides valuable insight into current symptoms, especially if we are correlating with concurrent environmental conditions. Examples of such tweets from our corpus include the following:

> *I am at -3 spoons right now at least. This sucks. #spoonie*
>
> *I feel like I have half a spoon right now and I just had a nap. #spoonie*

We also notice that the word “can” is identified within the top 10 and “can’t” has the 41st rank. These words may represent concepts of functional ability among individuals.

An example of a tweet containing the term “can”:

> *Waiting for the meds and sedative to kick in so I can go back to sleep. #spoonie*

An example of a tweet that includes “can’t”:

> *Can't sleep because of my back. Just took a hot shower and it didn't help enough. 1 spoon left right now. #spoonie*

We identified a total of 6 communities of communication patterns among tweets relating to FMS. This is considerably smaller than the number of communities detected within the domain of “pain” (ie, 161 communities) using the same community detection algorithm reported in a study by Tighe et al [17]. Of the 6 communities in our study, 2 accounted for the majority of terms (communities 1 and 3; Multimedia Appendix 1). It can be observed that community 1 mostly includes the terms about “subjective experience” that reflect a description of the current symptom state (eg, “now,” “feel,” “well,” “better”).

In contrast, the terms in community 3 tend to reference broader issues of diagnosis, community, support, and awareness (eg, “chronic,” “life,” “support,” “anyone”).

In this study, we hypothesized that community detection would identify specific weather-related terms. We were able to detect a number of weather-related terms in community 1 (see Table 4). Examples of these tweets include the following:

> *Of course, the rainy weather isn't helping. #spoonie #fibro*
>
> *Its cold and rainy in N.C!!! #fibro kick'N now!!! YuK,YuK!!! But it won't wiN! I will!*
>
> *Not liking this snow. body is revolting. pls send warm weather or send me somewhere warm. #fibro sux. should just go back 2 bed. #spoonie*

One of the tweets about the impact of the weather was posted from Scotland (March 18, 2010):

> *People say the weather has no effect on #fibro. THEY LIE ITS RAINING AND I'M ACHING. Sorry just had to get that out*

While the identified weather-related terms had a low degree (see Table 4), and some of these terms such as “warm” were used in other contexts (eg, “warm bath,” “warm clothes,” or “warm hugs”), the results show the potential of social media platforms for studying the impact of environmental factors on chronic diseases from a first-person perspective.

Given that the terms in communities 1 and 3 represented more than 80% of all terms in our corpus, it is likely that individuals who tweet about fibromyalgia predominantly use this social medium either as a means of immediate symptom expression or to access or develop a Web-based social structure for the purpose of interpersonal support, advice, and advocacy.

Limitations

Our study has several limitations. First, one of the keywords that we used was “spoonie.” This is because our first attempt to collect tweets using only #fibro and #fibromyalgia returned a limited number of tweets. When we examined the tweets, we realized that most individuals with fibromyalgia use #spoonie to tag their tweets. The inclusion of the search term #spoonie substantially improved the sensitivity of our search but at the cost of some loss of specificity. There were some tweets that were posted by individuals who might have other chronic conditions. This is reflected in the inclusion of some overlapping data related to other chronic illnesses such as SLE and chronic fatigue syndrome.

Second, on many occasions, multiple hashtags occurred together in a single tweet. This may reflect the high incidence of “secondary” FMS in individuals with other rheumatic diseases. Examples include the following:

> *Felt a little discouraged today when my doctor thought it would take about a year for me to get back to where I was. #spoonie #lupus #fibro*
>
> *Feeling horrible #Lupus, #Fibro, & now the FLU!! Ugh Going to the Dr on Wed Putting on headset & sleeping till Wed. lol*

Third, our tests for US states used relative location information (states); however, it is unlikely that more precise location data would have substantially affected the results. We cannot exclude an effect on the results if the Twitter users spent most of their time indoors [2,5].

Conclusions

Web-based social networking services enable users to publicly share their thoughts and opinions, including those related to health behavior. Twitter is one of the most widely used social networking and microblogging services. Tweets exist in the public domain and are associated with additional data including date and time, as well as location. Aggregation and sentiment analysis of a large number of messages can be used to better understand the effects of contextual variables such as weather on chronic diseases. It also introduces new possibilities of measuring safety and effectiveness of new treatments and vaccines in real time and over time through surveillance of public opinions on social media [31].

This study shows that computerized content analysis of social media data provides a novel and potentially powerful approach to understanding variation in the FMS experience from a first-person perspective. Yet, a uniform causal effect of weather variation on FMS symptoms at the group level remains unlikely. Any impact of weather on FMS symptoms may vary geographically or at an individual level. Future work will further explore geographic variation and interactions focusing on individual pain trajectories over different seasons. We also plan to extend our work on graph analysis and community identification by considering semantic relationships.

Acknowledgments

This research was supported by Monash ECR (Early Career Researcher) Small Grant 2014 and an Australian Government Collaborative Research Networks (CRN) grant—the Federation University Australia “Self-sustaining Regions Research and Innovation Initiative.” RB is supported by an Australian National Health and Medical Research Council (NHMRC) Senior Principal Research Fellowship. The authors thank Tuan Huynh for collecting the tweets and conducting sentiment analysis.

Authors' Contributions

Study concept and design: SW, PDH, FB, YK, and RB; correlation tests: PDH and YK; interpretation of data: SW, RB, FB, PDH, and YK; drafting of initial manuscript: PDH; critical revision of the manuscript for important intellectual content: SW, PDH, FB, YK, and RB; and administrative, technical, or material support: PDH and SW. All authors approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Terms frequency and degree centrality.

[PDF File (Adobe PDF File), 46KB - publichealth_v3i1e4_app1.pdf]

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Abbreviations

API: application program interface
FMS: fibromyalgia syndrome
SLE: systemic lupus erythematosus

Edited by G Eysenbach; submitted 13.07.16; peer-reviewed by C Heavin, M Lewis, H Narimatsu, F Shen; comments to author 08.11.16; revised version received 24.11.16; accepted 22.12.16; published 19.01.17.

Please cite as:
Delir Haghighi P, Kang YB, Buchbinder R, Burstein F, Whittle S
Investigating Subjective Experience and the Influence of Weather Among Individuals With Fibromyalgia: A Content Analysis of Twitter
JMIR Public Health Surveill 2017;3(1):e4
URL: http://publichealth.jmir.org/2017/1/e4/
doi:10.2196/publichealth.6344
PMID:28104577

Original Paper

Using Social Listening Data to Monitor Misuse and Nonmedical Use of Bupropion: A Content Analysis

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Abstract

Background: The nonmedical use of pharmaceutical products has become a significant public health concern. Traditionally, the evaluation of nonmedical use has focused on controlled substances with addiction risk. Currently, there is no effective means of evaluating the nonmedical use of noncontrolled antidepressants.

Objective: Social listening, in the context of public health sometimes called infodemiology or infoveillance, is the process of identifying and assessing what is being said about a company, product, brand, or individual, within forms of electronic interactive media. The objectives of this study were (1) to determine whether content analysis of social listening data could be utilized to identify posts discussing potential misuse or nonmedical use of bupropion and two comparators, amitriptyline and venlafaxine, and (2) to describe and characterize these posts.

Methods: Social listening was performed on all publicly available posts cumulative through July 29, 2015, from two harm-reduction Web forums, Bluelight and Opiophile, which mentioned the study drugs. The acquired data were stripped of personally identifiable identification (PII). A set of generic, brand, and vernacular product names was used to identify product references in posts. Posts were obtained using natural language processing tools to identify vernacular references to drug misuse-related Preferred Terms from the English Medical Dictionary for Regulatory Activities (MedDRA) version 18 terminology. Posts were reviewed manually by coders, who extracted relevant details.

Results: A total of 7756 references to at least one of the study antidepressants were identified within posts gathered for this study. Of these posts, 668 (8.61%, 668/7756) referenced misuse or nonmedical use of the drug, with bupropion accounting for 438 (65.6%, 438/668). Of the 668 posts, nonmedical use was discouraged by 40.6% (178/438), 22% (22/100), and 18.5% (24/130) and encouraged by 12.3% (54/438), 10% (10/100), and 10.8% (14/130) for bupropion, amitriptyline, and venlafaxine, respectively. The most commonly reported desired effects were similar to stimulants with bupropion, sedatives with amitriptyline, and dissociatives with venlafaxine. The nasal route of administration was most frequently reported for bupropion, whereas the oral route was most frequently reported for amitriptyline and venlafaxine. Bupropion and venlafaxine were most commonly procured from health care providers, whereas amitriptyline was most commonly obtained or stolen from a third party. The Fleiss kappa for interrater agreement among 20 items with 7 categorical response options evaluated by all 11 raters was 0.448 (95% CI 0.421-0.457).

Conclusions: Social listening, conducted in collaboration with harm-reduction Web forums, offers a valuable new data source that can be used for monitoring nonmedical use of antidepressants. Additional work on the capabilities of social listening will help further delineate the benefits and limitations of this rapidly evolving data source.

(JMIR Public Health Surveill 2017;3(1):e6) doi:10.2196/publichealth.6174

KEYWORDS

social media; Internet; prescription drug misuse; substance-related disorders; pharmacovigilance; harm reduction; community-based participatory research; bupropion; amitriptyline; venlafaxine hydrochloride

Introduction

Background

The nonmedical use of pharmaceutical products has become a significant public health concern [1]. The National Survey on Drug Use and Health (NSDUH) reported that in 2014, there were 6.5 million people aged 12 years and older in the United States who had used prescription psychotherapeutic drugs nonmedically in the previous month [2]. Although the focus of traditional surveillance systems is on controlled substances, concerns occasionally arise over patient-initiated nonmedical use of noncontrolled pharmaceutical substances and the potential associated morbidity and mortality [3]. These concerns go beyond nonadherence to recommended dosages, escalating to the use of drugs to experience psychotropic effects, and in combination with controlled substances to enhance euphoria or mitigate withdrawal.

An example is bupropion, a noncontrolled medicine approved in many countries for the treatment of depression and as an aid to smoking cessation. In early preclinical studies, bupropion showed amphetamine- and cocaine-like behavioral effects in animals [4-7]. However, human abuse potential studies determined that bupropion had lower abuse liability than amphetamine, methylphenidate, or caffeine when taken orally [8-11], which is the only approved route of administration. This research led to the noncontrolled classification of bupropion in the United States and elsewhere. More recently several published case reports of the nonmedical use of bupropion have emerged [12-18], with particular focus on criminal justice and prison settings [19-24]. In 2014, after reviewing several reports, GlaxoSmithKline updated the prescribing information, alerting clinicians to the risks of nonoral routes of administration [25]. A 2013 evaluation of the Drug Abuse Warning Network (DAWN) database to examine the number of reports for bupropion stratified by demographics, route of administration, and disposition of the patient during the study period 2004-2011 did not provide evidence that misuse and nonmedical use of bupropion was growing over time [26].

For newly marketed drugs that are suspected or confirmed to have misuse and abuse potential, traditional methods for pharmacovigilance signal detection include evaluation of spontaneous postmarketing reports; retrospective studies of observational databases, such as vital statistics and poison center calls; data from national surveys; surveys from surveillance systems that measure rates of abuse, misuse, and diversion, such as the Researched Abuse, Diversion and Addiction-Related Surveillance (RADARS) system; focused studies in geographic regions of interest; and literature reports. However, those who utilize prescription products nonmedically, for psychotropic effects, may be hesitant to report this use to health care providers, drug companies, and regulatory agencies, even when adverse events are experienced. In addition, traditional pharmacovigilance tools such as spontaneous adverse event reports, medical literature, observational databases, and national surveys have inherent time lags for data availability, often lack product specificity, and may not be specifically tailored for data collection on drug abuse [27].

With ease of access and instant feedback, more consumers are turning to social media (forms of electronic interactive media through which users create online communities to share information, ideas, personal messages, and other content) to discuss their medical experiences and ask questions about medications in general [28,29]. Others have proposed using social media data (Web forums; social network sites such as Facebook, Twitter, Instagram, and You Tube; blogs; and chat rooms) to support research findings [30-32], to conduct surveys [33-35], and for surveillance of pharmaceutical and illicit products [36-42]. Similar to the methodology of this study, some have also utilized social media specifically to evaluate the nonmedical use of prescription drugs [43-50]. Each of these studies used lexicon-based strategies for gathering social media content and qualitative analyses to identify perceptions and behaviors relating to nonmedical use of controlled pharmaceutical drugs. Although elements of the study designs reported in previous publications are similar to this study, they all focused on drugs with recognized abuse liability. However, this study focused on drugs that are neither controlled nor recognized by regulatory authorities as exhibiting abuse liability.

Conversations about nonmedical drug use do occur in harm-reduction Web forums. These websites first began to appear in the 1990s and are used to seek drug-related information, to share drug experiences with like-minded others, to reduce harm, to seek support, and to build a sense of belonging to a community, although often through participants using a pseudonym [51,52]. These functions of Web forums are particularly salient to people who are concerned about the social and legal ramifications of revealing illicit behaviors or stigmatized identities to their immediate personal networks [52]. The pseudonymous nature of Web forum identities sets them apart from those on the newer social media platform, Facebook, which has a “real name” policy [53]. Although many other

Web-based communication platforms have been superseded in the Facebook era, pseudonymous Web forums in which drugs are discussed continue to retain existing communities and attract new members.

Social listening, in the context of public health sometimes called Infodemiology or infoveillance [54], is the process of identifying and assessing what is being said about a company, product, brand or individual, within forms of electronic interactive media [38,55]. The objectives of this study were (1) to determine whether content analysis of social listening data could be utilized to identify posts discussing potential misuse or nonmedical use of bupropion and 2 comparators, amitriptyline and venlafaxine, and (2) to describe and characterize these posts.

Study Medication: Bupropion (Wellbutrin, Wellbutrin XL, Wellbutrin SR, Zyban)

Bupropion, a reuptake inhibitor of norepinephrine and dopamine, was approved by the United States Food and Drug Association (FDA) for the treatment of major depressive disorder in 1985 [25] and for the treatment of nicotine dependence as an aid to smoking cessation in 1997 [56]. Controlled clinical trials were conducted in normal volunteers, in subjects with a history of multiple drug abuse, and in depressed subjects. These studies showed some increase in motor activity and agitation or excitement, which is often typical of central stimulant activity. Evidence from single-dose trials suggests that the recommended daily dosage of bupropion, when administered orally in divided doses, is not likely to be significantly reinforcing to amphetamine or central nervous system stimulant seekers. Higher doses, which could not be tested because of the risk of seizure, might be modestly attractive to those who use the central nervous system drugs nonmedically. Stimulant adverse reactions reported from clinical trials include central nervous system stimulation and hypomania, and those reported from postmarketing include euphoria, hallucinations, and manic reaction [25]. Reports in the literature indicate cocaine-like high, stimulant high, and euphoric effects with bupropion [22,24,57].

Comparator Medications

Amitriptyline (Elavil, Endep)

Amitriptyline is a tricyclic antidepressant (TCA) with known sedative properties and was approved by the FDA for the relief of symptoms of depressive illness in 1961 [58]. Sedative adverse reactions reported with TCAs include drowsiness, fatigue, disorientation, confusional states, and disturbed concentration [58]. There are discussions in the literature, including case reports, regarding the nonmedical use of amitriptyline [59-63]. The majority of case reports do not identify the route of misuse administration. When reported, the medications were described as taken orally, and in some cases, in large doses to produce a “euphoria” and a “pleasant” feeling [3,64].

Venlafaxine (Effexor, Effexor XR)

Venlafaxine is a serotonin and norepinephrine reuptake inhibitor (SNRI) and its extended-release formulation was approved by the FDA in 1997 for major depressive disorder, generalized anxiety disorder, social anxiety disorder, and panic disorder [65]. In clinical studies, there was no indication of drug-seeking behaviors; however, venlafaxine has not been systematically studied in clinical studies for its potential for nonmedical use. The United States prescribing information suggests that physicians carefully evaluate patients for history of nonmedical use of drugs and follow them closely for misuse or nonmedical use. Dissociative adverse reactions reported from clinical trials include sweating, dizziness, hallucination, and depersonalization; postmarketing reports include delirium [65]. There are case reports in the literature that describe large doses of oral ingestion (4050 mg and up to 3750 mg/day) to achieve altered states (“amphetamine-like high,” “more empathic and sociable,” and “elated” mood) [66-67]. These cases suggest that the nonmedical use of SNRIs may result in amphetamine-like effects or the dissociative effects of excess serotonin [3].

Methods

Study Design

This was a retrospective, observational, and qualitative content analysis [68]. We analyzed all cumulative data on 3 noncontrolled antidepressant drugs (bupropion plus two comparators, amitriptyline and venlafaxine). As minimal work has been done in evaluating the nonmedical use of noncontrolled substances, comparator antidepressant data provided context in evaluating outcomes. Amitriptyline and venlafaxine were selected as comparators because they are indicated for depression; however, each one represents a unique mechanism of action for effect. In addition, similar to bupropion, the United States regulatory approvals of amitriptyline and venlafaxine predate the existence of the two target Web forums, thus increasing the chances of seeing the discussions reflecting these drugs. Summary statistics on numbers of posts, threads, and authors for 4 additional controlled substances (methylphenidate, alprazolam, buprenorphine, and oxycodone) were also collected and compared for contextualization.

Data Sources

Data were collected from two publicly available harm-reduction forums (Bluelight and Opiophile) from their launch dates (1997 and 2003, respectively) through July 29, 2015. The sites were chosen from pilot work suggesting that these were particularly rich databases for this type of information. Bluelight has been in operation continuously since 1997, and is the largest global drug discussion website with over 320,000 members and nearly 7 million posts. Opiophile, in contrast, has experienced several periods of downtime since its launch in 2003, owing to server issues. At the time of data analysis, it had been offline since mid-2015, and had only 7927 members and just fewer than 100,000 posts at study inception.

Data Processing

Message preparation began with extracting a set of generic, brand, and vernacular product names, including misspellings, from Epidemico’s MedWatcher Social product dictionary [38,69]. That set of product names was then used to identify posts. Posts from Opiophile were gathered by identifying and downloading all posts with references to the products via customized software developed by Epidemico. Posts from

Bluelight were gathered by creating and searching a copy of the forum's underlying database in cooperation with the forum's administrators. All posts containing references to the 3 antidepressants were subjected to customized natural language processing tools that identified formal and vernacular references to misuse-related Preferred Terms. The Preferred Terms were then associated with 1 of the 3 study drugs [38]. For this study we utilized the English Language Medical Dictionary for Regulatory Activities (MedDRA) version 18.0 terminology, including the broad scope Standardized MedDRA Query (SMQ) "Drug abuse, dependence, and withdrawal." MedDRA is a clinically validated international medical terminology utilized by regulatory authorities throughout the drug lifecycle process. It is the international medical terminology developed under the auspices of the International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH) [70]. In addition to this query, 3 Preferred Terms outside of this SMQ were added: Injection, Injection site reaction, and Legal problem (see Multimedia Appendix 1). All posts mentioning the target antidepressants were reviewed by a coding team composed of pharmacists, a physician, epidemiologists, Web-based harm-reduction forum administrators, and providers of health and social services to people who use drugs nonmedically (see Multimedia Appendix 2). Each post was evaluated by a single coder, and challenging posts were further reviewed by 1 or more additional members of the coding team. Coders extracted available information about authors' expressed behaviors, intentions, experiences, and sociodemographic profile for posts that referenced misuse or nonmedical use of antidepressants (see Multimedia Appendix 3). The population was thus self-selecting and voluntary and may include users from any country or background as long as they posted in the English language and agreed to the site's policies. In addition, the acquired data were stripped of personally identifiable identification (PII) and provided in a deidentified format.

Definitions

Complete alignment is not apparent among regulators, the pharmaceutical industry, and harm reductions practitioners regarding how to define the misuse or nonmedical use of prescription products [71]. The World Health Organization states that the nonmedical use of a drug is considered "misuse," whereas the FDA defines nonmedical use of a drug as "abuse" [72-74]. Abuse is a term that is widely used but varies in meaning. The term "abuse" sometimes conveys a negative connotation or denotes disapproval [75]. In the United States, the term generally refers to problems of psychoactive substance use for both prescription and nonprescription compounds (see Table 1).

In this study the SMQ Drug abuse, dependence, and withdrawal was utilized. Due to inherent regulatory commitments, the authors of this publication also opted to utilize the FDA definitions of abuse and misuse [73,74]. However, when referring to activities that fall under the FDA definition of abuse, we use the term "nonmedical use." When the term "abuse" is used, it is not the intention of the authors to disapprove of or pass judgment on any person involved in substance use or the online communities where this use is discussed. In addition, the information and discussion presented here should not be viewed as suggesting or approving of the misuse or nonmedical use of these antidepressants.

Table 1. Definitions of abuse and misuse.

Agency	Definition of "abuse"	Definition of "misuse"
World Health Organization [72]	Persistent or sporadic excessive drug use inconsistent with or unrelated to acceptable medical practice.	Use of a substance for a purpose not consistent with legal or medical guidelines, as in the nonmedical use of prescription medications.
Food and Drug Administration [73,74]	The nonmedical use of a drug, repeatedly or even sporadically, for the positive psychoactive effects it produces.	The use of a drug outside label directions or in a way other than prescribed or directed by a health care practitioner. This definition includes patients using a drug for a condition different from that for which the drug is prescribed, patients taking more drug than prescribed or at different dosing intervals, and individuals using a drug not prescribed for them, although for therapeutic purposes.

Manual Coding

Manual coding is the process of manually reviewing posts to extract medical insights, similar to chart abstraction in traditional studies. The coding team completed standardized training prior to evaluating posts for this project and met regularly to discuss challenging posts and determine standards. All decisions and guidance were tracked and documented in a coding manual, with updates added as new situations occurred and team decisions were made.

The FDA definitions of misuse and nonmedical use above were utilized to guide the coders. If a posting author described utilizing one of the drugs specifically for the potential psychoactive effects, the post was coded as "nonmedical use." Alternatively, if a posting author described taking the drug for medical purposes, but outside of how it was prescribed or labeled, the post was coded as "misuse."

The coding of posts was conducted utilizing a custom-built Web application called "In-sight Explorer," which helped ensure that each reviewer was presented with a randomized set of forum posts to evaluate [76]. Additionally, the source of the posts was blinded to the coders. If a coder had any concern about how to answer any question relating to an individual post, the software helped to facilitate collaboration among the reviewers by enabling them to send a request for secondary review to any of the other coders or the whole group.

The software takes advantage of contextually highlighting the post content through the use of RxNorm- and MedDRA-controlled vocabularies to help coders quickly identify those portions of the text that may be relevant to the review process. RxNorm is a catalog of the standard names given to clinical drugs and drug delivery devices in the United States to enable efficient and accurate communication between electronic systems, independent of software and hardware capacity [77]. A screenshot of the coding tool is shown in Multimedia Appendix 4. All of the metadata collected about each post by manual coding is then recorded into a central database, which serves as the basis for results presented in this paper.

Interrater Reliability (IRR)

Metrics of interrater agreement were calculated to assess the coding team's agreement on tagging of posts. A random sample of 10 posts was gathered from the dataset and evaluated by all members of the coding team using the same questions and response options available in the manual coding interface. Agreement between coder-applied tags was then evaluated by calculating Fleiss kappa metrics of interrater agreement [78]. The use of Fleiss kappa was justified by the number of raters being assessed (11) and the nominal-scale format of ratings that were applied. The analyses included responses to the first two questions in the coding protocol, which asked coders to identify whether the post included reference to misuse or nonmedical use of in-scope products and what type of reference was made where applicable. Additional questions were omitted from analysis to reflect the coding protocol instruction to leave default answers unchanged if relevant information was not present in each post, thereby preventing artificial inflation of interrater agreement.

Ethics

In this study, we analyzed the archives of two Web forums. Two main areas of ethical focus were considered for this work: informed consent from individuals and communities and the protection of PII.

We drew from the heuristic approach provided by McKee and Porter [79] that charts 2 dimensions against each other: private to public communication and sensitive to nonsensitive information. Content that is deemed sensitive and is in the public domain sits in a gray zone from an ethical perspective, and the extent of protection for the individuals who write the content and the communities that host the content should be assessed on a case-by-case basis. The community discussions demonstrate that contributors are aware of the public nature of the content that they post, and almost all contributors utilize pseudonyms to mask their identities. Although the subject matter may be seen as sensitive, these elements led the research authors to determine that consent from individual contributors was not necessary to conduct the research. It was also important to maintain any particular contributor's anonymity, as the extent to which their pseudonym may reveal identifying information about them is unknown to the researchers. Therefore, to protect the identity of all post authors, PII was removed from all posts by a third-party vendor before receipt of the posts for coding. The types of PII removed included screen names, user names, first and last names, and addresses. In addition, where posts were included as examples in this paper, the post text has been paraphrased and altered in nonmeaningful ways to protect people's identity and to prevent unmasking using Internet search engines. Because our research did not involve intervention or interaction with the individuals, nor is the information individually identifiable, our study did not meet the criteria of the Office for Human Research Protections (OHRP) framework that guides institutional review board (IRB) status. As such, IRB approval was not pursued.

Some researchers anonymize the names of the Web forums that they utilize as data in order to further assure confidentiality of the individual contributors or because the group had neither been actively involved in the research nor given consent to be involved [80,81]. Here, we took a participatory or partnership approach [82]. Bluelight has a research portal accessible from the front page of the website, which asserts Bluelight's ownership of the forum content and instructs researchers to contact Bluelight administrators to discuss proposals for research, including archival analyses. The researchers contacted Bluelight to initiate discussions regarding this project, resulting in a partnership approach involving regular contact and contribution of Bluelight representatives to this study.

We contacted Opiophile via email to request consent and terms of access for gathering data from that forum. As no response was received from Opiophile, we reviewed the site's privacy notice and user agreement and determined that gathering data for research purposes was within the scope of permitted uses. Opiophile forum posts were gathered using customized Web-crawling software that stored the primary body of text included in each post. Usernames, post titles, thread titles, or other information allowing retrospective identification of the authors' Web-based identities were not included in the dataset used for coding or analysis.

We contacted a third potential data source, Erowid, to request consent and terms of access for gathering samples from their database of user-reported experiences with drugs. No response was received from Erowid, and their usage agreement explicitly prohibited data gathering or publishing of analyses without prior permission. In light of those policies and in the absence of response from site administrators, Erowid was excluded as a data source for this study.

Results

General Results

A total of 7270 posts were reviewed, containing 7756 references to at least one of the chosen products (ie, about 500 posts referenced more than 1 antidepressant). For purposes of simplicity, we refer to the 7756 as the denominator for proportion calculations. Of the total 7756 posts, 668 contain reference to misuse or nonmedical use of the product as defined above. This was 8.61% (668/7756) of the total reviewed, and within those 668 posts, 425 (63.6%, 425/668) were about nonmedical use and 243 (36.4%, 243/668) were about misuse (see Multimedia Appendix 5). The remainder of the posts made reference to in-scope products and drug use, but did not describe specific acts, intentions, or effects of nonmedical consumption. This nonmedical use and misuse subset of the data (n=668) was further analyzed as noted below. A breakdown across the 3 in-scope products is shown in Table 2. For demographic information including age, gender, country, ethnicity, and socioeconomic status, none of these was available for more than 4% of the posts.

In total, 656 (98.2%, 656/668) posts came from Bluelight and 12 (1.8%, 12/668) from Opiophile. The difference between Bluelight and Opiophile numbers may be due to Opiophile's primary focus on opioids, periods when Opiophile was closed or down, length of time the 2 sites have been active (Bluelight since 1997 and Opiophile since 2003), and the difference in size between the 2 websites.

To better contextualize the overall numbers of these posts, the numbers of posts for controlled substances with nonmedical use potential are available for comparison in Table 3. Discussions for the noncontrolled substances (first 3 in Table 3) were considerably fewer than for controlled substances.

Table 2. Breakdown of posts among 3 antidepressants.

Posts	Bupropion	Amitriptyline	Venlafaxine	Total posts
Individual drug posts reviewed, n (%) of total posts reviewed	3472 (44.77)	1105 (14.25)	3179 (41)	7756
Misuse or nonmedical use-related posts, n (%) of total drug specific posts	438 (12.6)	100 (9.1)	130 (4.1)	668 (8.61)
Nonmedical use posts[a]	305 (69.6)	60 (60)	60 (46.2)	425 (63.6)
Misuse posts[a]	133 (30.4)	40 (40)	70 (53.9)	243 (36.4)

[a] If a post contained both a nonmedical use and misuse mention, it was captured as nonmedical use.

Table 3. Total number of posts for 7 different drugs.

Product	Bluelight	Opiophile	Total[a]
Bupropion	4058	39	4097
Amitriptyline	1183	6	1189
Venlafaxine	3508	19	3527
Methylphenidate	12,274	95	12,369
Alprazolam	41,334	835	42,169
Buprenorphine	44,639	1538	46,177
Oxycodone	104,270	2269	106,539

[a] Total numbers before any removal of duplicates or manual review of posts; thus different from the final product numbers for in-scope products presented above for the most appropriate comparisons to be made.

Misuse and Nonmedical Use Data Subset Results

Additional characteristics of each post were examined by the coding team. The results from each characteristic or data point extracted are shown in Multimedia Appendix 6, with paraphrased example posts for illustration.

Information about the desired effect of a drug was deduced from 266 total posts (39.8%, 266/ 668 post dataset). Figure 1 shows that although all 3 pharmaceuticals have the same antidepressant indications, their desired effects in nonmedical use are quite different. Bupropion seems to be most desired as a stimulant, whereas amitriptyline most desired as a sedative, and venlafaxine as a dissociative.

Example "desired effect" posts:

> *I dissolved a 150mg bupropian in warm water. Then I put it in the freezer and took a nap. The solution had frozen, but it thawed quickly upon shaking. I injected the solution into my arm after filtering twice through filters I got from needle exchange. Is it possible the bupropion was altered by either the freezing, or the boiling? I am definitely feeling stimulated, else I wouldn't be bothering to post and I'd continue lurking.*
>
> *I want to get more sedation without upping my benzos or opiates. Can I add Elavil to the mix, or maybe take something out of the mix and add amitriptyline since I know it is sedating.*
>
> *For me, going into rehab didn't stop me from finding drugs. I pretended to do well in rehab to get out. I was buddies with the nurse in rehab and he got me meth. I took my mom's prescription pad and wrote venlafaxine to induce mania, got her to prescribe me Ritalin, etc. Rehabilitation never ends.*

Information about route of administration for nonmedical use was deduced from 214 total posts (32%, 214/ 668 post dataset), with bupropion accounting for 182 posts (41.6 %, 182/438 of bupropion posts), amitriptyline for 17 posts (17%, 17/100 of amitriptyline posts), and venlafaxine for 15 posts (11.5%, 15/130 of venlafaxine posts). Of note, 21 bupropion posts mentioned more than 1 route to equal 196 route mentions within the 182 bupropion posts. Figure 2 shows that the preferred nonmedical route of administration for bupropion is intranasal followed by intravenous or injection. The "other" category includes plugging, rectal, parachuting, foiling, and "abusing any other way."

Example "route of administration" posts:

> *I scared myself to death once. Didn't have anything and I had heard that bupropians could be snorted for a high and I did, man that stuff hits you faster than cocaine...even numbs you the same. But it feels like your snorting knives...never again!*
>
> *I was dumb enough once to snort amitriptyline which is a great benzo and opiate activator. I guess I wanted a quick onset, instead I got 30 minutes of awful burning pain! I've only had light blue and yellow pills without any markings, I don't know if the brand name burns as much but I've learned my lesson now.*
>
> *Maybe I scored with my Effexor prescription if I took more. I took several 75mg tablets at one time and did feel more alert, happy. I can take them as prescribed and benefit from the effect it has on making methadone more effective or I can use the month's supply in a few days and get a great high.*

The means of procurement of the drug are shown in Figure 3. Overall, procurement method was mentioned in 62 (9.3%, 62/668) of the posts, with bupropion accounting for 38 (8.7%, 38/438 drug specific posts), amitriptyline for 13 (13%, 13/100 drug specific posts), and venlafaxine for 11 (8.5%, 11/130 drug specific posts). Although they have similar licensed indications, the 3 drugs show some differences in most common route of procurement, with amitriptyline showing a higher propensity for procurement via stealing or illegal purchase than bupropion or venlafaxine, which were most commonly acquired via prescription from a health care provider. The “other” category comprised implied pharmacy dispensing error, “found on ground,” “by accident,” and “came across.”

Example of “method of procurement” posts:

> *I have had some bupropion around from an old prescription. I had read about people snorting it in various forums. The reviews were more negative than positive and the positive seemed really weak to say the least. But I was bored one day after drinking a few beers and smoking weed and I thought that it won't hurt 1 time. I was wrong, the experience was turned bad after a while. I snorted 500 mg over the course of about 5 hours. The only positive sensation was somewhat more alert at first and having a buzz.*
>
> *My friend found a lot of amitriptyline so I’m wondering...does it have potential for recreational purposes if used with weed? What about starting dose, good recreational dose, and dangerous dose? Would codeine or valium be a good addition?*
>
> *Last week, I found some venlafaxine pills on the street...Anyone else taken these while drinking and have an intense experience?*

Figure 1. Desired effect posts by drug.

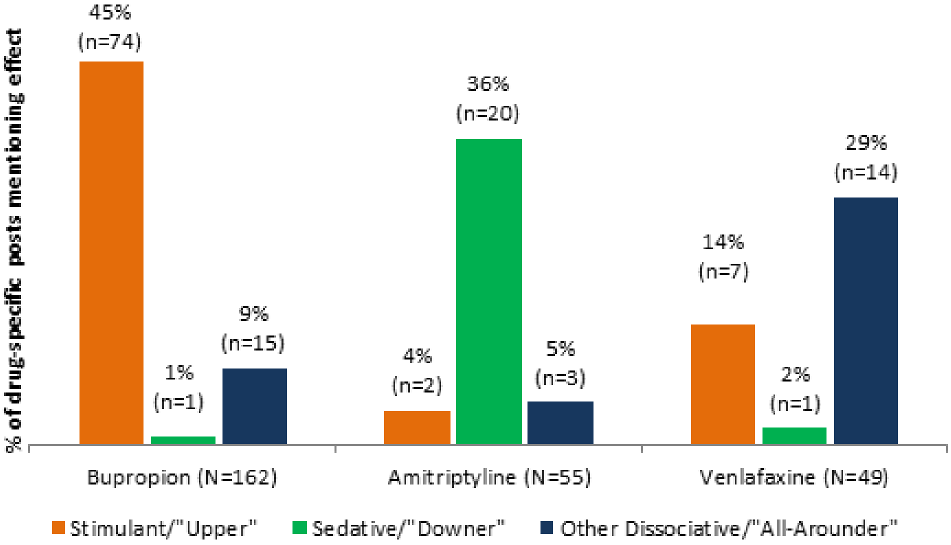


Figure 2. Route of administration details by drug.

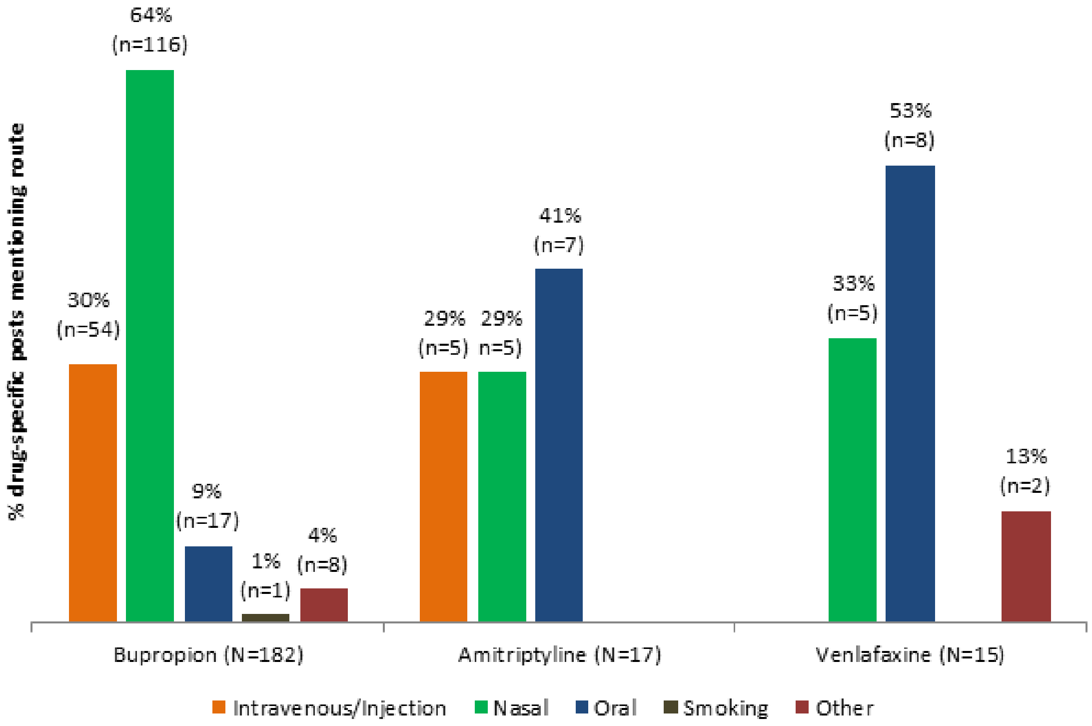
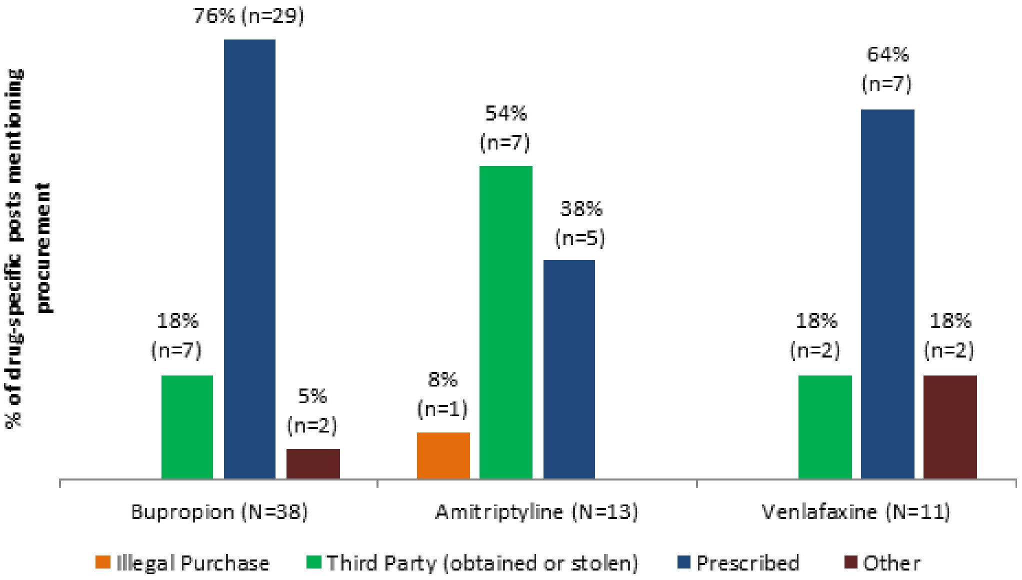


Figure 3. Method of procurement details by drug.



Interrater Reliability Results (IRR)

The Fleiss kappa for interrater agreement among 20 items with 7 categorical response options evaluated by all 11 raters was 0.448 (95% CI 0.421-0.457).

Discussion

Principal Findings

This paper makes 2 contributions. First, we were able to design a methodology that detects misuse and nonmedical use of noncontrolled substances in harm-reduction Web forums, a novel pharmacovigilance process. Second, we were able to validate this methodology by confirming the formerly sparse literature and spontaneous adverse reports regarding the nonmedical use of bupropion, previously unconfirmed by the DAWN database study. The evidence from these forums suggests that despite being noncontrolled substances, these 3 antidepressants have properties sought out by those seeking positive psychoactive effects. Collectively, the data reveal that nonmedical use of the 3 antidepressants differs markedly. The most commonly discussed types of effects were stimulant for bupropion, sedative for amitriptyline, and dissociative for venlafaxine. This is consistent with what is seen in literature reports for each drug, respectively. The data also indicate that amitriptyline was sought most frequently in combination with other (usually controlled) substances for euphoric effect; such a combination was reported much less frequently for bupropion and venlafaxine. Nasal insufflation was the most popular route for abuse of bupropion, seen nearly twice as often as with either comparator drug. One of the most interesting findings overall was the high percentage of posts in these forums which actually discouraged the nonmedical use of bupropion, whereas posts encouraging nonmedical use were relatively constant across the 3 drugs. Nonmedical use was discouraged either owing to side effect profile (nasal burning), danger (risk of seizure), or failure to achieve the desired effect by various post authors. These data also provide a rare glimpse into the combinations of antidepressants and other substances that are used outside of a medical context, providing a basis for harm-reduction messaging.

Methodology Strengths

This novel methodology allows for the differentiation between misuse and nonmedical use patterns among 3 commonly prescribed antidepressants, all of which are noncontrolled substances according to international treaties. This study reveals that the posted experiences of antidepressants when misused or used nonmedically are heterogeneous. Whereas animal studies have suggested some of these differences, rodent models are limited in their ability to discern certain mammalian effects, such as dissociative effects, sought out by nonmedical users. In addition, epidemiologic surveillance systems have not had the product-level resolution to discern the subjective differences, often combining all medications in this therapeutic area into 1 category. The methodology provided herein suggests that Web forums may be able to fill this key information gap.

The medications selected for this evaluation are antidepressants, noncontrolled substances that have limited epidemiologic surveillance for misuse and nonmedical use. Lingering questions about antidepressant misuse and nonmedical use typically are not captured and measured by most large-scale epidemiologic surveys, making it challenging to characterize from both a drug misuse and a toxicological perspective [3]. The social listening methodology outlined in this paper provides a framework for further exploration of the misuse and nonmedical use of other noncontrolled substances.

The “controlled substance” classification is used in accordance with international treaties to designate drugs (both medicinal and illicitly manufactured) that have shown potential for abuse [83]. The World Health Organization’s Expert Committee on Drug Dependence (WHO-ECDD) makes scientific recommendations that are codified into international treaty obligations by the International Narcotics Control Board (INCB) in Vienna, Austria. In order to conduct this work, these multilateral bodies make extensive use of surveillance systems across member states [84]. Although many privately and publicly sponsored surveillance systems exist for pharmaceutical and illicitly manufactured controlled substances [85-90], there is a paucity of information about the nonmedical use of noncontrolled substances. Social listening may potentially drive validation or rejection of already existing hypothesis generating data sources utilized in traditional safety surveillance that on their own may contain small numbers or missing information (spontaneous reports, literature, surveys). This may be particularly fruitful with challenging areas of surveillance, such as the nonmedical use of noncontrolled drugs, as presented here.

This is an entirely new data source and method of data collection for pharmacovigilance activities. This dataset provided much more detail than traditional forms of pharmacovigilance data sources and holds great potential, especially in areas such as the nonmedical use of noncontrolled substances, where data have been difficult to obtain through standard pharmacovigilance practices. The unscripted and unsolicited format of the data provides an understanding of the thoughts of people who use these drugs, in their own words. The longevity of these forums to date may provide an ongoing means of monitoring the extent of abuse of various drugs.

Methodology Limitations

It is unclear how representative the experiences of those who post anonymously on the Web are of those of the general nonmedical drug-using population and nonmedical use of bupropion in particular, and prevalence of drug use in the greater population cannot be extrapolated from these data. Access to Internet connections, literacy, and social norms for public discussion on drug nonmedical use vary considerably around the world. In addition, there may be a bias toward younger age groups, who are “digital natives” and have more plasticity with their Web-based identities. For example, in a survey of 897 Bluelight members in 2012, the mean age was 25 years and 76% were male [34]. The representativeness of posts is also compromised by the “1% rule,” which states that 1% of a Web community posts the vast majority of content (“superusers”), whereas another 9% is posted by “contributors,” and 90% do not post content at all (“lurkers”). This concept has been recently confirmed [91]. Although there are clear differences in the experiences, uses, and perceptions of the antidepressants studied here, limitations in representativeness could compromise attempts to extrapolate prevalence from the quantification of post content.

There are other limitations with this methodology. In order to protect privacy, the identity of authors was masked to the researchers. As a result, it is not known how many post authors are represented in the 7270 posts. However, maintaining multiple accounts over time is a practice endorsed by long-term users. Even with transparency into author pseudonyms, we still would not gain insights into a direct 1:1 ratio of authors and pseudonyms. Also limiting is the inherent scale limitations associated with manual coding, which can be labor and time intensive. For larger or ongoing projects, computational techniques should be considered. Finally, this is a novel methodology and the weight of evidence of a social media study and where it sits in the hierarchy of evidence still needs to be formally assessed and determined.

Bluelight is considered to be the largest repository for discussions about nonmedical use and misuse of substances. At the time of writing (September 13, 2016), Bluelight had a more popular global ranking than other drug discussion websites, such as Drugs-forum, Opiophile, and Erowid, based on the traffic ranking at Alexa, which was “calculated using a combination of average daily visitors to the site and pageviews on the site over the past 3 months. The site with the highest combination of visitors and pageviews was ranked “#1” [92]. Therefore, we believe this lends credibility of confidence to our work.

A common approach among researchers who analyze the content of publicly available Web forum communities is to copy the available data and produce their research independently [80,81,93-95]. Some researchers may believe that the community itself would not welcome research collaborations. They may also be unaware of intellectual property implications, applicable copyright laws, or terms of service specific to these communities which prohibit noncollaborative practices, such as unauthorized mining or harvesting of data, often referred to as “scraping.” Bluelight’s experience has been that many researchers simply do not consider the Bluelight community leaders as key stakeholders in their research: researchers may describe concerns about the ethics of engaging with individual contributors, but often appear unaware about the forum community’s broader interest in how the community is contributing to scientific knowledge and is represented by researchers.

The collaborative or participatory approach described here and previously published [82] is an alternative ethical framework that has a number of advantages. First, the researchers can identify the Web community in publications confidently, providing greater transparency and context for their findings. Second, Web community representatives can be engaged in the research process, working alongside researchers to help interpret and contextualize emergent understandings arising from the research. For example, in this study, it was helpful when community representatives resolved ambiguities arising from commonly used expressions and identified PII, such as pseudonyms embedded in text, that were not completely obvious to community outsiders. Third, researchers taking the collaborative approach can be confident that they are not breaching the terms of service or intellectual property rights of Web communities because the dataset was obtained directly and with authorization from community leaders. While not all Web communities welcome this kind of collaboration, the authors of this paper believe it is important for researchers who wish to utilize community data to attempt to engage communities in the first instance, rather than assume a lack of interest or capacity from the outset.

Conclusions

This study demonstrates the potential impact of anonymous conversations in Web-based harm-reduction forums, where safe communities are created for the exchange of ideas and experiences regarding drug use. Our experience suggests benefit from collaboration directly with Web forum communities. The evaluation of 2 harm-reduction forums across 3 antidepressants revealed a level of misuse and nonmedical use detail not seen in traditional surveillance data sources and confirmed previous observations for bupropion. Particular insights were seen in identifying and characterizing desired effects of misuse and nonmedical use, routes of administration for nonmedical use, and methods of drug procurement. In addition, the majority of forum posters discouraged the misuse and nonmedical use of all 3 antidepressants. Although social media listening is a promising data source for pharmacovigilance, concerns remain around the generalizability of these results and the value for clinicians and regulatory agencies. Despite these limitations, it warrants noting that this study captured detailed data around the historically difficult-to-monitor area of misuse and nonmedical use of noncontrolled substances. Further study is needed to establish the benefits and limitations of social media listening in this area of safety surveillance.

Acknowledgments

The authors thank colleagues who provided review and insights, including Harry Seifert, John Ascher, Greg Powell, Sanman Ghorpade, Kalpesh Joshi, Bill Christopher, Lorrie Schifano, Mary Wheeler, Eric Smith, and Eric Struth. The authors also thank Anna Torrence and Christine Durst at 23K Studios and James Andrews and Clare Slater from Fishawack for formatting the manuscript for submission. Their work was funded by GlaxoSmithKline.

Research was funded by GlaxoSmithKline. The data from Bluelight was purchased by GlaxoSmithKline. All analyses and manuscript development were conducted by the authors listed. Ongoing and continuous development of the social listening platform is supported by Epidemico, Inc. through government contracts and commercial engagement, but these resources were not used to directly support the specific content of this research.

This material is based on datasets obtained from Bluelight and Opiophile. Bluelight is a nonprofit Web-based community dedicated to reducing drug-related harm. This work was conducted with support from Bluelight. The content is solely the responsibility of the authors and does not necessarily represent the official views of Bluelight or Opiophile.

Monica Barratt is supported by an Australian National Health & Medical Research Council Early Career Researcher Fellowship (APP1070140). The National Drug and Alcohol Research Centre is supported by funding from the Australian Government under the Substance Misuse Prevention and Service Improvement Grants Fund.

Conflicts of Interest

Laurie S. Anderson, Jeffery Painter, Christina Winter, Beta Win, Julie Davidson, and Heidi Bell were employees of or contractors to GlaxoSmithKline during the study. Laurie Anderson, Christina Winter, Beta Win, Julie Davidson, and Jeffery Painter are GlaxoSmithKline shareholders. Christopher Menone, Michael Gilbert, and Nabarun Dasgupta are employees of or contractors to Epidemico, Inc, a technology company intending to commercialize the software platform used in this research. Epidemico is a wholly-owned subsidiary of Booz Allen Hamilton. Jonathan Sayegh and Monica Barratt are cofounders of Kadiant Analytics, a company that empowers digital communities to harness the value of their data through collaborative partnerships with research and industry.

Multimedia Appendix 1

Study Preferred Terms.

[PDF File (Adobe PDF File), 20KB - publichealth_v3i1e6_app1.pdf]

Multimedia Appendix 2

Number of posts per individual coder.

[PDF File (Adobe PDF File), 16KB - publichealth_v3i1e6_app2.pdf]

Multimedia Appendix 3

Criteria evaluated during coding.

[PDF File (Adobe PDF File), 12KB - publichealth_v3i1e6_app3.pdf]

Multimedia Appendix 4

Insight Explorer for manual coding.

[PDF File (Adobe PDF File), 42KB - publichealth_v3i1e6_app4.pdf]

Multimedia Appendix 5

Example nonmedical use and misuse posts.

[PDF File (Adobe PDF File), 172KB - publichealth_v3i1e6_app5.pdf]

Multimedia Appendix 6

Further details of posts extracted by manual coders with example posts.

[PDF File (Adobe PDF File), 114KB - publichealth_v3i1e6_app6.pdf]

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Abbreviations

DAWN: Drug Abuse Warning Network
INCB: International Narcotics Control Board
IRB: institutional review board
IRR: interrater reliability
MedDRA: Medical Dictionary for Regulatory Activities
NSDUH: National Survey on Drug Use and Health
OHRP: Office for Human Research Protections
PII: personally identifiable identification
PTs: preferred terms
RADARS: Researched Abuse, Diversion and Addiction-Related Surveillance
SMQ: Standardised MedDRA Query
SNRI: serotonin and norepinephrine reuptake inhibitor
TCA: tricyclic antidepressant
FDA: Food and Drug Association
WHO: World Health Organization
WHO-ECDD: World Health Organization’s Expert Committee on Drug Dependence

Edited by G Eysenbach; submitted 10.06.16; peer-reviewed by C Giraud-Carrier, R Daniulaityte; comments to author 20.09.16; revised version received 02.11.16; accepted 07.01.17; published 01.02.17.

Please cite as:
Anderson LS, Bell HG, Gilbert M, Davidson JE, Winter C, Barratt MJ, Win B, Painter JL, Menone C, Sayegh J, Dasgupta N
Using Social Listening Data to Monitor Misuse and Nonmedical Use of Bupropion: A Content Analysis
JMIR Public Health Surveill 2017;3(1):e6
URL: http://publichealth.jmir.org/2017/1/e6/
doi:10.2196/publichealth.6174
PMID:28148472

Original Paper

Using Web-Based Search Data to Study the Public's Reactions to Societal Events: The Case of the Sandy Hook Shooting

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Abstract

Background: Internet search is the most common activity on the World Wide Web and generates a vast amount of user-reported data regarding their information-seeking preferences and behavior. Although this data has been successfully used to examine outbreaks, health care utilization, and outcomes related to quality of care, its value in informing public health policy remains unclear.

Objective: The aim of this study was to evaluate the role of Internet search query data in health policy development. To do so, we studied the public's reaction to a major societal event in the context of the 2012 Sandy Hook School shooting incident.

Methods: Query data from the Yahoo! search engine regarding firearm-related searches was analyzed to examine changes in user-selected search terms and subsequent websites visited for a period of 14 days before and after the shooting incident.

Results: A total of 5,653,588 firearm-related search queries were analyzed. In the after period, queries increased for search terms related to "guns" (+50.06%), "shooting incident" (+333.71%), "ammunition" (+155.14%), and "gun-related laws" (+535.47%). The highest increase (+1054.37%) in Web traffic was seen by news websites following "shooting incident" queries whereas searches for "guns" (+61.02%) and "ammunition" (+173.15%) resulted in notable increases in visits to retail websites. Firearm-related queries generally returned to baseline levels after approximately 10 days.

Conclusions: Search engine queries present a viable infodemiology metric on public reactions and subsequent behaviors to major societal events and could be used by policymakers to inform policy development.

(JMIR Public Health Surveill 2017;3(1):e12) doi:10.2196/publichealth.6033

KEYWORDS

Internet; search engine; firearms; health policy; information seeking behavior; public health informatics; gun control debate

Introduction

Nearly 9 out of every 10 Americans have Internet access at home [1] and Web browsing accounts for an average of 23 hours per week that includes activities such as communication, entertainment, news, shopping, and social networking [1,2]. Importantly, searching the Web for information using search engines far surpasses most other types of activities with over 91% of US adults contributing to Web traffic of this nature [3]. Consequently, Web searches generate a vast amount of data in the form of users' search queries which capture their information-seeking preferences (eg, what they search for) and behavior (eg, what sites they visit). Analysis of this information—a form of infodemiology [4]—could be used to improve our understanding of various issues which in turn can inform policy development.

Infodemiology is an emerging discipline that focuses on analyzing electronic information from the Internet (eg, search queries, social media, and so on) in order to provide information on public health and policy [4]. Previous infodemiology literature has examined Web search query data to evaluate various public health and health care research questions. For example, several studies used Web search query data to identify influenza outbreaks ahead of conventional population detection methods in the United States [5-13] and abroad [14-20], as well as other public health surveillance [21-24]. Researchers have also analyzed search queries for the detection and prevention of adverse drug events, or any other drug related complications [25-27]. Finally, Web-based search logs have been utilized to predict health care utilization and costs following information seeking on search engines [22,28-30]. To our knowledge, no study has examined search data to better understand the public's sentiments, reactions, and behaviors to major societal events.

We consider major societal events consistent with the "social crises" definition from the crisis management literature. These events are characterized by the severe consequences of the incident, low probability of incident occurrence, and the informational and situational uncertainty that occur among members of the public [31,32]. These situations are inevitably accompanied by collective anxiety, improvised group behaviors, and adaptive collaboration among the public [32-36]. Public mass shooting events share these characteristics; they have a low probability of occurrence, they are followed by lack of reliable information regarding details and consequences of the event, and generate heightened anxiety and public outcry in response to the situation.

The purpose of this paper was to analyze search query data in the context of a major societal event. We decided to study the Sandy Hook Elementary Shooting incident that occurred on December 14, 2012, in Newton Connecticut to determine whether such data can be used to better understand the public's reactions to such an event. The act of a lone gunman causing the deaths of 20 children and 6 adults received national and international attention, prompting renewed public interest in gun issues [37]. We are interested in understanding how firearm-related information seeking (eg, looking up relevant laws, learning about advocacy) and Web-based behavior (eg, visits to firearm-related retailers) changed immediately after the incident. Understanding these trends will provide insights into how Americans responded to the incident which can enhance societal debates and inform policy development related to firearms.

Methods

Data Source and Preparation

We examined deidentified data from Yahoo! search engine queries in a 28-day period before (14-day) and after (14-day) the Sandy Hook shooting incident. Our population consisted of all users of the Yahoo! search engine located in the United States (including Puerto Rico and Mariana Islands) that queried firearm-related searches during the study period. The majority of the information consumed on the Web starts as search queries entered by the user. The choices made by the user in the form of websites they click from the list of populated search results present a much more comprehensive picture of a user's information needs. Our goal was to use the search query data to evaluate patterns of information seeking regarding firearms and to evaluate broadly the changes in intent based on differences in the content (retail, news, education, and so on) and sources (commercial entities, noncommercial organizations, government entities, and so on) of information sought.

From the complete Yahoo! search query database, we identified all firearm-related queries from November 31, 2012 to December 28, 2012. Queries were text strings consisting of single words or phrases that users typed into the search engine; we identified these using keywords that would match partially or completely with words in the queries. Firearm-related search queries were identified by using keywords in the following categories: Gun type (gun, firearm, handgun, rifle, pistol, revolver, and shotgun), ammunition (ammunition, ammo, and bullets), law related (Brady Act, second amendment of the US constitution), and shooting. In order to choose keywords in each category, we examined Web-based trends of firearm-related search queries for December 2012 using Google Trends. We did this by first examining simpler queries (eg, handgun), and the 10 most correlated searches for these queries. This was repeated recursively with each of the correlated queries until we found no new or correlated searches. This gave us a set of 247 queries that were related to firearms. We wanted our keywords to have the ability to identify these 247 queries as well as any other searches that may be firearm related. Thus our keywords consisted of single words which could identify most firearm-related searches based on complete or partial matches with user queries. As such, our analysis included users' actual search queries that included keywords in any of the 4 categories.

In addition, we also analyzed the uniform resource locators (URLs) that each individual user clicked from the search results generated by their search queries. First, we identified the domain for each URL that the user clicked; for example, if the user clicked the URL "http://en.wikipedia.org/wiki/Second_Amendment," the domain was identified as "wikipedia.org." Next, we categorized these URLs based on the top-level domain (TLD) into commercial entities (.com), noncommercial organizations (.org), government entities (.gov, .state.us, and .mil), educational institutions (.edu), and others (country specific, .pro, .tv, and so on). Including TLDs in our analysis allows us to infer the nature of the organization; for instance, TLDs such as .gov, .mil, and .edu have legal restrictions which prevent them from being used by organizations other than government, military, and educational entities. Moreover, search ranking algorithms are unlikely to place URLs from entities with erroneously used TLDs higher in the search results. These factors allow the use of TLDs to categorize the nature of organizations fairly reliably. Next, each domain was categorized as retail (websites for the purchase of guns, ammunition, and gun accessories; including gun shows), news (websites of newspapers, news channels etc), educational (websites, regardless of TLD, that host information regarding gun safety, gun laws, gun maintenance, and may include websites of gun advocacy groups), showbiz (websites of movies, television shows, music videos, and so on) or "other" which included all remaining uncategorized websites.

The TLD and the content describe different characteristics of the same website and thus examining them together provides a richer understanding of the information seeking patterns. As such we created a variable that assigns a class to each website in the dataset derived from its content category and TLD. Thus, a website with retail content hosted by a commercial entity would be classified as "retail content, .com." Finally, we created a variable to capture all of the websites owned or affiliated with the National Rifle Association (NRA) as listed on the NRA's website [38]. Such websites were classified as gun rights advocacy groups. The NRA website also identifies other sites that it categorizes as "antigun lobbying organizations" [39]. We categorized these websites as gun control advocacy groups.

To evaluate the association between the Sandy Hook incident and the nature of information sought, we first examined the distributions of various characteristics of the domains visited by users following the search query (category of keyword, top-level domain, category of the website's content, and advocacy view of the websites visited). Next, we investigated differences in website characteristics in the period before and after the shooting incident using the website classes. We also examined the percentage change in website visits for each of the characteristics relative to the total websites in the before period to those in the after period. Additionally, we examined the percent change in website visits for each of the characteristics in the after period to the website visit for the same characteristics in the before period.

Finally, it is possible that observed changes in information-seeking behavior over time may be due to the presence of secular or temporal trends and not as a result of the Sandy Hook shooting incident. For example, given that our study period overlapped with the holiday shopping season, one might expect an increase in Web-based shopping activity that can include increases in firearm-related searches, independent of the Sandy Hook incident. To differentiate the shopping activity related increase in search activity from that related to the shooting incident, we included a control query that would be agnostic to the trend due to the Sandy Hook incident but sensitive to the temporal trends of the holiday season. Thus, a query for "bicycle" (and related synonyms) was used as a control search term.

Limitations

The following limitations must be noted. First, given that Yahoo! search accounted for about 12% of the US search engine market share in December 2012 [40], we recognize that caution must be used before generalizing to the entire US population. Additionally, the Web pages visited by the users may also be associated with result-ranking algorithms which vary by search engines. Since 2011, Yahoo! search is powered by Bing [41] and whereas the exact algorithms are proprietary, evidence suggests that Bing emphasizes keywords (search strings) in ranking search results [42]. Second, our analysis was focused on the query-level (ie, website visited after each search) and not the user level which may include several queries in a given search episode. Third, approximately 30% of all observations consisted of a large number of unique domains occurring with a low frequency and thus could not be classified. Nevertheless, these domains individually accounted for less than 1% of all observations and thus their effect on the findings is likely minimal. Finally, our work represents an exploratory study to examine whether search data can be used for a new purpose. Thus, the existing body of literature provided little guidance on the methods or approaches to analyzing such data. We recognize that future studies may identify additional techniques for analyzing similarly complex data.

Results

A total of 5,653,588 firearm-related search queries were identified by our keywords in a 28-day period before (14-day) and after (14-day) the Sandy Hook shooting incident. By each search query category (see Table 1), the majority (59.62%; 3,370,523/5,653,588) focused on a gun type (eg, queries with the term pistol, shotgun, or rifle) with the rest focused on the shooting incident (22.47%; 1,270,122/5,653,588), ammunition (16.88%; 954,363/5,653,588), or law related searches (1.04%; 58,580/5,653,588). Based on TLD, users were most likely to visit websites of commercial entities (.com: 88.03%; 4,976,990/5,653,588) followed by noncommercial organizations (.orgs: 6.63%; 374,863/5,653,588) and government entities (.gov, state.us, mil: 1.06%; 59,939/5,653,588). Users most frequently clicked on links that brought them to retail websites (30.33%; 1,714,504/5,653,588), followed by news websites (23.38%; 1,321,706/5,653,588), educational websites (20.32%; 1,148,897/5,653,588), and showbiz websites (2.09%; 118,174/5,653,588). A total of 66,581 websites that users visited could be classified as those of gun rights (68.86%; 45,848/66,581) or gun control (31.14%; 20,733/66,581) advocacy groups. Finally, our control search query for bicycle synonyms yielded 597,859 individual observations during the same study period.

Table 1. Characteristics of the search query data. Source: Authors' analysis of Yahoo! search queries for December 2012.

Variables		Proportion n (%)
Search keywords		
Firearm-related (n=5,653,588)		
	Gun type	3,370,523 (59.62)
	Shooting incidents	1,270,122 (22.47)
	Ammunition	954,363 (16.88)
	Law related	58,580 (1.04)
Counterfactual (n=597,859)		
	Bicycle	597,859 (100.00)
Top-level domain		
Firearm-related (n=5,653,588)		
	Commercial entities	4,976,990 (88.03)
	Noncommercial organizations	374,863 (6.63)
	Government entities	59,939 (1.06)
	Educational institutions	9419 (0.17)
	Other	232,377 (4.11)
Category		
Firearm-related (n=5,653,588)		
	Retail	1,714,504 (30.33)
	News	1,321,706 (23.38)
	Educational	1,148,897 (20.32)
	Showbiz	118,174 (2.09)
	Other or uncategorized	1,350,307 (23.88)
Stance on gun control		
Firearm-related (n=66,581)		
	Gun control advocacy group	20,733 (31.14)
	Gun rights advocacy group	45,848 (68.86)

Bivariate relationships between user search queries and the class of websites visited based on content and TLD are presented in Table 2. In all categories there was an increase in firearm-related search queries in the period after the shooting. Gun type searches which were the most common firearm-related query showed the least relative change after the shooting incident with a 50.06% increase in the proportion of user searches. In contrast, the law category of search queries after the shooting incident had a 535.47% increase in the proportion of searches although it was the least searched. Although users searching for gun types (+61.02%) or ammunition (+173.15%) were more likely to visit retail content on commercial entity websites after the shooting incident, a greater proportion (+1054.37%) visited news content on commercial entity websites for shooting incident searches. Law-related searches, however, had a greater proportion of visits to websites with educational content from noncommercial organizations (+702.70%), commercial entities (+484.20%), and educational institutions (+593.97%). Importantly, when examining changes to bicycle-related search terms (the counterfactual) in the before and after period, we observed a relatively modest decrease in overall searches (−8.64 %).

Table 2. Changes in search patterns before and after the Sandy Hook school shooting incident (December 14, 2012). Source: Authors' analysis of Yahoo! search queries for December 2012.

Search query	n	Before period[a]	After period[a]	Delta %	Cumulative %
Gun type					
Retail content, .com	965,795	370,002 (38.31%)	595,793 (61.69%)	61.02%	28.70%
News content, .com	595,689	340,883 (57.22%)	254,806 (42.78%)	−25.25%	46.40%
Educational content, .com	560,295	196,435 (35.06%)	363,860 (64.94%)	85.23%	63.05%
Educational content, .org	184,979	46,886 (25.35%)	138,093 (74.65%)	194.53%	68.54%
Other content, .com	774,034	293,009 (37.85%)	481,025 (62.15%)	64.17%	91.54%
Total	3,365,359	1,345,833 (39.99%)	2,019,526 (60.01%)	50.06%	100%
Shooting incidents					
News content, .com	648,233	51,678 (7.97%)	596,555 (92.03%)	1054.37%	51.45%
Educational content, .com	94,150	26,941 (28.61%)	67,209 (71.39%)	149.47%	58.93%
Educational content, .org	54,830	7911 (14.43%)	46,919 (85.57%)	493.09%	62.28%
Showbiz related content, .com	44,135	15,732 (35.65%)	28, 403 (64.35%)	80.54%	66.78%
Other content, .com	319,892	98,564 (30.81%)	221,328 (69.19%)	124.55%	92.18%
Total	1,259,817	236,050 (18.74%)	1,023,767 (81.26%)	333.71%	100%
Ammunition					
Retail related content, .com	609,246	163,272 (26.80%)	445,974 (73.20%)	173.15%	63.85%
Educational content, .com	95,687	31,256 (32.66%)	64,431 (67.34%)	106.14%	73.88%
News content, .com	61,025	10,849 (17.78%)	50,176 (82.22%)	362.49%	80.28%
Other content, .com	100,711	36,104 (35.85%)	64,607 (64.15%)	78.95%	90.83%
Total	954,158	268,670 (28.16%)	685,488 (71.84%)	155.14%	100%
Laws					
Educational content, .org	25,429	2817 (11.08%)	22,612 (88.92%)	702.70%	43.41%
Educational content, .com	12,473	1823 (14.62%)	10,650 (85.38%)	484.20%	64.70%
Educational content, .edu	3422	431 (12.59%)	2991 (87.41%)	593.97%	70.54%
News content, .com	2663	383 (14.38%)	2280 (85.62%)	495.30%	75.09%
Other content, .com	8978	1502 (16.73%)	7476 (83.27%)	397.74%	90.41%
Total	58,580	7965 (13.60%)	50,615 (86.40%)	535.47%	100%
Bicycle					
Retail related content, .com	142,209	75,551 (53.13%)	66,658 (46.87%)	−11.77%	24.08%
Educational content, .com	87,964	45,550 (51.78%)	42,414 (48.22%)	−6.88%	38.98%
Other content, .com	266,220	137,068 (51.49%)	129,152 (48.51%)	−5.78%	84.06%
Other content, .other	23,605	12,254 (51.91%)	11,351 (48.09%)	−7.37%	88.06%
Other content, .org	19,957	10,233 (51.28%)	9724 (48.72%)	−4.97%	91.44%
Total	590,530	308,603 (52.26%)	281,927 (47.74%)	−8.64%	100%

[a] Indicates ± 14 days from the Sandy Hook event.

Table 3 presents the bivariate relationship between the time period and the advocacy view (gun rights vs gun control) of the websites visited by users following search queries for each category of firearm-related searches. Search results increased in all categories in the period after the shooting incident (range: 79.94%-418.39%). The majority of search queries for gun type (67.92%; 40,069/58,998), shooting incident (84.55%; 2490/2945), and ammunition (93.16%; 2316/2486) resulted in users visiting websites of gun rights advocacy groups, whereas those searching for laws were more likely to visit websites of gun control advocacy groups (54.79%; 1179/2152). On the whole, Web-based users had an increase of between 285.71% and 660.58% of visiting gun control advocacy group websites after the shooting incident.

Table 3. Bivariate relationship between time period and the advocacy view of the websites visited by users for each category of firearm-related searches. Source: Authors' analysis of Yahoo! Search queries for December 2012.

Search query	n (%)	Before[a]	After[a]	Delta %
Gun type				
Gun rights	40,069 (67.92)	28.29%	71.71%	153.53%
Gun control	18,929 (32.08)	14.97%	85.03%	467.93%
Total	58,998	24.01%	75.99%	216.42%
Shooting incidents				
Gun rights	2490 (84.55)	39.04%	60.96%	56.17%
Gun control	455 (15.45)	17.58%	82.42%	368.75%
Total	2945	35.72%	64.28%	79.94%
Ammunition				
Gun rights	2316 (93.16)	36.44%	63.56%	74.41%
Gun control	170 (6.84)	20.59%	79.41%	285.71%
Total	2486	35.36%	64.64%	82.82%
Laws				
Gun rights	973 (45.21)	21.69%	78.31%	261.14%
Gun control	1179 (54.79)	11.62%	88.38%	660.58%
Total	2152	16.17%	83.83%	418.39%

[a] Indicates ±14 days from the Sandy Hook event.

Figure 1 presents the trend data graphed in the before and after period for firearm-related and bicycle-related searches for 4 categories of TLDs. As can be seen, Web traffic as a result of firearm-related search queries saw a sharp increase corresponding to the Sandy Hook shooting incident for domains of commercial entities, educational institutions, government entities, and noncommercial organizations. Additionally, depending on the TLD, a relatively smaller peak in Web traffic is seen at days 6 and 11 before the shooting incident following firearm-related searches, with the greatest increase seen for .com domains. Conversely, bicycle-related searches during the same period appear relatively unchanged. Figure 2 presents the trend data graphed in the before and after period for firearm-related search queries for advocacy view. Websites of both gun control and gun rights advocacy groups saw a sharp increase in traffic corresponding to the shooting incident following firearm-related searches. The traffic decreased slowly for both over the after period with slight increase in traffic at day 11.

Figure 1. Websites visited following firearm-related and bicycle-related search queries by top-level domain. Source: Authors' analysis of Yahoo! Search queries for December 2012.

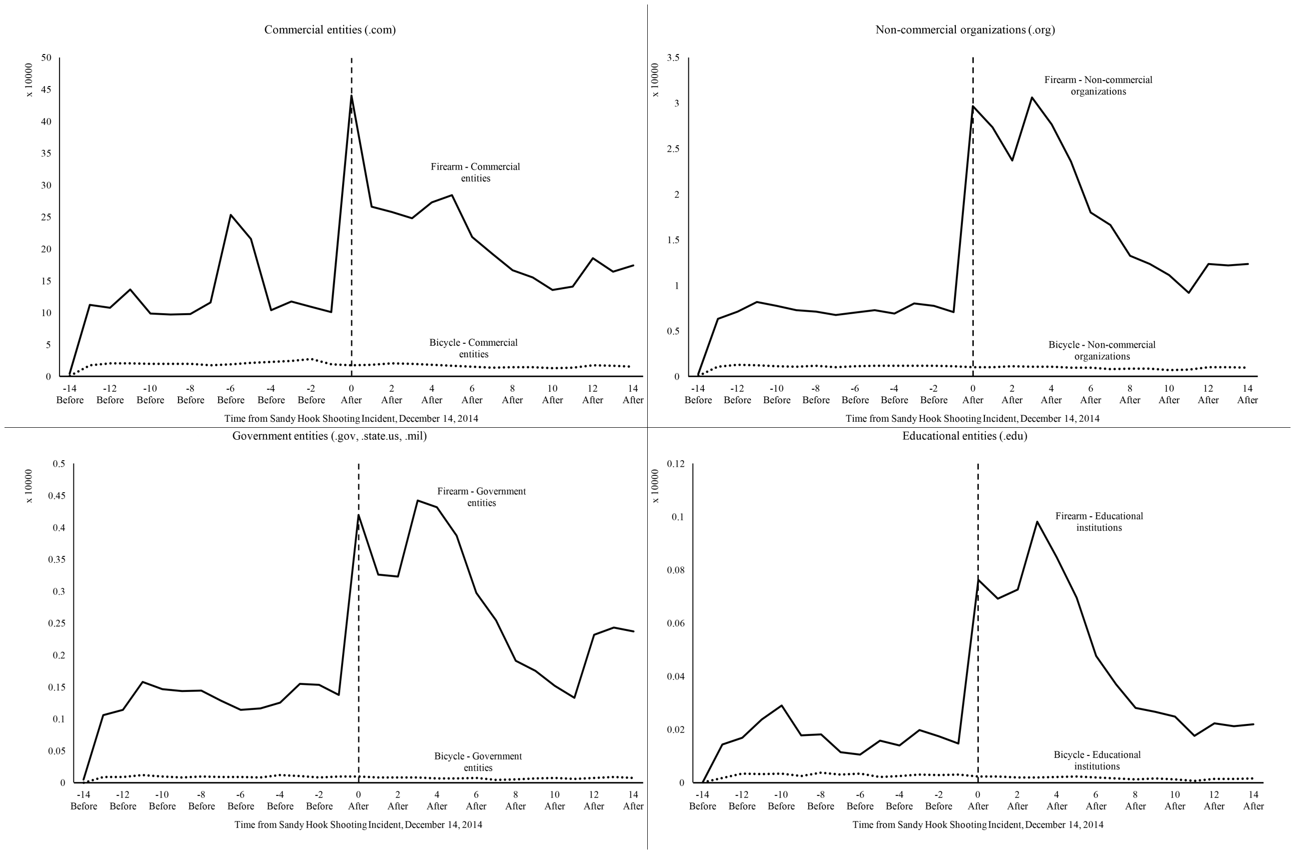
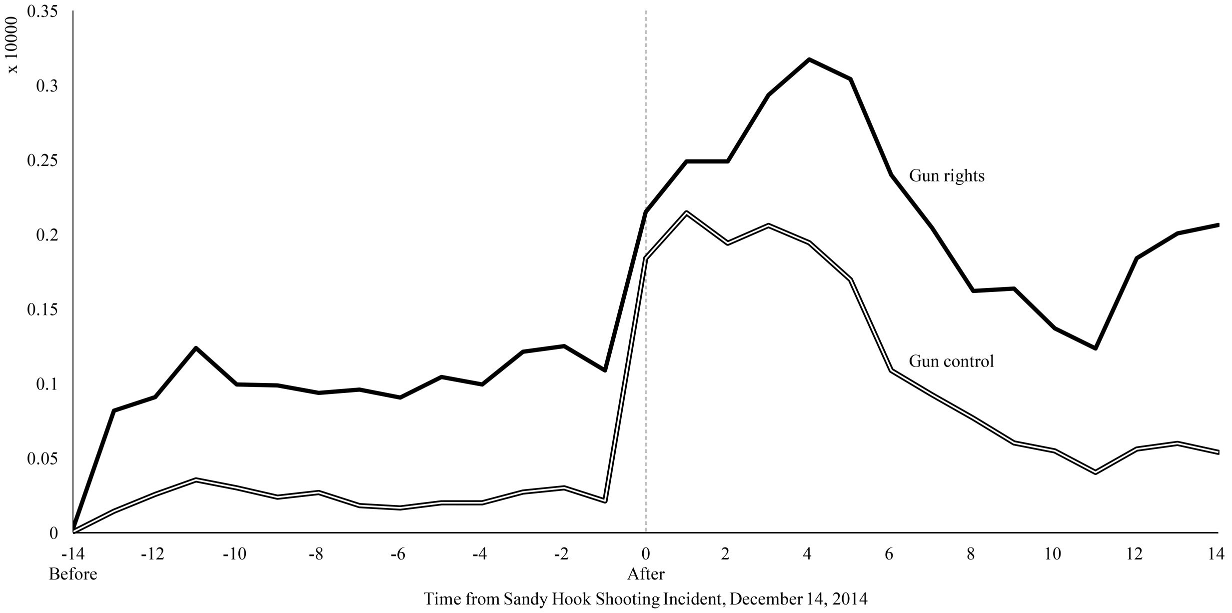


Figure 2. Trends in website visits by advocacy view. Source: Authors' analysis of Yahoo! search queries for December 2012.



Discussion

Principal Findings

One of the key findings of our analysis was that firearm-related searches more than doubled immediately after the Sandy Hook shooting incident in contrast to the control searches for "bicycle" which showed a small change with a decrease in the number of searches in the after period. This finding suggests that Web-based user search queries capture the immediate change in public interest following events of the nature of Sandy Hook shooting and can thus potentially serve as real-time indicators of the public psyche.

Overall, retail websites were the most visited websites following searches for gun types and ammunition. A salient finding was that gun type and ammunition searches had a 2-fold to 3-fold increase after the shooting incident. Furthermore, although it may seem natural to expect a greater interest in news articles following a major societal event, retail website visits had the highest and second highest increase after the shooting incident for gun type and ammunition searches, respectively. This finding may possibly be the result of a heightened interest in purchasing firearms and/or ammunition for one's protection against the apparent public safety concerns raised by the mass shooting [43]. Additionally, it is possible that some individuals may anticipate an increase in regulatory control over access to firearms as a ramification of the Sandy Hook incident and as such prompt purchase of firearms before any such legislative action is passed.

Furthermore, there was a 6-fold increase in law-related firearm queries in the period immediately after the shooting. Importantly, these were the least likely searched terms in the before period and noted the greatest percent increase in the after period. This increased interest may be due—in part —to the purchase-related search or inquiry conducted by the potential firearm and ammunition buyers discussed above, not to mention the renewed interest in the gun-policy debate after Sandy Hook. Interestingly, most users seeking law-related information were interested in educational information and chose websites of noncommercial organizations, commercial entities, or educational institutions. From the advocacy perspective, more people visited websites of gun rights groups than did the gun control groups. However, despite gun control websites forming a lower proportion of all websites supporting an advocacy stance, they experienced the greatest percent increase from before to the after period. This trend was seen in all categories of firearm-related searches, with Web traffic to gun control advocacy groups exhibiting between almost 4-fold and 6-fold increase in the after period.

In addition to the trends discussed previously, a key feature of user searches and the subsequent URL clicks was that in all categories users were far less likely to choose content from a government entity. For example, even though the majority of the law-related searches are directed toward educational content, users are more likely to choose noncommercial organizations (including gun control or gun rights advocacy groups), commercial entities, and educational institutions as their preferred sources of information. The nature of advocacy groups is such that they exist to influence stakeholder decision to align with their agenda and therefore, the resulting conflict of interest may be an impediment to providing unbiased information. Thus, it is also likely that users seeking information about gun laws may obtain this information from websites of advocacy groups.

Our analysis of user search query data presents several key implications from a policy perspective. First, as stated above, user search queries present a valuable real-time indicator of the attitudes of the population as shown by the effect of the Sandy Hook shooting incident. In fact, the spike seen 6 days before the Sandy Hook event corresponds to 2 news stories: one on December 7, when supermarket employees found a handgun in frozen meat [44] and another on December 9, when a 7-year-old boy was fatally shot in the parking lot of a gun store [45]. Similarly, the spike seen around day 12 corresponds with the much publicized advocacy speech given by a prominent American sportscaster on television [46]. These spikes highlight user search queries as a timely measure of the public's reaction to societal events. The time period immediately after a major event is characterized by heightened awareness and information-seeking behavior that may not be representative of public action during normal states (eg, buying firearms at twice the regular prices [43]). Indeed, Oh et al note that "rumormongering" is common after major societal events including shooting events [32]. On the one hand, this may indicate that policymakers should consider the timing of their actions noting that while a societal event can trigger interest in a topic, it ironically may not the best time to debate major tenets of policy change. On the other hand, some observed behavior may be due to fears arising from misinformation. For example, the increased purchase-related queries in our findings corroborate increased firearm sales due to fear of increased gun control legislation [43].

Second, it is possible that people are accessing information sources with either commercial or advocacy-related interest, at the same time being far less likely to choose content from government and educational institution websites. This may be because websites of government and educational institutions rank lower in the search results compared with those of commercial and advocacy interest groups. Although search engine optimization (SEO) may play a role in the higher ranking of commercial and advocacy interest websites, it is also possible the information presented by government and educational institutions may be less accessible. This may be due to suboptimal website design, jargon-filled language, poor SEO, lack of up-to-date information, and so on. Policy efforts should focus on providing reliable information as well as improved dissemination of this information by government institutions. Government entities may collaborate with educational institutions toward the creation of information portals focused on dissemination of accurate, timely, and high-quality information that is easy to understand. Furthermore, resources allocated toward making the public aware of these portals as well as on SEO may ensure that these websites rank higher in search results and thus visited more often.

Finally, the increased interest generated by the shooting incident appears to start tending toward normal levels around day 10, eventually returning to the levels before the shooting. This indicates that the increased interest generated due to incidents such as Sandy Hook presents a short window in which to form the public's opinion. As discussed previously, this may not present the best opportunity to engage in public debate due to the increased anxiety and fear following these events. Whether this fear was driven by the need to protect oneself or the possibility of losing the right to purchase a firearm, it is unlikely that political sentiment for policy change will be easy to accomplish when fear is driving some stakeholder's perspectives. Instead, policymakers should consider preemptively addressing some of the anticipated fears by implementing targeted campaigns that focus on specific groups of individuals. A recent US study reported that 3 percent of the US population owns nearly half of all firearms in the country with an average of 17 firearms each [43,47-49]. The median firearm ownership, however, remains at 1 to 2 firearms per owner. These individuals are likely to indulge in firearm purchases [43] after events such as the Sandy Hook shooting. Furthermore, given that personal protection against other people remains the most prevalent reason for firearm ownership in the US [47], mass shooting events may also motivate those on the fence to purchase firearms. As such, targeted campaigns that focus on these groups of individuals in order to allay fears and reduce reactionary purchase of firearms may help achieve some policymaker's goals of lower rates of firearm ownership.

Conclusions

Our findings enabled us to identify directions for future research; web browsing choices and attitudes toward firearms may be affected by numerous other factors. As such, it may be valuable to examine the differences between attitudes toward firearms based on state characteristics such as political affiliation, socioeconomic status, and gun ownership. It may also be interesting to look at ordered queries nested within each deidentified user based on the order in which the user clicked each URL to provide richer data on users' search intent. Search query data presents a valuable infodemiology metric of near real-time analysis of peoples' attitudes and responses to major societal events. We believe future studies can employ the use of other search query datasets possibly with active user participation to examine the impact of society events over a longer period of time.

Acknowledgments

This work was done when the author, Mandar Rahurkar was employed at Yahoo! Labs. The authors would like to thank Suju Rajan at Yahoo! Labs for reviewing the manuscript and supporting this research.

Conflicts of Interest

None declared.

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Abbreviations

NRA: National Rifle Association
SEO: search engine optimization
TLD: top level domain
URL: uniform resource locator

Edited by G Eysenbach; submitted 08.06.16; peer-reviewed by D Walker, Y Kwon; comments to author 04.08.16; revised version received 29.10.16; accepted 03.02.17; published 23.03.17.

Please cite as:
Menachemi N, Rahurkar S, Rahurkar M
Using Web-Based Search Data to Study the Public's Reactions to Societal Events: The Case of the Sandy Hook Shooting
JMIR Public Health Surveill 2017;3(1):e12
URL: http://publichealth.jmir.org/2017/1/e12/
doi:10.2196/publichealth.6033
PMID:28336508

Original Paper

Whiplash Syndrome Reloaded: Digital Echoes of Whiplash Syndrome in the European Internet Search Engine Context

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Abstract

Background: In many Western countries, after a motor vehicle collision, those involved seek health care for the assessment of injuries and for insurance documentation purposes. In contrast, in many less wealthy countries, there may be limited access to care and no insurance or compensation system.

Objective: The purpose of this infodemiology study was to investigate the global pattern of evolving Internet usage in countries with and without insurance and the corresponding compensation systems for whiplash injury.

Methods: We used the Internet search engine analytics via Google Trends to study the health information-seeking behavior concerning whiplash injury at national population levels in Europe.

Results: We found that the search for “whiplash” is strikingly and consistently often associated with the search for “compensation” in countries or cultures with a tort system. Frequent or traumatic painful injuries; diseases or disorders such as arthritis, headache, radius, and hip fracture; depressive disorders; and fibromyalgia were not associated similarly with searches on “compensation.”

Conclusions: In this study, we present evidence from the evolving viewpoint of naturalistic Internet search engine analytics that the expectations for receiving compensation may influence Internet search behavior in relation to whiplash injury.

(JMIR Public Health Surveill 2017;3(1):e15) doi:10.2196/publichealth.7054

KEYWORDS

search engine; whiplash injuries; legislation & jurisprudence; medicolegal aspects; compensation and redress; compensation; accidents, traffic; adult; female; humans; incidence; insurance claim reporting; male; neck pain; prognosis; search engine analytics; whiplash syndrome; Google Trends

Introduction

In many Western countries, after a motor vehicle collision, those involved seek health care for the assessment of injuries and for insurance documentation purposes. In contrast, in many less wealthy countries, there may be limited access to care and insurance may only be available to the wealthy. Against this background, the “whiplash syndrome” (ICD-10: S13.4) has been one special focus of continuous and controversial scientific research since the 1950s [1-5] (Figure 1) as the worldwide incidence of such injuries varies enormously 16-2000 per 100,000 population and the late whiplash syndrome in these cases varies between 18% to 40% [6]. Whiplash injuries are estimated to cost European society up to 10 billion euro per year [7]. Recently, and after extensive evaluation of over 1600 publications about whiplash listed in *Pubmed* [8] since 1996, the nosology of the chronic whiplash syndrome has been still classified as “doubtful” [9].

Now, 2 decades after Schrader et al’s important work in *The Lancet* showing that late whiplash syndrome after a motor vehicle collision is rare or uncommon in Lithuania [10], and Cassidy et al’s conclusion in the New England Journal of Medicine that “the elimination of compensation for pain and suffering is associated with a decreased incidence and improved prognosis of whiplash injury" [11], a new method of examining different types of "contagiosity" of diseases has evolved using the Internet search engine analytics [12-15].

According to Wikipedia, search analytics "is the use of search data to investigate particular interactions among Web searchers, the search engine, or the content during searching episodes. (...) Search analytics includes search volume trends and analysis, reverse searching (entering websites to see their keywords), keyword monitoring, search result and advertisement history, advertisement spending statistics, website comparisons, affiliate marketing statistics, and multivariate ad testing" [16]. The Internet usage especially in some European countries is presented in Table 1 [17].

Table 1. Internet usage on November 30, 2015.

Internet usage	Internet users	Penetration rate (% population)
Worldwide	3,366,261,156	46.37
Europe	604,147,280	73.54
Switzerland (CH)	7,180,749	87.18
Germany (DE)	71,727,551	88.36
Finland (FI)	5,117,660	93.53
France (FR)	55,429,382	83.82
Greece (GR)	6,834,560	63.21
Lithuania (LT)	2,399,678	82.15
United Kingdom (UK)	59,333,154	91.61

The number of Europeans using the Internet to obtain health information is significantly growing in all age groups, but there is especially strong growth among young women [18,19]. Individuals presented with chronic pain associated with whiplash injury are more likely to be female [20]. Internet search queries are exhaustively cataloged for marketing purposes by search engine providers [21]. Thus, as a "side-effect," an analysis of Internet search queries can also "detect" public interests in infectious (eg, influenza) [22] and noninfectious [23,24] diseases. In addition to gathering epidemiologic data on disease incidence and prevalence through traditional, labor-intensive processes involving large surveys, chart reviews, prospective studies, or extraction from previously created databases, Internet search trend analysis tools, since they provide self-reported information by consumers, represent a complementary source of information on a population level [25,26]. The subjectively perceived "anonymity" in using the most popular organic Internet search engine may be attractive to consumers because some diseases are burdened with a social stigma [27] or are controversial and linked to monetary [28] or secondary gain [29]. Thus, Internet search data may reduce selection bias in some aspects, even though it is equally challenging to confirm the source. At the very least, using an Internet tool, culture-related attributions can be mapped on a global population level [30].

Thus, this source has the potential to reveal epidemiologic trends and patterns in near real time and with minimal expense. The current leading Internet search engine provider is owned by Alphabet Inc (marketed as Alphabet), Google Inc, which is also the brand name of the most visited website worldwide [31]. This information is freely provided to the public through Google Trends. It is of note that globally there are at present more than 3.5 billion Google searches per day and 1.2 trillion searches per year worldwide [32].

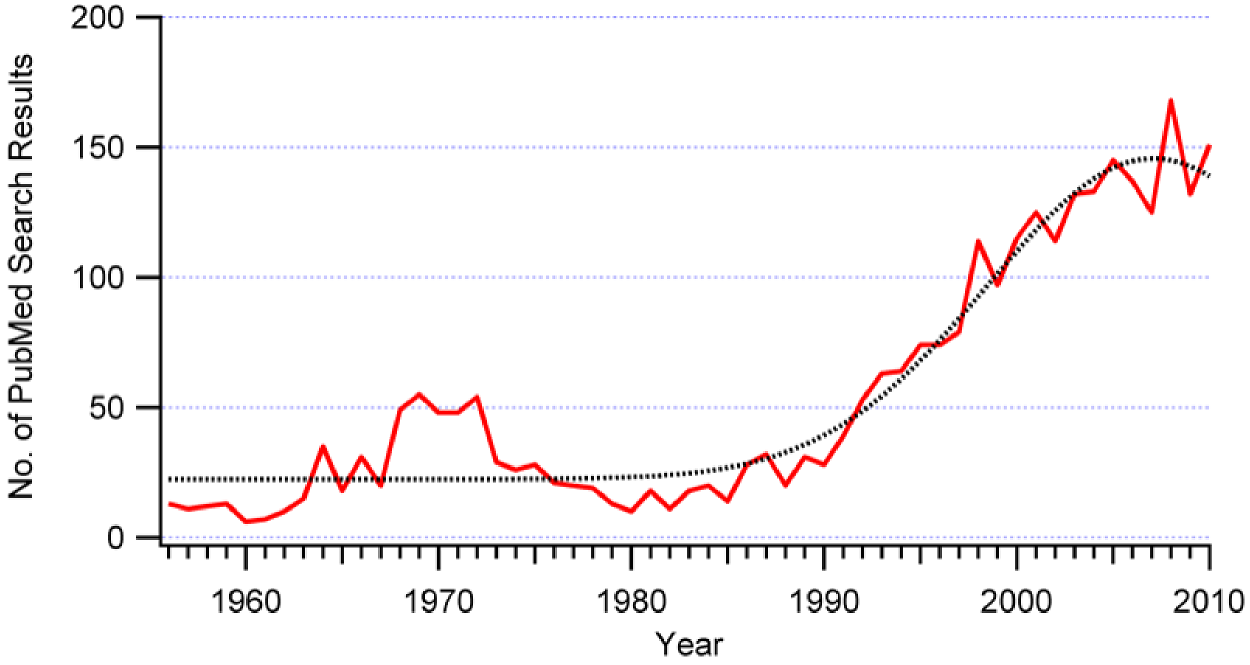
In terms of the controversial whiplash syndrome, countries in which there is an established compensation system for whiplash injury might be expected to have more Internet traffic and volume regarding whiplash injury than in countries without an established compensation system. In other words, "diverse assessments and principles for approving a claim are reflected in the fact that the prevalence of chronic spine pain after whiplash injuries (late whiplash syndrome) varies between 16% and 71% in different countries, and the proportion of whiplash injuries involved in petitions for compensation differs greatly across Europe" [33] as France and Finland [34] have the lowest and Great Britain the highest incidence of minor cervical spine trauma (eg, United Kingdom 75%, Germany 47%, Switzerland 33%, Finland 8.5%, and France 3% of all personal injuries), whereas in Greece and Lithuania whiplash injury is reported to be an almost nonexistent condition [6].

Regarding the latter, Obelieniene et al state, "Lithuania is a country in which there is no or little awareness or experience among the general population of the notion that a whiplash injury may cause chronic pain and disability. Accident victims with acute symptoms from rear end collisions generally view this as a benign injury not requiring any medical attention" [35]. Thus, it has been "hypothesized that cultural [36] and psychosocial [37-39] factors may be important in explaining why accident victims in some other societies report chronic symptoms. Such factors may include expectation of disability, symptom amplification as a result of this expectation, the effects of inappropriate therapy, insurance [40], and attribution of symptoms from nonaccident related causes (spontaneous symptoms, occupational symptoms, symptoms before an accident being amplified after an accident)"[35].

As a pilot effort, this paper deals with Google-based Internet search engine statistics on the search for "whiplash syndrome" in European countries to offer insight into both the method of

Internet-based population epidemiology in whiplash-associated disorders, and the condition itself in the context of various pain cultures and national social insurance or compensation systems [41]. Specifically, the first purpose of this infodemiology or infoveillance study was to compare the Internet search patterns in Germany and the United Kingdom, countries with established compensation systems for whiplash injury, to those used in Greece and Lithuania, countries where a system for monetary compensation for motor vehicle collision injury has not yet been established. Second, in order to validate our data, we looked for the European countries for which the lowest incidence of minor cervical spine trauma has been described, that is, Finland and France [6]. Third, we compared the “googled” whiplash data with Internet search patterns concerning frequent or traumatic painful injuries; diseases and disorders like arthritis, headache, radius, and hip fracture; depressive disorders [42]; and fibromyalgia. Finally, we wanted to test if there were hints that search engine usage may reflect national changes in the medicolegal compensation rules as has been shown for Saskatchewan, Canada, where the tort-compensation system for traffic injuries, that includes payments for health and suffering, was changed to a no-fault system in 1995, which did not include such payments, resulting in a decreased incidence and improved prognosis of whiplash injury [11]. As publicly available records of search engine analytics in Google start with 2005, we chose a similar event in Switzerland; the federal court abridged the possibilities for receiving a disability pension after whiplash injury in August 2010 [43] (modified again in 2015: DFR - BGer 9C_492/2014; 03.06.2015). In this context it is interesting to know that Switzerland has the highest expenditure per claim at an average cost of €35,000 compared with the European average of €9,000, and there are large differences between German-speaking and French- or Italian-speaking parts of Switzerland [6].

Figure 1. Number of publications on "whiplash" or "whiplash associated disorders" cited in Pubmed during the period from 1956 to 2010.



Methods

Internet Search Engine Analytics via Google Trends and the Whiplash Syndrome

In order to compare the pattern of the Internet usage surrounding whiplash injury and compensation in Germany, Finland, France, Greece, Lithiania, and the United Kingdom, we first used Google Trends to search for uncapitalized national lay terminologies related to whiplash syndrome, such as the English word “whiplash injury,” the Finnish equivalent “piiskansiima” or “piiskaniskuvammoilta vammoja,” the French equivalent “coup de fouet (cervicale)” or “coup du lapin,” the German equivalent “schleudertrauma,” the Greek “αυχενικοὐ τραυματισμοὐ,” and the Lithuanian “Bicz žalos” or “kaklo nyris” or “kaklo slankstelių trauma,” and, for a more lenient “threshold,” “kaklo skausmas” (neck pain). Then we searched for the term “injury compensation” (and the respective appropriate translations and back-translations with native speakers) in Germany, Finland, France, Greece, Lithuania, and the United Kingdom.

Then, to obtain an impression of whether or not overall Internet usage in Europe for health information was different in Finland, France, Greece, and Lithuania in general, we repeated this language-adapted assessment of Google usage for arthritis (a condition known to be associated with chronic pain) in all mentioned countries, to determine how searches for this term may have differed among Germany, France, Greece, Lithuania, and the United Kingdom. In Northern Europe, the incidence of rheumatoid arthritis, the clinically most relevant subtype of arthritis, is estimated at 20-50 cases per 100,000 population and the prevalence at 0.5-1.1%, lower incidences and prevalence have been reported in Southern Europe [44]. Moreover, as more than 50% of community-dwelling adults in Europe indicate that they suffer from headache in general during the last year or less, with most headaches more prevalent in women [45], we searched for “headache” (ICD-10: R51). Important traumatic events apart from whiplash injury are hip fracture (ICD-10: S72) and radius fracture (ICD-10: S52), which are a major public health problem in the elderly and the active younger adults, respectively [46-50]. Having said this, the incidence rates of hip fracture vary from northern to southern Europe, with the highest levels in Sweden and Norway and the lowest in France and Switzerland. The reported age-standardized annual incidence rate of hip fracture, for example, in Switzerland is 346/10,000 and 137.8/100,000 in women and men, respectively [51]. The incidence of distal radius fracture is in patients >35 years of age 0.37% in females, 0.09% in males.

Finally, we searched for “depression” (ICD-10: F32 and F33) and “fibromyalgia” (ICD-10: M97) [52-54]. According to the World Health Organization (WHO), “depression is a common mental disorder. Globally, an estimated 350 million people of all ages suffer from depression. Depression is the leading cause of disability worldwide and is a major contributor to the overall global burden of disease” [55]. The 12-month prevalence of major depression is estimated as 6.9% among all Europeans [52]. Fibromyalgia is a disorder both characterized basically by chronic widespread pain and mental symptoms like fatigue, cognitive disturbances, and other symptoms, and likewise controversially or dogmatically or ideologically discussed as (late) whiplash injury. Thus, fibromyalgia appears to be a common condition in most European countries affecting up to 2% of the general population [56-60].

The Web browser we used was Mozilla Firefox 11ff [61]. The search window in Google Trends was, where not otherwise stated, restricted to the 6-year time period between January 1, 2005 and December 31, 2010: during 2011, Google updated the categorization taxonomy and modified their geographical assignment, which may lead to contorted results — therefore we skipped the year 2011 for this analysis. Moreover, we did not want to include ongoing Google searches in 2012, as this would change the data, although we cannot guarantee that Google will or has changed the Google Trends algorithms that would affect analysis of the retrospective data shown here. Finally, all of the data presented here can be most easily validated by individually using Google Trends repeating our analysis. With regard to data consistency, all data was obtained in Germany starting in March 2012 with at least annual verifications ending in August 2016, always with continuous consistent results for the time period specified previously.

Technical Background of Internet Search Engine Analytics via Google Trends

The current world-leading search engine provider, Google Inc, provides, since August 2008, a publicly free available Internet search analytics tool based on Google search queries currently named Google Trends until September 27, 2012, known as Google Insights for Search (GIS) [62]. Google, in each case in its nationalized version, is, if uncensored, the most visited website internationally, with by far the highest market share in the search engine market in Europe [63]. For more information in the audience demographics for Google in each of mentioned countries see, for example, Alexa Internet, Inc [64].

According to information on the Google Trends website, one “can explore ‘trending stories’ in real time by category and location” using the Google Trends homepage [65]. In the appropriate frequently asked questions (FAQ) section, Google elaborates:

> *A trending story is a collection of Knowledge Graph topics, Search interest, trending YouTube videos, and/or Google News articles detected by our algorithms. Trending Stories rely on technology from the Knowledge Graph across Google Search, Google News, and YouTube to detect when topics are trending on these three platforms. The Knowledge Graph enables our technology to connect searches with real-world things and places. The algorithm for trending stories groups topics together that are trending at the same time on Google News, Google Search, and YouTube and ranks stories based on the relative spike in volume and the absolute volume of searches. (...) Google Trends analyzes a percentage of Google web searches to figure out how many searches were done over a certain period of time. Trends only analyzes data for popular terms, so search terms with low volume appear as 0, eliminates repeated searches from the same person over a short period of time, and filters out queries with apostrophes and other special characters. (...) Google Trends adjusts search data to make comparisons between terms easier. Otherwise, places with the most search volume would always be ranked highest. To do this, each data point is divided by the total searches of the geography and time range it represents, to compare relative popularity. The resulting numbers are then scaled to a range of 0 to 100. Data is relative across regions, i.e., just because two regions show the same number of searches for a term doesn't mean that their total search volumes are the same.*

The calculation of search numbers is performed using the spelling, exactly as entered, and appropriate language [66] for Google search queries over a given period of time. The data do not contain personal information. The Internet protocol (IP) addresses of the protocols establish an educated guess on the search origins. Google elaborates that the data are normalized by dividing the datasets by a common variable to remove the effect of that variable on the data. This normalization allows a comparison of the underlying dataset characteristics. Thus, this tool does not provide absolute numbers of searches but rather a relative estimation based on search activity for the time period under study [67]. The analysis can compare 5 search terms simultaneously. If Google displayed the absolute rankings, data from regions generating the most search volume would always be ranked high (for details see [22,68]). Wikipedia states that query analysis in the context of geographical and temporal parameters produces so-called “vectors,” which may partially represent the life- and interest-space of the respective searchers [69]. Separate searches in a common context are feasible in many cases, which provide more differentiated vectors. Informative relationships and common motivators can be determined using parallel search volumes and cross-comparisons, which may be profitable as forecasts and may be retrospectively instructive for both research and marketing.

“Top searches” are search terms with the most significant levels of interest. Google states: “These terms are related to the term you’ve entered; if you didn’t enter in a search term, the top searches will be related to the category or country/territory you’ve chosen. Google determines relativity by examining searches that have been conducted by a large group of users preceding the search term you’ve entered, as well as after.”

Furthermore, as “Insights for Search examines the past values for the terms you’ve entered, it can extrapolate the future values, creating a forecast of search trends for those terms. This prediction model doesn’t take into account the context of the search term or its category, nor does it account for any business cycles that may be driving a specific market (for details, see [70]).”

Finally, Google warns on their website that the analytical data provided “aims to provide insights into broad search patterns. Several approximations are used to compute these results. The Insights for Search (or Google Trends) map is intended for general analysis of volume patterns. Borders are an approximation and may not be accurate.” Thus, Google releases its own data only in an aggregated way and often without assigning absolute values, such as the number of visitors to its graphs.

Results

Main Results

A comparison of the normalized data for the countrywide Google searches revealed that Google top searches for whiplash injury in Germany and the United Kingdom showed sufficient search volume and were frequently accompanied by searches for “compensation.” In other words, the concatenation of national search interest between these 2 topics such as “whiplash injury compensation” or its German counterpart “schmerzensgeld schleudertrauma,” was apparently common (see Multimedia Appendix 1). The top searches for whiplash injury in the “health” and “law and government” category for Germany and the United Kingdom can be found in Multimedia Appendix 1, respectively. Searching for “whiplash” (without “injury”) in the United Kingdom revealed the following top searches (spelling not corrected), where 18 out of 47 or ~38% of the top search results were at least semantically associated with *compensation* (Table 2).

Table 2. Google Trends-ranked “top searches” for “whiplash” in the United Kingdom.

Rank (#)	Top searches
1	symptoms whiplash
2	whiplash injury
3	*compensation*
4	*compensation* whiplash
5	whiplash *claim*
6	whiplash injuries
7	accident whiplash
8	miss whiplash
9	whiplash *claims*
10	neck whiplash
11	*compensation* for whiplash
12	symptoms of whiplash
13	*claim* for whiplash
14	iron man whiplash
15	car accident whiplash
16	whiplash injury *compensation*
17	whiplash treatment
18	what is whiplash
19	whiplash *payout*
20	whiplash injury *claim*
21	neck pain
22	whip lash
23	whiplash injury symptoms
24	whiplash lyrics
25	whiplash injury *claims*
26	whiplash neck injury
27	neck injury
28	*claims* for whiplash
29	whiplash trash
30	whiplash *claiming* whiplash
31	whiplash scooter
32	whiplash effects
33	average whiplash *payout*
34	whiplash marvel
35	accident *claims*
36	whiplash guidelines
37	whiplash symptoms
38	symptoms for whiplash
39	whiplash monkey
40	whiplash *payouts*
41	whiplash braid
42	Berkley whiplash

Rank (#)	Top searches
43	average whiplash *claim*
44	treatment for whiplash
45	whiplash syndrome
46	*compensation* calculator
47	whiplash *compensation* uk

The mentioned combination of Google users search interest for "whiplash" with "compensation" was not detected in the nationalized search queries in Finland ("not enough search volume to show graphs"), France ("top searches: not enough search volume to show results"), Greece ("not enough search volume to show graphs"), or Lithuania ("not enough search volume to show graphs").

Searching for "compensation" under the Google category "health" in the United Kingdom revealed that "whiplash" and "whiplash compensation" where ranked third and fourth under top searches, after "injury compensation" (rank 1) and "compensation act" (rank 2). Searching in the United Kingdom for "compensation" in "all categories" revealed "whiplash" for the first time at rank 14, and searching for "compensation" in "law and government category" revealed "whiplash" at rank 8 (Multimedia Appendix 1). Searching for "injury compensation" in the Google category "health" in the United Kingdom revealed "whiplash injury" at rank 1 of concatenated top searches (Multimedia Appendix 1).

Looking for analog searches in "all categories" in Germany for "schmerzensgeld" (injury compensation) shows that "schleudertrauma" (whiplash injury) is at rank 3 of "top searches" (Multimedia Appendix 1). The differing distribution of "whiplash" in the different Google categories with respect to Germany and the United Kingdom may be due to categorization inconsistencies by Google.

However, no similar correlation could be detected for Lithuania searching for "atlyginimas už kūno sužalojimą," "žalos atlyginimas," or "žalos kompensacija," for "kipuraha+vamman korvaukset" (injury compensation) in Finland or "αποζημίωση τραυματισμών" in Greece, as these searches revealed "not enough search volume to show graphs." Searching for "indemnisation+dommages et intérêts" in France revealed the following results: "indemnisation chomage, chomage, indemnisation assedic, indemnisation accident, indemnisation maladie, indemnisation assurance, accident travail indemnisation, chomage partiel, indemnisation chomage partiel, assedic indemnisation chomage, indemnisation pole employ, indemnisation licenciement, accident du travail, (...)."

Comparison With Other Diseases

Checking for top searches in all categories for "arthritis" in Switzerland (German-speaking part of Switzerland) and Germany, "niveltulehdus" in Finland, "arthrite" in France, "αρθρίτιδα" in Greece, "artritas" in Lithuania, and "arthritis" in the United Kingdom revealed the results shown in Multimedia Appendix 1. Searching for arthritis, the Internet users were transnationally most interested in terms like arthritis symptoms or arthritis treatment. As an aside, we did not find a concatenation of top searches or rising searches of arthritis with compensation in any of the 3 countries.

Checking for top searches for "headache" in the United Kingdom, "kopfschmerzen" in Switzerland and Germany, "päänsärky" in Finland, "mal de tête " in France, "πονοκέφαλο" in Greece ("not enough search volume to show graphs"), and "galvos skausmas" in Lithuania ("not enough search volume to show results") revealed the results presented in Multimedia Appendix 1.

Checking for top searches in all categories for "hüftfraktur" (hip fracture) were done for Switzerland (German-speaking part of Switzerland) and Germany (both: "not enough search volume to show graphs"), "fracture de la hanche" in France ("not enough search volume to show results"), "lonkkamurtuman" in Finland ("not enough search volume to show graphs"), "κάταγμα ισχίου" in Greece ("not enough search volume to show graphs"), "šlaunikaulio lūžis" in Lithuania ("not enough search volume to show graphs"), and "hip fracture" in the United Kingdom (ranked geographic information system [GIS] top searches in the United Kingdom: "fracture of hip, hip fractures, neck of femur, hip replacement, hip fracture database, hip pain, hip fracture treatment, fractured hip, hip fracture guidelines, hip fracture classification, and hip fracture management").

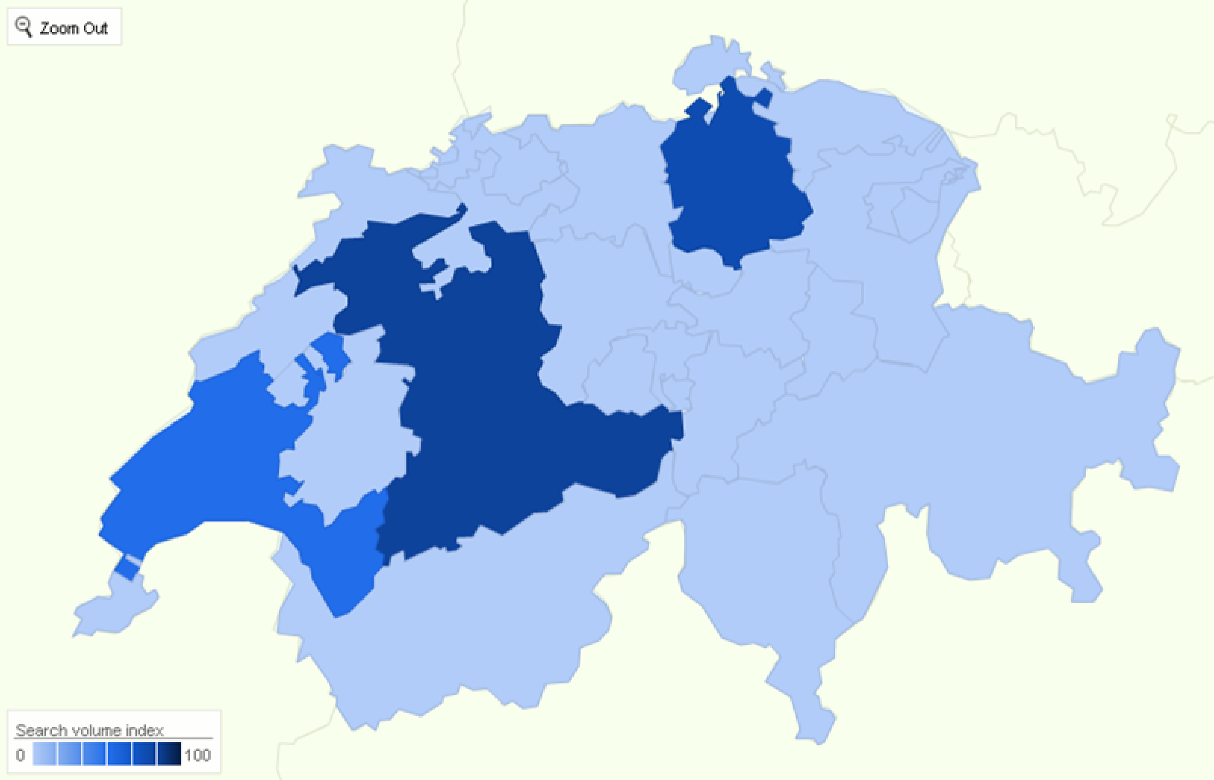
We also checked the top searches in all categories for "radius fracture" in the United Kingdom, "radiusfraktur" in Switzerland and Germany, "säde murtuma" in Finland ("not enough search volume to show results"), "fracture du radius" in France, "ακτίνα κάταγμα" in Greece ("not enough search volume to show results"), and "spindulys lūžis" in Lithuania ("not enough search volume to show results"); Multimedia Appendix 1.

We checked for top searches in all categories for "depression" in Switzerland, Germany, France, and the United Kingdom (same spelling in mentioned countries), "masennus" in Finland, "κατάθλιψη" in Greece, and "depresija" in Lithuania (we did not rule out the economic meaning of this term choosing the "health" category because this category isn't, eg, available for Lithuania) and the results are shown in Multimedia Appendix 1. Searching for depression, the Internet users were transnationally most interested in terms like "depression symptoms" or "depression tests" (Multimedia Appendix 1). As an aside, we did not find a concatenation of top searches or rising searches with "compensation" in any of the 3 countries.

We checked for "fibromyalgia" in the United Kingdom, Finland, and France, "fibromyalgie" in Switzerland and Germany, "ινομυαλγία" in Greece ("not enough search volume to show graphs"), and "fibromialgija" in Lithuania ("not enough search volume to show graphs"). Remarkably, no concatenation of "fibromyalgia" and "compensation" (or their respective translations) could be found (Multimedia Appendix 1).

Searching for "schleudertrauma+coup de fouet cervicale+coup du lapin+colpo di frusta" (German, French, and Italian search term) in the health category for Switzerland for the years 2007-2009 and 2010-2011, respectively, revealed a decline in Google search queries for "whiplash" (Figure 2).

Figure 2. Google Insights Screenshot of cumulative regional interest for "schleudertrauma+coup de fouet cervicale+coup du lapin+colpo di frusta" in Switzerland during the period from 2005 to 2010. Regional Interest (search volume) was highest in 1. Bern, 2. Zurich and 3. Vaud. Left Upper Inset: The search interest for mentioned search terms declined ~ 40% comparing the years 2007-2009 (mean: 33) with 2010-2011 (mean: 20).



Supplementary Notes

Searching for the number of advertisers for the respective national queries for "whiplash" on Alexa—the leading provider of global Web metrics—revealed that attorneys offering their assistance in law suits on personal injuries are among the top 5 in search ads for "whiplash" searches on major search engines in Germany and the United Kingdom, but not Lithuania [64].

Searching for "whiplash injury" on YouTube [71], which also belongs to Google, Inc, shows that there are about 43,700 unfiltered results (as on November 27, 2016), in which the top videos are more or less advertisements for nonevidence-based methods of "treatment" (in particular, showing the "benefits" or "secrets" of chiropractic care) and "whiplash injury compensation."

Discussion

Principal Findings

This study shows that, in general, Lithuanians, Greeks, and Finns use the Internet to search for health information on conditions such as arthritis and depression in much the same way as do those from Germany, the United Kingdom, and Switzerland. However, there is a marked difference in the patterns of searches for whiplash injury or similar terms in the two former countries and Germany, the United Kingdom, and Switzerland, countries known to have high compensation rates for whiplash injury. Searches in Germany, the United Kingdom, and Switzerland for whiplash are high ranking when one examines searches combined with terms like "compensation."

One main result is that the aforementioned combination of Google searches reflecting combined consumer interests in "whiplash injury" and "compensation" was not detected in Lithuania and other European countries (Finland, France, Greece) where cultural and psychosocial factors, including expectations, and insurance systems, have been described as significantly different from countries in which the problem of chronic whiplash is highly prevalent [72]. Actually, in Lithuania there is no formal compensation system for late whiplash injury pain and suffering, and this fact may, amongst others, influence the coping styles of the respective persons concerned [73]. Moreover, our findings reflect the low incidence of late whiplash in Finland [6,34], where total socioeconomic costs are estimated as about 1.5 million euro per annum, France [6,74], and Greece [75,76]. There has been a 70% rise in motor insurance injury claims over the 6 years leading up to 2012 in the United Kingdom, despite a 23% drop in the number of casualties actually caused by road accidents—and whiplash accounted for 70% of the total. That amounted to roughly 554,000 whiplash claims from 2010-11, that is more than 1500 claims a day. The whiplash injury costs in the United Kingdom are approximately 4.6 billion euro per annum [77]. In Germany, whiplash injury is number 1 of consequences after vehicle accidents with about 20,000 cases per year, and costs the insurance companies at least 500 million euro per annum, "official" compensation for pain and suffering due to whiplash is about 2000 euro (higher regional court (OLG) Frankfurt VRS 90, 254).

These different signs synoptically suggest that a biopsychosocial [78] understanding of chronic whiplash is important [79], especially in the "social" aspect, and the Internet is a social medium. Despite many years of research, the evidence regarding unquestionable risk factors for late whiplash is sparse but seems to include personal, societal, medicolegal, and environmental factors [80]. Against this background one should also mention an experimental study in 2001 in which participants were placed in a stationary vehicle with a curtain blocking their rear view, and exposed to a simulated rear-end collision [81]. Twenty percent of patients had symptoms at 3 days, despite the fact that no collision actually occurred [38].

Until now, the Internet search statistics [82] and social media [83] in medicine are mainly used for outbreak detection and/or the monitoring of transmissible [22,68,84,85], whereupon noninfectious diseases noticeably gain attention (eg, [86,87]). Google Insights for Search (now: Google Trends), initially developed by Google's research and development center in Israel, is the most important freely available application on the World Wide Web. These systems are growing, and they provide multifaceted information concerning old and emerging disorders [88]. This intrinsic "predictive power" is associated with the phenomena of "swarm intelligence" [89] and typical, sometimes enigmatic properties of "social networks" [90]. However, the impact and reliability of these systems on medical and public health and individual physicians is not certain [91]. Information overload [92] in times of "Health 2.0" [93], incorrect reports (as has been shown, eg, for psychological trauma-related [94]), or Web-based information on low back pain [95]), the lack of signal specificity [96], information filtered by Internet search engine providers (ie, economic [97], political or social search engine bias) [98], media or marketing [99] interest, differing search strategies (eg, [100]), misspellings, Internet availability and local specialties [101,102], age-related differences in the accuracy of Web query-based predictions [103], seasonal effects [104], problems with incidence peaks [82,105], the unforeseeable or undisclosed evolution of search algorithms or models [106], noise [107], and (last, not least) statistical issues concerning the analysis of time series [108,109] are among the manifold confounding factors that may interfere with the development and reliability of the Internet search engine analytics, even in the medical sector [91,110]. Moreover, and from a more clinical point of view, Web-based information gathering may foster greater patient engagement in health maintenance and care [111]. Conversely, there is a relationship between searching for health information on the Web and health anxiety, a phenomenon recently named "cyberchondria," which may inversely influence the health of the respective Internet searchers [112,113]. Against this background, we may have to develop feasible models and tools for consumers to assess and filter health information on the Internet [114]. It is of note that other societal factors appear to also play significant roles in the rate of development of late whiplash disorder as it has been shown that, at least within Canada, regions with similar compensation systems have large differences in rates occurrence [11].

Perspective

Future investigations will deepen our knowledge in the growing field of search engine analytics as kind of infodemiology [85,115] (or "i-epidemiology") of the worldwide social network named Internet. Google Correlate [116], for example, enables one to find queries with a similar pattern to a target data series. The target can either be a real-world trend that one provides (eg, a dataset of event counts over time) or a query that one enters. In this context, Google Correlate uses Web search activity data to find queries with a similar pattern to a target data series. The results can be viewed on the Google Correlate website or downloaded as a comma-separated values (CSV) file [117] for further analysis. In other words, Google Correlate is like Google Trends in reverse. With Google Trends, one types in a query and receives a data series of activity. With Google Correlate, one enters a data series (the target) and receives a list of queries with a data series that follows a similar pattern.

These investigations should include the evolving impact of other social media, such as "Google+," "Facebook" (eg, [118]), "YouTube" [119], "Wikipedia" [120], "Twitter" [121-124], and "IBM Watson" [125-127] on public health and reflect on the dark sides of the aforementioned developments, for example in terms of the possible impact of search engine analytics (on the companies behind them) on our privacy (eg, [128,129]). Second, the evolving contagiosity of ambient awareness, that is "awareness created through regular and constant reception, and/or exchange of information fragments through social media" (see [130]) has been neglected in public health thus far and could be a new form of "viral environment" for the upcoming generation. Finally, successful communication among health care providers and their patients from various sociocultural backgrounds depends on developing awareness of the normative cultural values of patients, how concepts of health and disease develop [131], and how these differ.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Supplementary tables S1 - S11.

[PDF File (Adobe PDF File), 172KB - publichealth_v3i1e15_app1.pdf]

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Abbreviations

CSV: comma-separated values
FAQ: freaquently asked questions
GIS: Google Insights for Search
IP: Internet protocol

Edited by G Eysenbach; submitted 27.11.16; peer-reviewed by R Ferrari, D Snider; comments to author 05.01.17; revised version received 22.01.17; accepted 20.02.17; published 27.03.17.

Please cite as:
Noll-Hussong M
Whiplash Syndrome Reloaded: Digital Echoes of Whiplash Syndrome in the European Internet Search Engine Context
JMIR Public Health Surveill 2017;3(1):e15
URL: http://publichealth.jmir.org/2017/1/e15/
doi:10.2196/publichealth.7054
PMID:28347974

Original Paper

Tweet for Behavior Change: Using Social Media for the Dissemination of Public Health Messages

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Abstract

Background: Social media public health campaigns have the advantage of tailored messaging at low cost and large reach, but little is known about what would determine their feasibility as tools for inducing attitude and behavior change.

Objective: The aim of this study was to test the feasibility of designing, implementing, and evaluating a social media–enabled intervention for skin cancer prevention.

Methods: A quasi-experimental feasibility study used social media (Twitter) to disseminate different message “frames” related to care in the sun and cancer prevention. Phase 1 utilized the Northern Ireland cancer charity’s Twitter platform (May 1 to July 14, 2015). Following a 2-week “washout” period, Phase 2 commenced (August 1 to September 30, 2015) using a bespoke Twitter platform. Phase 2 also included a Thunderclap, whereby users allowed their social media accounts to automatically post a bespoke message on their behalf. Message frames were categorized into 5 broad categories: humor, shock or disgust, informative, personal stories, and opportunistic. Seed users with a notable following were contacted to be “influencers” in retweeting campaign content. A pre- and postintervention Web-based survey recorded skin cancer prevention knowledge and attitudes in Northern Ireland (population 1.8 million).

Results: There were a total of 417,678 tweet impressions, 11,213 engagements, and 1211 retweets related to our campaign. Shocking messages generated the greatest impressions (shock, n=2369; informative, n=2258; humorous, n=1458; story, n=1680), whereas humorous messages generated greater engagement (humorous, n=148; shock, n=147; story, n=117; informative, n=100) and greater engagement rates compared with story tweets. Informative messages, resulted in the greatest number of shares (informative, n=17; humorous, n=10; shock, n=9; story, n=7). The study findings included improved knowledge of skin cancer severity in a pre- and postintervention Web-based survey, with greater awareness that skin cancer is the most common form of cancer (preintervention: 28.4% [95/335] vs postintervention: 39.3% [168/428] answered “True”) and that melanoma is most serious (49.1% [165/336] vs 55.5% [238/429]). The results also show improved attitudes toward ultraviolet (UV) exposure and skin cancer with a reduction in agreement that respondents “like to tan” (60.5% [202/334] vs 55.6% [238/428]).

Conclusions: Social media–disseminated public health messages reached more than 23% of the Northern Ireland population. A Web-based survey suggested that the campaign might have contributed to improved knowledge and attitudes toward skin cancer among the target population. Findings suggested that shocking and humorous messages generated greatest impressions and engagement, but information-based messages were likely to be shared most. The extent of behavioral change as a result of the campaign remains to be explored, however, the change of attitudes and knowledge is promising. Social media is an inexpensive, effective method for delivering public health messages. However, existing and traditional process evaluation methods may not be suitable for social media.

(JMIR Public Health Surveill 2017;3(1):e14) doi:10.2196/publichealth.6313

KEYWORDS

social media; Twitter; awareness; public heath; skin cancer; behavior change; communication

Introduction

Background

Social media is defined as “a group of Internet-based applications that build on the ideological and technological foundations of the Web 2.0, and that allow the creation and exchange of user-generated content” [1]. The considerable rise in the use of social media provides not only an opportunity to reach a large audience [2], but also access to a wealth of user data and the ability to monitor the activities of the audience whom the messages have reached, which will greatly aid our understanding of the underlying mechanisms. Social media statistics from 2015 indicate that 65% of adults are now using social networking sites [3], with more than 310 million monthly active users on Twitter [4] and 1.09 billion daily active users on Facebook [5]. Although largely used by a younger demographic, recent reports point to increased use of Facebook in those 65 years and older [6].

Social media has become ubiquitous, with more people accessing Web-based content by following links on social media than through direct searches [7]. Thus, as a platform used by the public and by health care professionals [8], it presents an ideal opportunity for health promotion. Social media also brings substantial change to the way organizations and individuals can communicate [9-10]. For example, through engaging with social media, the charity Cancer Research UK benefited from a viral social media campaign, the #nomakeupselfie [11]. The charity utilized multiple social media platforms to promote its work, answer questions, and engage in conversations with the public.

We live in a world where, due to the popularity of the smartphone, we have almost instantaneous access to a wealth of specialist information at our fingertips. There is an expectation that health information diffusion will follow suit and health care organizations are turning to social media. For example, Public Health England has responded to the changing landscape of social media and health communication by engaging with digital technologies and switching to an “always on” approach rather than traditional annual campaigns [7].

George et al [12] postulated that social media had direct public health relevance because social networks could have an important influence on health behaviors and outcomes. However, public health agencies have not yet harnessed the full potential of social media [13-14]. Chou et al [14] particularly noted the need for public health interventions to “harness the participatory nature of social media.” Heldman et al [15] proposed that public health organizations and practitioners too often used social media for the traditional 1-way broadcast of information, rather than utilizing the opportunity to engage audiences in 2-way communications, or as they call it, being “truly social.”

There is a wealth of opportunity to use social media for health promotion, through targeted messages, the ability to interact with the public, target hard-to-reach groups, and create dynamic campaigns [12,13,16-18]. Pagoto et al [19] alluded to the ability to be “in the participant’s pocket” through social media providing advice and support. Opportunities for discussion (social connection) are considered to be 14 times more effective with social media compared with the written word [20], with reports that information shared via social media resulted in greater knowledge scores than when shared via pamphlets [21]. With this lies the potential of social media to overcome barriers with regard to access to information [22] and literacy. Social media has, in essence, flattened the world with regard to health information, providing potential for building bridges between disconnected groups.

Despite a recent review alluding to a positive effect of social network interventions on health behavior-related outcomes [23], studies of social media as a channel for health promotion are limited [18]. Although social media is being increasingly used by public health departments, from a research perspective, it is not yet clear how best to capitalize on social media for raising awareness and, ultimately, triggering behavioral change. Research is lacking with regard to developing and implementing such campaigns. Nor do we know what a successful campaign entails, be that (as some have suggested) the number of followers of the campaign social media platforms, the number of retweets or shares of a given message, or simply the number of people who see a given message. It has been proposed that through surveillance of Twitter, such data can be used as a proxy measure of the success or effectiveness of a given health message or public health campaign [24]. However, we still find ourselves asking, “What makes a social media campaign successful?” Do shares or “likes” imply behavior change? In the marketing sector, it may be clearer with regard to increased sales or website clicks, but in the realm of public health, such questions remain unanswered.

As such, there have been calls for more research to focus on social media and communication technologies [25]. Given the number of unanswered questions around the feasibility of using social media for health promotion and public health, this study aims to address some of these through reporting the findings of a mass communication Twitter campaign for the prevention of skin cancer.

Aim

The aim of this study was to test the feasibility of designing, implementing, and evaluating a bespoke social media-enabled intervention for the dissemination of public health messages to prevent skin cancer.

Research Objectives

This mixed-methods study investigated the feasibility of implementing a social media–enabled public health campaign focusing on skin cancer to increase knowledge and attitudes toward care in the sun. The research had the following objectives:

- To investigate the feasibility of a bespoke social media-enabled campaign on skin cancer attitudes and knowledge
- To investigate the impact of employing different message frames on social media
- To investigate whether there are benefits to using promoted messages, influencers, and a Thunderclap for the diffusion of messages on social media
- To determine the appropriate process evaluation measures and access to data for a social media campaign (user demographic details including gender)
- To investigate whether there is an appropriate control group for a social media campaign

Methods

Why a Skin Cancer Campaign?

Skin cancer is the most common form of cancer diagnosed in Northern Ireland, with more than 4000 cases diagnosed annually [26-27]. In Australia, campaigns such as “Slip, Slap, Slop” have been run for more than two decades. Such campaigns have increased skin cancer awareness and sun-safe behaviors [28]. Nationally, Cancer Research UK have developed the “SunSmart” campaign [29], which focused on raising awareness on skin cancer through skin protection, avoiding sunburn and use of sunscreens. Regionally, the leading cancer charity in partnership with the Public Health Agency has coordinated the “Care in the Sun” campaign (which is similar in many respects to SunSmart). This study was conducted to assess baseline and post campaign levels of sun-safe knowledge, attitudes, and behavior.

To establish the baseline parameters for the campaign, we utilized a household survey based on the questions used in the SunSmart omnibus survey. A postcode stratified sample of 750 was selected based on a representative distribution across Northern Ireland. The results from the household survey demonstrated that although the majority of respondents were aware that sun exposure could cause skin cancer (80.7%, 605/750), and aware that skin cancer could lead to death (88.9%, 667/750), few were aware that skin cancer was the most common cancer and that melanoma was the most serious type (41.1%, 308/750, answered “Don’t Know”). Almost 50% of participants considered a suntan to look healthy (49.2%, 369/750) and fewer than 10% reported frequent skin checks (6.4%, 48/750). This knowledge of the known gaps in sun-safe attitudes pertaining to skin cancer evidence was the motivation for the regional Public Health Agency identifying skin cancer as a priority area for its social media campaign.

Why Twitter?

Twitter was selected as the social media platform for diffusing our campaign messages, as Twitter information is posted voluntarily and is in the public domain. Unlike other social media platforms, Twitter provides several application programming interfaces (APIs) that allow real-time access to vast amounts of content, thereby aiding our understanding of social media processes. *Adoreboard*, a University spin-out company, enabled access to Twitter streaming data, which are preprocessed to minimize “noise,” and allow maximal recovery of textual information and user metadata. Thus, the captured data are cleaned by removing unwanted messages and irrelevant tweets, which constitute noise in the message corpus. We aimed to remove tweets that did not contain the relevant hashtags of the campaign. The data cleaning process was initially simplified by the use of unique hashtags, and included the removal of blank tweets and spam tweets posted for promotion of a product or service or those automatically broadcast by robots. Preprocessing of the data still remains paramount. Thus, the setting of the message filters on the Twitter stream ensures that only the required messages are captured and analyzed.

Design

A quasi-experimental feasibility study—specifically an interrupted time series with comparison design—was implemented to assess the efficacy of the social media intervention. A “cross-over” design was utilized, whereby the regional cancer charity’s Twitter account hosted the campaign between May 1 and July 14, 2015 (Phase 1), followed by a gap of 2 weeks (“washout”), and then a phase of campaign messages posted from a new social media account between August 1 and September 30, 2015 (Phase 2). The 2 intervention phases were differentiated on the basis of the host platform to establish whether starting a new social media account would impact on message diffusion in comparison to using an already established social media account of a local cancer advocacy charity. Phase 1 was longer in duration (by 2 weeks) to account for any reduced social media interactions due to a national holiday period in early July. The protocol was developed in accordance with the CONSORT-EHEALTH checklist [30].

Control Group

Social media analytics were tracked in 2 geographical areas, through geo-location information contained within a subset of tweets: 1 area exposed to the campaign (Northern Ireland), and another area that did not receive the specific elements of the campaign; this was used as a control area for comparison (Wales). The volume of tweets related to a list of predefined keyword search terms (Multimedia Appendix 1) was compared pre-and postcampaign in order to track the messages in each location.

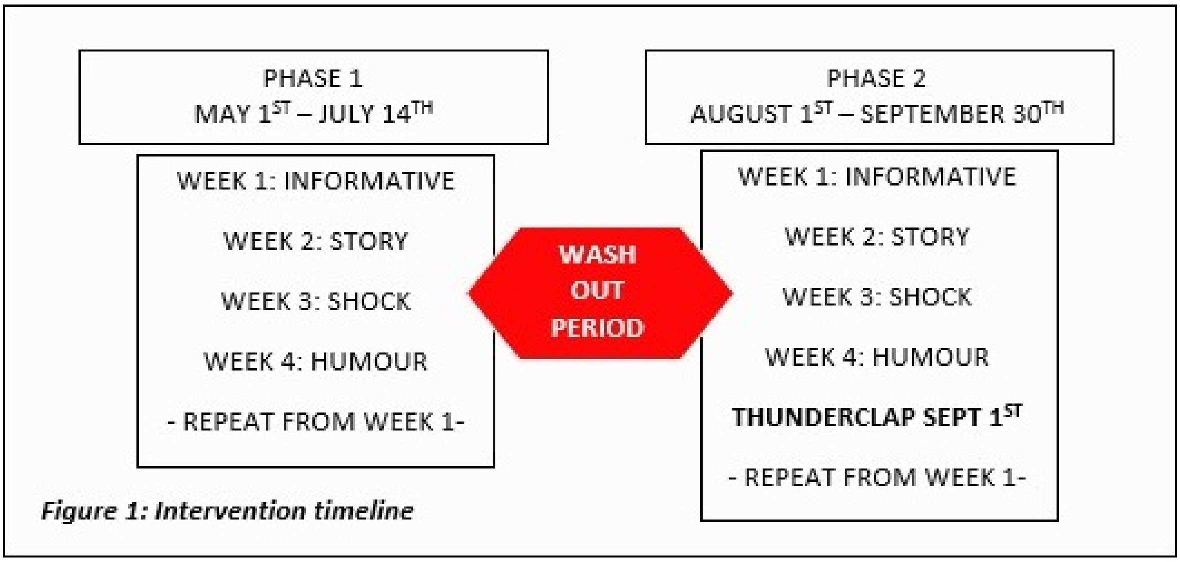
Intervention Development and Implementation

A detailed description of the intervention design can be found in Multimedia Appendix 2. During Phase 1 of the campaign (May 1 to July 14, 2015), we utilized the existing regional cancer charity Twitter account. Each week, the different message frames (informative, story, shock, humor, and a final opportunistic or responsive category) were utilized (Figure 1). Messages were focused on both skin surveillance and general care in the sun and skin cancer prevention. Seed user and opportunistic messages were utilized where appropriate.

Phase 2 of the campaign utilized a bespoke Twitter account to disseminate messages. Similar content was used for the second phase as in the first, which included both skin surveillance and general care in the sun or cancer prevention. Phase 2 also included a Thunderclap, a Web-based “flash-mob” of messages involving users to permit their social media accounts to automatically post a common message, related to the campaign, on their behalf. The Thunderclap took place on midday of September 1, 2015.

In both phases of the campaign, paid-for promoted posts on Twitter, to the value of £10, were used to enhance Web-based content by increasing the number of people who saw the messages. Promoted tweets work on a “cost per click” basis, whereby an allocated budget is set by the user (eg, £10) and that tweet is promoted to the specified audience until the budget runs out. Audiences for the promoted posts were specifically targeted to those living in Northern Ireland and aged 18 years or older.

Figure 1. Intervention timeline.



Measures

Twitter analytics for key search terms (Multimedia Appendix 1) related to skin cancer and care in the sun were collected both before and after the campaign (April 2015 and October 2015) to serve as a comparison with the control group to establish whether the campaign resulted in greater use of such search terms, in Northern Ireland, following the campaign. Throughout the campaign, social media analytics were collected from Twitter dashboards. Access to Twitter streaming data was also enabled by *Adoreboard*, a University spin-out company. The most commonly cited and readily available social media metrics collected are defined and described later [17,24,31]. Such metrics may tell us the extent to which a message spreads by detailing the number of users who see it, who respond to it, or who subsequently share that message with their friends or followers.

Impressions: The number of views of a particular post from users who saw it appearing on their timeline or through search results.

Engagements: The number of clicks on the message, the picture posted, or the number of people who actively engaged with a post including likes, comments, shares, and retweets.

Engagement rate: The ratio of engagements to impressions.

Likes: Posts can be endorsed by the friends or followers of users that post messages by “liking” them (alternatively known as “favorites” on Twitter).

Shares: Similarly readers of a post or status update who found the message interesting could also rebroadcast them by simply sharing (or retweeting) them.

Data related to social media user demographics are limited. Twitter provides limited public information about the profile of its users within the description field. Typically this does not include gender, but we subsequently aimed to infer the gender of the participants in the study based on their given names on Twitter.

Pre- and Postintervention Web-Based Survey

The Checklist for Reporting Results of Internet E-Surveys (CHERRIES) checklist for the reporting of Web-based surveys [32] was taken into account in this study (Multimedia Appendix

3). An advertisement (Multimedia Appendix 4) was placed on social media in April 2015, and again in October 2015, inviting adults aged >18 years in Northern Ireland to participate in a survey for the chance to win an iPad Mini. Those who clicked on the advertisement were redirected to a Qualtrics survey website modeled on the Cancer Research UK SunSmart survey [29]. The survey took approximately 15-20 minutes to complete. Paid-for "promoted" tweets were used to reach a wider audience. In line with recommendations from the regional cancer charity, adverts were promoted to the value of £15 on Facebook and £10 on Twitter. The sample was stratified by age and region. As an example of reach of promoted posts on Facebook, a £15 limit has the potential to reach 770-2000 people living in Northern Ireland aged 18-65+ years. The surveys consisted of 37 multiple-choice questions subdivided into 3 broad subsections: sociodemographic information; skin cancer prevention; and psycho-social mediators of behavioral change. Differences between the preintervention period and postintervention period served as an assessment of the impact of the intervention. The primary outcomes were change in sun protection attitudes and knowledge regarding skin cancer. Completed surveys, as indicated by completion of the final question, were included for analyses. IP addresses were not checked for duplicate users.

Data Analysis

Focus group and workshop discussions were audio-recorded and transcribed verbatim and anonymized. Transcripts were read repeatedly, initial codes identified, and themes collated and analyzed using an "a priori" thematic "Framework" method to produce themes related to perspectives of professionals and users [33].

Data were compared for the pre- and postintervention survey, including social media usage, demographics, and knowledge and attitudes toward UV exposure and skin cancer prevention. Descriptive statistics (frequencies) of responses to questions were tabulated, and cross-tabulations used to report responses to questions by gender, age, and other sociodemographic characteristics. Tests of significance were omitted due to the nature of the study and the appropriateness of applying such tests to feasibility studies [34].

Social media analytics were gathered for each post, for each message frame and the overall campaign, and frequencies utilized to compare impressions, engagement, and shares for message frames.

Measuring Twitter Analytics

Twitter data, collected via a service provider (Adoreboard), allowed greater access to the Twitter Firehose compared with the public APIs. The retrieved tweets and metadata were used to tabulate information such as the impressions and engagements of each tweet and to establish the frequencies of hashtag use and message spread (retweets). Metadata fields were also searched for relevant search terms (Multimedia Appendix 1) for the pre- and postcampaign frequency comparison.

Results

Can a Bespoke Social Media Campaign on Skin Cancer Impact on Attitudes and Knowledge?

Demographic Characteristics

A total of 337 participants completed the precampaign Web-based survey, compared with 429 who completed the postintervention Web-based survey (Table 1). The age distribution of participants both pre- and postcampaign was similar, with 41% of each aged 18-29 years, and respondents were more likely to be females (84.6% [281/337] preintervention; 80.4% [345/429] postintervention). Marital status and educational attainment distributions were also similar pre- and postcampaign, with more than half respondents reporting a University degree or higher (preintervention 54.6% [184/339] vs postintervention 51.5% [221/429]). More of the preintervention households reported an annual income greater than £20,001 (preintervention 52.8% [158/300] vs postintervention 40.4% [152/376]). A substantial proportion of respondents lived in Belfast (preintervention 41.9% vs postintervention 35.4%). About 15.5% of the general population of Northern Ireland lives in Belfast according to the Northern Ireland census [35].

As reported by the 2011 Northern Ireland Census [35], the population of Northern Ireland has 51% females and 49% males; thus, a greater number of females responded to both the pre- and postcampaign [36]. Campaign respondents were more educated than the Northern Ireland population (29% aged 16+ years had no qualifications) and were of a similar age (2011 Northern Ireland Census median age, 37 years).

Table 1. Respondent demographic characteristics in the pre- and postintervention Web-based surveys.

Demographic characteristics		Precampaign (n=337)	Postcampaign (n=429)
Age (year)		35.6	35.2
Gender, n (%)			
	Male	51 (15.4)	84 (19.6)
	Female	281 (84.6)	345 (80.4)
Marital status, n (%)		n=33	n=429
	Single	150 (44.5)	182 (42.4)
	Married or cohabiting	161 (47.8)	224 (52.2)
	Divorced or widowed	26 (7.7)	23 (5.4)
Highest level of education, n (%)		n=339	n=429
	None	13 (3.9)	11 (2.6)
	GCSE or equivalent	37 (11.0)	41 (9.6)
	“A” level or equivalent	103 (30.6)	156 (36.4)
	Degree or higher	184 (54.6)	221 (51.5)
Housing tenure, n (%)		n=336	n=429
	Rent or other	134 (39.9)	162 (37.8)
	Mortgage or co-ownership	150 (44.6)	189 (44.1)
	Owned outright	52 (15.5)	78 (18.2)
Annual income, n (%)		n=300	n=376
	<£12,000	77 (25.8)	105 (27.9)
	£12,001 to £20,000	64 (21.4)	119 (31.6)
	>£20,001	158 (52.8)	152 (40.4)

Attitudes to UV Exposure and Skin Cancer Prevention

Postcampaign, there was a trend toward improved attitudes toward UV exposure and skin cancer with a reduction in agreement that respondents “like to tan” (pre- 60.5% [202/334] vs postcampaign 55.6% [238/428]), that “a tanned person looks more healthy” (55.9% [186/333] vs 52.7% [225/427]) or attractive (48.6% [162/333] vs 43.7% [186/426]). The postcampaign also noted a trend toward improved attitude to UV exposure, with greater agreement that protection from the sun can help avoid skin cancer (62.6% [209/334] vs 65.0% [278/428]). Trends in change of care in the sun attitudes are shown in Table 2.

Table 2. Trends in change of care in the sun attitude and knowledge.

Trends		Precampaign	Postcampaign
Care in the sun attitude			
I like to tan, n (%)		n=334	n=428
	Agree	186 (60.5)	238 (55.6)
	Neutral	66(19.8)	98 (22.9)
	Disagree	66 (19.8)	92 (21.5)
A suntanned person looks more healthy, n (%)		n=333	n=427
	Agree	186 (55.9)	225 (52.7)
	Neutral	74 (22.2)	102 (23.9)
	Disagree	73 (21.9)	100 (23.4)
If I protect myself from the sun I can avoid skin cancer, n (%)		n=334	n=428
	Agree	209 (62.6)	278 (65.0)
	Neutral	41 (12.3)	68 (15.9)
	Disagree	84 (25.1)	82 (19.2)
Care in the sun knowledge			
Sun exposure causes most skin cancers, n (%)		n=336	n=428
	True	269 (80.1)	346 (80.8)
	Don’t Know	46 (13.7)	49 (11.4)
	False	21 (6.3)	33 (7.7)
Skin cancer is the most common form of cancer, n (%)		n=335	n=428
	True	95 (28.4)	168 (39.3)
	Don’t Know	133 (39.7)	166 (38.8)
	False	107 (31.9)	94 (22.0)
Melanoma is the least serious form of skin cancer, n (%)		n=336	n=429
	True	35 (10.4)	36 (8.4)
	Don’t Know	136 (40.5)	155 (36.1)
	False	165 (49.4)	238 (55.5)

Knowledge of Skin Cancer Prevention

Postintervention there was a trend toward improved knowledge of skin cancer prevention (Table 2), with greater awareness that skin cancer is the most common form of cancer (28.4% [95/335] vs 39.3% [168/428] answered “True”) and that melanoma is most serious (49.1% [165/336] vs 55.5% [238/429]). There was also a trend toward improved awareness that sun’s rays are strongest at midday (91.3% [306/335] vs 93.5% [400/428]) and that people with fair-colored skin require the most protection (73.8% [248/336] vs 77.6% [332/428]).

Campaign Reach

Influence of Message Frames on Social Media

Of the 4 specific message frames utilized (informative; personal story; shock or disgust; humorous), a shock or disgust tweet (#eek) achieved the most impressions (n=2369), followed by an informative message (#info, n=2258; Table 3). The most engaging tweet was that with humor (#geg, n=148), followed by 1 characterized by shock or disgust (#eek; n=147). The most retweeted message was that of an informative nature (#info), shared by 17 followers. The most retweeted #story message was shared 7 times, compared with 9 for #eek and 10 for #geg messages. When comparing the median values for each message frame, shocking messages achieved greater impressions (median 565), engagements (15.5), and retweets (2.5), whereas humor messages achieved a greater median engagement rate (2.5%).

Are There Benefits to Using Promoted messages, Influencers, and a Thunderclap for the Diffusion of Messages on Social Media?

Influencers

Tweets that included an influencer in the message generated greater numbers of impressions. Influencer posts also created the most impressions when on a #eek post (n=11,349) and a #story post (n=9612). Tweets that were paid-for—promoted posts—did not notably increase impressions, engagements, or retweets. Table 3 shows the top Twitter analytics for each message frame.

Opportunistic Messages

Considering messages that were of an opportunistic nature, the greatest number of impressions for a single message was 2993, whereas the greatest number of engagements on an opportunistic tweet was 103. The greatest number of retweets for an opportunistic message was 8.

Thunderclap

The campaign Thunderclap had a minimum goal of 100 supporters (in order for the Thunderclap to activate), and achieved a total of 122 supporters and social reach of 454,207 (sum total of the friends and followers of campaign supporters). Top tweets mentioning or encouraging support for the Thunderclap achieved 2527 impressions, 2 engagements, and 7 retweets. Thunderclap-related tweets, which included an influencer in the tweet, achieved greater numbers of impressions (n=11,740) than Thunderclap tweets that did not (n=2527).

What Are Appropriate Process Evaluation Measures?

Twitter Analytics

During the campaign period, there was a total of 417,678 tweet impressions based on the campaign (Table 3). Post engagements reached 11,213, and there was a total of 1211 retweets. Of these, 92 retweets were part of the Thunderclap. A single tweet achieved 11,349 impressions. The same tweet was the most engaging, resulting in 811 engagements. The most retweets on any 1 post was 17.

Table 3. Twitter analytic attributes for message frames.

Message frames		Impressions (median)	Engagement (median)	Engagement rate in % (median)	Retweet (median)
All tweets					
	All tweets	6367	196	14.8	17
	+ Influencer	11349	811	12.0	13
	+ Promoted	4808	304	11.5	12
Info (informative)					
	Info	2258 (443.0)	100 (8.0)	8.3 (2)	17 (2)
	+ Influencer	3161	106	8.1	7
	+ Promoted	2335	98	4.2	13
Story (personal story)					
	Story	1680 (390.5)	117 (6.5)	3.6 (1.3)	7 (1)
	+ Influencer	9612	52	3.0	5
	+ Promoted	1210	19	7.0	3
Eek (shock or disgust)					
	Eek	2369 (565.0)	147 (15.5)	10.1 (2.2)	9 (2.5)
	+ Influencer	11349	811	7.1	11
	+ Promoted	2655	301	11.5	5
Geg (humorous)					
	Geg	1458 (487.0)	148 (12.0)	14.8 (2.5)	10 (2)
	+ Influencer	1459	21	5.7	2
	+ Promoted	4808	67	1.4	11
Opportunistic					
	Opportunistic	2993 (385)	103 (5)	8.40 (1.5)	8 (1)
	+ Influencer	10674	211	12.00	12
	+ Promoted	6367	196	4.60	14
Influencer					
	Influencer	11349	811	12.00	11
	+Promoted	2110	76	11.50	4
Thunderclap					
	Thunder	2527	2	4.80	7
	+ Influencer	11740	3	7.80	6
	+Promoted	135	3	2.20	0

Is There an Appropriate Control Group for a Social Media Campaign?

A search for keywords relating to sun exposure and skin cancer, geo-tagged to NI, returned 15,964 and 14,168 tweets for April and October 2015, respectively (Multimedia Appendix 1). For Wales, 50,164 and 51,634 tweets were returned for April and October 2015, respectively (The population of Northern Ireland is 1.8 million, while that of Wales is 3.0 million). Comparing the total key words retrieved for an Northern Ireland geo-located word search with that of Wales in the pre- and postcampaign period, postcampaign there was an increase in those geo-located to Wales whereas there was a decrease in those geo-located to

NI. However, our designated campaign hashtags did not appear among the key word seaerch retrieved from Wales.

Discussion

Principal Findings

The aim of this study was to develop, implement, and evaluate a social media public health campaign. In doing so, we sought to uncover the feasibility of using social media (Twitter) for the dissemination of public health messages, to investigate the impact and appropriateness of different message frames, promotion techniques, and evaluation measures. Our findings suggested that social media was indeed a feasible platform for the delivery of a public health campaign.

Investigating the Impact of a Bespoke Social Media Campaign on Skin Cancer Attitudes and Knowledge

Social media is a feasible platform for the dissemination of public health messages owing to the ability to provide dynamic and tailored messages to an audience in real time. The results from the pre- and postcampaign Web-based survey showed a trend toward improvements in both knowledge and attitudes with improved awareness that sun protection can reduce skin cancer risk and greater awareness of the severity of skin cancer. The results of Web-based surveys have to be interpreted cautiously [37-38], as they cannot serve as accurate indices of overall population knowledge about public health issues. Nevertheless there is probably greater correspondence between the characteristics of respondents to Web-based surveys and those of social media users, who are the natural target of a social media campaign, than is the case with traditional respondents to face-to-face household surveys.

Investigating the Impact of Employing Different Message Frames on Social Media

Message frames with shocking (#eek) content generated the greatest number of impressions, whereas humorous (#geg) messages resulted in greater public engagement on social media, compared with personal story messages. Message framing on social media has been the topic of much debate in the research literature. The idea of gain-framed versus loss-framed messages to encourage illness prevention behaviors has been explored in relation to skin cancer prevention, with mixed results. Gallagher and Updegraff [39] found that gain-framed messages were more likely than loss-framed messages to encourage skin cancer prevention behaviors, whereas others found no difference [40]. Moreover, graphic warning messages, like some used in this study, have been shown to be more effective in promoting behavioral change, particularly related to tobacco use, as they attract attention and evoke emotion and motivation to quit [41,42]. For example, some work has employed graphic content and message framing for skin cancer prevention and indoor tanning [42] while others [43] appropriated negative emotions to generate discussion. It has been postulated that exposure to negative emotions may affect risk perceptions and thus talking about them can serve as a means of dealing with such emotions [43,44].

Previous work has highlighted the role of fear-based approaches related to public health campaigns [45-46] in raising awareness by attracting attention, much like this study, which found that more impressions were evident from “shocking” messages tweeted. With fear-based approaches too comes the possibility of unintended effects such as dissonance or desensitization, as alluded to by Cho and Salmon [47]. However, a recent work from Bail [48] found that positive emotional content increased the virility of messages used for a social media Facebook campaign. Bail [48] suggests that social media campaigns must not rely on fear-based tactics to draw attention to their cause, but that campaigns may benefit from the use of positive emotional language. The use of humor in public health messages for behavioral change has been explored [31. Through use of a “Laugh Model,” the authors sought to learn from business, marketing, and branding strategies in order to prioritize the use of humor and entertainment in health promotion messages. They implemented a social media campaign to promote healthy family meals in the Utah region, with humor and entertainment underpinning the campaign. The campaign was deemed to be successful in reaching 10%-12% of the target population, achieving 17,377 Facebook impressions, 28,800 Twitter impressions, and 5591 Web-based engagements. The population of Utah is 2.9 million, and their Twitter impression and engagement rates were thus 0.01/100,000 and 0.002/100,000, respectively, compared with 0.22/100,000 and 0.006/100,000 in this campaign. The authors found their humorous posts to be most successful, with an engagement rate of 9.7%, suggesting that such engaging techniques might be more effective than educational techniques. In line with the Laugh Model [31], a humorous message in this study achieved the greatest engagement rate, reaching 14.8%.

Twitter users have a variety of motivations for re-Tweeting. Ramdhani [49] suggested that the motivating factors included self-enhancement, social interaction, personal benefit and appreciation, and (through humor), entertainment. Ramdhani [49] also noted that providing information was of little importance as a motivating factor. However, in this study, the most retweeted message was that of an informative nature. Kandadai et al [50] noted that users were selective in determining what to retweet, and when the information was deemed valuable and credible, it was shared. The psychology of sharing has recently been explored in a study among 2500 Web-based users of the New York Times [51], which found that the most common reasons for people to share material with others across social media were to provide entertainment (94%), spread the word about a cause or issue they care about (84%), as a method of “information management” allowing them to process information more thoroughly when sharing it (73%), and self-fulfillment (69%). Future qualitative work would be required to tease out the motives of social media followers in choosing which health messages to retweet. Moreover, it would be advantageous for message types to be rated by social media users in order to ensure consistency with regard to categorization assigned by the research team.

Investigating Whether There Are Benefits to Using Promoted Messages, Influencers, and a Thunderclap for the Diffusion of Messages on Social Media

Promoted Messages

Although Lister et al [31] used paid posts to increase the number of followers and website traffic, this study did not find value in the use of paid-for, promoted tweets. Actually overall, promoted posts resulted in fewer impressions and retweets than both "organic posts" and those that included an influencer. However, promoted posts had the potential advantage of targeting specific groups, by location, age, gender, interest, and so forth. As this study had quite a broad target audience of adults (+18 years) living in Northern Ireland, future studies and interventions with a more specific target may see greater benefit from using promoted posts.

Influencers

Based on the feedback from the focus groups and "co-design" workshops, we included the use of "influencers" or seeds and a unique hashtag for the social media campaign. By doing so, there was suggestive evidence in this study that the number of impressions and engagements was greater where influencers were utilized (Table 3). This was in line with the recommendations from the Social Bakers blog ("What we can learn from the top 2 Twitter accounts") [52], which included working with viral influencers, the use of a unique hashtag. It is not surprising that greater impressions result from influencer posts because they tend to have large numbers of followers. However, following Ramdhani's [49] and Bret's [51] findings related to motives for tweeting, the selection of influencers is of utmost importance. Thus, rather than selecting influencers based on their large following, to drive post impressions, further thought should be given to the influencer's social media "tone of voice" and whether the intervention messages are in line with the influencer's and their following. Ultimately this may help a given message reach an audience primed to engage with the content.

The problem of identifying the most influential users in social networks has been considered by many studies. The most common factors that have been considered as indicators of user's influence in social media are the number of followers, the number of friends, the number of days that the user exists on Twitter, the number of tweets posted by the user in the past, or the number of times the user was mentioned in the past [53]. More empirical research is required to measure the influence of a user based on his past activities [54] (ie, how many users he influenced in the past conversations).

The purpose of using influential users in the campaign was to increase the impact of the messages, so that more people might engage with the conversation. In social media the impact of a message is determined by how well the message propagates in the network. This is commonly referred to as information diffusion. A number of ways of assessing information diffusion has been considered in different studies. The most common way of quantifying the diffusion of a message in a network is through the volume of users influenced by the message [55-58]. Influenced users (often referred to as activated users) are those who engaged with a post through liking, commenting, sharing, or retweeting. Studies have evaluated the diffusion of a tweet through its retweetability (ie, the length of the retweet chain) [55,58]. According to Wang et al [59], a message tends to propagate better if not only your friends, but also friends of friends, are getting involved in the conversation. Therefore, the number of friendship hoops that a message has traveled was taken under consideration while assessing the information diffusion.

Lots of work has been focused on the challenge of predicting diffusion of a message in social media. The relation between the influence of a user and the information diffusion has been investigated in a number of studies. The factor that is most commonly applied to estimate the level of user's influence is the number of his or her followers. It has been demonstrated that there is a correlation between the number of followers and the length of the retweet chain [55]. The study by Yang and Counts [56] suggested that the number of times a user has been mentioned in the past is a good predicator of the number of his or her followers who might be influenced. Other studies have focused on developing predictive models for information diffusion using machine learning-based approaches. Naveed et al [58], for example, built a predictive retweet model using logistic regression. They used some of the aforementioned user-related features with additional features related to the content of the tweets (eg, whether the message contains a uniform resource locator, hashtag, or mention). Hong et al addressed the problem of predicting the popularity of a tweet (ie, number of retweets) by formulating it as a classification problem [60]. Instead of predicting the exact number of retweets, each tweet was assigned to a category representing an estimated volume of retweets. Another approach to modeling the information diffusion was presented by Yang and Leskovec [61], where the number of newly influenced users was modeled as a function of which other users were influenced in the past. Wang et al [59] proposed an alternative model that was able to predict the density of influenced users over time based on how well the message spread in the early phase.

These machine learning approaches highlight a number of interesting ideas that can be applied in future social media campaigns, suggesting that there are methods that can be used to automate and enhance campaign assessment processes. Both identifying the most influential users in the network and predicting the propagation of messages could be used to increase the impact of a social media campaign. The results of this study indicate that using influencers as seeds increases the number of impressions and engagements. At the same time, we noticed that the level of influence differed among different seed users. Therefore, it could be beneficial to consider factors other than the number of followers while selecting the seed users for the campaign. Using some of the predictive models described earlier could help in the assessment of the propagation of the messages that could be used as the predicator of the campaign's impact.

Thunderclap

The Thunderclap campaign exceeded its target of reaching 100 supporters, (and achieved a total of 122 supporters). This target was somewhat arbitrary but exceeded the number achieved by previous campaigns of the Regional Public Health Agency. The Thunderclap required users to pledge their support and thus allow a bespoke campaign message to be posted from their chosen social media account, resulting in widespread social reach with more than 450,000 people seeing the campaign message. Thus, a Thunderclap is a useful tool for spreading awareness provided it is utilized correctly, and adequately promoted and explained prior to launch. Thus, it is important to ensure awareness among users and actively pledge support by following the Thunderclap link, rather than simply retweeting or "liking" the message advertising the Thunderclap.

The scheduling of campaign messages was informed by both the focus groups and availability of the host's (a regional cancer charity) social media accounts. Messages were posted between 3 and 4 days per week on Twitter, with the same message (or minor variations of the same message) posted up to 4 times in a day at different times. Moz Blog [62], in 2012, reported that the average lifespan of a tweet was 18 minutes, for accounts with fewer than 1000 followers, and that although retweets extended the lifespan, most retweets happened in the first 7 minutes of a message being posted. Such detailed analysis was beyond the scope of this study; however, we did observe that the greatest lifespan of 1 of our tweets was 64 days (ie, there was a retweet 64 days following the original tweet). Increasing numbers of social media marketing tools have appeared in recent years, and future work may benefit from utilizing such applications. Such tools include Twitalyzer for Twitter or Likealyzer for Facebook, which offer more than is available from the traditional social media platform dashboard analytics, including recommendations for the best times to publish social media posts, whether users respond more to photos or videos, and ranking comparisons to similar social media profiles. Future work should therefore attempt to capitalize on such resources. Moreover, in this study, it may be possible that greater tweeting frequency of content further instilled the message to users or provided opportunity to reach different social media users at various time points. However, on the contrary, the increased volume of content may, as has been suggested [63], inadvertently decrease the perceived importance of the content, particularly as "shares" were few in this study. Thus, a "less is more" approach may be beneficial if the aim is to achieve shareable content and subsequent message diffusion.

Determining the Appropriate Process Evaluation Measures and Access to Data for a Social Media Campaign

This study utilized commonly cited and most readily available Twitter analytics to evaluate the campaign: impressions, engagements, likes, and shares. Although such markers are commonly used in the literature [17,24,31], one might contest their appropriateness as evaluation measures for a public health campaign [64]. Although measures such as impressions are useful in determining how many users see a given message, and retweets in determining the number who share such messages with friends or followers, it may not be appropriate to infer specific meanings from such actions. Does liking or retweeting a message infer that the user supports the campaign message or wants their friends to be aware of such advice or will indeed take heed of the message and act on such advice—or example in our case—to apply sunscreen? It would be naive to infer that they are good barometers of impending behavioral change.

Thus, with calls specifically for eHealth interventions across the board and particularly with regard to melanoma [65], new research methods for social media are needed, perhaps through the adaptation of traditional methods. For example, this study delivered its Web-based survey via social media. Moreover, applications of traditional methods (to inform the design of search terms) for social media are beginning to emerge, such as the use of netnography, a fusion of ethnography with Internet analytics [66]. Crowdsourcing and photo and video elicitation techniques may also be adapted for social media to gain a deeper understanding of perceptions, attitudes, and behavioral change.

Investigating Whether There Is an Appropriate "Control Group" for a Social Media Campaign

This feasibility study was unable to ascertain an appropriate "control group" for a social media–enabled public health intervention. Wales was chosen as a "control group" for the campaign. However, with the use of our specific hashtags, we did not expect any impact or social media footprint in Wales and we found virtually none. For a campaign based around behavior in the sun, clearly local geography and weather conditions are likely to have an impact on message reach and engagement. Although there are bound to be very local variations, Northern Ireland and Wales "enjoy" broadly the same weather, and so we anticipated that social media traffic in Wales could tell us something about the background influence of these weather effects. Moreover, although weather data was collected for Northern Ireland throughout the campaign period, stronger associations between weather and retweets emerged during Phase 2 of the campaign. This was at a time frame that was closer to the "peak" of summer in Northern Ireland. However, during the summer of 2015, Northern Ireland experienced one of the coldest, wettest summers in approximately 30 years, and so any conclusions must be tentative.

Although this study identified the appropriateness of social media for a public health campaign, the challenge is to find how to transfer traditional evaluation principles into the world of social media. Innovative methods are emerging with regard to social media. An instrumental variable approach to study happiness and weather effects has also been reported [67]. Techniques are also emerging to better measure and assess the effects on sentiment in social media through the use of "emoji" [68]. With few studies having examined the success of social media to promote knowledge and adoption of health behaviors [69], there is room for methodological innovation because traditional randomized controlled trial methods and process evaluation measures (MRC Guidance) have little to say on social media interventions.

This study sought guidance from a statistician to determine the best course of action for handling Twitter data. Traditional statistical analyses may not be appropriate given the clustered and dependent nature of tweets. The results of this study should be considered within the context of other limitations. Although a shocking tweet (#eek) achieved the greatest number of impressions, this was likely driven by the associated "influencer" because median impressions for tweets were substantially less. Nonetheless, taking median values, shocking tweets achieved most impressions. Moreover, tweet content was determined by the research team and verified by participants at a codesign workshop. Future work would benefit from an assessment of content agreement when determining message frames applied to tweets. For example, what was considered to be a humorous message by the research team may be deemed as shocking to another user.

The National Institute for Health and Care Excellence guidelines for sunlight exposure [70] were updated after the completion of this intervention, and its recommendations essentially echoed what this work sought to achieve. The campaign was delivered in a way to meet the target audience needs via social media, developed and piloted with the target audience, and integrated with existing local promotion programs. Twitter, as a vehicle for dissemination and as an opportunity to reach new audiences, is endorsed by The Centers for Disease Control and Prevention [71]; however, fundamental challenges remain. Although respondents to our Web-based surveys were similar to those to the household survey, Twitter users are not representative of the general offline population. There are also ethical and privacy issues surrounding social media and Twitter that have not yet been tackled head on by most public health agencies [72]. For example, difficulties may arise in reporting content, as Tweets can be searched, thus increasing the potential for subjects to be identified [73]. It is not clear to what extent publicly available social media data can be regarded as "public," and as such, "concerns over consent, privacy and anonymity do not disappear simply because subjects participate in Web-based social networks; rather, they become even more important" [74,75]. Issues involving informed consent to social media research have also arisen. For example, Kramer et al's [75] work utilizing Facebook caused expressions of concern from publishers over principles of informed consent. A number of bodies are developing guidelines and protocols for corporate use of social media. Indeed the *Journal of Medical Internet Research* has produced a special issue on "Ethics, Privacy, and Legal Issues" [76], but clear guidance is required whether public health research is to harness its full potential.

Limitations

This study has generated a number of hypotheses that require testing in a larger, definitive trial. However, a number of limitations have been identified from this study. The issue of contamination across phases remains a key methodological concern in social media research. Future research should seek to employ a phase-based pre-post design and analysis with adequate wash-out period. Another potential threat to the validity of this study, and indeed social media research in general, relates to the unrepresentativeness of the Twitter population. Given the limited social media traffic and interaction with the campaign, our findings should be interpreted with caution. Although we targeted some different types of influencers to aid engagement and reach of the campaign, there were limitations in terms of their number of followers and their overall engagement with the campaign, and therefore these findings too should be interpreted with caution.

Acknowledgments

The intervention was funded by the Medical Research Council, Public Health Intervention Development scheme, and implemented in collaboration with the Northern Ireland Public Health Agency and the largest regional cancer charity in Northern Ireland, Cancer Focus NI. This work was supported by the Centre of Excellence for Public Health (Northern Ireland), a UKCRC Public Health Research Centre of Excellence. RFH was funded by a Career Development Fellowship from the National Institute of Health Research (NIHR). Approval was sought and granted by the Research Ethics Committee of the School of Medicine, Dentistry and Biomedical Sciences, Queen's University Belfast, Northern Ireland (Ref 14/55).

Conflicts of Interest

None declared.

Multimedia Appendix 1

Word searches.

[PDF File (Adobe PDF File), 24KB - publichealth_v3i1e14_app1.pdf]

Multimedia Appendix 2

Intervention development.

[PDF File (Adobe PDF File), 194KB - publichealth_v3i1e14_app2.pdf]

Multimedia Appendix 3

Checklist for Reporting Results of Internet E-Surveys (CHERRIES).

[PDF File (Adobe PDF File), 56KB - publichealth_v3i1e14_app3.pdf]

Multimedia Appendix 4

Survey advertisement on Twitter.

[PDF File (Adobe PDF File), 160KB - publichealth_v3i1e14_app4.pdf]

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Abbreviations

UV: Ultraviolet
CHERRIES: Checklist for Reporting Results of Internet E-Surveys

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Edited by G Eysenbach; submitted 08.07.16; peer-reviewed by C Giraud-Carrier, H Yang, TR Soron; comments to author 04.08.16; revised version received 17.10.16; accepted 21.01.17; published 23.03.17.

Please cite as:
Gough A, Hunter RF, Ajao O, Jurek A, McKeown G, Hong J, Barrett E, Ferguson M, McElwee G, McCarthy M, Kee F
Tweet for Behavior Change: Using Social Media for the Dissemination of Public Health Messages
JMIR Public Health Surveill 2017;3(1):e14
URL: http://publichealth.jmir.org/2017/1/e14/
doi:10.2196/publichealth.6313
PMID:28336503

Original Paper

HIV Care and Viral Suppression During the Last Year of Life: A Comparison of HIV-Infected Persons Who Died of HIV-Attributable Causes With Persons Who Died of Other Causes in 2012 in 13 US Jurisdictions

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Abstract

Background: Little information is available about care before death among human immunodeficiency virus (HIV)–infected persons who die of HIV infection, compared with those who die of other causes.

Objective: The objective of our study was to compare HIV care and outcome before death among persons with HIV who died of HIV-attributable versus other causes.

Methods: We used National HIV Surveillance System data on CD4 T-lymphocyte counts and viral loads within 12 months before death in 2012, as well as on underlying cause of death. Deaths were classified as “HIV-attributable” if the reported underlying cause was HIV infection, an AIDS-defining disease, or immunodeficiency and as attributable to “other causes” if the cause was anything else. Persons were classified as “in continuous care” if they had ≥2 CD4 or viral load test results ≥3 months apart in those 12 months and as having “viral suppression” if their last viral load was <200 copies/mL.

Results: Among persons dying of HIV-attributable or other causes, respectively, 65.28% (2104/3223) and 30.88% (1041/3371) met AIDS criteria within 12 months before death, and 33.76% (1088/3223) and 50.96% (1718/3371) had viral suppression. The percentage of persons who received ≥2 tests ≥3 months apart did not differ by cause of death. Prevalence of viral suppression for persons who ever had AIDS was lower among those who died of HIV but did not differ by cause for those who never had AIDS.

Conclusions: The lower prevalence of viral suppression among persons who died of HIV than among those who died of other causes implies a need to improve viral suppression strategies to reduce mortality due to HIV infection.

(JMIR Public Health Surveill 2017;3(1):e3) doi:10.2196/publichealth.6206

KEYWORDS

HIV; AIDS; causes of death; care

Introduction

As human immunodeficiency virus (HIV)–infected persons are surviving to older ages, the spectrum of causes of death among them is changing—the proportion of deaths in which HIV infection was the underlying cause has decreased, while the proportion of deaths due to causes not clearly attributable to HIV has increased [1-3]. Retention in medical care and effective treatment to achieve a suppressed viral load are essential to reduce morbidity and mortality, as well as the potential for onward transmission of the virus [4]. However, little information is available about care and outcomes before death among persons living with HIV who eventually died of either HIV-attributable or other causes. Assessment of predeath care by cause of death can inform opportunities for intervention. This study is an update on a recent study that examined HIV care within the year before death [5]. We expanded the investigation to compare HIV-infected persons who died of an HIV-attributable underlying cause with those who died of another underlying cause with respect to (1) disease stage within 12 months before death and (2) measures of care in terms of frequency of CD4 T-lymphocyte counts or viral load measurements and viral suppression.

Methods

All US states and the District of Columbia require reporting of cases of HIV infection to their health departments; however, not all have mandatory reporting of all values of CD4 T-lymphocyte cell counts and viral load test results by laboratories. We used data reported to the National HIV Surveillance System (NHSS) of the Centers for Disease Control and Prevention through July 2015 from 13 jurisdictions with mandated laboratory reporting of all results from HIV-related tests to their HIV surveillance programs and that also collected cause of death information (California, District of Columbia, Hawaii, Iowa, Louisiana, Maryland, Michigan, Missouri, New Hampshire, New York, South Carolina, Texas, West Virginia). The analysis was restricted to persons who died in 2012, were ≥13 years old at the time of death, and resided in the selected areas at both diagnosis and death. The purpose of the residential restriction was to enhance the completeness of data on laboratory test results, because laboratories report test results to the health departments of the jurisdictions corresponding to the patient's residential address reported by the health care provider. Among the health departments of these 13 jurisdictions, at least 85% of the deaths they reported to NHSS had data on the underlying cause, which they obtained by linking HIV surveillance data with either state or local vital records data or the National Death Index. The health departments reported the data to NHSS without key personal identifiers (eg, name, Social Security number) that they used to link HIV cases to death records and laboratory test results. Causes of death were identified by codes in the *International Classification of Diseases, Tenth Revision (ICD-10)* [6]. We classified a death as "HIV-attributable" if the reported underlying cause was HIV infection, indicated either explicitly (by an ICD code for HIV infection itself) or implicitly (by an ICD code for an AIDS-defining opportunistic illness or immunodeficiency—cell-mediated or unspecified type, not an antibody-mediated or congenital type). We assumed HIV infection was underlying an opportunistic illness or immunodeficiency because all the decedents had HIV infection reported to NHSS, even if HIV was not mentioned on the death certificate. If the underlying cause was known but was not HIV infection, we classified the death as "non–HIV-attributable death" (and the underlying cause as "other" than HIV infection; Multimedia Appendix 1). Persons missing information on underlying causes of death were excluded from the analyses. Stage of disease was based on the most recent CD4 cell count or percentage, and was defined in a reversible way, so that a person whose HIV disease had previously met the criteria for stage 3 (AIDS) could be reclassified in stage 1 if the most recent CD4 cell count was ≥500 cells/µL [7]. Persons were considered to be "in care" within 12 months before death if they had ≥1 CD4 or viral load test result in that period and "in continuous care" if they had ≥2 CD4 or viral load test results at least 3 months apart within the last 12 months before death [8]. Viral suppression (defined as <200 copies/mL) was based on the most recent viral load in the 12 months before death.

We assessed indicators overall and by sex, age, race/ethnicity, and transmission category (male-to-male sexual contact, ie, men who had sex with men or MSM; injection drug use; MSM and injection drug use; heterosexual contact; and other). We also determined care and viral suppression by disease severity (whether a person's infection had ever been classified as stage 3 disease, AIDS), the length of time since diagnosis of HIV infection, and urban versus rural area of residence at the time of diagnosis (metropolitan statistical area population ≥500,000; metropolitan statistical area population 50,000-499,999; and nonmetropolitan population <50,000). Using log-binomial regression, we calculated prevalence ratios and 95% CIs to determine statistical differences on measures of care between persons who died of HIV-attributable underlying causes and those who died of non–HIV-attributable underlying causes. To control for potential confounding covariates, the analyses were adjusted for sex, age at death, race/ethnicity, transmission category, and ever AIDS. Analyses were adjusted for missing risk factor information. Analyses were performed using SAS version 9.3 statistical software (SAS Institute Inc), with the GenMod procedure for the log-binomial regression.

Results

Among 6594 persons who died in 2012 with diagnosed HIV infection, 48.88% (3223/6594) died of HIV-attributable underlying causes and 51.12% (3371/6594) died of non–HIV-attributable underlying causes. Of those who died of HIV-attributable causes, most were male (2374/3223, 73.66%) and ≥40 years old at death (2673/3223, 82.94%); their racial/ethnic distribution was 47.35 % (1526/3223) non-Hispanic black or African American, 23.30% (751/3223) non-Hispanic white, 22.25% (717/3223) Hispanic or Latino, and 7.11% (229/3223) other; 40.80% (1315/3223) were MSM (Table 1). Among those who died of non–HIV-attributable causes, most were male (2493/3371, 73.95%) and ≥40 years old at death (3064/3371, 90.89%); their racial/ethnic distribution was 45.57% (1536/3371) non-Hispanic black or African American, 29.01% (978/3371) non-Hispanic white, 18.30% (617/3371) Hispanic or Latino, and 7.12% (240/3371) other; 36.78% (1240/3371) were MSM (Table 2). Overall, the percentage of persons with late-stage disease (stage 3, AIDS, based on the most recent indicator, ie, CD4 test or opportunistic illness diagnosis) in the 12 months before death was more than twice as great among persons who died of HIV-attributable causes (65.28%, 2104/3223; Table 1) as among persons who died of non–HIV-attributable causes (30.88%, 1041/3371; Table 2). The percentage with stage 3 disease was similarly higher in almost all demographic groups and transmission categories of persons who died of HIV-attributable causes than in their counterparts who died of other causes.

Table 1. Most recent stage of disease within 12 months before death, among persons aged ≥13 years who died of HIV-attributable causes in 2012, in 13 US jurisdictions.

Decedent characteristics	Most recent stage[a] of disease before HIV-attributable death[b]									
	Total		Stage 1 (CD4[c]≥500 cells/µL or ≥29%)		Stage 2 (CD4 200-499 cells/µL or 14%-28%)		Stage 3 (AIDS; OI[d] or CD4<200 cells/µL or <14%)		Unknown	
	n	%[e]	n	%[f]	n	%[f]	n	%[f]	n	%[f]
Total	3223	100	244	7.6	542	16.8	2104	65.3	333	10.3
Sex										
Male	2374	73.7	175	7.4	394	16.6	1543	65.0	262	11.0
Female	849	26.3	69	8.1	148	17.4	561	66.1	71	8.4
Age (years) at death, year-end 2012										
13-29	154	4.8	7	4.5	18	11.7	121	78.6	8	5.2
30-39	396	12.3	8	2.0	40	10.1	321	81.1	27	6.8
40-49	914	28.4	58	6.3	112	12.3	666	72.9	78	8.5
50-59	1107	34.3	90	8.1	201	18.2	681	61.5	135	12.2
≥60	652	20.2	81	12.4	171	26.2	315	48.3	85	13.0
Race or ethnicity										
American Indian or Alaska Native	2	0.1	0	0	0	0	2	100	0	0
Asian	20	0.6	0	0	1	5.0	17	85.0	2	10.0
Black or African American	1526	47.3	112	7.3	239	15.7	1030	67.5	145	9.5
Hispanic or Latino[g]	717	22.2	43	6	124	17.3	483	67.4	67	9.3
Native Hawaiian or other Pacific Islander	3	0.1	0	0	0	0	2	66.7	1	33.3
White	751	23.3	74	9.9	143	19.0	432	57.5	102	13.6
Multiple races	204	6.3	15	7.4	35	17.2	138	67.6	16	7.8
Transmission category[h]										
Male-to-male sexual contact (MSM[i])	1315	40.8	98	7.4	216	16.4	854	65.0	148	11.2
Male injection drug use	513	15.9	43	8.3	86	16.8	333	64.7	52.7	10.3
Female injection drug use	305	9.5	26	8.5	63	20.5	189	61.8	28	9.2
MSM[i] and injection drug use	251	7.8	19	7.6	48	19.2	154	61.4	30	11.8
Male heterosexual contact	271	8.4	12	4.4	42	15.4	188	69.3	30	10.9
Female heterosexual contact	521	16.2	42	8.0	81	15.4	359	68.9	40	7.6
Other	47	1.4	6	11.8	7	15.3	28	60.9	6	12.0
Ever AIDS										
Yes	2946	91.4	171	5.8	448	15.2	2104	71.4	223	7.6
No	277	8.6	73	26.4	94	33.9	0	0	110	39.7

[a] Stage of disease within 12 months before death based on most recent CD4 test performed.

[b] HIV-attributable deaths were those for which HIV infection, AIDS-indicative opportunistic illness, or immunodeficiency was the underlying cause.

[c] CD4: CD4$^+$T-lymphocyte count (cells/µL) or percentage.

[d] OI: opportunistic illness (ie, AIDS-defining condition).

[e] Column percent.

[f] Row percent.

[g] Hispanic or Latino can be of any race.

[h] Data on transmission category statistically adjusted to account for missing transmission category.

[i] MSM: men who had sex with men.

Table 2. Most recent stage of disease within 12 months before death, among persons aged ≥13 years who died of non–HIV-attributable causes in 2012.

Decedent characteristics	Most recent stage[a] of disease before non–HIV-attributable death[b]									
	Total		Stage 1 (CD4[c]≥500 cells/µL or ≥29%)		Stage 2 (CD4 200-499 cells/µL or 14%-28%)		Stage 3 (AIDS; OI[d] or CD4<200 cells/µL or <14%)		Unknown	
	n	%[e]	n	%[f]	n	%[f]	n	%[f]	n	%[f]
Total	3371	100	686	20.4	987	29.3	1041	30.9	657	19.5
Sex										
Male	2493	74.0	482	19.3	741	29.7	782	31.4	488	19.6
Female	878	26.0	204	23.2	246	28.0	259	29.5	169	19.2
Age (years) at death, year-end 2012										
13-29	74	2.2	16	21.6	17	23.0	20	27.0	21	28.4
30-39	233	6.9	55	23.6	55	23.6	77	33.0	46	19.7
40-49	786	23.3	163	20.7	208	26.5	264	33.6	151	19.2
50-59	1292	38.3	259	20	393	30.4	416	32.2	224	17.3
≥60	986	29.2	193	19.6	314	31.8	264	26.8	215	21.8
Race or ethnicity										
American Indian or Alaska Native	2	0.1	0	0	0	0	1	50.0	1	50.0
Asian	17	0.5	3	17.6	7	41.2	5	29.4	2	11.8
Black or African American	1536	45.6	294	19.1	452	29.4	481	31.3	309	20.1
Hispanic or Latino[g]	617	18.3	105	17.0	196	31.8	218	35.3	98	15.9
Native Hawaiian or other Pacific Islander	3	0.1	1	33.3	0	0	2	66.7	0	0
White	978	29	230	23.5	262	26.8	264	27.0	222	22.7
Multiple races	218	6.5	53	24.3	70	32.1	70	32.1	25	11.5
Transmission category[h]										
Male-to-male sexual contact (MSM[i])	1240	36.8	263	21.2	371	29.9	373	30.1	234	18.8
Male injection drug use	677	20.0	110	16.3	202	29.9	226	33.5	138	20.4
Female injection drug use	397	11.8	85	21.3	121	30.5	112	28.2	79	20.0
MSM[i] and injection drug use	287	8.5	56	19.6	85	29.5	94	32.8	52	18.1
Male heterosexual contact	273	8.1	52	19.1	76	27.8	85	31.1	60	22.0
Female heterosexual contact	471	14.0	118	24.9	122	26.0	143	30.4	88	18.8
Other	27	0.8	3	11.7	11	39.6	7	26.7	6	22
Ever AIDS										
Yes	2564	76.1	401	15.6	779	30.4	1041	40.6	343	13.4
No	807	23.9	285	35.3	208	25.8	0	0	314	38.9

[a] Stage of disease within 12 months before death based on most recent CD4 test performed.

[b] Non–HIV-attributable deaths were all deaths for which the underlying cause was known other than those for which the underlying cause was HIV disease, an AIDS-indicative opportunistic illness, or immunodeficiency.

[c] CD4: CD4$^+$T-lymphocyte count (cells/µL) or percentage.

[d] OI: opportunistic illness (ie, AIDS-defining condition).

[e] Column percent.

[f] Row percent.

[g] Hispanic or Latino can be of any race.

[h] Data on transmission category statistically adjusted to account for missing transmission category.

[i] MSM: men who had sex with men.

Overall, 91.34% (2944/3223) and 82.74% (2789/3371) of persons who died of HIV-attributable or non–HIV-attributable causes, respectively, had care within 12 months before death (≥1 CD4 or viral load test; Table 3). The percentage of persons who received continuous care (≥2 CD4 or viral load tests, 3 months apart) was similar among persons who died of HIV-attributable and non–HIV-attributable causes (66.15%, 2132/3223 and 65.89%, 2221/3371, respectively; Table 4). The percentage of persons with viral suppression was substantially lower among those who died of HIV-attributable causes (33.76%, 1088/3223) than among those who died of non–HIV-attributable causes (50.96%, 1718/3371; adjusted prevalence ratio 0.69, 95% CI 0.65-0.73; Table 4). Prevalence of viral suppression for persons who ever had stage 3 (AIDS) was lower among those who died of HIV but did not differ by cause of death for persons who never had stage 3 (AIDS).

The percentages with ≥1 CD4 or viral load test was ≥74% for most demographic groups and transmission categories but somewhat lower for persons who never had stage 3 disease (AIDS; 69.0%, 191/277 and 64.7%, 522/807 among persons who died of HIV-attributable and non–HIV-attributable causes, respectively) and persons whose diagnosis of HIV infection was ≤12 months before their death due to non–HIV-attributable causes (67.8%, 124/183).The percentage of persons with viral suppression was lower in most demographic and behavioral groups of persons who died of HIV-attributable causes than in their counterparts of persons who died of other causes.

Most persons in this study had HIV infection diagnosed more than 5 years before death (2368/3223, 73.47% and 2762/3371, 81.93% among those who died of HIV-attributable and non–HIV-attributable causes, respectively; Table 3).

Table 3. Care and viral suppression within 12 months before death, among persons aged ≥13 years, comparing those who died of HIV-attributable causes with those who died of non–HIV-attributable causes in 2012, in 13 US jurisdictions: “in care” (≥1 CD4 or viral load test).

Decedent characteristics	Total		≥1 CD4 or VL[a] test						Unknown if had CD4 or VL test			
	HIV deaths[b]	Non-HIV deaths[c]	HIV deaths		Non-HIV deaths		APR[d]	95% CI[e]	HIV deaths[b]		Non-HIV deaths[c]	
	n	n	n	%	n	%			n	%	n	%
Total	3223	3371	2944	91.3	2789	82.7	1.05	1.03-1.06	279	8.7	582	17.0
Sex												
Male	2374	2493	2159	90.9	2060	82.6	1.05	1.03-1.07	215	9.1	433	17.4
Female	849	878	785	92.5	729	83.0	1.05	1.02-1.09	64	7.5	149	17.0
Age (years) at death, year-end 2012												
13-29	154	74	146	94.8	55	74.3	1.02	0.92-1.14	8	5.2	19	25.7
30-39	396	233	371	93.7	193	82.8	1.02	0.97-1.07	25	6.3	40	17.2
40-49	914	786	848	92.8	655	83.3	1.06	1.03-1.10	66	7.2	131	16.7
50-59	1107	1292	999	90.2	1095	84.8	1.03	1.00-1.06	108	9.8	197	15.2
≥60	652	986	580	89.0	791	80.2	1.09	1.05-1.13	72	11.0	195	19.8
Race or ethnicity												
Black or African American	1526	1536	1397	91.5	1254	81.6	1.05	1.02-1.08	129	8.5	282	18.4
Hispanic or Latino[f]	717	617	661	92.2	529	85.7	1.04	1.00-1.08	56	7.8	88	14.3
White	751	978	671	89.3	790	80.8	1.07	1.03-1.11	80	10.7	188	19.2
Other races	229	240	215	93.9	216	90.0	1.02	0.97-1.07	14	6.1	24	10.0
Transmission category[g]												
Male-to-male sexual contact (MSM[h])	1315	1240	1198	91.1	1041	84.0	1.03	1.01-1.06	117	8.9	199	16.0
Male injection drug use	513	676	470	91.6	548	81.1	1.08	1.03-1.12	43	8.4	128	18.9
Female injection drug use	305	397	281	92.0	327	82.2	1.08	1.02-1.14	24	7.9	70	17.6
MSM[h] and injection drug use	251	287	225	89.6	240	83.7	1.05	0.98-1.12	26	10.4	47	16.4
Male heterosexual contact	271	273	246	90.6	215	79.1	1.06	1.00-1.12	25	9.2	58	21.2
Female heterosexual contact	521	471	486	93.2	394	83.6	1.04	0.99-1.08	35	6.7	77	16.3
Other	47	27	39	83.9	23	85.3	0.93	0.77-1.12	8	17.0	4	14.8
Ever AIDS												
Yes	2946	2564	2753	93.4	2267	88.4	1.05	1.03-1.06	193	6.6	297	11.6
No	277	807	191	69.0	522	64.7	1.05	0.96-1.16	86	31.0	285	35.3
Time since HIV diagnosis												
≤12 months	450	183	410	91.1	124	67.8	1.34	1.21-1.49	40	8.9	59	32.2
13-24 months	108	93	100	92.6	77	82.8	1.12	1.00-1.24	8	7.4	16	17.2
3-5 years	297	333	281	94.6	251	75.4	1.26	1.17-1.34	16	5.4	82	24.6
More than 5 years	2368	2762	2153	90.9	2337	84.6	1.07	1.04-1.09	215	9.1	425	15.4
MSA[i] at diagnosis												
MSA (population ≥500,000)	2688	2937	2468	91.8	2445	83.2	1.05	1.03-1.07	220	8.2	492	16.8
MSA (population 50,000-499,999)	397	337	352	88.7	268	79.5	1.07	1.01-1.13	45	11.3	69	20.5
Nonmetropolitan area (population <50,000)	128	81	115	89.8	66	81.5	0.98	0.91-1.05	13	10.2	15	18.5

Decedent characteristics	Total		≥1 CD4 or VL[a] test						Unknown if had CD4 or VL test			
	HIV deaths[b]	Non-HIV deaths[c]	HIV deaths		Non-HIV deaths		APR[d]	95% CI[e]	HIV deaths[b]		Non-HIV deaths[c]	
	n	n	n	%	n	%			n	%	n	%
Unknown	10	16	9	90.0	10	62.5	-		1	10.0	6	37.5

[a] VL: viral load (copies/mL).

[b] HIV deaths (HIV-attributable deaths) were those for which HIV infection, AIDS-indicative opportunistic illness, or immunodeficiency was the underlying cause of death.

[c] Non-HIV deaths (non–HIV-attributable deaths) were all other deaths for which the underlying cause was known.

[d] APR: adjusted prevalence ratio, adjusted for sex, age at death, race/ethnicity, transmission category, and ever AIDS.

[e] CI: confidence interval

[f] Hispanic or Latino can be of any race.

[g] Data on transmission category have been statistically adjusted to account for missing transmission category.

[h] MSM: Men who had sex with men.

[i] MSA: metropolitan statistical area.

Table 4. Care and viral suppression within 12 months before death, among persons aged ≥13 years, comparing those who died of HIV-attributable causes with those who died of non–HIV-attributable causes in 2012, in 13 US jurisdictions: "in continuous care" (≥2 CD4 or viral load tests at least 3 months apart).

Decedent characteristics	≥2 CD4 or VL[a] test at least 3 months apart						VL <200 copies/mL					
	HIV deaths[b,j]		Non-HIV deaths[c,j]		APR[d]	95% CI[e]	HIV deaths[b,j]		Non-HIV deaths[c,j]		APR[d]	95% CI[e]
	n	%	n	%			n	%	n	%		
Total	2132	66.1	2221	65.9	0.96	0.92-0.99	1088	33.8	1718	51.0	0.69	0.65-0.73
Sex												
Male	1532	64.5	1642	65.9	0.93	0.89-0.97	843	35.5	1324	53.1	0.69	0.64-0.74
Female	600	70.7	579	65.9	0.99	0.93-1.06	245	28.9	394	44.9	0.69	0.61-0.79
Age (years) at death, year-end 2012												
13-29	97	63.0	41	55.4	0.94	0.72-1.23	34	22.1	20	27.0	1.12	0.60-2.09
30-39	248	62.6	129	55.4	0.99	0.86-1.15	69	17.4	98	42.1	0.42	0.32-0.56
40-49	607	66.4	497	63.2	0.97	0.90-1.04	284	31.1	361	45.9	0.67	0.59-0.76
50-59	750	67.8	888	68.7	0.95	0.90-1.00	396	35.8	672	52.0	0.66	0.60-0.73
≥60	430	66.0	666	67.5	0.95	0.88-1.01	305	46.8	567	57.5	0.8	0.73-0.89
Race or ethnicity												
Black or African American	1055	69.1	987	64.3	1.01	0.96-1.06	453	29.7	678	44.1	0.71	0.64-0.78
Hispanic or Latino[f]	464	64.7	459	74.4	0.89	0.83-0.96	245	34.2	353	57.2	0.63	0.56-0.72
White	458	61.0	600	61.3	0.97	0.90-1.05	309	41.1	559	57.2	0.72	0.65-0.80
Other races	155	67.7	175	72.9	0.9	0.80-1.00	81	35.4	128	53.3	0.7	0.57-0.87
Transmission category[g]												
Male-to-male sexual contact (MSM[h])	813	61.8	806	65.0	0.9	0.85-0.96	456	34.7	696	56.1	0.65	0.59-0.71
Male injection drug use	362	70.6	459	68.0	1.01	0.94-1.08	202	39.4	349	51.6	0.78	0.69-0.89
Female injection drug use	230	75.3	268	67.5	1.05	0.96-1.16	94	30.7	181	45.5	0.72	0.59-0.88
MSM[h] and injection drug use	171	68.2	199	69.3	0.95	0.84-1.06	92	36.7	161	56.2	0.66	0.54-0.81
Male heterosexual contact	171	63.3	167	61.2	0.95	0.84-1.08	82	30.3	109	40.0	0.79	0.62-1.00
Female heterosexual contact	354	68.0	303	64.4	0.95	0.87-1.04	142	27.3	209	44.5	0.65	0.54-0.78
Other	30	65.2	18	65.6	0.86	0.63-1.18	19	41.7	13	48.7	1.08	0.61-1.94
Ever AIDS												
Yes	1986	67.4	1848	72.1	0.94	0.91-0.98	970	32.9	1395	54.4	0.66	0.62-0.71
No	146	52.7	373	46.2	1.13	0.99-1.29	118	42.6	323	40.0	1.05	0.90-1.23
Time since HIV diagnosis												
≤12 months	116	25.8	48	26.2	0.97	0.73-1.30	80	17.8	31	16.9	0.89	0.59-1.34
13-24 months	75	69.4	66	71.0	0.99	0.80-1.22	39	36.1	46	49.5	0.68	0.47-0.98
3-5 years	193	65.0	181	54.4	1	0.88-1.14	103	34.7	139	41.7	0.9	0.72-1.12
More than 5 years	1748	73.8	1926	69.7	1.02	0.99-1.06	866	36.6	1502	54.4	0.71	0.67-0.76
MSA[i] at diagnosis												
MSA (population ≥500,000)	1816	67.6	1977	67.3	0.96	0.93-1.00	941	35.0	1520	51.8	0.7	0.66-0.75
MSA (population 50,000-499,999)	230	57.9	189	56.1	0.95	0.83-1.08	108	27.2	144	42.7	0.69	0.56-0.86
Nonmetropolitan area (population <50,000)	79	61.7	47	58.0	0.9	0.72-1.11	36	28.1	48	59.3	0.43	0.31-0.60

Decedent characteristics	≥2 CD4 or VL[a] test at least 3 months apart						VL <200 copies/mL					
	HIV deaths[b,j]		Non-HIV deaths[c,j]		APR[d]	95% CI[e]	HIV deaths[b,j]		Non-HIV deaths[c,j]		APR[d]	95% CI[e]
	n	%	n	%			n	%	n	%		
Unknown	7	70.0	8	50.0	-		3	30.0	6	37.5	-	

[a] VL: viral load (copies/mL).

[b] HIV deaths (HIV-attributable deaths) were those for which HIV infection, AIDS-indicative opportunistic illness, or immunodeficiency was the underlying cause of death.

[c] Non-HIV deaths (non–HIV-attributable deaths) were all other deaths for which the underlying cause was known.

[d] APR: adjusted prevalence ratio, adjusted for sex, age at death, race/ethnicity, transmission category, and ever AIDS.

[e] CI: confidence interval

[f] Hispanic or Latino can be of any race.

[g] Data on transmission category have been statistically adjusted to account for missing transmission category.

[h] MSM: men who had sex with men.

[i] MSA: metropolitan statistical area.

[j] Total HIV and non-HIV deaths (denominators) are shown in Table 3.

Discussion

Principal Findings

Our results indicated poorer outcome in terms of viral suppression in the last 12 months before death among persons who died of HIV-attributable causes, consistent with other studies [9]. Almost two-thirds (65.28%) of persons who died of HIV-attributable causes had late-stage disease (stage 3, AIDS) in the 12 months before death, compared with 30.88% of those who died of other causes, and the percentage with a suppressed viral load was lower among persons who died of HIV-attributable causes (33.76%) than among those who died of other causes (50.96%). This association between death due to HIV-attributable causes and both late-stage disease and lack of viral suppression could be explained by the latter two conditions being characteristic of late (delayed) diagnosis of HIV infection, inadequate care and treatment, inadequate adherence to medication regimens, or treatment failure [9,10].

Although a high percentage of persons who died received care, a low percentage of them had viral suppression, particularly among persons who died of HIV-attributable causes. This is consistent with other studies [9,10]. Although receipt of care might be expected to lead to viral suppression, the causal relationship may actually be in the reverse direction—being “in care” or “in continuous care,” as measured by frequency of CD4 or viral load tests, could be a marker for clinical deterioration with high viral loads, due to lack of adherence or treatment failure, which then resulted in more frequent care.

Limitations

Our analyses were subject to some limitations. First, our analyses were based on data from 13 jurisdictions, representing 41% of all persons 13 years and older who died in 2012 in the United States, and, therefore, may not be representative of all persons with HIV who died in the United States. Second, cause of death information from death certificates may underestimate deaths due to HIV [11,12]. The finding that a substantial percentage (30.88%) of the persons who died of non–HIV-attributable causes had stage 3 (AIDS) suggests that some of these deaths might actually have been HIV-attributable. Conversely, HIV infection may have been characterized as underlying cause of death for some patients without actually playing a role in their death if the physicians who certified the deaths ignored the instructions on the death certificate to list as causes only those conditions that “resulted in” or “contributed to” death, or incorrectly assumed that HIV infection did so. Third, information was not available on highly active antiretroviral therapy (HAART) or treatment adherence. Fourth, CD4 and viral load testing may not adequately capture the full spectrum of HIV care in the last 12 months before death [5].

Conclusions

HAART has prolonged the survival of HIV-infected persons by reducing deaths due to HIV-attributable causes [13]. To further decrease mortality, HIV-infected persons should seek early testing and, when diagnosed, be linked to care as soon as possible and be retained in such care so as to reduce the risk of death due to HIV and enable persons with HIV to have a life expectancy similar to that of persons without HIV [13]. This is in consonance with the recommendation by the Panel on Antiretroviral Guidelines for Adults and Adolescents that diagnosis of HIV be made early in the course of infection so as to initiate therapy early and at any CD4 count [14,15].

Acknowledgments

The findings and conclusions in this article are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

Conflicts of Interest

None declared.

Multimedia Appendix 1

[PDF File (Adobe PDF File), 43KB - publichealth_v3i1e3_app1.pdf]

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Abbreviations

HAART: highly active antiretroviral therapy
HIV: human immunodeficiency virus
ICD-10: International Classification of Diseases, Tenth Revision
MSM: men who had sex with men
NHSS: National HIV Surveillance System

Edited by P Sullivan; submitted 15.06.16; peer-reviewed by K Delaney, J McKenney, PG Farnham; comments to author 02.10.16; revised version received 21.10.16; accepted 27.11.16; published 24.01.17.

Please cite as:
Adih WK, Hall HI, Selik RM, Guo X
HIV Care and Viral Suppression During the Last Year of Life: A Comparison of HIV-Infected Persons Who Died of HIV-Attributable Causes With Persons Who Died of Other Causes in 2012 in 13 US Jurisdictions
JMIR Public Health Surveill 2017;3(1):e3
URL: http://publichealth.jmir.org/2017/1/e3/
doi:10.2196/publichealth.6206
PMID:28119277

Original Paper

Detailed Knowledge About HIV Epidemiology and Transmission Dynamics and Their Associations With Preventive and Risk Behaviors Among Gay, Bisexual, and Other Men Who Have Sex With Men in the United States

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Abstract

Background: Gay, bisexual, and other men who have sex with men (GBMSM) in the United States remain disproportionately affected by human immunodeficiency virus (HIV). Yet their testing frequency is suboptimal and condomless anal sex (CAS) is increasing. Behavioral theories posit that information about HIV is a pivotal construct in individual risk reduction. However, measurements of knowledge have traditionally focused on ever hearing about HIV and being aware of the most common routes of spread.

Objective: Using a national Web-based sample of sexually active GBMSM, we sought to (1) quantify levels of detailed knowledge about HIV epidemiology and transmission dynamics, (2) describe variations in detailed knowledge levels across demographic strata, and (3) evaluate potential associations of increasing levels of detailed knowledge with HIV testing in the past year and engaging in CAS with a male partner in the past 3 months.

Methods: GBMSM were recruited through a social networking website (Facebook) from August to September 2015 and asked 17 knowledge-based questions pertaining to the following 2 domains using a Web-based survey: HIV epidemiology (9 questions including statistics on incidence, prevalence, and distribution) and HIV transmission dynamics (8 questions including modes of spread and per-act transmission probabilities). Ordinal domain-specific indices of detailed knowledge were created for each respondent by summing their number of correct responses. Separate cumulative logit models were used to identify factors independently associated with each index, and multivariable logistic regression models were used to characterize associations with HIV testing history and recently engaging in CAS.

Results: Of the 1064 participants in our study, only half (49.62%, 528/1064) had been tested for HIV in the past year, and almost half (47.84%, 509/1064) had engaged in CAS with a male partner in the past 3 months. Majority scored 3 of 9 epidemiology questions correct (26.88%, 286/1064) and 5 of 8 transmission dynamics questions correct (25.00%, 266/1064). Participants younger than 35 years, of non-Hispanic non-white or Hispanic race and ethnicity, with lower educational levels, and who reported a sexual orientation other than homosexual or gay were significantly less knowledgeable about HIV transmission dynamics. Increasing levels of knowledge about this domain were independently associated with testing in the past year (adjusted odds ratio for each additional correct response: 1.10, 95% CI 1.01-1.20) but not with recent CAS. Increasing knowledge about HIV epidemiology was not associated with either outcome.

Conclusions: Increasing detailed knowledge about HIV epidemiology might not be as important as educating sexually active GBMSM regarding transmission dynamics. Researchers and practitioners designing prevention messages targeting GBMSM should bear in mind that not all knowledge is equal and that some aspects might have a greater positive impact than others. Future research to identify influential content and contemporary modes of delivery is needed.

(JMIR Public Health Surveill 2017;3(1):e11) doi:10.2196/publichealth.7255

KEYWORDS

HIV infections; sexual minorities; social networking; risk reduction behavior; sexual behavior

Introduction

Gay, bisexual, and other men who have sex with men (GBMSM) continue to bear the greatest burden of human immunodeficiency virus (HIV) in the United States. From 2005 to 2014, HIV diagnoses in this risk group increased by 6%, driven predominantly by increases among non-Hispanic black or African American and Hispanic GBMSM [1]. Two-thirds (67%) of the total estimated 44,073 new diagnoses in 2014 were attributable to male-to-male sexual contact [2]. According to a recent analysis, 15% of the approximately 4.5 million GBMSM in the United States are living with HIV, and the prevalence in this community is estimated to be as high as 57.5 times that of other US men [3]. Given these trends, allocating resources toward high-impact HIV prevention services for GBMSM and improving outcomes at every step of the care continuum have been recognized as national priorities by the White House [4].

Despite significant advances in our understanding of biomedical approaches to reduce HIV transmission, such as preexposure prophylaxis (PrEP) [5], actual utilization among high-risk individuals has been suboptimal. Data from the 2014 National HIV Behavioral Surveillance (NHBS) system indicate that only 3% of 6847 HIV-negative GBMSM reported taking PrEP in the preceding year [6]. Mathematical modeling suggests that 40% coverage among GBMSM indicated for PrEP could avert up to 33% of incident HIV infections over the next 10 years [7]. Treatment as prevention (TasP) is another strategy that has been shown to reduce sexual transmission from people living with HIV by more than 96% [8]. Although there have been recent improvements in antiretroviral therapy prescription and viral suppression among GBMSM, racial and ethnic disparities persist [9].

HIV testing itself may be considered an important prevention activity, as it is the critical first step in accessing prophylactic services among at-risk individuals [10] and for initiating antiretroviral therapy among those who are living with HIV. Unfortunately, many GBMSM in the United States do not test annually, as recommended by the Centers for Disease Control and Prevention (CDC) [11]. Almost a third (29%) of 8243 GBMSM participating in the 2014 NHBS reported not having been tested in the past year, and a quarter (25%) of 1888 GBMSM living with HIV were unaware of their serostatus [6]. Perhaps even more troubling is the increasing prevalence of high-risk sexual behavior in this community. The overall proportions of GBMSM who reported engaging in condomless anal sex (CAS) with a male partner within 12 months preceding their NHBS interview were 48% in 2005, 54% in 2008, 57% in 2011, and 64% in 2014 [6,12].

Interventions to prevent HIV transmission have been guided by several theoretical approaches, including the information-motivation-behavioral skills model [13], the AIDS risk reduction model [14], the transtheoretical model of behavior change [15], the health belief model [16], and social cognitive theory [17]. According to the information-motivation-behavioral skills model for individual-level changes in HIV risk behavior, risk reduction can be conceptualized as a function of people’s information about HIV, their motivation to reduce risk, and their behavioral skills to successfully undertake specific prevention activities. A pivotal construct of this model is information, which refers generally to an individual’s knowledge about HIV that might include how the disease develops, its expected course, and effective strategies for its prevention and management [18].

Although knowledge around HIV has been the cornerstone of public health research throughout the epidemic, measurements of knowledge have traditionally focused on whether one has ever heard about HIV [19] and being aware of the most common routes of spread [20,21]. Surveys seeking to measure multiple dimensions of HIV awareness have also been developed for college students. For example, the Attitudes Toward AIDS Scale uses a true-false format to tap basic knowledge about prevalence, medical facts, misconceptions, transmission, and prevention methods [22], and the International AIDS Questionnaire uses a 5-point Likert item format to capture increasing levels of agreement with myths and facts about transmission and statements evaluating attitudes toward people living with HIV [23]. However, we are not aware of previous research that has assessed the extent of detailed knowledge about HIV epidemiology and transmission dynamics specifically among GBMSM in the United States and how these domains might relate to preventive and high-risk sexual behaviors.

Using a large national sample of sexually active GBMSM, we sought to quantify levels of detailed HIV knowledge (such as publicly available statistics on disease burden and distribution and per-act transmission probabilities) and to describe variations across strata of demographic characteristics. Furthermore, we sought to evaluate potential associations of increasing levels of detailed knowledge about HIV epidemiology and transmission dynamics with HIV testing history and with recently engaging in CAS with a male partner. Understanding these issues can help guide future HIV education and prevention efforts in the United States, particularly among disproportionately affected subgroups of GBMSM.

Methods

Participants were recruited through selective placement of banner advertisements featured on a social networking website

(Facebook from August to September 2015. Recruitment was targeted toward user profiles that were male, 18 years of age or older, resided within the United States, and reflected a variety of gay or bisexual-related interests. Within the advertising management software, "interests" represent topical categories of information that users have accessed through posts on their timeline, keywords from pages they have liked, as well as advertisements they have clicked on previously. In our case, potential participants' interests could have been broad in scope (eg, lesbian, gay, bisexual, and transgender community, same-sex marriage) or specific (eg, BuzzFeed LGBT, Out Magazine). Rather than focusing solely on men who indicated they were interested in other men in their Facebook profiles, interest-based targeting allowed for the possibility of recruiting GBMSM who were not out to their families or friends. The advertisements included images of men kissing or holding hands, the survey title ("The Prioritizing U survey: Tell us what matters"), as well as the following call-to-action text: "Help the University of Michigan understand what's important to you and your health." Individuals who clicked through the banner advertisements were directed to a Web-based informed consent module, and those who consented were screened to determine eligibility before being administered a Web-based survey. The eligibility criteria for the study included reporting a male gender identity, being 18 years of age or older, currently residing within the United States, and having sex with a male partner in the past 6 months. No monetary incentives were provided to the participants for completing our survey. Ethical approval for this study was obtained from the University of Michigan's Institutional Review Board.

Demographic information collected from all participants included their age, race and ethnicity, educational level, employment status, sexual orientation, relationship status, and state of residence. Participants were also asked to report the number of people that they personally knew who were living with HIV and those who had died of HIV-related complications. Several questions were used to elicit information on participants' HIV testing history and recent potentially high-risk sexual behavior. Responses for "Have you ever been tested for HIV, the retrovirus that causes AIDS?" and "When were you last tested for HIV?" were combined to construct a dichotomous variable: tested for HIV in the past year versus not. Data on the number of male anal sex partners in the past 3 months, sexual positioning (insertive or receptive role), and condom use during each encounter were used to construct another dichotomous variable: engaged in CAS in the past 3 months versus not. Finally, participants were asked a series of 17 knowledge-based questions pertaining to the following 2 domains: HIV epidemiology (9 multiple-choice questions including statistics on the incidence, prevalence, and distribution in different populations) and HIV transmission dynamics (8 multiple-choice questions including common modes of spread and per-act transmission probabilities). These domains were selected because their factual details are readily available to the public on CDC's HIV website. Our knowledge-based questions along with their response options are presented in Multimedia Appendices 1 and (HIV epidemiology and HIV transmission dynamics, respectively). For analytical purposes, ordinal domain-specific indices of detailed knowledge were created for each respondent by summing their number of correct responses, in a manner similar to previous studies [24,25]. Given their ordinal nature, the Spearman rank correlation coefficient was calculated to assess any potential relationship between the 2 indices.

Statistical analyses were conducted using SAS version 9.4 (SAS Institute Inc). Because of our focus on whether detailed HIV knowledge influences preventive and risky sexual behaviors among at-risk GBMSM, we restricted our analyses to participants who reported being HIV-negative or of unknown status, had anal sex with a male partner in the past 3 months, and answered all knowledge-based questions. Selected demographic and behavioral characteristics were summarized using descriptive statistics. The proportions of participants, who reported testing for HIV in the past year and engaging in CAS in the past 3 months, were estimated within strata of response validity for each knowledge-based question. Separate cumulative logit models were used to identify factors independently associated with each of the ordinal domain-specific indices of detailed knowledge. Finally, 2 multivariable logistic regression models were used to characterize associations of domain-specific knowledge levels with HIV testing and with recently engaging in CAS, after controlling for several potential confounders. Each model included the following covariates: detailed HIV epidemiology knowledge (ordinal), detailed HIV transmission dynamics knowledge (ordinal), age group (18-34, 35-54, ≥55 years), race and ethnicity (non-Hispanic white, non-Hispanic non-white, Hispanic), educational level (associate's or technical degree or lower, bachelor's degree, master's or doctoral degree), employment status (work full-time, work part-time, other), sexual orientation (homosexual or gay, other), relationship status (single, partnered: monogamous, partnered: open relationship), region (West, Midwest, Northeast, South), know people living with HIV (no, yes: 1-2 people, yes: ≥3 people), and know people who died of HIV-related complications (no, yes: 1-2 people, yes: ≥3 people). Assessments for potential multicollinearity issues between explanatory variables were conducted by examining condition indices and variance decomposition proportions [26]. Results from all models are presented as adjusted odds ratios with their 95% CIs.

Results

Overall, 352,997 advertising impressions resulted in 14,968 click-throughs to the survey landing page over a 4-week period. Of these, 5968 proceeded to the Web-based consent form, and 3734, who provided consent, were screened for eligibility. Our final analytical sample was restricted to 1064 of 2161 eligible study participants who provided data on their HIV testing history, reported they were not living with HIV, volunteered information on engaging in anal sex with a male partner in the past 3 months, and answered all 17 knowledge-based questions pertaining to HIV epidemiology and transmission dynamics (see Figure 1). Excluded individuals were more likely to have lower levels of education and to report an orientation other than homosexual or gay but were similar with respect to other demographic characteristics.

Table 1 summarizes the descriptive characteristics of 1064 participants included in our analyses. Majority of the participants were middle-aged (mean 45 years, median 49 years), were non-Hispanic white, had an associate’s or technical degree or lower educational level, and worked full-time. Almost two-thirds (60.34%, 642/1064) reported having a primary male partner (described as “Someone you feel committed to above all others. You might call this person your boyfriend, partner, significant other, spouse, or husband.”). More than a third (38.82%, 413/1064) reported personally knowing ≥3 people living with HIV, and a third (32.99%, 351/1064) reported knowing ≥3 people who died of HIV-related complications.

Regarding participants’ HIV testing history, half (49.62%, 528/1064) reported having been tested in the past year, 317 (60.04%) of whom had been tested in the past 6 months. Of the 1064 participants, 136 (12.78%) had never been tested for HIV. Additionally, almost half (47.84%, 509/1064) of our sample reported engaging in CAS in the past 3 months. Of these 509 participants, 321 (63.06%) had CAS with 1 man, 49 (9.63%) had CAS with 2 men, and 139 (27.31%) had CAS with ≥3 men. Regarding sexual positioning, 221 (43.42%) engaged in both insertive and receptive CAS, 137 (26.92%) engaged in only insertive CAS, and 151 (29.67%) engaged in only receptive CAS.

Table 1. Descriptive characteristics of 1064 HIV-negative or unknown status gay, bisexual, and other men who have sex with men, United States, August-September 2015.

Characteristic	Frequency and percentage distribution, n (%)	Tested for HIV[a] in the past year (n=528), n (%)[b]	Engaged in CAS[c] in the past 3 months (n=509), n (%)[d]
Age group, years[e]			
18-34	315 (29.6)	184 (58.4)	188 (59.7)
35-54	435 (40.9)	212 (48.7)	212 (48.7)
≥55	314 (29.5)	132 (42.0)	109 (34.7)
Race and ethnicity			
Non-Hispanic white	852 (80.1)	387 (45.4)	411 (48.2)
Non-Hispanic non-white[f]	94 (8.8)	57 (60.6)	42 (44.7)
Hispanic	118 (11.1)	84 (71.2)	56 (47.5)
Educational level			
Associate's or technical degree or lower[g]	457 (43.0)	223 (48.8)	224 (49.0)
Bachelor’s degree	336 (31.6)	161 (47.9)	164 (48.8)
Master’s or doctoral degree	271 (25.5)	144 (53.1)	121 (44.6)
Employment status			
Work full-time	778 (73.1)	390 (50.1)	397 (51.0)
Work part-time	121 (11.4)	63 (52.1)	59 (48.8)
Other[h]	165 (15.5)	75 (45.5)	53 (32.1)
Sexual orientation			
Homosexual or gay	897 (84.3)	453 (50.5)	451 (50.3)
Other[i]	167 (15.7)	75 (44.9)	58 (34.7)
Relationship status			
Single	422 (39.7)	223 (52.8)	139 (32.9)
Partnered: monogamous[j]	462 (43.4)	185 (40.0)	274 (59.3)
Partnered: open relationship[k]	180 (16.9)	120 (66.7)	96 (53.3)
Region			
West	232 (21.8)	134 (57.8)	108 (46.6)
Midwest	269 (25.3)	118 (43.9)	133 (49.4)
Northeast	195 (18.3)	83 (42.6)	93 (47.7)
South	368 (34.6)	193 (52.4)	175 (47.6)
Know people living with HIV			
No	356 (33.5)	143 (40.2)	143 (40.2)
Yes: 1-2 people	295 (27.7)	143 (48.5)	158 (53.6)
Yes: ≥3 people	413 (38.8)	242 (58.6)	208 (50.4)
Know people who died of HIV-related complications			
No	458 (43.0)	244 (53.3)	242 (52.8)
Yes: 1-2 people	255 (24.0)	119 (46.7)	130 (51.0)
Yes: ≥3 people	351 (33.0)	165 (47.0)	137 (39.0)

[a] HIV: human immunodeficiency virus.

[b] Percentages indicate the proportion who had been tested for HIV in the past year within each stratum of demographic and behavioral characteristics.

[c] CAS: condomless anal sex.

[d] Percentages indicate the proportion who engaged in CAS in the past 3 months within each stratum of demographic and behavioral characteristics.

[e] Age: mean 45 years, median 49 years, range 18-87 years.

[f] Includes 30 non-Hispanic black or African American, 18 Asian, 12 Native American or Alaskan Native, 2 Native Hawaiian or Pacific Islander, and 32 other.

[g] Includes 110 with an associate's or technical degree, 261 with some college education, 77 with a high school diploma or General Educational Development (GED), and 9 with some high school education.

[h] Includes 78 retired, 30 unemployed, 26 who are collecting disability, 18 students, and 13 other.

[i] Includes 139 bisexual, 10 heterosexual or straight, 13 questioning or unsure, 2 queer, and 3 other.

[j] Described as “You and your partner are exclusively having sex with one another.”

[k] Includes 150 in an open relationship with restrictions (described as “You and your partner are allowed to have sex with other people but under certain rules.”) and 30 in an open relationship without restrictions (described as “You and your partner are allowed to have sex with other people without rules.”).

Individual questions assessing participants’ detailed knowledge about HIV epidemiology and transmission dynamics (with answers) are presented in Tables 2 and 3, respectively. The proportion of correct responses selected for questions pertaining to epidemiology ranged from 20.86% (for question 8) to 57.33% (for question 9). Majority (26.88%, 286/1064) of the participants scored 3 of 9 epidemiology questions correct (median 3, range 0-8). The proportion of correct responses selected for questions pertaining to transmission dynamics ranged from 21.05% (for question 4) to 68.98% (for question 5). Majority (25.00%, 266/1064) of the participants scored 5 of 8 transmission dynamics questions correct (median 4, range 0-7). Similar proportions reported testing for HIV in the past year and engaging in CAS in the past 3 months within each stratum of response validity for almost all questions. The 2 domain-specific indices of detailed knowledge were not correlated (Spearman rank correlation coefficient=.03, *P*=.28).

Table 2. Detailed knowledge about HIV epidemiology among 1064 HIV-negative or unknown status gay, bisexual, and other men who have sex with men, United States, August-September 2015.

Questions assessing detailed knowledge about HIV[a] epidemiology (correct answer)	Validity of selected response, n (%)	Tested for HIV in the past year (n=528), n (%)[b]	Engaged in CAS[c] in the past 3 months (n=509), n (%)[d]
1. Approximately how many people in the United States are newly infected with HIV each year? (50,000)			
Correct	250 (23.5)	124 (49.6)	115 (46.0)
Incorrect	814 (76.5)	404 (49.6)	394 (48.4)
2. Approximately how many people in the United States are currently living with HIV? (1.2 million)			
Correct	531 (49.9)	264 (49.7)	256 (48.2)
Incorrect	533 (50.1)	264 (49.5)	253 (47.5)
3. What percentage of all those living with HIV in the United States do not know that they are infected? (14%)			
Correct	287 (27.0)	140 (48.8)	134 (46.7)
Incorrect	777 (73.0)	388 (49.9)	375 (48.3)
4. Even though men who have sex with men comprise only 2% of the United States population, what proportion of new HIV infections did they account for annually from 2008-2010? (3/4)			
Correct	302 (28.4)	154 (51.0)	150 (49.7)
Incorrect	762 (71.6)	374 (49.1)	359 (47.1)
5. Even though African Americans comprise only 12% of the United States population, what percentage of new HIV infections did they account for in 2010? (44%)			
Correct	427 (40.1)	210 (49.2)	214 (50.1)
Incorrect	637 (59.9)	318 (49.9)	295 (46.3)
6. Even though young people aged 13-24 years comprise only 16% of the United States population, what percentage of new HIV infections did they account for in 2010? (26%)			
Correct	506 (47.6)	257 (50.8)	243 (48.0)
Incorrect	558 (52.4)	271 (48.6)	266 (47.7)
7. Who had the highest percentage of newly identified HIV-positive test results in 2010? (Transgender individuals or those who do not identify with their assigned sex at birth)			
Correct	230 (21.6)	112 (48.7)	123 (53.5)
Incorrect	834 (78.4)	416 (49.9)	386 (46.3)
8. Specifically among young people aged 13-24 years, what percentage of all new HIV infections did young men who have sex with men account for in 2010? (72%)			
Correct	222 (20.9)	116 (52.3)	116 (52.3)
Incorrect	842 (79.1)	412 (48.9)	393 (46.7)
9. Among gay and bisexual men in 2013, _____ accounted for the largest estimated percentage of HIV diagnoses followed by _____ and _____. (African Americans, Whites, Hispanics or Latinos)			
Correct	610 (57.3)	324 (53.1)	305 (50.0)
Incorrect	454 (42.7)	204 (44.9)	204 (44.9)

[a] HIV: human immunodeficiency virus.

[b] Percentages indicate the proportion who had been tested for HIV in the past year within each stratum of response validity.

[c] CAS: condomless anal sex.

[d] Percentages indicate the proportion who engaged in CAS in the past 3 months within each stratum of response validity.

Table 3. Detailed knowledge about HIV transmission dynamics among 1064 HIV-negative or unknown status gay, bisexual, and other men who have sex with men, United States, August-September 2015.

Questions assessing detailed knowledge about HIV[a] transmission dynamics (correct answer)	Validity of selected response, n (%)	Tested for HIV in the past year (n=528), n (%)[b]	Engaged in CAS[c] in the past 3 months (n=509), n (%)[d]
1. The estimated probability of HIV infection per-act of receptive anal intercourse (receiving the penis into the anus, also known as bottoming) without any means of prevention is _____ per 10,000 exposures. (138)			
Correct	486 (45.7)	254 (52.3)	233 (47.9)
Incorrect	578 (54.3)	274 (47.4)	276 (47.8)
2. The estimated probability of HIV infection per-act of insertive anal intercourse (inserting the penis into the anus, also known as topping) without any means of prevention is _____ per 10,000 exposures. (11)			
Correct	493 (46.3)	252 (51.1)	238 (48.3)
Incorrect	571 (53.7)	276 (48.3)	271 (47.5)
3. The estimated probability of HIV infection per-act of receptive vaginal intercourse (receiving the penis into the vagina) without any means of prevention is _____ per 10,000 exposures. (8)			
Correct	348 (32.7)	170 (48.9)	160 (46.0)
Incorrect	716 (67.3)	358 (50.0)	349 (48.7)
4. The estimated probability of HIV infection per-act of insertive vaginal intercourse (inserting the penis into the vagina) without any means of prevention is _____ per 10,000 exposures. (4)			
Correct	224 (21.1)	106 (47.3)	105 (46.9)
Incorrect	840 (78.9)	422 (50.2)	404 (48.1)
5. The estimated probability of acquiring HIV from kissing without any means of prevention is _____ per 10,000 exposures. (0)			
Correct	734 (69.0)	379 (51.6)	366 (49.9)
Incorrect	330 (31.0)	149 (45.2)	143 (43.3)
6. The estimated probability of acquiring HIV from needle-sharing during injection drug use without any means of prevention is _____ per 10,000 exposures. (63)			
Correct	707 (66.4)	359 (50.8)	343 (48.5)
Incorrect	357 (33.6)	169 (47.3)	166 (46.5)
7. The estimated probability of acquiring HIV from a mosquito bite without any means of prevention is _____ per 10,000 exposures. (0)			
Correct	653 (61.4)	338 (51.8)	310 (47.5)
Incorrect	411 (38.6)	190 (46.2)	199 (48.4)
8. What is the probability of acquiring HIV from receptive or insertive oral sex without using any means of prevention? (Extremely low)			
Correct	676 (63.5)	345 (51.0)	337 (49.9)
Incorrect	388 (36.5)	183 (47.2)	172 (44.3)

[a] HIV: human immunodeficiency virus.

[b] Percentages indicate the proportion who had been tested for HIV in the past year within each stratum of response validity.

[c] CAS: condomless anal sex.

[d] Percentages indicate the proportion who engaged in CAS in the past 3 months within each stratum of response validity.

Table 4 presents results from our cumulative logit models used to identify factors independently associated with each of the domain-specific indices of detailed knowledge. Regarding detailed HIV epidemiology knowledge, participants with a master’s or doctoral degree were significantly more likely to have higher knowledge levels compared with those with an associate’s or technical degree or lower educational level. However, relative to participants residing in the West of the United States, those from the Midwest and the Northeast were significantly less knowledgeable about this domain. Regarding detailed HIV transmission dynamics knowledge, participants aged ≥35 years were significantly more likely to have higher knowledge levels compared with those who were younger. Similar findings were observed for participants with a bachelor’s degree or higher educational level versus a lower educational level and for those who personally knew ≥3 people living with HIV versus none. However, non-Hispanic non-white and Hispanic participants were significantly less knowledgeable about HIV transmission dynamics compared with non-Hispanic whites. Finally, relative to participants who reported being homosexual or gay, those who reported some other sexual orientation were also significantly less knowledgeable about this domain.

Table 4. Factors independently associated with detailed knowledge about HIV epidemiology and transmission dynamics among 1064 HIV-negative or unknown status gay, bisexual, and other men who have sex with men, United States, August-September 2015.

Characteristic	Detailed HIV[a] epidemiology knowledge[b] aOR[c] (95% CI)	Detailed HIV transmission dynamics knowledge[d] aOR (95% CI)
Age group, years[e]		
18-34	Reference	Reference
35-54	0.79 (0.59-1.07)	1.48 (1.10-2.01)[f]
≥55	0.70 (0.50-1.00)	1.56 (1.10-2.21)[f]
Race and ethnicity		
Non-Hispanic white	Reference	Reference
Non-Hispanic non-white[g]	1.11 (0.75-1.63)	0.63 (0.43-0.92)[f]
Hispanic	0.90 (0.63-1.28)	0.70 (0.49-0.99)[f]
Educational level		
Associate's or technical degree or lower[h]	Reference	Reference
Bachelor’s degree	1.01 (0.78-1.30)	1.74 (1.35-2.25)[f]
Master’s or doctoral degree	1.36 (1.04-1.79)[f]	2.41 (1.82-3.17)[f]
Employment status		
Work full-time	Reference	Reference
Work part-time	0.72 (0.50-1.04)	0.80 (0.55-1.14)
Other[i]	0.73 (0.53-1.00)	1.06 (0.77-1.45)
Sexual orientation		
Homosexual or gay	Reference	Reference
Other[j]	0.82 (0.60-1.13)	0.57 (0.41-0.78)[f]
Relationship status		
Single	Reference	Reference
Partnered: monogamous[k]	1.00 (0.78-1.28)	0.90 (0.70-1.15)
Partnered: open relationship[l]	1.34 (0.97-1.85)	0.99 (0.72-1.36)
Region		
West	Reference	Reference
Midwest	0.71 (0.52-0.97)[f]	0.86 (0.63-1.18)
Northeast	0.71 (0.50-0.99)[f]	0.80 (0.57-1.13)
South	0.91 (0.68-1.22)	0.95 (0.71-1.28)
Know people living with HIV		
No	Reference	Reference
Yes: 1-2 people	0.89 (0.67-1.17)	1.11 (0.83-1.47)
Yes: ≥3 people	0.95 (0.71-1.27)	1.76 (1.31-2.36)[f]
Know people who died of HIV-related complications		
No	Reference	Reference
Yes: 1-2 people	0.85 (0.63-1.15)	0.98 (0.73-1.32)
Yes: ≥3 people	0.95 (0.69-1.31)	0.80 (0.58-1.10)

[a] HIV: human immunodeficiency virus.

[b] Ordinal index created by summing the number of correct responses on questions pertaining to HIV epidemiology. Majority (26.88%, 286/1064) of participants scored 3 of 9 questions correct (median 3, range 0-8).

[c] aOR: adjusted odds ratio.

[d] Ordinal index created by summing the number of correct responses on questions pertaining to HIV transmission dynamics. Majority (25.00%, 266/1064) of participants scored 5 of 8 questions correct (median 4, range 0-7).

[e] Age: mean 45 years, median 49 years, range 18-87 years.

[f] These results indicate a statistically significant association.

[g] Includes 30 non-Hispanic black or African American, 18 Asian, 12 Native American or Alaskan Native, 2 Native Hawaiian or Pacific Islander, and 32 other.

[h] Includes 110 with an associate's or technical degree, 261 with some college education, 77 with a high school diploma or General Educational Development (GED), and 9 with some high school education.

[i] Includes 78 retired, 30 unemployed, 26 who are collecting disability, 18 students, and 13 other.

[j] Includes 139 bisexual, 10 heterosexual or straight, 13 questioning or unsure, 2 queer, and 3 other.

[k] Described as “You and your partner are exclusively having sex with one another.”

[l] Includes 150 in an open relationship with restrictions (described as “You and your partner are allowed to have sex with other people but under certain rules.”) and 30 in an open relationship without restrictions (described as “You and your partner are allowed to have sex with other people without rules.”).

Results from our multivariable logistic regression models used to characterize associations of domain-specific knowledge levels with HIV testing in the past year and with engaging in CAS in the past 3 months are summarized in Table 5. After adjusting for other characteristics, increasing levels of detailed knowledge about HIV epidemiology were not significantly associated with either of these analytical outcomes. However, increasing levels of detailed knowledge about HIV transmission dynamics were significantly associated with HIV testing in the past year. For each additional correct response to questions in this domain, the adjusted odds of reported testing increased by 10%. Finally, increasing levels of detailed knowledge about HIV transmission dynamics were not significantly associated with recently engaging in CAS.

Table 5. Factors independently associated with testing for HIV in the past year and engaging in condomless anal sex in the past 3 months among 1064 HIV-negative or unknown status gay, bisexual, and other men who have sex with men, United States, August-September 2015.

Characteristic	Tested for HIV[a] in the past year aOR[b] (95% CI)	Engaged in CAS[c] in the past 3 months aOR (95% CI)
Detailed HIV epidemiology knowledge[d]	1.01 (0.93-1.11)	1.06 (0.97-1.17)
Detailed HIV transmission dynamics knowledge[e]	1.10 (1.01-1.20)[f]	1.05 (0.96-1.15)
Age group, years[g]		
18-34	Reference	Reference
35-54	0.53 (0.37-0.77)[f]	0.46 (0.32-0.67)[f]
≥55	0.44 (0.29-0.67)[f]	0.33 (0.22-0.52)[f]
Race and ethnicity		
Non-Hispanic white	Reference	Reference
Non-Hispanic non-white[h]	1.81 (1.13-2.90)[f]	0.82 (0.51-1.30)
Hispanic	2.67 (1.70-4.18)[f]	0.82 (0.54-1.26)
Educational level		
Associate’s or technical degree or lower[i]	Reference	Reference
Bachelor’s degree	0.92 (0.67-1.26)	0.76 (0.56-1.04)
Master’s or doctoral degree	1.20 (0.85-1.68)	1.77 (0.54-1.08)
Employment status		
Work full-time	Reference	Reference
Work part-time	1.06 (0.69-1.65)	0.90 (0.58-1.40)
Other[j]	1.04 (0.71-1.53)	0.55 (0.37-0.83)[f]
Sexual orientation		
Homosexual or gay	Reference	Reference
Other[k]	0.93 (0.63-1.36)	0.81 (0.54-1.20)
Relationship status		
Single	Reference	Reference
Partnered: monogamous[l]	0.57 (0.42-0.76)[f]	3.10 (2.30-4.19)[f]
Partnered: open relationship[m]	1.79 (1.21-2.66)[f]	2.34 (1.59-3.45)[f]
Region		
West	Reference	Reference
Midwest	0.59 (0.40-0.87)[f]	1.11 (0.76-1.63)
Northeast	0.61 (0.40-0.92)[f]	1.10 (0.73-1.67)
South	0.84 (0.59-1.20)	1.02 (0.71-1.45)
Know people living with HIV		
No	Reference	Reference
Yes: 1-2 people	1.59 (1.13-2.24)[f]	2.05 (1.45-2.91)[f]
Yes: ≥3 people	3.05 (2.12-4.40)[f]	2.27 (1.57-3.29)[f]
Know people who died of HIV-related complications		
No	Reference	Reference
Yes: 1-2 people	0.84 (0.59-1.21)	0.99 (0.69-1.42)

Characteristic	Tested for HIV[a] in the past year aOR[b] (95% CI)	Engaged in CAS[c] in the past 3 months aOR (95% CI)
Yes: ≥3 people	0.68 (0.46-1.01)	0.63 (0.42-0.93)[f]

[a] HIV: human immunodeficiency virus.

[b] aOR: adjusted odds ratio.

[c] CAS: condomless anal sex.

[d] Ordinal index created by summing the number of correct responses on questions pertaining to HIV epidemiology. Majority (26.88%, 286/1064) of participants scored 3 of 9 questions correct (median 3, range 0-8).

[e] Ordinal index created by summing the number of correct responses on questions pertaining to HIV transmission dynamics. Majority (25.00%, 266/1064) of participants scored 5 of 8 questions correct (median 4, range 0-7).

[f] These results in italics indicate a statistically significant association.

[g] Age: mean 45 years, median 49 years, range 18-87 years.

[h] Includes 30 non-Hispanic black or African American, 18 Asian, 12 Native American or Alaskan Native, 2 Native Hawaiian or Pacific Islander, and 32 other.

[i] Includes 110 with an associate's or technical degree, 261 with some college education, 77 with a high school diploma or General Educational Development (GED), and 9 with some high school education.

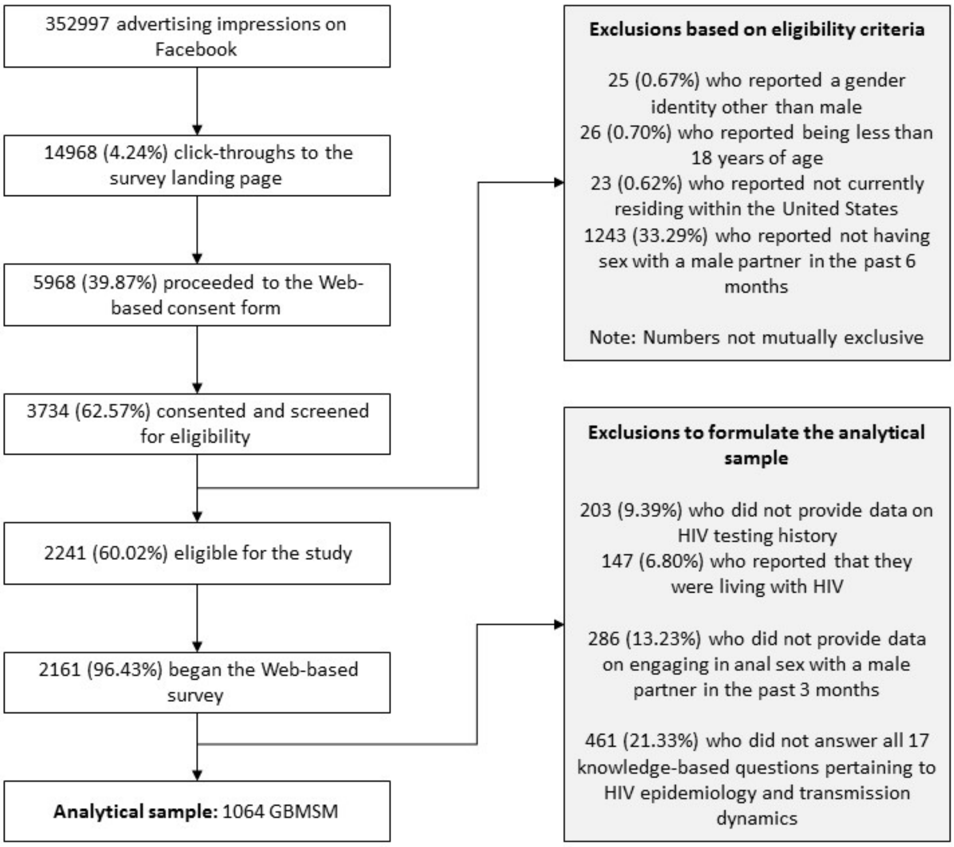
[j] Includes 78 retired, 30 unemployed, 26 who are collecting disability, 18 students, and 13 other.

[k] Includes 139 bisexual, 10 heterosexual or straight, 13 questioning or unsure, 2 queer, and 3 other.

[l] Described as “You and your partner are exclusively having sex with one another.”

[m] Includes 150 in an open relationship with restrictions (described as “You and your partner are allowed to have sex with other people but under certain rules.”) and 30 in an open relationship without restrictions (described as “You and your partner are allowed to have sex with other people without rules.”).

Figure 1. Formulation of the analytical sample of 1064 HIV-negative or unknown status gay, bisexual, and other men who have sex with men (GBMSM), United States, August-September 2015.



Discussion

Principal Findings

Our study found substantial variations in the levels of detailed HIV knowledge across strata of Web-using GBMSM in the United States. Demographic differences were more pronounced in the knowledge domain of HIV transmission dynamics compared with HIV epidemiology. Younger participants, racial and ethnic minorities, those with a lower educational level, those who did not identify as homosexual or gay, and those who personally knew fewer than 3 people living with HIV were significantly less knowledgeable about HIV transmission dynamics. In light of our result that increasing levels of detailed knowledge about this domain were positively associated with testing for HIV in the past year, directing prevention education efforts toward subgroups of GBMSM that might be currently underserved could help improve testing behavior. However, the lack of an association with engaging in CAS in the past 3 months in our sample suggests that increasing HIV transmission dynamics knowledge might not be sufficient in reducing risky sexual behavior. Our results also suggest that educating GBMSM about specific details regarding HIV epidemiology might not confer a public health benefit.

PrEP and TasP are promising biomedical strategies for preventing incident HIV infections among high-risk persons [8,10]. HIV testing is the gateway to accessing these services, and regular testing among at-risk populations needs to be prioritized. Current national recommendations state that all sexually active GBMSM should be tested for HIV at least annually [11], and those who have multiple partners or use illicit drugs concurrent with sexual activity might benefit from more frequent screening, such as every 3 to 6 months [27]. The fact that only half of our sample reported having been tested in the past year is disconcerting. This estimate is considerably lower than the 2014 NHBS wherein more than two-thirds of GBMSM interviewed had been tested for HIV in the preceding 12 months [6]. Additionally, more than 1 in 10 participants in our study reported never having been tested, highlighting the need to promote novel and effective approaches to increase prevention service utilization in this community.

Our findings suggest that increasing GBMSM's detailed knowledge about HIV transmission dynamics (including common modes of spread and per-act transmission probabilities) might help improve their testing behavior. Practically, this task may be achieved by encouraging them to access publicly available information on CDC's HIV website and other federal Web-based HIV resources. From 2005 to 2014, black or African American and Hispanic GBMSM aged 13-24 years saw the steepest increases in HIV diagnoses of approximately 87% [1]. Given that our younger, racial and ethnic minority participants were significantly less knowledgeable about HIV transmission dynamics, targeting these subgroups could potentially yield substantial prevention benefits. Previous research with racial and ethnic minorities has found a correlation between subjective HIV knowledge and testing [28]. Furthermore, the variety of acceptable testing options now available to GBMSM (eg, rapid home self-testing, individual voluntary counseling and testing, couples' HIV testing and counseling) could facilitate both initial and repeated testing [29]. Regular testing could in turn increase knowledge about different components of the HIV prevention tool kit, thereby helping GBMSM protect themselves and their partners [30].

Regarding high-risk sexual behavior, almost half of our participants reported having engaged in CAS in the past 3 months, more than a third of whom had 2 or more male partners. According to a recent meta-analysis, the risk of HIV acquisition through sexual contact is the greatest for receptive CAS, ranging from 102 to 186 per 10,000 exposures [31]. Therefore, it is a cause for concern that more than a third of our sample had engaged in receptive CAS in the past 3 months. Besides HIV, CAS also increases the risk of other sexually transmitted diseases such as chlamydia, gonorrhea, and syphilis [32]. Consistent PrEP use has been demonstrated to reduce the risk of HIV infection among GBMSM by up to 92% [10] but fails to offer protection against other sexually transmitted diseases. Although our survey did inquire about current PrEP use, only 254 (24%) participants responded to that particular question, 12 (5%) of whom reported being on PrEP. This estimate is similar to the national prevalence of PrEP use among GBMSM in the United States [6].

Our study did not find an association between increasing levels of detailed knowledge about HIV epidemiology or transmission dynamics and engaging in CAS in the past 3 months. This contrasts with previous research among GBMSM that has linked greater knowledge concerning HIV with safer sexual practices [33,34]. Given that those studies used a true-false format to assess basic knowledge about HIV and associated risk factors, our findings suggest that a greater awareness of specific factual details might not be necessary to effect risk reduction. Another explanation for our null result could be that theoretical constructs other than information, such as motivation to practice preventive behaviors, might be more influential in reducing high-risk sexual behavior. The information-motivation-behavioral skills model states that information and motivation could be independent of each other, as observed when well-informed individuals are not motivated to change their HIV risk behavior or when persons who are motivated to practice preventive behaviors are not particularly well informed [35]. A relatively recent study with 391 at-risk GBMSM found that self-rated motivation was a significant predictor of CAS, as were behavioral skills such as keeping condoms nearby, reducing the number of sexual partners, and discussing safer sex with a partner [36].

Strengths and Limitations

Strengths of our study include evaluating associations of detailed knowledge pertaining to the separate domains of HIV epidemiology and transmission dynamics with preventive and risky sexual behaviors in a large sample of GBMSM. Participants were recruited through the Web in a time-, cost-, and resource-efficient manner and represent sexually active GBMSM from all geographic regions of the United States. Because our survey was entirely voluntary and could only be accessed by clicking on our banner advertisements, it is unlikely that the same individual would have responded more than once. The perceived anonymity of a Web-based environment contributes to a greater honesty in reporting sensitive information, thereby reducing the possibility of social desirability bias [37]. Considering that the Web has become an increasingly popular venue among GBMSM to access sexual health information, including HIV testing resources [38-40], and to negotiate both high-risk and safe sex [41-43], we believe that understanding the relationships between these issues is critical in advancing Web-based HIV prevention efforts targeting members of this community.

However, we acknowledge there are several limitations to our study. Caution must be exercised in generalizing results to users of other social networking websites, all Web-using GBMSM, and those in the general US population. Our convenience sampling process yielded a group that was older and predominantly non-Hispanic white, characteristics that do not typically reflect persons at highest risk of acquiring HIV. Nevertheless, the low levels of testing and the high prevalence of CAS observed in our study highlight the need to engage all GBMSM in future comprehensive HIV prevention programs. Although it is surprising that the age distribution was skewed away from younger individuals, the unfortunate underrepresentation of racial and ethnic minority GBMSM in our sample is analogous to previous Web-based research studies [44]. Reduced access to and the use of both basic and high-speed Web services in this demographic may explain this disparity [45]. Finally, the cross-sectional nature of our data precludes drawing firm conclusions about the temporality of the association between detailed HIV transmission dynamics knowledge and testing history.

Conclusions

Despite these limitations, our study provides preliminary evidence regarding whether and how different knowledge domains relate to preventive and high-risk sexual behaviors among GBMSM. Increasing detailed knowledge about HIV epidemiology might not be as important as educating those who are sexually active regarding transmission dynamics. Researchers and practitioners designing public health messages targeting GBMSM should bear in mind that not all knowledge is equal and that some aspects might have a greater positive impact than others. Future research to identify more influential content and contemporary modes of delivery is needed to generate and disseminate effective HIV prevention messaging.

Acknowledgments

The authors report no external funding source for this study.

Conflicts of Interest

None declared.

Multimedia Appendix 1

List of 9 questions with response options assessing detailed knowledge about HIV epidemiology.

[PDF File (Adobe PDF File), 29KB - publichealth_v3i1e11_app1.pdf]

Multimedia Appendix 2

List of 8 questions with response options assessing detailed knowledge about HIV transmission dynamics.

[PDF File (Adobe PDF File), 28KB - publichealth_v3i1e11_app2.pdf]

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Abbreviations

CAS: condomless anal sex
CDC: Centers for Disease Control and Prevention
GBMSM: gay, bisexual, and other men who have sex with men
HIV: human immunodeficiency virus
NHBS: National HIV Behavioral Surveillance
PrEP: preexposure prophylaxis
TasP: treatment as prevention

Edited by G Eysenbach; submitted 03.01.17; peer-reviewed by A McNaghten, S Stahlman, B Sheoran; comments to author 28.01.17; revised version received 06.02.17; accepted 08.02.17; published 06.03.17.

Please cite as:
Sharma A, Sullivan SP, Stephenson RB
Detailed Knowledge About HIV Epidemiology and Transmission Dynamics and Their Associations With Preventive and Risk Behaviors Among Gay, Bisexual, and Other Men Who Have Sex With Men in the United States
JMIR Public Health Surveill 2017;3(1):e11
URL: http://publichealth.jmir.org/2017/1/e11/
doi:10.2196/publichealth.7255
PMID:28264795

Original Paper

Analysis of Patient Narratives in Disease Blogs on the Internet: An Exploratory Study of Social Pharmacovigilance

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Abstract

Background: Although several reports have suggested that patient-generated data from Internet sources could be used to improve drug safety and pharmacovigilance, few studies have identified such data sources in Japan. We introduce a unique Japanese data source: *tōbyōki*, which translates literally as “an account of a struggle with disease.”

Objective: The objective of this study was to evaluate the basic characteristics of the TOBYO database, a collection of *tōbyōki* blogs on the Internet, and discuss potential applications for pharmacovigilance.

Methods: We analyzed the overall gender and age distribution of the patient-generated TOBYO database and compared this with other external databases generated by health care professionals. For detailed analysis, we prepared separate datasets for blogs written by patients with depression and blogs written by patients with rheumatoid arthritis (RA), because these conditions were expected to entail subjective patient symptoms such as discomfort, insomnia, and pain. Frequently appearing medical terms were counted, and their variations were compared with those in an external adverse drug reaction (ADR) reporting database. Frequently appearing words regarding patients with depression and patients with RA were visualized using word clouds and word cooccurrence networks.

Results: As of June 4, 2016, the TOBYO database comprised 54,010 blogs representing 1405 disorders. Overall, more entries were written by female bloggers (68.8%) than by male bloggers (30.8%). The most frequently observed disorders were breast cancer (4983 blogs), depression (3556), infertility (2430), RA (1118), and panic disorder (1090). Comparison of medical terms observed in *tōbyōki* blogs with those in an external ADR reporting database showed that subjective and symptomatic events and general terms tended to be frequently observed in *tōbyōki* blogs (eg, anxiety, headache, and pain), whereas events using more technical medical terms (eg, syndrome and abnormal laboratory test result) tended to be observed frequently in the ADR database. We also confirmed the feasibility of using visualization techniques to obtain insights from unstructured text-based *tōbyōki* blog data. Word clouds described the characteristics of each disorder, such as “sleeping” and “anxiety” in depression and “pain” and “painful” in RA.

Conclusions: Pharmacovigilance should maintain a strong focus on patients’ actual experiences, concerns, and outcomes, and this approach can be expected to uncover hidden adverse event signals earlier and to help us understand adverse events in a patient-centered way. Patient-generated *tōbyōki* blogs in the TOBYO database showed unique characteristics that were different from the data in existing sources generated by health care professionals. Analysis of *tōbyōki* blogs would add value to the assessment of disorders with a high prevalence in women, psychiatric disorders in which subjective symptoms have important clinical meaning, refractory disorders, and other chronic disorders.

(JMIR Public Health Surveill 2017;3(1):e10) doi:10.2196/publichealth.6872

KEYWORDS

Internet; social media; adverse drug reaction; pharmacovigilance; text mining

Introduction

Current Pharmacovigilance

The World Health Organization defines pharmacovigilance (PV) as the science and activities related to the detection, assessment, understanding, and prevention of adverse effects or any other drug-related problems [1]. In this era of what Edwards calls "information explosion," we must rethink PV [2] to effectively incorporate a variety of data sources while ensuring the timely decision-making that is crucial to avoiding unnecessary harm caused by adverse events (AEs) in real-world health care practice.

Current PV activities depend heavily on voluntary, spontaneous AE reports obtained from health care professionals (HCPs). It is generally accepted that one advantage of spontaneous reporting is its speed at detecting AE signals as early as possible. However, it is also acknowledged that spontaneous reports by HCPs alone may not be enough to capture all AE signals in a timely fashion. Because some symptomatic AEs can be expected to be reported only by patients who have firsthand experience of drug treatment [3], incorporating patient-generated data into PV is one of the most important challenges [4]. Several studies have suggested that self-reporting by patients is useful for catching AE signals earlier, and many countries have implemented patient AE reporting schemes [5-8]. The Japanese regulatory authority started preliminary implementation of a self-reporting system for patients in March 2012 [9,10]; however, the system is still under development and will require more time to be used effectively in a routine PV system [11].

Prior Research on Applying Internet Resources in Pharmacovigilance

Analyzing information on the Internet would add significant knowledge about public health, as shown in Eysenbach's study outlining the framework of infodemiology and infoveillance [12]. In PV, there has been recent growing interest in utilizing patient-generated Internet resources such as social media [13-17]. A survey conducted in 2001 and 2002 in the United States showed that the Internet is an important resource for the public; approximately 40% of respondents there obtained information on health-related topics through Internet sources [18]. In response to the increasing use of social media to share health care information, the US Food and Drug Administration announced in 2015 that they had started a collaboration with PatientsLikeMe [19], a patient networking website, to apply patient-generated data to risk management activities [20]. In Europe, the Medicines and Healthcare products Regulatory Agency in the United Kingdom started working with the WEB-RADR project in 2014 to develop a mobile phone app that helps HCPs and patients report AEs to national health care authorities [21]. The European Medicines Agency has also released guidelines on good pharmacovigilance practices, of which Module VI requires companies having the European Union marketing authorization to monitor the Internet or digital media under their management or responsibility for potential reports of suspected adverse reactions [22]. These ongoing efforts are expected to lead to important developments in PV. Like Americans and Europeans, approximately 39% of Japanese obtain health information via the Internet [23]. However, to our knowledge, no studies have explicitly identified such Japanese data sources for use in PV.

Patient-Generated Data and Study Objectives

Our motivation was to take the first step toward enhancing PV by considering the application of patient-generated data sources in Japan. In this study, we focused on the potential use of health-related disease blogs called *tōbyōki*. The term *tōbyōki* translates literally to "an account of a struggle with disease," and this form of writing predates the Internet. Although it is difficult to pinpoint when patients started writing *tōbyōki*, a sociological study has reported that the number of *tōbyōki* has been increasing in Japan since the 1970s [24]. In these diary-like accounts, patients record observations about their lives and diseases in handwritten journals. Recently, some patients have started sharing their *tōbyōki* as blogs on the Internet.

It has already been suggested that analyzing *tōbyōki* blogs is useful for understanding patients' feelings when they receive a cancer diagnosis [25], although there was no discussion on their potential use in PV. In this study, we introduce a growing database called TOBYO, which is a collection of a broad range of *tōbyōki* blogs on the Internet [26]. The objective of this exploratory study was to address the following questions: (1) what kinds of data elements exist in the TOBYO database? (2) what are the differences in population distribution between the TOBYO database and other external databases generated by HCPs? (3) what kinds of analytic approaches are useful to obtain insights from the TOBYO database? and (4) can the TOBYO database be useful for PV?

To achieve our objective, we conducted 2 analyses (Analysis A and Analysis B). In Analysis A, we used the whole TOBYO database to describe data elements and understand the overall characteristics of this database. In Analysis B, we used a data subset of selected disorders from the TOBYO database to explore the usefulness of the database in greater detail. Here, we focused on depressive disorders and rheumatoid arthritis (RA) because these conditions were expected to entail subjective patient symptoms such as discomfort, insomnia, and pain. Finally, we included a discussion of the potential of the TOBYO database and practical challenges from the PV perspective.

Methods

Data Source

In this study, we considered health-related *tōbyōki* blogs as a resource for patient-generated data. Some examples of excerpts from *tōbyōki* blogs are shown in Table 1. As shown in these examples, patients shared information about AEs, drug name, dosage, and AE-related distress.

Table 1. Example of excerpts from *tōbyōki* blog.

Name of disorder	Excerpt from each *tōbyōki* blog[a]
Breast cancer	I showed my leg with a ruptured blister to my doctor. He said it is a side effect of docetaxel and it needs a long time to be cured. Also, I was advised to avoid secondary infection from this site.
Depression	After changing clinics, I reduced the number of drugs I’m taking. At first I couldn’t help being nervous, but I’m feeling well now; morning milnacipran 15 mg, alprazolam 0.4 mg, mid-afternoon alprazolam 0.4 mg (as needed), evening milnacipran 15 mg, alprazolam 0.4 mg. That’s all.
Rheumatoid arthritis	Thanks to my second dose of etanercept, the pain in my joints is completely gone! Because of this dramatic improvement, my doctor reduced my prescription of methotrexate to 2 mg/day, and also promised to reduce my steroids, too. I am really happy because I can escape from the side effects of steroids, which are the hardest thing for me...

[a] All entries are translated from Japanese. To protect patient privacy, minor changes were made to texts while maintaining the meaning of original contexts.

The TOBYO database consisted of a Web-based collection of *tōbyōki* blogs written in Japanese [26] and maintained by Initiative Inc (Tokyo, Japan). The overall flow of data in the TOBYO database is shown in Figure 1. Blogs written in Japanese were identified and extracted daily from the Internet using a proprietary crawling method. Before being registered in the TOBYO database, each *tōbyōki* blog was manually checked to judge whether it was a *tōbyōki* blog or noise, which was excluded. Each blog registered to the TOBYO database met all of the following selection criteria: (1) Language criteria: blogs written in plain Japanese language without extensive use of emoticons, symbols, or colloquial expressions were included; (2) Blogger criteria: blogs written by patients or their families were included. Blogs not written by patients or their families, such as those by manufacturers or HCPs who were providing medical care, were excluded (because such blogs generally described the HCP’s records and did not contain a patient perspective); and (3) Content criteria: blogs containing at least ten pages of *tōbyōki* entries on patients’ actual experiences were included. Blogs comprising excerpts from news media, books, health-related websites, or treatment guidelines were excluded. Blogs intended for marketing or promotion of commercial services or religious or political beliefs were also excluded.

At the time of registration in the TOBYO database, information on gender, age at onset, and the primary disorder of each patient was determined by checking the profile or introduction page of each *tōbyōki* blog and stored as structured data for each patient. Text-based data in *tōbyōki* blogs were stored as unstructured data for each patient.

Figure 1. Overall flow of data in the TOBYO database.(1) This study focuses on tōbyōki blogs that are publicly available on the Internet. Generally, there is a substantial volume of noise (white) unrelated to tōbyōki blogs (shaded). (2) Based on selection criteria described in Methods, filtering of tōbyōki blogs is performed manually, (3) and noise such as blogs written by companies is excluded. (4) Appropriate tōbyōki blogs are registered in the TOBYO database and stored for additional analysis.

Analysis A: Using the Whole TOBYO Database

Demographic Characteristics of the TOBYO Database

To understand the demographic characteristics of the TOBYO database, structured data elements such as gender, age at onset, and frequently mentioned primary disorders were summarized in contingency tables. We also evaluated demographic characteristics by comparing population pyramids for the TOBYO database and 2 external databases generated by HCPs. The first HCP-generated database was the Japanese Adverse Drug Event Report (JADER) database maintained by the Pharmaceuticals and Medical Devices Agency. It comprised individual case safety reports (ICSRs) about the occurrences of serious adverse drug reactions (ADRs) for drugs approved in Japan. Similar to a previous report [27], we obtained the JADER dataset updated in September 2016 and extracted all ICSRs to create a population pyramid for the JADER database. The other HCP-generated database was the Japanese health insurance claims database maintained by Japan Medical Data Center, Ltd (Tokyo, Japan). It comprised medical claims information submitted from medical institutions to health insurance organizations for both corporate employees and their dependents [28]. Using this database, we created a population pyramid by determining the number of patients who had at least one record of drug prescription or disease from January 2011 to December 2015. As an additional comparison, we used national statistical surveillance data on all citizens living in Japan and publicly available through the Japanese government's website [29].

Distribution of Disorders in the TOBYO Database

To understand the distribution of primary disorders in the TOBYO database, frequently mentioned disorders were summarized. The name of each disorder was independently reviewed by 2 reviewers (ST and MS) and coded using Medical Dictionary for Regulatory Activities (MedDRA) version 19.1. MedDRA is a widely used, standardized medical terminology developed by the International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use [30]. Both reviewers had at least two years of experience in processing and evaluating ICSRs.

Additional Characteristics of the TOBYO Database

We analyzed additional characteristics of *tōbyōki* blogs that might be useful to understand the data. Behavioral characteristics about writing *tōbyōki* blogs, such as the time and day of week for blog postings, were determined for all postings accompanied by relevant identifiable information. Continuity of *tōbyōki* blogs was calculated by counting the number of days from the first entry to the latest update for each patient.

Analysis B: Using Subset of Selected Disorders in the TOBYO Database

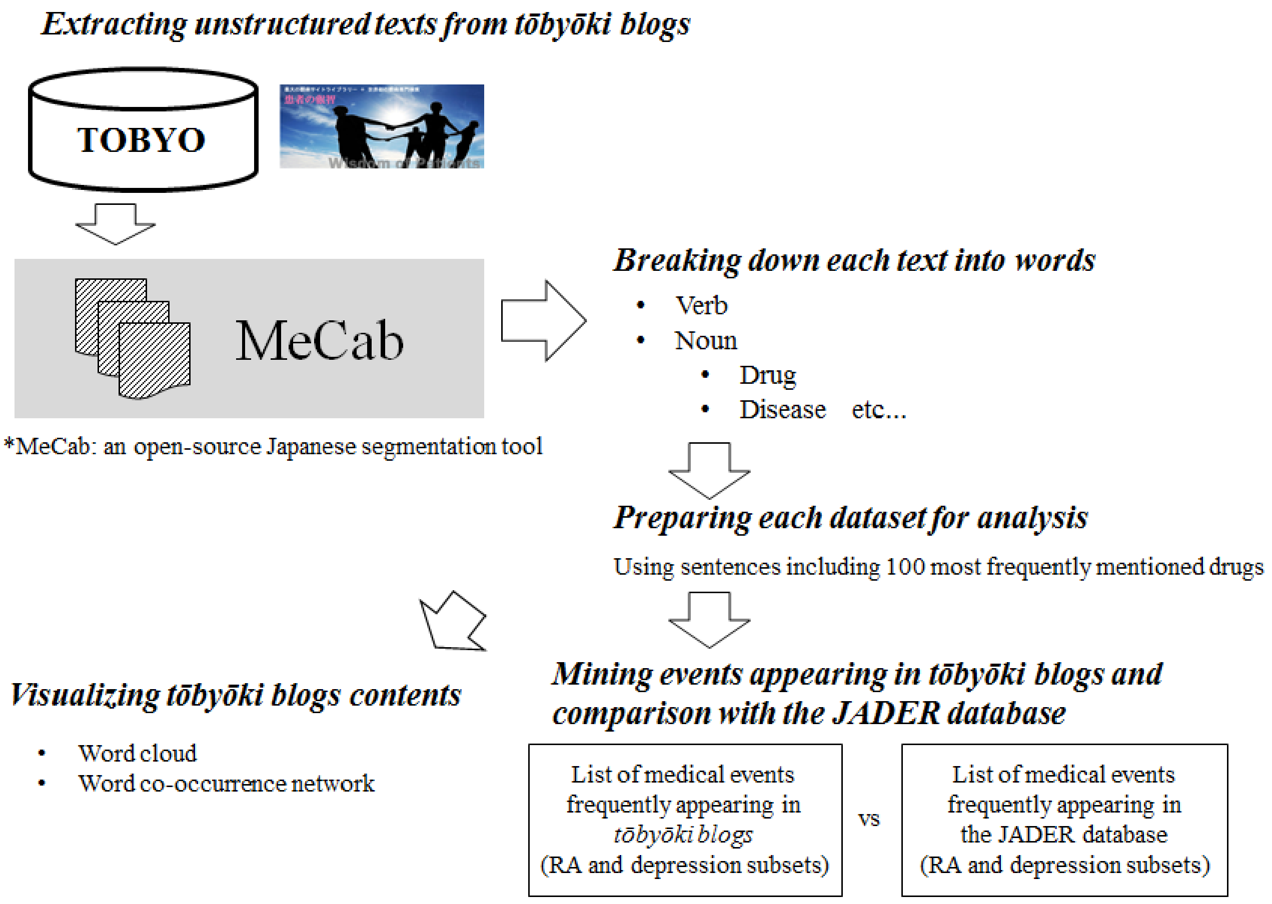
Mining Events Appearing in Tōbyōki Blogs

As depicted in Figure 2, we applied natural language processing techniques to unstructured text-based data to prepare each dataset, which were then analyzed to answer specific questions (eg, what identifying words are frequently used by a particular population?). In this study, we extracted 2 different sets of *tōbyōki* blogs from the TOBYO database, 1 for patients with depression and 1 for patients with RA, and we prepared separate datasets containing all unstructured text written by patients with each disorder. We then analyzed the drugs and medical events mentioned in each dataset.

To process the unstructured text, we first performed a morphological analysis using MeCab, an open-source Japanese segmentation tool [31], to break down each text into words. This preprocessing approach is commonly used to delimit words in texts that do not delimit words with spaces, which is a characteristic of the Japanese language [32]. Because *tōbyōki* blogs contained many entries unrelated to disease, such as those related to everyday life, making the data noisy, we also identified the 100 most frequently mentioned drugs in each dataset (depression and RA). Then, for each dataset, we extracted every sentence containing at least one of the 100 most frequently mentioned drugs identified earlier, and these extracted sentences were used for subsequent analysis. This approach enabled us to focus on drug-related contexts rather than on everyday diary-like content. As mentioned earlier, 2 reviewers (ST and MS) independently reviewed summary tables containing the 300 most frequently mentioned words in each dataset (depression and RA) to identify medical events (eg, name of symptom, diagnosis, and disorder), which were coded using MedDRA. Because original descriptions written by patients tended to have some degree of ambiguity (eg, words such as suffering, feeling down, feeling unwell), discrepancies in coding sometimes occurred between the results of the 2 reviewers. The reviewers discussed any such discrepancies and determined a single appropriate Preferred Term in accordance with the standard guidance for MedDRA coding procedures (MedDRA Term Selection: Points to Consider [33]). Any discrepancies in coding results were resolved by discussion.

In addition to identifying medical events frequently observed in *tōbyōki* blogs, we examined differences in the types and frequencies of events between *tōbyōki* blogs and existing HCP-generated data sources. For this purpose, we compared medical terms frequently observed in *tōbyōki* blogs (as identified earlier) and those frequently observed in the JADER database. Using the JADER database, we first produced separate tables of the 30 most frequent ADRs reported for 4 biological drugs approved for RA (adalimumab, etanercept, infliximab, and tocilizumab were selected because they were the first 4 biologics approved in Japan around 2000 and were thus expected to contain enough data for comparison) and that of the 30 most frequent ADRs reported for 4 selective serotonin reuptake inhibitors approved for depression (escitalopram, fluvoxamine, paroxetine, and sertraline were selected because these were widely prescribed and also used in the previous study [14]). Then by comparing these lists of events from *tōbyōki* blogs and the JADER database, we identified the words appearing in both databases and those appearing in either database. This focused comparison based on frequently appearing events enabled us to highlight the major characteristics of these databases. This process of review and comparison was carried out independently by the 2 aforementioned reviewers (ST and MS).

Figure 2. Work flow for morphological analysis and preparation of datasets.



Visualization of Tōbyōki Blog Contents

Because visualization approaches could be useful for PV, we used all sentences containing at least one of the above 100 drugs to calculate Jaccard coefficients to measure the similarity between term pairs. Jaccard coefficients index the degree of cooccurrence between term pairs by showing how much the terms overlap. For instance, Figure 3 shows the calculation of the Jaccard coefficient for drug A and verb X [34].

Figure 3. Calculation of the Jaccard coefficient.

$$J(A,X) = \frac{|A \cap X|}{|A \cup X|}$$

Using these Jaccard coefficients, we visually represented the words associated with depression or RA in word clouds. In the word clouds, the size of each word reflected the frequency with which the word appeared in text (ie, the more frequently a word appeared, the larger the word was shown in the word cloud). The colors of each word were randomly assigned and did not have any meaning. Word clouds could be used in PV to achieve an initial, intuitive understanding of data. We also created a word cooccurrence network for patients with RA to evaluate the occurrence of words in conjunction with the names of 4 biological drugs approved for RA. Word cooccurrence network analysis could be used in PV to explore terms related to specific drugs.

Statistical software R, JMP software version 11.2.1 (SAS institute), and Microsoft Excel were used for the analysis.

Ethics Approval

The study protocol was reviewed and approved by the nonprofit MINS Institutional Review Board [35]. The board waived informed consent because the data source did not contain personal information. In addition, we presented the data at the group level rather than at the individual level.

Results

Analysis A: Using the Whole TOBYO Database

Demographic Characteristics of the TOBYO Database

As of June 4, 2016, the *tōbyōki* blogs aggregated in the TOBYO database comprised 54,010 blogs representing 1405 disorders. The blogs were started from 1994 to 2016, but more than 90% of them were started from 2005 to 2015.

As shown in Table 2, information on gender could be identified in most of the blogs (99.60%, 53,794/54,010). More blogs were written by female bloggers (68.80%, 37,161/54,010) than by male bloggers (30.80%, 16,633/54,010). Of approximately 40% of *tōbyōki* blogs in the TOBYO database with information on age at onset, more than half were written by people less than 50 years old. The peak age at onset was 20-34 years (24.44%, 13,201/54,010), followed by 35-49 years (16.35%, 8830/54,010) and less than 20 years (16.16%, 8730/54,010).

Table 2. Distribution of gender and age at onset in TOBYO database.

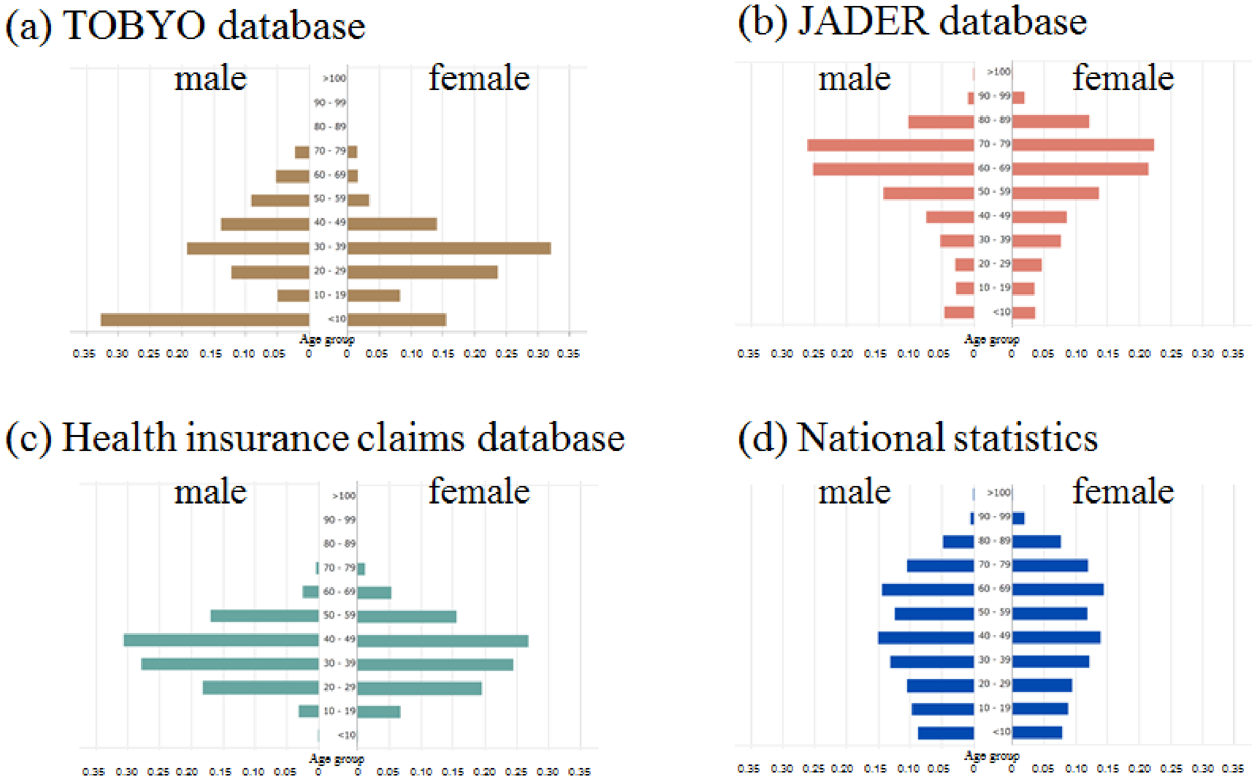
Variable	Category	All, n (%)[a]	Male, n (%)[a]	Female, n (%)[a]	Unknown, n (%)[a]
Gender		54,010 (100)	16,633 (31)	37,161 (69)	216 (0)
Age at onset of primary disorder[b]	≤19 years old	8730 (16)	4045 (24)	4654 (13)	31 (14)
	20-34 years old	13,201 (24)	2726 (16)	10,460 (28)	15 (7)
	35-49 years old	8830 (16)	2450 (15)	6371 (17)	9 (4)
	50-64 years old	2048 (4)	1083 (7)	961 (3)	4 (2)
	≥65 years old	808 (2)	381 (2) 426 (1)	1 (1)	
	Unknown	20,393 (38)	5948 (36)	14,289 (39)	156 (72)

[a] Number of blogs equals number of patients. Because of rounding, total values for proportion are not always 100%.

[b] Age at onset of primary disorder was obtained by checking profile or introductory page of each blog.

We found apparent differences in population distribution between the TOBYO database and existing data sources such as the Japanese health insurance claims database, JADER database, and national population statistics (Figure 4). Compared with national statistics as a standard, the population in the TOBYO database tended to be younger and contained relatively more females than males. In contrast, the population of the JADER database was older with no particular gender differences between ages. The health insurance claims database did not include people older than 75 years, but data for the young to middle-aged group seemed to be abundant with no particular gender differences between age groups.

Figure 4. Comparison of population distribution between the TOBYO database and external databases.



Distribution of Disorders in the TOBYO Database

As shown in Table 3, the most frequently appearing disorders in the TOBYO database were breast cancer (9.23%, 4983/54,010), depression (6.58%, 3556/54,010), infertility (4.50%, 2430/54,010), RA (2.07%, 118/54,010), and panic disorder (2.02%, 1090/54,010). These disorders were observed more frequently in females than in males in the TOBYO database. Categorization of disorders according to disease organ groups by a proprietary TOBYO classification system similar to MedDRA classification showed that the frequently appearing categories were neoplasms benign, malignant, and unspecified (31.20%, 16,851/54,010), psychiatric and behavior disorders (22.84%, 12,334/54,010), kidney, urological, or genital disorders (8.34%, 4507/54,010), and muscular, bone, or articular disorders (8.28%, 4471/54,010; Table 4).

Table 3. Primary disorders frequently described in the TOBYO database.

Name of disorders	Corresponding preferred term of MedDRA (version 19.1)	Gender: all, number of blogs and proportion among all disorders, n (%)[a]	Gender: male, number of blogs and proportion among each disorder, n (%)[a]	Gender: female, number of blogs and proportion among each disorder, n (%)[a]	Gender: unknown, number of blogs and proportion among each disorder, n (%)[a]
Breast cancer	Breast cancer	4983 (9)	6 (0)	4974 (100)	3 (0)
Depression	Depression	3556 (7)	1467 (41)	2077 (58)	12 (0)
Infertility	Infertility	2430 (5)	16 (1)	2411 (99)	3 (0)
Rheumatoid arthritis	Rheumatoid arthritis	1118 (2)	71 (6)	1045 (94)	2 (0)
Panic disorder	Panic disorder	1090 (2)	202 (19)	881 (81)	7 (1)
Schizophrenia	Schizophrenia	1024 (2)	336 (33)	683 (67)	5 (1)
Cervical cancer	Cervix carcinoma	934 (2)	0 (0)	933 (100)	1 (0)
Hysteromyoma	Uterine leiomyoma	802 (2)	0 (0)	802 (100)	0 (0)
Type 1 diabetes mellitus	Type 1 diabetes mellitus	792 (2)	188 (24)	602 (76)	2 (0)
Ulcerative colitis	Colitis ulcerative	683 (1)	253 (37)	428 (63)	2 (0)
Systemic lupus erythematosus	Systemic lupus erythematosus	665 (1)	33 (5)	631 (95)	1 (0)
Eating disorder	Eating disorder	664 (1)	11 (2)	651 (98)	2 (0)
Others		35,269 (65)			

[a] Number of blogs equals number of patients. Because of rounding, total values for proportion are not always 100%.

Table 4. Category for primary disorders frequently described in the TOBYO database.

Name of grouped category of disorders	Corresponding System Organ Class of MedDRA (version 19.1)	Gender: all, number of blogs and proportion among all disorders, n (%)[a]	Gender: male, number of blogs and proportion among each disorder, n (%)[a]	Gender: female, number of blogs and proportion among each disorder, n (%)[a]	Gender: unknown, number of blogs and proportion among each disorder, n (%)[a]
Neoplasms benign, malignant, and unspecified	Neoplasms benign, malignant, and unspecified (including cysts and polyps)	16,851 (31)	4196 (25)	12,621 (75)	34 (0)
Psychiatric and behavior disorders	Psychiatric disorders	12,334 (23)	4281 (35)	7998 (65)	55 (0)
Kidney, urological, or genital disorders	Renal and urinary disorders	4507 (8)	774 (17)	3710 (82)	23 (1)
Muscular, bone, or articular disorders	Musculoskeletal and connective tissue disorders	4471 (8)	648 (15)	3813 (85)	10 (0)
Congenital disorders or abnormal chromosome	Congenital, familial, and genetic disorders	2972 (6)	1455 (49)	1496 (50)	21 (1)
Neurological disorders	Nervous system disorders	2877 (5)	1171 (41)	1691 (59)	15 (1)
Endocrine, nutritional, or metabolic disorders	Metabolism and nutrition disorders[b]	2269 (4)	636 (28)	1626 (72)	7 (0)
Digestive system disorders	Gastrointestinal disorders	1876 (4)	773 (41)	1093 (58)	10 (1)
Circulatory conditions	Cardiac disorders	1523 (3)	933 (61)	580 (38)	10 (1)
Infections and infestations	Infections and infestations	849 (2)	480 (57)	357 (42)	12 (1)
Blood, hematopoietic, or immunological disorders	Blood and lymphatic system disorders	777 (1)	314 (40)	458 (59)	5 (1)
Skin disorders	Skin and subcutaneous tissue disorders	755 (1)	230 (31)	521 (69)	4 (1)
Others		1949 (4)			

[a] Number of blogs equals number of patients. Because of rounding, total values for proportion are not always 100%.

[b] There was an another possible MedDRA coding: endocrine disorders.

Additional Characteristics of the TOBYO Database

We also highlighted unique data elements by analyzing behavioral characteristics of writing *tōbyōki* blogs and found that most writers updated their blogs between 9 PM and 0 AM (Figure 5). No particular patterns were observed according to which days of the week blog entries were posted. About 40% of the blogs in the TOBYO database (36.81%, 19,879) had continued for more than 3 years.

Figure 5. Additional characteristics of the TOBYO database.

Analysis B: Using Subset of Selected Disorders in the TOBYO Database

Mining Events Appearing in Tōbyōki Blogs

Comparison of depression (Table 5) and RA (Table 6) events in *tōbyōki* blogs and the JADER database showed apparent differences in the types and frequencies of events observed. Subjective, symptomatic terms and general terms for patients tended to be frequently observed in *tōbyōki* blogs (eg, anxiety, headache, and pain), whereas more technical, medical terms (eg, syndrome and abnormal laboratory test result) tended to be observed frequently in the JADER database. Exceptionally, the fact that "interstitial lung disease" in patients with RA was observed frequently in both *tōbyōki* blogs and the JADER database suggested relatively high attention for this event.

Table 5. Comparison of events in patients with depression in the TOBYO database and JADER database.

Medical terms observed in the TOBYO database				Medical terms observed in the JADER database		
Rank	Event description in the TOBYO database	MedDRA Preferred Terms in the TOBYO database	Number of events	Rank	MedDRA Preferred Terms in the JADER database	Number of events
1	Adverse reaction[c]	Adverse reaction	9977	1	Inappropriate antidiuretic hormone secretion	247
2	Depression	Depression	6218	2	Serotonin syndrome	226
3[a]	Anxiety	Anxiety	5695	3	Suicide attempt	213
4	Headache	Headache	2977	4	Seizure	153
5	Pain	Pain	2016	5	Completed suicide	152
6	Withdrawal symptom	Withdrawal syndrome	1848	6	Hyponatraemia	143
7	Stress	Stress	1194	7[a]	Mania	121
8	Malaise	Malaise	1162	8	Neuroleptic malignant syndrome	108
9[a]	Feeling queasy	Nausea	1140	9[a]	Dizziness	103
10	Constipation	Constipation	897	10[a]	Nausea	101
11	Psychosis[c]	Mental disorder	777	11	Aggression	100
12[a]	Dizzy	Dizziness	762	12	Suicidal ideation	96
13	Paroxysmal attack[c]	Seizure-like phenomena	691	13	Hepatic function abnormal	93
14	Emotional instability[c]	Affect lability	685	14[a]	Tremor	92
15	Abnormality	NA[b]	641	15	Altered state of consciousness	90
16	Suffering[c]	Sense of oppression	637	16	Activation syndrome[d]	86
17	Feeling down[c]	Depressed mood	619	17	Irritability	85
18	Sleep disorder	Sleep disorder	601	18	Loss of consciousness	78
19	Schizophrenia	Schizophrenia	479	19[a]	Anxiety	75
20	Allergy	Hypersensitivity	474	20	Hallucination	74
21[a]	Mania	Mania	472	21	Somnolence	69
22	Migraine	Migraine	445	22	Delirium	68
23	Pollinosis	Seasonal allergy	427	23	Liver disorder	61
24	Hypersomnia	Hypersomnia	418	24	Urinary retention	60
25	Bipolar disorder	Bipolar disorder	376	25	Overdose	58
26	Diarrhea	Diarrhea	368	26[a]	Intentional self-injury	57
27[a]	Trembling	Tremor	326	27	Electrocardiogram QT prolonged	56
28	Panic disorder	Panic disorder	314	28	Drug withdrawal syndrome neonatal	53
29	Asthma	Asthma	294	29	Insomnia	50
30	Weight increased	Weight increased	284		Intentional overdose	50
31	Diabetes mellitus	Diabetes mellitus	281			
32	Ache stomach	Abdominal pain upper	277			
33	Psychiatric disorder[c]	Mental disorder	266			
34	Vomiting	Vomiting	240			
35	Abdominal pain	Abdominal pain	237			
36	Slight fever	Pyrexia	231			

Medical terms observed in the TOBYO database				Medical terms observed in the JADER database		
Rank	Event description in the TOBYO database	MedDRA Preferred Terms in the TOBYO database	Number of events	Rank	MedDRA Preferred Terms in the JADER database	Number of events
37	Influenza	Influenza	228			
38	Physical deconditioning	Asthenia	226			
39	Myalgia	Myalgia	225			
40	Dependence	Dependence	210			
41	Inflammation	Inflammation	206			
42	Panic attack	Panic attack	197			
43[a]	Self-injury	Intentional self-injury	194			
44	Hypertension	Hypertension	179			
45	Severe pain	Pain	152			

[a] Events appearing in both databases (the TOBYO database and JADER database).

[b] NA (not applicable) in columns for MedDRA PTs (preferred terms) means there was no corresponding term in MedDRA.

[c] Coding discrepancies occurred between the 2 reviewers (the different suggestions from the reviewers are shown in parentheses): Adverse reaction (adverse reaction or adverse drug reaction), Psychosis (mental disorder or psychotic disorder), Paroxysmal attack (seizure-like phenomena or seizure), Emotional instability (affect lability or feeling abnormal), Suffering (sense of oppression or emotional distress), Feeling down (depressed mood or emotional distress), and Psychiatric disorder (mental disorder or psychotic disorder).

[d] Activation syndrome is a generic term used for central nervous system stimulation symptoms that are potential adverse effects caused by selective serotonin reuptake inhibitors.

Table 6. Comparison of events in patients with rheumatoid arthritis in the TOBYO database and JADER database.

Medical terms observed in the TOBYO database				Medical terms observed in the JADER database		
#	Event description in the TOBYO database	MedDRA PTs in the TOBYO database	Number of events	#	MedDRA PTs in the JADER database	Number of events
1	Rheumatoid arthritis	Rheumatoid arthritis	9193	1[a]	Pneumonia	1109
2	Pain	Pain	6471	2[a]	Interstitial lung disease	835
3	Adverse reaction[c]	Adverse reaction	4378	3	*Pneumocystis jirovecii* pneumonia	575
4	Inflammation	Inflammation	1044	4	Cellulitis	330
5	Swelling	Swelling	761	5	Sepsis	292
6	Feeling queasy	Nausea	661	6	Herpes zoster	255
7	Abnormality	NA[b]	440	7	Pyrexia	252
8	Headache	Headache	419	8	Pneumonia bacterial	216
9	Allergy	Hypersensitivity	385	9	Infusion-related reaction	215
10	Stress	Stress	380	10	Pulmonary tuberculosis	189
11	Collagen disorder	Collagen disorder	373	11	White blood cell count decreased	159
12	Diarrhoea	Diarrhoea	370	12	Arthritis bacterial	149
13	Unwell	Malaise	357	13	Lymphoma	147
14	Pollinosis	Seasonal allergy	340	14	Atypical mycobacterial infection	130
15	Severe pain	Pain	306	15[a]	Hepatic function abnormal	121
16	Osteoporosis	Osteoporosis	276	16	Pancytopenia	116
17	Muscle stiffness[c]	Musculoskeletal stiffness	272	17	Organizing pneumonia	104
18	Influenza	Influenza	261		Histiocytosis hematophagic	104
19	Infections	Infection	241	19	Pleurisy	99
20[a]	Tuberculosis	Tuberculosis	236	20	Platelet count decreased	98
21	Stomatitis	Stomatitis	218	21	Urinary tract infection	97
[a]	Pneumonia	Pneumonia	218		Disseminated tuberculosis	97
23	Asthma	Asthma	181	23	Disseminated intravascular coagulation	94
24	Eczema	Eczema	165	24	Breast cancer	88
25	Arthralgia	Arthralgia	162	25	Peritonitis	87
26	Slight fever	Pyrexia	147	26[a]	Tuberculosis	86
27	Dizzy	Dizziness	145		Pyelonephritis	86
28[a]	Interstitial pneumonia	Interstitial lung disease	137	28	Septic shock	85
29	Numbness	Hypoesthesia	132	29	Neutrophil count decreased	79
30	Hemorrhage	Hemorrhage	116		Gastric cancer	79
31	Depressed mood[c]	Depressed mood	115			
32	Constipation	Constipation	115			
33	Suffering[c]	Sense of oppression	106			
34	Abdominal pain	Abdominal pain	103			
35	Diabetes mellitus	Diabetes mellitus	100			
36	Rash	Rash	99			
37	Moon face[c]	Cushingoid	98			

Medical terms observed in the TOBYO database				Medical terms observed in the JADER database		
#	Event description in the TOBYO database	MedDRA PTs in the TOBYO database	Number of events	#	MedDRA PTs in the JADER database	Number of events
38	Edema	Edema	96			
39	Death	Death	96			
40	Itch	Pruritus	95			
41[a]	Hepatic function abnormal	Hepatic function abnormal	93			
42	Urticaria	Urticaria	92			
43	Vomiting	Vomiting	91			
44	Physical deconditioning	Asthenia	90			
45	Hyperthermia	Hyperthermia	89			
46	Paroxysmal attack[c]	Seizure-like phenomena	85			
47	Cataract	Cataract	84			

[a] Events appearing in both databases (the TOBYO database and JADER database).

[b] NA (not applicable) in columns for MedDRA PTs (preferred terms) means there was no corresponding term in MedDRA.

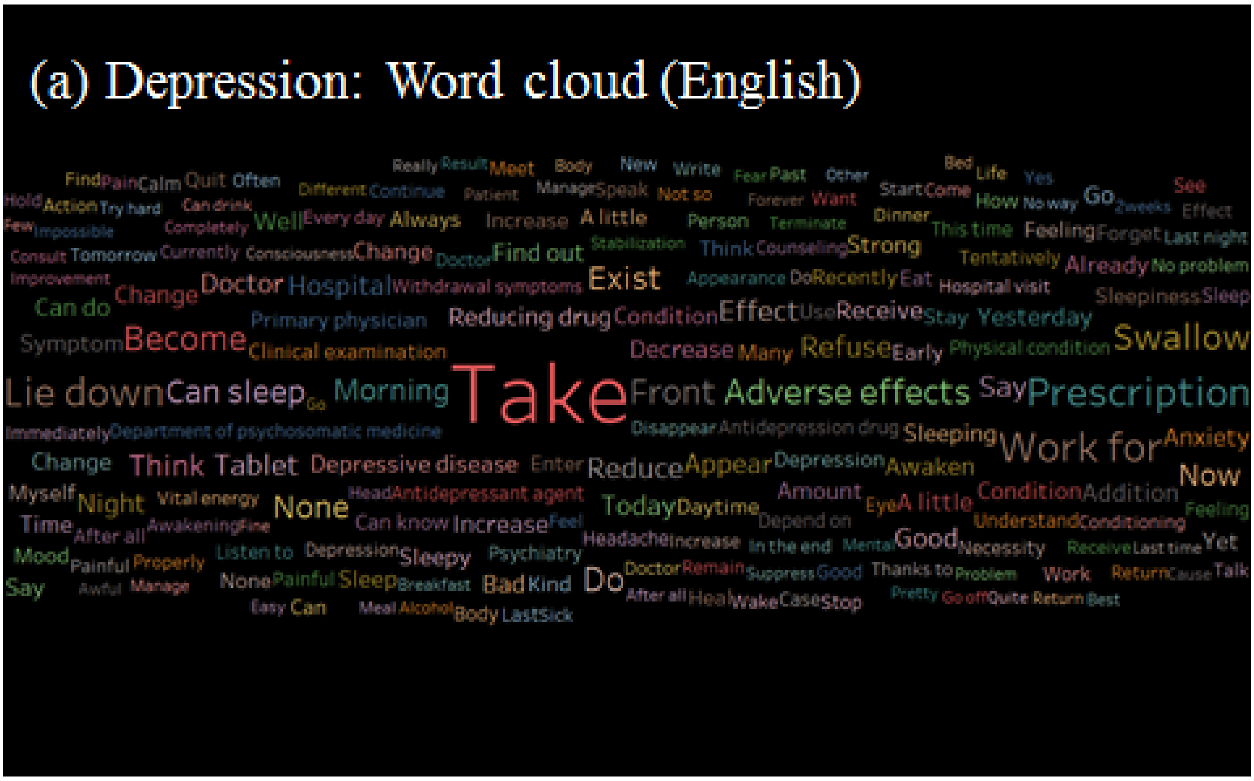
[c] Coding discrepancies occurred between the 2 reviewers (the different suggestions from the reviewers are shown in parentheses): Adverse reaction (Adverse reaction or Adverse drug reaction), Muscle stiffness (Musculoskeletal stiffness or Muscle rigidity), Depressed mood (Depressed mood or Listless), Suffering (Sense of oppression or Emotional distress), Moon face (Cushingoid or Face edema), and Paroxysmal attack (Seizure-like phenomena or Seizure).

Visualization of Contents in Tōbyōki Blogs

As depicted in Figures 6 and 7, “take” (as in “take medicine”) was the most frequent word in the datasets for depression and RA, suggesting that extraction of *tōbyōki* blog content containing the 100 most frequently mentioned drugs helped focus the data. Among patients with depression (Figure 6), sleep-related terms such as “lie down,” “sleep (noun),” “sleep (verb),” “sleepiness,” “awakening,” and “awaken” were observed, indicating that patients shared information about their disease conditions. We also found therapy-specific words such as “adverse effects,” “antidepressant agent,” “depression drug,” and “withdrawal symptoms.” Among patients with RA (Figure 7), pain-related terms such as “pain,” “painful,” “swelling,” and “stiffness” were frequently noted, indicating that these were important words for characterizing RA.

As depicted in Figure 8, the words “rheumatism,” “give relief,” “pain,” and “painful” were located at the center of the word cooccurrence networks of the 4 biological drugs considered in this study, meaning that these words were frequently used in association with all 4 drugs. The characteristics of each drug were also observed in the margins of the word cooccurrence networks. For example, adalimumab and etanercept, administered as subcutaneous injections, were associated with the word “self-injection,” and infliximab and tocilizumab, administered as intravenous infusions, were associated with the word “infusion.”

Figure 6. Word cloud: visualization of words frequently observed in tōbyōki blogs of patients with depression.(a) English version translated from the original Japanese and (b) the original Japanese version.



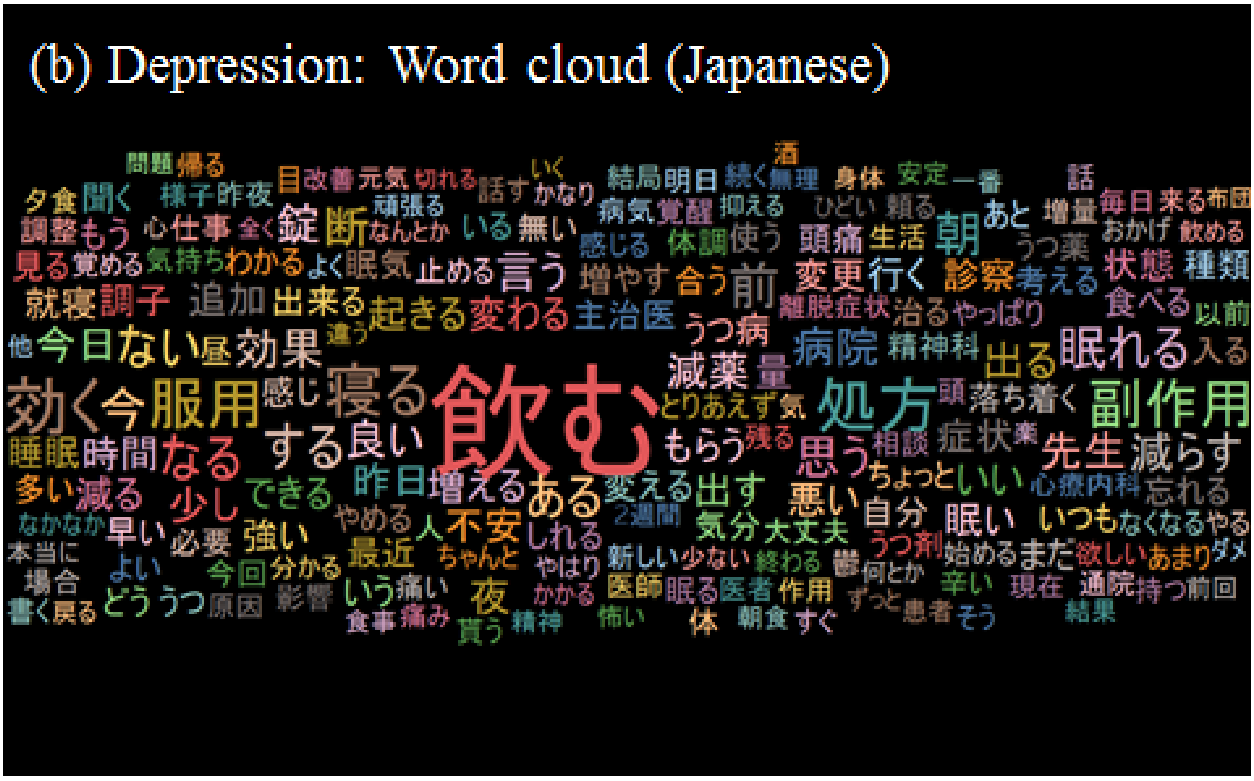
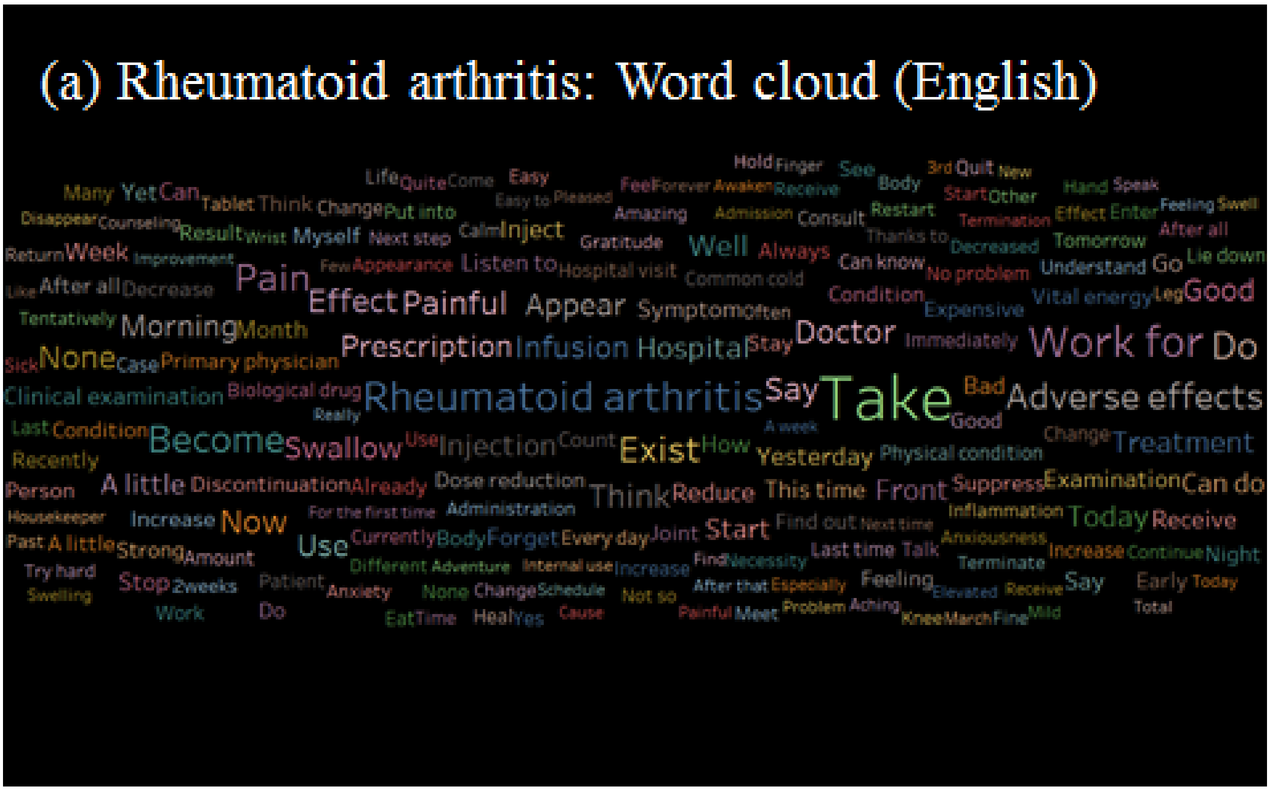


Figure 7. Word cloud: visualization of words frequently observed in tōbyōki blogs of patients with rheumatoid arthritis.(a) English version translated from the original Japanese and (b) the original Japanese version.



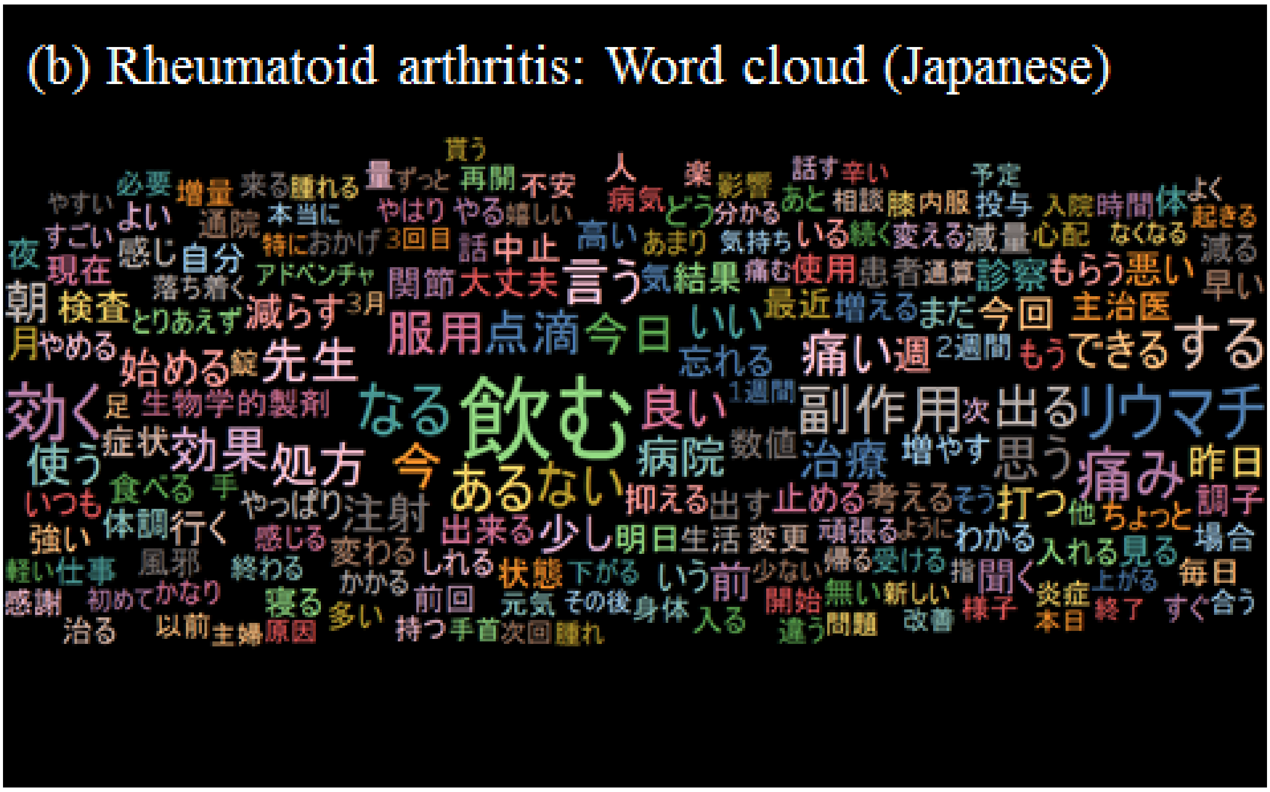
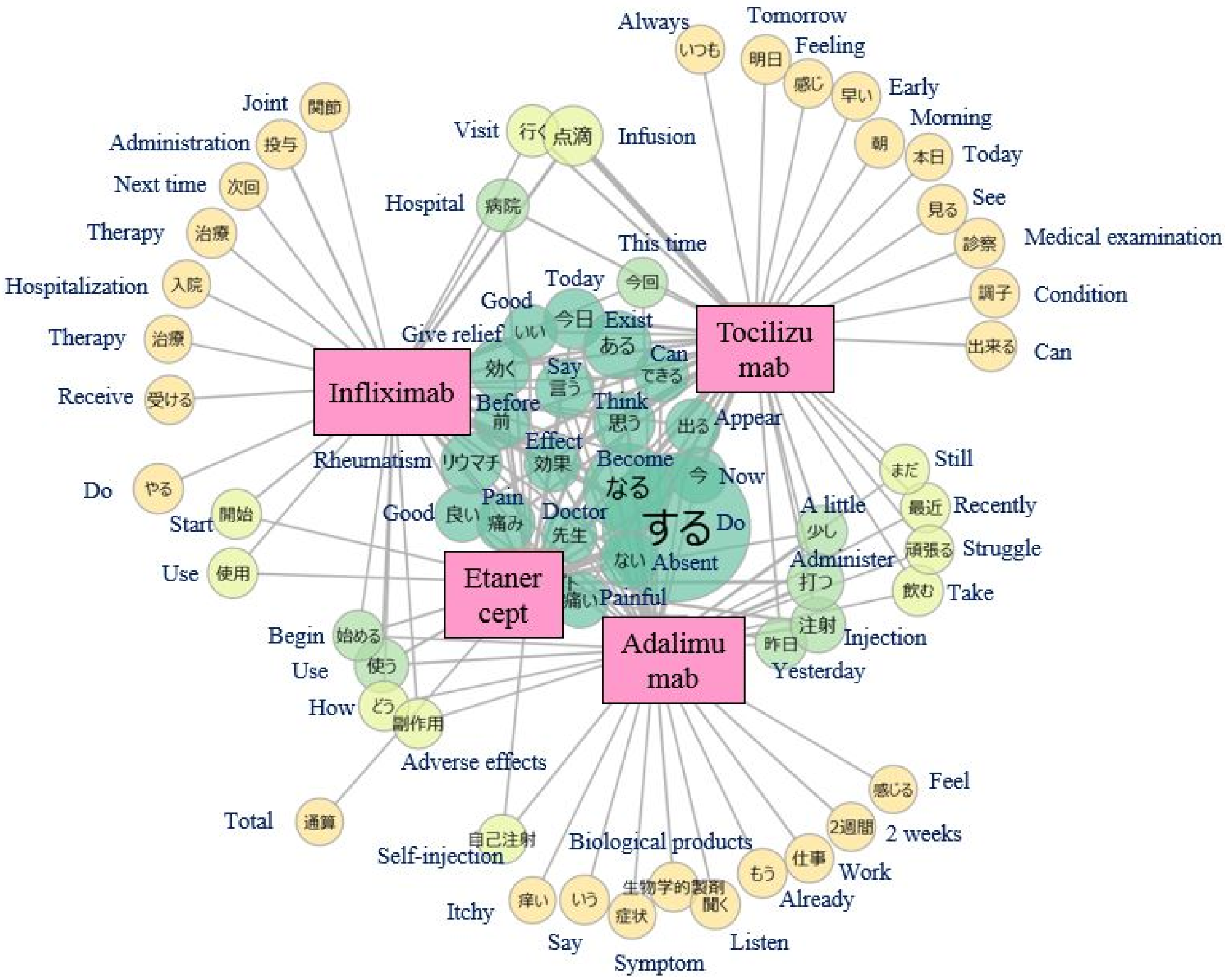


Figure 8. Word co-occurrence network: visualization of words occurring with biological drugs in tōbyōki blogs of patients with rheumatoid arthritis.Because the original language is Japanese, English translations are shown together.



Discussion

Principal Findings

Patient-generated data is likely to play a key role in improving PV [36]. In Japan, however, a system of self-reporting by patients is still being considered [10] and no patient-generated data resources have been explicitly identified. As one option for such a resource, this study evaluated the TOBYO database from the PV perspective.

In the whole TOBYO database, more blogs were written by female bloggers, and fewer blogs were written by people older than 50 years (Table 2). These findings were consistent with the results of a general survey of Internet usage in Japan [23]. Reflecting the fact that a higher percentage of *tōbyōki* blogs were written by women, the most frequently appearing disorders in the TOBYO database tended to have a higher prevalence in women: breast cancer, cervical cancer [37], RA [38], and panic disorder [39] (Table 3). Additional analysis of *tōbyōki* blogs would be more realistic for these disorders with a high prevalence in women. Our findings also suggested the relevance to frequently appearing disorders such as psychiatric disorders with subjective symptoms that have important clinical meaning, refractory disorders, autoimmune disorders, and other chronic disorders.

As shown in Tables 5 and 6, *tōbyōki* blogs written by patients with depression or RA contained symptomatic, subjective terms rather than the medical diagnosis or other medical terms. This revealed a difference between *tōbyōki* blogs and the JADER database generated by HCPs and implied that the TOBYO database might have the advantage of enabling the analysis of patient-level outcomes that could not be captured in existing data sources. Indeed, previous research has shown that psychiatric events are difficult to identify in health care administrative databases because physicians have difficulty detecting them and patients avoid reporting the symptoms to their physicians [40]. Another interesting possibility is that even if a patient reporting system is implemented, patients may not voluntarily report events that they do not consider to be AEs, as suggested by a previous research conducted on patients with Parkinson's disease [41]. In such a situation, in which patients themselves do not consider the possibility of AEs, the TOBYO database can be useful for capturing initial symptoms as AE signals.

We confirmed the feasibility of analyzing patient narratives using text mining to draw insights from *tōbyōki* blogs. Word clouds suggested characteristic words associated with selected conditions, such as “sleeping” and “anxiety” with depression and “pain” and “painful” with RA. This suggested that *tōbyōki* blogs were a useful resource for understanding characteristic information for each disorder. We were also able to identify words commonly associated with the 4 biological drugs located at the center of the word cooccurrence networks (Figure 8). The common words revealed in this study were not particularly noteworthy, but further research using the same approach with different drugs or disease areas might be useful for exploring drug safety concerns such as unknown AEs. For example, a report analyzing tweets written by Japanese patients with cancer suggested that visualizing narratives with word cooccurrence networks could be a useful approach to obtain insights from social media [42].

We noted several strengths of *tōbyōki* blogs as a resource for data analysis in this study. One was the ease of obtaining patient background information as summarized in Table 2. In contrast to other data sources such as Web-based discussion forums in which patient background information was inherently limited [43], *tōbyōki* blogs usually had a profile or introduction page from which a substantial level of information could be collected. Another strength was that most *tōbyōki* bloggers wrote their blogs voluntarily to record and share their experiences with others, resulting in primarily subjective descriptions of patient experiences. This first-hand, observational quality, free from obligations or interventions, might enable researchers to better understand patients’ actual concerns. A third strength was that compared with common blogs or social media (even those written by patients), *tōbyōki* blogs might be more likely to contain analyzable information on health-related or life-related topics because serious disease and other health crises were typical motivations for starting *tōbyōki* blogs.

Limitations

This study had several limitations. First, because *tōbyōki* blogs were written by only a segment of the patient population, generalization of the findings required caution. For instance, the elderly population might be underrepresented in Internet sources [23]. In addition, as a patient’s condition became more severe, it might be more difficult for them to continue writing their *tōbyōki* blogs. These biases should be considered when interpreting the results. Second, the insights obtained from qualitative text-mining approaches were based on some degree of subjective interpretation by researchers. For example, in word clouds, the relative size of each word reflected its frequency. It would be helpful to identify frequent or important words that were mentioned by many bloggers. On the other hand, because the size of each word did not reflect its clinical significance, it was possible that some smaller words might have greater clinical significances. Although word clouds have the potential to provide some insights from textual data, interpretation should be done in caution, keeping their pros and cons in mind. Third, some technical improvements would be necessary to extract more meaningful knowledge from the texts used in this study. For instance, we only considered fragmented words for analysis. By excluding phrases and other word combinations, we might have missed some important concepts or patient feelings. Additional techniques such as entity linking or named entity recognition should be considered in future studies to improve the results. Finally, because the language in social media tends to be highly informal and contain a wide variety of expressions, identification of specific concepts such as AEs and medicinal drugs from the unstructured narratives is a challenge. Although we could identify frequently appearing medical events in the TOBYO database, as shown in Tables 5 and 6, it is apparent that not all these events were AEs because we did not consider whether they had occurred before or after drug administration. Additional work is necessary to identify AEs occurring after drug administration.

Future Challenges for Social Pharmacovigilance

We also recognized future challenges for the effective use of social media data in PV. First, there is a need for an official guidance or policy about the necessity of obtaining informed consent from patients and protecting privacy. Although research interest in the use of social media is growing, there is currently no consensus or guideline [44]. We think there is no need for artificial constraints such as obtaining subsequent informed consent for the use of blog data because they are already publicly available on the Internet. Regarding patients’ decisions on whether to share data, a study showed that patients in the cancer community tended to think positively about sharing as long as the benefit of sharing data outweighed the risk [45], and the authors recommended that researchers should be careful to protect patient anonymity. In accordance with this recommendation, we prepared all analysis output as summarized data and not individual-level data in consideration of patients’ rights to protected privacy. Second, we acknowledge that issues exist with the reliability and reproducibility of social media, particularly from the regulatory, good pharmacovigilance practice perspective. Concerns about the incorporation of false information have been noted previously [46]. Considering our study using *tōbyōki* blogs, we assume that the extent of this problem would not be very large because there is no conceivable incentive for maintaining a fake *tōbyōki* blog at this time. Selecting blogs with more than 10 pages in the screening process before registration in the TOBYO database would help to prevent the inclusion of fake blogs. Concerns about the reproducibility of analysis present a practical challenge. It is not realistic to keep a dynamic dataset that is updated every day and that may be updated retrospectively. To ensure the reproducibility of individual research, storing the final dataset as a snapshot is recommended. Finally, because the volume of data on the Internet is continuously growing, there may be a need to think about how to efficiently detect and process AE information on the Internet. One option is to improve the text-mining algorithm using dictionary-based methods by preparing an annotated corpus to recognize AEs and drugs. However, this process would be time-consuming and costly. Another option is the application of a machine learning approach by preparing a classifier algorithm that does not necessarily require the preparation of annotated corpora, and there has been a report of the application of a deep-learning technique to detect potential AEs from social media texts [47]. In summary, we need to tackle several practical and technical issues to efficiently incorporate social media resources into PV.

Conclusions

PV activities should have a strong focus on patients' actual experiences, concerns, and outcomes, and this approach is expected to uncover hidden AE signals earlier and help us understand AEs in a patient-centered way. This study described the fundamental characteristics of *tōbyōki* blogs in the TOBYO database and provided insights into considering the use of such data for PV. Specific application possibilities for the TOBYO database include the analysis of disorders with a high prevalence in women, psychiatric disorders with important subjective symptoms, refractory disorders, and other chronic disorders. Further research would facilitate the enhancement of PV by incorporating patient-generated data from the Internet.

Acknowledgments

The authors thank Hiraku Miyake and Masaru Okuyama for providing *tōbyōki* blog data from the TOBYO database. The authors also thank Sawako Satomi and Terumi Nakayama for their invaluable input on designing this study and Matthew Mckeehan for writing assistance.

Conflicts of Interest

All authors are employees of Chugai Pharmaceutical Co, Ltd. Chugai Pharmaceutical Co, Ltd provided support in the form of salaries for all authors, but did not have any additional role in the study design, data analysis, decision to publish, or preparation of the manuscript.

Authors' Contributions

SM took primary responsibility for conducting this study. All authors contributed to the conception and study design. Data analyses and interpretation were done by SM, ST, MS, HK, and RT. SM drafted the manuscript with support from ST and MS. All authors contributed revisions of the manuscript and approved the final version.

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Abbreviations

AE: adverse event
ADR: adverse drug reaction
HCP: health care professional
ICSR: individual case safety report
JADER: Japanese Adverse Drug Event Report
MedDRA: Medical Dictionary for Regulatory Activities
PV: Pharmacovigilance
RA: rheumatoid arthritis

Edited by G Eysenbach; submitted 08.12.16; peer-reviewed by S Blackburn, E Aramaki; comments to author 03.01.17; revised version received 30.01.17; accepted 31.01.17; published 24.02.17.

Please cite as:
Matsuda S, Aoki K, Tomizawa S, Sone M, Tanaka R, Kuriki H, Takahashi Y
Analysis of Patient Narratives in Disease Blogs on the Internet: An Exploratory Study of Social Pharmacovigilance
JMIR Public Health Surveill 2017;3(1):e10
URL: http://publichealth.jmir.org/2017/1/e10/
doi:10.2196/publichealth.6872
PMID:28235749

Original Paper

Self-Reported Psychosomatic Complaints In Swedish Children, Adolescents, and Young Adults Living in Rural and Urban Areas: An Internet-Based Survey

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Abstract

Background: Frequencies in reported psychosomatic illnesses have increased in Sweden among children, adolescents, and young adults. Little is known about demographic differences in self-reported psychosomatic complaints, such as between urban and rural areas, and whether surveys launched on the Internet could be a useful method in sampling such data.

Objectives: This study examines the connection between psychosomatic illnesses and demographics in Swedish children and youth. The feasibility of using the Internet to gather large amounts of data regarding psychosomatic complaints in this group is another major objective of this study.

Methods: A cross-sectional study using 7 validated questions about psychosomatic health, were launched in a controlled way onto a recognized Swedish Internet community site, which targeted users 10 to 24 years of age. The subjects were able to answer the items while they were logged in to their personal domain. The results were analyzed cross-geographically within Sweden.

Results: In total, we received 100,000 to 130,000 individual answers per question. Subjects of both sexes generally reported significantly higher levels of self-reported psychosomatic complaints in major city areas as compared with minor city/rural areas, even though the differences between the areas were small. For example, 12.00% (4472/37,265) of females in minor regions reported always feeling tense, compared with 13.80% (3156/22,873) of females in major regions (P<.001). In males, the answer pattern was similar, 16.40% (4887/29,801) in major regions versus 15.60% (2712/17,386) in minor regions, (P=.006). Females reported significantly higher frequencies of psychosomatic complaints than males (P<.001).

Conclusions: In subjects aged 10 to 24 years, higher levels of psychosomatic complaints appear to correlate with living in major city areas in comparison with minor city/rural areas. Surveys launched on the Internet could be a useful method in sampling data regarding psychosomatic health for this age group.

(JMIR Public Health Surveill 2017;3(1):e9) doi:10.2196/publichealth.5902

KEYWORDS

adolescents; children; environmental risk; psychosomatic; urban living; Internet

Introduction

Children, adolescents, and young adults in Sweden frequently report mental health issues [1,2]. The mental health issues we are referring to in this Swedish population are most commonly complaints about perceived stress and psychosomatic symptoms. It is speculated that current lifestyles, environments, and societal demands, with increased exposure to stress, play a role in the changing patterns of mental health problems in this population. With less opportunity for physical activity, play, and recovery, stress reactions may become chronic, which increases the risk for psychosomatic complaints and mental disorders [3-6].

The development from chronic stress to psychosomatic symptoms and eventually disease depends on multiple factors, such as genetic vulnerability [7], socioeconomic situation [8], adverse or stressful life events and the timing of such [9], disturbances in important relationships, and school performance, which all fit into a bio-psycho-social model [10], as well as the concept of the developmental origin of health and disease [11].

In addition, the surrounding environment has an impact on disease development [12]. For example, while cities are centers of wealth creation, culture, and innovation, they are also associated with adverse health outcomes that are less prevalent in rural areas. The “unhealthy” urban environment may be due to increased exposure to harmful pollutants and denser, more stressful living. Previous research has shown that living in an urban environment is associated with an increased prevalence of mental health disorders, such as schizophrenia and depression [13-16]. This has been partly ascribed to higher levels of social stress in cities as compared with in rural areas. Lederbogen et al [17] recently showed that both city upbringing and current city living were associated with increased amygdala activity, which, among other functions, signals negative affect, stress, and environmental threat. Increased amygdala activity has been strongly implicated in anxiety disorders and depression [13]. Assuming that a rural population is more exposed to nature, this would confirm the increasing evidence that natural (green and blue) environments have a restorative influence, resulting in decreased stress levels and positive effects on mental health [18-20]. These benefits may also be gained by moving to urban green areas [21,22]. A recent study, investigating symptoms of depression, demonstrated that walking in nature decreased both self-reported rumination and neural activity in the subgenual prefrontal cortex (associated with stress and negative thought activity), while such changes were not found after a walk in an urban environment [23]. In particular, children and young people seem to benefit the most from natural environments with improvements in cognitive and behavioral function and development [24,25]. For example, this may be due to trees’ contribution to reduction of toxic environmental exposures, such as traffic-related air pollution and noise [26-29], which are risk factors for poor development and mental health problems [30-32]. These environmental risks are less pronounced in rural environments. In an increasingly urbanized world, these issues are important to explore. Thus, genetic, social, and physical environmental factors interact in the development of stress and psychosomatic reactions in such a way that in due course they may influence children's well-being and ill health, with salient implications also for development of future health and disease in the life course perspective [33].

In a previous Internet-based study, we have shown that stress and psychosomatic health complaints are common in children, adolescents, and young adults. Older teenage females (16-18 years of age) had the highest levels of complaints, and both sexes reported a slightly worse self-perceived general health status in 2010 than in 2007 [2]. However, this study did not investigate the impact of living environment on self-reported psychosomatic complaints. Previous studies have found a positive environmental impact on mental health, with a protective effect of natural, less urbanized areas, but most of these studies are performed on adult populations [33].

The purpose of the present study was to examine self-reported psychosomatic complaints among children and adolescents, to unravel potential differences with regard to these complaints depending on sociodemographic factors and residential environment in Sweden. Our hypothesis is that psychosomatic complaints are more prevalent among the young in urban areas and more frequent in females

Methods

Participants

The use of Internet has the benefit of providing a high number of respondents in all categories concerning age, sex, and geographical region. We recruited 130,000 study participants by convenience sampling through the website LunarStorm. LunarStorm's website was one of the first social Web communities to be established in Sweden. At the time of our sampling (2005), LunarStorm was the largest Internet community in Sweden. It had 1.3 million active members and approximately 360,000 unique visitors per day who spent approximately 40 minutes per visit on the site (TNS Gallup/Red Measure, Nielsen/Net Ratings). Among 15- to 20-year olds in Sweden by that time, 83% were LunarStorm members, and 25 of 30 pupils in every secondary school class were connected (Lunarworks AB/SCB). Of members, 53% were females.

Measures and Design

To assess psychosomatic complaints among the participants we used the well-established Psychosomatic Problems Scale (PBS) [1,34,35]. The scale has been tested for reliability by Hagquist, using Rasch analysis, and has sound psychometric properties as a whole [1,34,35]. The Swedish National Board of Health and Welfare use it in studies of children and adolescents and their psychosomatic health and wellbeing. PBS is a composite measure of subjective health experienced during the last 6 months, encompassing the following items (which were delivered in question form): ‘difficulty concentrating,’ ‘difficulty sleeping,’ ‘suffers from headaches,’ ‘suffers from stomach aches,’ ‘feels tense,’ ‘poor appetite,’ and ‘feels low’. The 6 response categories to the items were: ‘don't know’; ‘no, never’; ‘no, seldom’; ‘yes, sometimes’; ‘yes, often’; and ‘yes, always.’

Our data were collected by launching the questions on 7 consecutive days in the spring of 2005. We posted 1 question per day rather than presenting the complete questionnaire on a single occasion because the Web community administrator had the experience that using long composite questionnaires substantially decreased the participation rate. However, it is therefore not possible to directly compare the results of this study with results from studies using the original composite measure. Each participant could log into their own ‘LunarStorm corner' and voluntarily choose to complete the questions in private and in their own time on the community site. These privacy and time aspects may contribute to more reliable replies [36]. All data on self-reported psychosomatic complaints from the Lunarstorm platform were sampled through a noncommercial collaboration between the research team and Lunarstorm .

While the use of computerized psychological assessment has increased with time, there are a limited number of validation analyses regarding Internet-based surveys among young people. However, most research to date seems to conclude that results from Internet-based recruitment corresponds well to results from more traditional administration means. In a recent study, a brief Web-based screening questionnaire for common mental disorders was validated with follow-up phone interviews, using a Diagnostic and Statistical Manual of Mental Disorders–based interview manual as a gold standard [37]. Good agreement between responses to hand out questionnaires and those administered via the Internet was demonstrated in yet another study from 2005 [38], as well as in a recent review, where most scales show high interformat reliability [39]. Internet distribution may potentially also improve participation rate, particularly so among adolescents, by avoiding certain barriers, such as putting a questionnaire in the mail [40]. Equally, it widens geographical access and facilitates the recruitment of rural populations [41].

Members saw the question after login, and only 1 answer per login was permitted and counted. Each answer was registered as unique; hence, it was not possible repeat login and reply more than once. We focused on young people aged 10 to 24 years. The age groups were differentiated as follows: 10 to 12 years (children), 13 to 16 years (adolescents), and 17 to 24 years (young adults). The percentage of LunarStorm members in these different age groups, ranged between 20% and 88%, with the highest values (>80%) being adolescents between 13 and 16 years of age.

Based on individual Internet protocol adresses, we made a geographical categorization of the subjects into 3 major city regions (Stockholm, Göteborg, and Malmö) and 18 minor cities and regions with lower population density in Sweden (Blekinge, Dalarna, Gotland, Gävleborg, Halland, Jämtland, Jönköping, Kalmar, Kronoberg, Norrbotten, Södermanland, Uppsala, Värmland, Västerbotten, Västernorrland, Västmanland, Örebro, and Östergötland). This sample was then dichotomized into ‘major city regions’ and ‘minor city/rural regions.’

The LunarStorm site did not provide data on socioeconomic background. Therefore, we added demographic data separately via Statistics Sweden, from the Swedish Living Conditions Surveys [42], and assigned to the participants on a group level determined by geographical location. This general Swedish sampling from the Swedish Living Conditions Survey was made in 2005 by interviews at home visits, and 75.10% (4277/5698) of eligible subjects were interviewed. Data on household income for 2005 was accessed separately via Statistics Sweden [43]. The data from Statistics Sweden are categorized in similar categories as ours; however, the major cities are contained within counties with additional smaller cities, towns, and villages around the large cities.

Statistical Analysis

Each of the possible responses to each of the 7 questions in the Likert format was assigned a number: ‘no, never=1’; ‘no, seldom=2’; ‘yes, sometimes=3’; ‘yes, often=4’ and ‘yes, always=5’. Respondents answering, “don’t know” were excluded from the analysis. The response frequency was calculated and independent samples *t* tests were conducted to investigate any significant differences in mean ranks depending on geographic location (major and minor regions) or gender. Variables were tested for normal distribution by Kolmogorov-Smirnov test. Normally distributed variables are presented as means (SD). A two-sided P=.05 was considered as statistically significant. All statistical analyses were performed with SPSS22.0.

Ethical Considerations

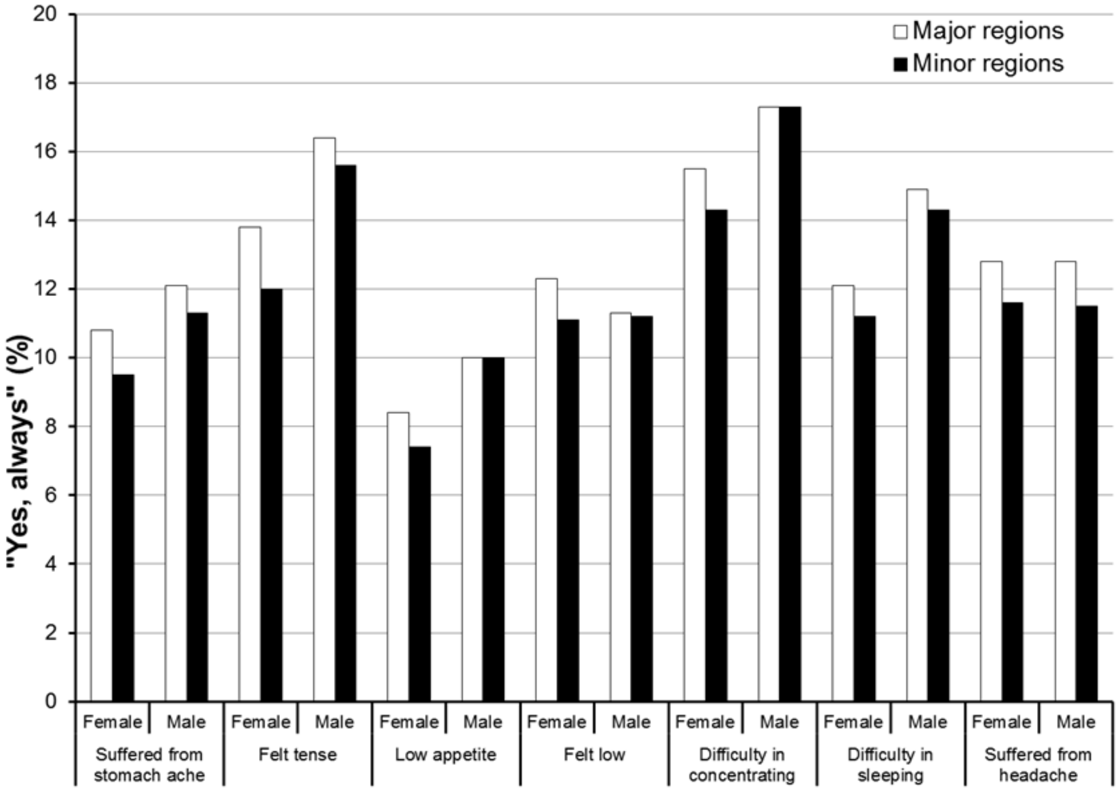
Ethical approval was obtained from the chairman of the review board. According to the ethical guidelines of the ethics board in Gothenburg, Sweden, posting questionnaires on the Internet does not require formal ethical approval from a committee. However, we choose to discuss these issues thoroughly with the chairman and received full approval.

Results

Participant Characteristics

Females answered the questions more frequently, and also reported significantly higher frequencies of psychosomatic complaints than males on all 7 questions (P<.001) (Table 1). This was a consistent pattern for the majority of the questions with the exception of 3 questions in males, where there was no significant difference between the major city regions and the minor city/rural areas regarding ‘difficulty in concentrating,’ ‘low appetite,’ and ‘felt low’ (Figure 1).

Figure 1. The percentage of ”Yes, always” responses to different psychosomatic complaints for 10- to 24-year-old females and males from major and minor regions of Sweden.



Outcomes

For all 7 questions, females from the small city/rural areas presented with better self-perceived health as compared with those from the major city areas (Table 2, Figure 1).

Table 1. Sex differences regarding self-reported psychosomatic complaints.

Question/alternative			Yes, always, %	Yes, often, %	Yes, sometimes, %	No, seldom, %	No, never, %	Number of responders	Overall *P* value
Suffered from stomach ache									
	Major regions								
		Females	10.80	16.10	46.20	19.50	7.40	24,846	
		Males	12.10	6.20	31.90	27.90	22.00	16,408	<.001
	Minor regions								
		Females	9.50	16.10	46.10	20.60	7.60	41,661	
		Males	11.30	6.00	31.50	28.30	23.00	28,198	<.001
Felt tense									
	Major regions								
		Females	13.80	21.90	44.50	14.00	5.80	22,873	
		Males	16.40	10.90	41.70	17.80	13.20	17,386	<.001
	Minor regions								
		Females	12.00	21.10	45.40	15.50	6.10	37,265	
		Males	15.60	9.80	41.30	18.70	14.60	29,801	<.001
Low appetite									
	Major regions								
		Females	8.40	9.40	41.20	22.80	18.10	22,770	
		Males	10.00	5.00	28.70	23.40	33.00	15,785	<.001
	Minor regions								
		Females	7.40	8.90	41.50	23.60	18.60	36,860	
		Males	10.00	4.70	28.20	24.10	33.00	26,919	<.001
Felt low									
	Major regions								
		Females	12.30	27.00	47.70	9.90	3.10	31,056	
		Males	11.30	11.20	43.40	21.60	12.50	19,817	<.001
	Minor regions								
		Females	11.10	27.00	48.30	10.60	3.10	50,511	
		Males	11.20	11.50	42.90	22.30	12.20	33,409	<.001
Difficulty in concentrating									
	Major regions								
		Females	15.50	21.90	47.60	10.50	4.60	27,883	
		Males	17.30	14.60	44.40	14.70	9.00	20,114	<.001
	Minor regions								
		Females	14.30	21.90	48.70	10.70	4.40	46,293	
		Males	17.30	14.60	44.60	14.70	8.80	33,792	<.001
Difficulty in sleeping									
	Major regions								
		Females	12.10	13.10	44.10	21.80	8.80	29,488	
		Males	14.90	9.30	35.40	24.20	16.10	20,621	<.001
	Minor regions								
		Females	11.20	12.70	44.40	22.60	9.20	48,583	

Question/alternative			Yes, always, %	Yes, often, %	Yes, sometimes, %	No, seldom, %	No, never, %	Number of responders	Overall *P* value
		Males	14.30	8.90	35.70	24.60	16.60	34,999	<.001
Suffered from headache									
	Major regions								
		Females	12.80	18.60	48.90	18.50	5.30	26,494	
		Males	12.80	8.70	38.60	27.30	12.60	17,899	<.001
	Minor regions								
		Females	11.60	18.30	45.20	19.60	5.20	43,164	
		Males	11.50	8.10	38.70	28.90	12.90	30,808	<.001

Table 2. Percentage demographic distribution of responders across Sweden, answering 7 items of self- reported psychosomatic complaints on the web in May 2005.

Question/alternative		Yes, always %	Yes, often %	Yes, sometimes %	No, seldom %	No, never %	Number of responders	Overall *P* value	Interpretation
Suffered from stomachache									
	Females, major regions	10.80	16.10	46.20	19.50	7.40	24,846		
	Females, minor regions	9.50	16.10	46.10	20.60	7.60	41,661	<.001	Females in minor regions fewer complaints
	Males, major regions	12.10	6.20	31.90	27.90	22.00	16,408		
	Males, minor regions	11.30	6.00	31.50	28.30	23.00	28,198	<.001	Males in minor regions fewer complaints
Felt tense									
	Females, major regions	13.80	21.90	44.50	14.00	5.80	22,873		
	Females, minor regions	12.00	21.10	45.40	15.50	6.10	37,265	<.001	Females in minor regions fewer complaints
	Males, major regions	16.40	10.90	41.70	17.80	13.20	17,386		
	Males, minor regions	15.60	9.80	41.30	18.70	14.60	29,801	<.001	Males in minor regions fewer complaints
Low appetite									
	Females, major regions	8.40	9.40	41.20	22.80	18.10	22,770		
	Females, minor regions	7.40	8.90	41.50	23.60	18.60	36,860	<.001	Females in minor regions fewer complaints
	Males, major regions	10.00	5.00	28.70	23.40	33.00	15,785		
	Males, minor regions	10.00	4.70	28.20	24.10	33.00	26,919	.41	No difference
Felt low									
	Females, major regions	12.30	27.00	47.70	9.90	3.10	31,056		
	Females, minor regions	11.10	27.00	48.30	10.60	3.10	50,511	<.001	Females in minor regions fewer complaints
	Males, major regions	11.30	11.20	43.40	21.60	12.50	19,817		
	Males, minor regions	11.20	11.50	42.90	22.30	12.20	33,409	.74	No difference
Difficulty in concentrating									
	Females, major regions	15.50	21.90	47.60	10.50	4.60	27,883		
	Females, minor regions	14.30	21.90	48.70	10.70	4.40	46,293	.006	Females in minor regions fewer complaints

Question/alternative		Yes, always %	Yes, often %	Yes, sometimes %	No, seldom %	No, never %	Number of responders	Overall *P* value	Interpretation
	Males, major regions	17.30	14.60	44.40	14.70	9.00	20,114		
	Males, minor regions	17.30	14.60	44.60	14.70	8.80	33,792	0.61	No difference
Difficulty in sleeping									
	Females, major regions	12.10	13.10	44.10	21.80	8.80	29,488		
	Females, minor regions	11.20	12.70	44.40	22.60	9.20	48,583	<.001	Females in minor regions fewer complaints
	Males, major regions	14.90	9.30	35.40	24.20	16.10	20,621		
	Males, minor regions	14.30	8.90	35.70	24.60	16.60	34,999	.006	Males in minor regions fewer complaints
Suffered from headache									
	Females, major regions	12.80	18.60	48.90	18.50	5.30	26,494		
	Females, minor regions	11.60	18.30	45.20	19.60	5.20	43,164	<.001	Females in minor regions fewer complaints
	Males, major regions	12.80	8.70	38.60	27.30	12.60	17,899		
	Males, minor regions	11.50	8.10	38.70	28.90	12.90	30,808	<.001	Males in minor regions fewer complaints

In the separate data sampling performed via Statistics Sweden [44], the informants answered questions regarding socioeconomic status and the results the indicated differences between urban and rural areas (the same city regions as in the Lunarstorm data sampling). The data suggest that inhabitants in the major city regions generally have better education, access to the Internet, and higher employment levels. In contrast, in the major city regions the populations are in general more economically disadvantaged.

When analyzing household income data (Table 3) it seems that although there is a generally even distribution of income across Sweden, the poorest of the adult population (rated as receiving zero income) are found in counties containing the large city areas as well as the high earners [43].

Table 3. Demographic distribution of population with zero income.

% 0 income	All age groups	20-24 years	25-29 years	30-34 years	35-39 years	40-44 years	45-49 years
Urban, mean (SD)							
	5.70 (0.87)	10.20 (2.19)	6.43 (1.43)	4.49 (1.17)	3.84 (0.87)	3.74 (0.91)	3.48 (0.88)
Rural, mean (SD)							
	4.13 (0.78)	7.79 (1.58)	4.63 (0.86)	2.61 (0.56)	2.07 (0.52)	2.10 (0.52)	1.91 (0.49)
P (*t* test)	.005	.031	.006	Not significant	<.001	<.001	<.001

Discussion

Principal Findings

The major finding of this study was that psychosomatic complaints were reported to a significantly higher degree in females from the major city areas as compared with the minor city/rural areas. This pattern also prevailed for males, although there was no statistically significant difference regarding the following items: difficulty in concentrating, low appetite, and felt low (Figure 1).

The higher levels of complaints in females compared with males in both area categories support and extend the results from earlier studies [1,2,8]. Similar findings, using the same questionnaire items, have been reported in other studies where youth were recruited from small regions in Sweden [1,34,35] and psychosomatic complaints were examined using the questionnaires in a manual format handed out in schools at regular intervals since 1985. To our knowledge, the current study is the first large study with more than 100,000 participants to investigate differences in psychosomatic health in relation to living in large city regions versus minor city/rural regions.

These results are in line with a study by Samanta et al [45] where rural living appeared protective against development of mental health issues among male adolescents (13-15 years), as well as with an earlier study in New Zealand, where adolescents from larger population centers reported more life event stresses than those from smaller centers [46]. The mechanisms underlying these region-related differences in psychosomatic health cannot be revealed by the current study. However, it is interesting to mention that the study by Lederbogen et al [17] shows that urban living is a risk factor for decreased social stress resilience with subsequently higher prevalence of mental disorders than rural living. There could also be regional differences in coping with mental health. Wang et al [47] recently showed that rural participants had a larger total number of visiting days, in a in a Web-based trauma intervention and visited more program modules than urban participants. With few exceptions [28], most studies on general psychiatric disorders show that the admission rates are higher in urban than in rural areas [3,4,48]. Even though the current study did not investigate specific psychiatric diagnoses, our findings are in line with the research on the effects of urbanization, especially the effect on stress-related disorders.

Several other factors are known to increase the risk for psychosomatic complaints among children and adolescents, such as housing, school system, neighborhood context, and other environmental issues [8,9,49-51]. These factors are often interrelated and the causality is complex. In general, living under poor socioeconomic conditions is strongly correlated to adverse mental and physical health outcomes [52]. In order to get complementary information on the sociodemographic background for our sample, we used data from Statistics Sweden collected in 2005 [43]. While we were unable to include these data as confounders in the analysis, due to group level reporting, the data suggest that living in 1 of the minor regions is associated with a less adverse economic situation, and with higher access to a daily newspaper than the major city regions, but it was also apparent that access to the Internet in the home, completed postsecondary education, and employment was higher in the major city regions than the minor regions. Our analysis of income shows a pattern of clusters of zero income earners being concentrated in the urban areas. In the counties containing the major cities, 0.58% of the population had exceptionally high earnings as compared with 0.20% for the rest of the country, which is pointing to some inequalities regarding income in urban areas.

We speculate that these large socioeconomic differences in the urban areas may contribute to the ratings of higher degrees of psychosomatic complaints in our subjects living in these areas. These complementary data may have provided a partial explanation for the regional differences in self-reported psychosomatic health found in the current study. Our approach did not allow matching on an individual level for the 2 different datasets (the data collected from the website and the data from Statistics Sweden), but merely provides a spatial correlation for the major and the minor areas. However, it provides a general picture of the geographical distribution of socioeconomic issues in Sweden and how these, at least partly, overlap with the general picture of the distribution of psychosomatic complaints in respective areas.

We are unable to draw any conclusion about the causality between city living and the potentially increased risk for psychosomatic complaints from this cross-sectional study. One hypothesis is that differences in exposure to nature and green areas for recreation may account for some of the variance. Numerous studies show that access to green spaces has been associated with health benefits at both individual and neighbourhood levels [22,53,54] and that components of urban city living, such as traffic noise, air pollution, and crowds have negative effects on psychological health [55-57]. In addition, socioeconomically related health differences seem to decrease with increasing amount of green in the living area [58]. Although our data did not provide information on land use or environmental characteristics, we can assume that the major city areas are less green than the more rural areas. Sweden is a scarcely populated country and the majority of the population is concentrated to the large city areas. Thus, natural environments and less densely populated towns and cities characterize the rest of the country. The socioeconomic inequalities in urban areas are also an interesting observation that possibly contributes to the wellbeing of young people [59].

A common stressor in adults is having a low perceived degree of control over ones day to day life: it is plausible that living in an urban environment with plenty of potentially challenging outer structures, such as living in dense areas, commuting and fighting for resources on highly competitive social arenas could be stress factors also accounting for this variability in young people. Social stress and lack of control [50] could mediate the stressful effects of city life, and might account for some of the individual differences seen [17].

Limitations

Because the data were gathered in collaboration with the LunarStorm site that did not provide information regarding specific age, socioeconomic background, ethnicity, family background, living conditions, or general wellness the analytical base of the study is limited, with restricted control for confounding variables. Some accountancy for this was taken by the additional dataset from Statistics Sweden displaying sociodemographic patterns of the populations on a regional spatial level.

The PBS was originally analyzed when all items were answered at the same time, and the good psychometric properties cannot automatically be supposed to also be valid in this sample, where each item was answered on a separate day. We did omit 1 item:

‘felt giddy.’ This was due to low reply frequencies, which means that the scale presented was incomplete.

Another limitation is that approximately 350,000 people logged in on a given day, raising the possibility of selection bias. Due to the fact that the subjects were anonymous, we could not investigate selection effects. However, a recent study using the Internet for health-related topics was independent of gender, age, and diagnosis in a group of patients with psychosomatic disorders [60]. Additionally, the response rate obtained at LunarStorm was very high for such a generalized Internet-based survey. Data were sampled in 2005, and it is possible that response patterns could have been different, if the survey would have been launched in 2016, considering, for example, the global economic crisis that has emerged during this time span. Societal and environmental changes as well as changing attitudes toward psychosomatic symptoms, increasing Internet access, and the readiness to report complaints on a Web community could be some of the factors, which might have had an impact on response patterns.

Because studies on Internet-based assessment are a relatively recent phenomenon, the validity of the data gathered in this manner is uncertain and worth further exploration. In our study, the spatial resolution is low and areas with some of the highest variability in socioeconomic factors were merged together by the LunarStorm site administrator and classified as “major city area.” Because perceived stress and ill health have a strong association with socioeconomic status, the merging of areas might have attenuated our findings. A higher spatial resolution might have shown more pronounced differences between areas, also because within city areas there are large socioeconomic and neighborhood differences [61].

Strengths

One of the strengths of the present study is that the subject could log into her/his own LunarStorm corner privately and at a suitable time, and voluntarily chose to participate. While representing a convenience sample, this raises the probability of sincere replies.

Another advantage is the 100,000 to 130,000 of subjects of various ages who responded. The received responses from 100,000 to 130,000 individuals per day, represents on average 36% of the entire population of members logging in daily (n=360,000). This volume of responders would be difficult to reach in such a short time space by other ways of communication. Furthermore, such administrative factors as data transcription, the risk of excluded values and ‘odd’ answers, and the concern that other people might read the answers can be overcome by computer- and Internet-based surveys.

Conclusion

Young people in Sweden have a generally high prevalence of self-reported psychosomatic complaints, and these seem to be more common in major city areas as compared with minor city/rural areas. As urbanization progresses globally this might be of importance as a risk factor hampering the wellbeing of children and adolescents. The current study provides valuable information on the importance of regional differences and the potential benefit of living closer to nature, which should be taken into account when planning for healthier living environments. The study inspires to identifying urban environmental features that promote health as well as finding interventions to raise subjective and collective psychological resilience of, especially young, city dwellers. In addition, it motivates further studies exploring the causality and mechanistic explanations for environmentally as well as socioeconomically related links to psychosomatic health.

Acknowledgments

We would like to thank Thomas Karlsson for statistical help. This study was funded by Sahlgrenska Hospital, Olle Engkvist Foundation, Kempe-Carlgrenska Foundation, and the Public Health Committee of West Sweden.

Authors' Contributions

The study was jointly designed by WO and PF. All authors were responsible for the data analyses. PF and WO were responsible for data acquisition. All authors jointly interpreted findings. KLF drafted the paper outline. All authors contributed to successive drafts. All authors approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

PBS: psychosomatic problems scale

Edited by G Eysenbach; submitted 25.04.16; peer-reviewed by R Choubisa, YS Bin, EB Davies; comments to author 25.07.16; revised version received 09.12.16; accepted 03.01.17; published 07.03.17.

Please cite as:
Laundy Frisenstam K, van den Bosch M, Chen Y, Friberg P, Osika W
Self-Reported Psychosomatic Complaints In Swedish Children, Adolescents, and Young Adults Living in Rural and Urban Areas: An Internet-Based Survey
JMIR Public Health Surveill 2017;3(1):e9
URL: http://publichealth.jmir.org/2017/1/e9/
doi:10.2196/publichealth.5902
PMID:28270381

Rapid Surveillance Report

The Annual American Men's Internet Survey of Behaviors of Men Who Have Sex With Men in the United States: 2015 Key Indicators Report

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Abstract

The American Men's Internet Survey (AMIS) is an annual Web-based behavioral survey of men who have sex with men (MSM) living in the United States. This Rapid Surveillance Report describes the third cycle of data collection (September 2015 through April 2016; AMIS-2015). The key indicators are the same as previously reported for AMIS (December 2013-May 2014, AMIS-2013; November 2014-April 2015, AMIS-2014). The AMIS survey methodology has not substantively changed since AMIS-2014. MSM were recruited from a variety of websites using banner advertisements and email blasts. Additionally, participants from AMIS-2014 who agreed to be recontacted for future research were emailed a link to the AMIS-2015 survey. Men were eligible to participate if they were age 15 years and older, resided in the United States, provided a valid US ZIP code, and reported ever having sex with a man. We examined demographic and recruitment characteristics using multivariable regression modeling ($P<.05$) stratified by participants' self-reported human immunodeficiency virus (HIV) status. The AMIS-2015 round of data collection resulted in 10,217 completed surveys from MSM representing every US state and Puerto Rico. Participants were mainly non-Hispanic white, older than 40 years, living in the US South, living in urban areas, and recruited from general social networking websites. Self-reported HIV prevalence was 9.35% (955/10,217). Compared to HIV-negative/unknown status participants, HIV-positive participants were more likely to have had anal sex without a condom with any male partner in the past 12 months (75.50%, 721/955 vs 63.09%, 5843/9262, $P<.001$) and more likely to have had anal sex without a condom with a serodiscordant or unknown status partner (34.45%, 329/955 vs 17.07%, 1581/9262, $P<.001$). The reported use of marijuana and other illicit substances in the past 12 months was higher among HIV-positive participants than HIV-negative/unknown status participants (marijuana use: 24.61%, 235/955 vs 22.96%, 2127/9262; other illicit substance use: 28.59%, 273/955 vs 17.51%, 1622/9262, respectively; both $P<.001$). Most HIV-negative/unknown status participants (79.11%, 7327/9262) reported ever having a previous HIV test, and 55.69% (5158/9262) reported HIV testing in the past 12 months. HIV-positive participants were more likely to report sexually transmitted infection (STI) testing and diagnosis compared to HIV-negative/unknown status participants (STI testing: 71.73%, 685/955 vs 38.52%, 3568/9262; STI diagnosis: 25.65%, 245/955 vs 8.12%, 752/9262, respectively; both $P<.001$).

(JMIR Public Health Surveill 2017;3(1):e13) doi:10.2196/publichealth.7119

KEYWORDS

MSM; gay; homosexual; bisexual; HIV; STD; Internet; survey; surveillance; rapid surveillance report

Introduction

The American Men’s Internet Survey (AMIS) is an annual online behavioral survey of men who have sex with men (MSM) who live in the United States. The methods have been previously published [1,2]. This supplemental report updates that previous manuscript with the most current data available from AMIS (AMIS-2015). Methods in AMIS-2015 are unchanged from the previously published manuscript unless otherwise noted.

Methods

Recruitment and Enrollment

As in the prior year, AMIS participants were recruited through convenience sampling from a variety of websites using banner advertisements or email blasts to website members (hereafter referred to generically as “ads”). The survey was not incentivized. Data on the number of clicks on all banner ads were obtained directly from the websites. In AMIS-2014, data on the number of clicks on geospatial social networking banner ads were instead obtained by counting the number of clicks on the survey landing page. Men who clicked on the ads were taken directly to the survey website hosted on a secure server administered by SurveyGizmo (Boulder, CO, USA). Participants were also recruited by emailing participants from the previous cycle of AMIS (AMIS-2014) who consented to be recontacted for future studies. To be eligible for the survey, participants had to be 15 years of age or older, consider themselves to be male, and report that they had oral or anal sex with a man at least once in the past (hereafter referred to as MSM). Persons who reported being younger than 15 years of age or refused to provide their age were not asked any other screening questions. Those MSM who met the eligibility criteria and consented to participate in the study started the online survey immediately. The full questionnaire for AMIS-2015 is presented in Multimedia Appendix 1.

AMIS-2015 ran from September 2015 through April 2016, and resulted in 137,608 persons clicking on the ads and landing on the study’s recruitment page (Table 1). Most persons who clicked on the ads were from general social networking websites (66,500/137,608, 48.33%). Of the 1248 participants who completed the AMIS-2014 survey and were emailed links to the AMIS-2015 survey, 9.13% (114/1248) clicked on the link. One-third (33.58%, 46,207/137,608) of those who landed on the study’s page started the screening process and 56.09% (25,919/46,207) of those were eligible. The most common reason for ineligibility was not ever having male-male sex. More than three-quarters (78.52%, 20,351/25,919) of those who were eligible consented to participate in the survey. There were 2291 of 20,351 (11.26%) surveys determined to likely be from duplicate participants. Deduplication of survey responses was performed in the same manner as in previous AMIS cycles [1,2]. Among unduplicated surveys, almost two-thirds (64.21%, 11,597/18,060) were considered successful (ie, observations with no missing values for the first question of at least two consecutive sections). Most successful surveys were among men who reported having sex with another man in the past 12 months (89.07%, 10,330/11,597). Finally, 1.09% (113/10,330) of the sample was found to have provided an invalid ZIP code and was excluded from the final analytical sample.

Table 1. Recruitment outcomes for the American Men's Internet Survey, United States, 2015.

Recruitment outcomes	Total	Recruitment type				
		Gay social networking (n=1)	General gay interest (n=2)	General social networking (n=4)	Geospatial social networking (n=2)	AMIS-2014 participants
Clicked ad, n	137,608	4680	3968	66,500	62,261	199
Screened,[a] n (%)	46,207 (33.58)	3671 (78.44)	1165 (29.36)	30,581 (45.99)	10,630 (17.07)	160 (80.40)
Ineligible,[b]n (%)	20,288 (43.91)	740 (20.16)	463 (39.74)	16,206 (52.99)	2868 (26.98)	11 (6.88)
Not age ≥15 years[c]	14,246 (70.22)	615 (83.11)	369 (79.70)	11,056 (68.22)	2197 (76.60)	9 (81.82)
Not male[c]	15,255 (75.19)	559 (75.54)	381 (82.29)	11,800 (72.81)	2505 (87.34)	10 (90.91)
Not ever MSM[c]	19,804 (97.61)	620 (83.78)	454 (98.06)	16,046 (99.01)	2673 (93.20)	11 (100.00)
Nonresident[c]	15,502 (76.41)	624 (84.32)	377 (81.43)	11,469 (70.77)	2573 (89.71)	9 (81.82)
Eligible,[b] n (%)	25,919 (56.09)	2931 (79.84)	702 (60.26)	14,375 (47.01)	7762 (73.02)	149 (93.13)
Consented,[d] n (%)	20,351 (78.52)	2181 (74.41)	586 (83.48)	10,818 (75.26)	6623 (85.33)	143 (95.97)
Unduplicated,[e] n (%)	18,060 (88.74)	2032 (93.17)	552 (94.20)	9410 (86.98)	5926 (89.48)	140 (97.90)
Success,[f] n (%)	11,597 (64.21)	1568 (77.17)	426 (77.17)	6372 (67.72)	3104 (52.38)	127 (90.71)
MSM past 12 months,[g] n (%)	10,330 (89.07)	1456 (92.86)	381 (89.44)	5425 (85.14)	2953 (95.14)	115 (90.55)
Valid ZIP code,[h] n (%)	10,217 (98.91)	1451 (99.66)	381 (100.00)	5396 (99.47)	2875 (97.36)	114 (99.13)

[a] Proportion is of total who clicked ad. Includes those who started the screening questionnaire.

[b] Proportion is among total screened. Ineligible includes those who did not complete the screening questionnaire.

[c] Proportion is among total ineligible. Includes those who may not have responded to the question. MSM: men who have sex with men.

[d] Proportion is among eligible.

[e] Proportion is among consented. Unduplicated removes participants who were marked as duplicates using IP address and demographic data matching.

[f] Proportion is among unduplicated. Success removes participants who did not pass the test for survey completeness.

[g] Proportion is among successes.

[h] Proportion is among MSM in the past 12 months. Valid US ZIP codes were those that could be matched to the ZIP code-to-county crosswalk files created by the US Department of Housing and Urban Development. Any ZIP codes that could not be matched to this list were then hand-validated by checking against the ZIP code locator tool on the USPS website. ZIP codes that could not be found were classified as invalid.

Almost all these surveys (10,217/10,330, 98.91%) provided a valid US ZIP code. ZIP codes provided by participants were validated by merging them with the 2015 ZIP code-to-county crosswalk files created by the US Department of Housing and Urban Development [3]. Any ZIP codes that could not be matched to this list were then hand-validated by checking against the ZIP code locator tool on the United States Postal Service website [4]. ZIP codes that could not be found were classified as invalid. Overall, the completion rate was 7.4% (10,217/137,608), with an analytical sample consisting of 10,217 surveys out of 137,068 clicks.

Measures and Analyses

For AMIS-2015 analyses, participants were categorized as either being AMIS-2014 participants who took the survey again or new participants from website/app types based on target audience and purpose: gay social networking (n=1), gay general interest (n=2), general social networking (n=4), and geospatial social networking (n=2). Recruitment outcomes and demographic characteristics for the AMIS-2014 participants are presented and for all behavioral outcomes, they are recategorized according to their original recruitment source. We do not provide the names of the websites/apps to preserve operator and client privacy, particularly where a category has only one operator. The participants who were eligible, consented, unduplicated, successful, reported male-male sex in the past 12 months, and provided a valid US ZIP code were included in analyses of participant characteristics and behavior.

For AMIS-2015, we created a more refined population density variable for each participant's county of residence as determined by their ZIP code. The levels of the population density variable are from the National Center for Health Statistics (NCHS) Rural-Urban classification scheme [5]. The NCHS classifies counties into six categories: central (ie, inner city) or fringe (ie, suburban) areas of large metropolitan statistical areas (MSAs; population size ≥1,000,000), medium-sized MSAs (population size 250,000-999,999), small MSAs (population size <250,000), micropolitan area (counties that contain all or part of a city of 10,000 or more), and noncore (counties that do not contain any part of a city of 10,000 or more). We further collapsed these categories into a four-level urbanicity variable: urban (central), suburban (fringe), medium/small metropolitan, and rural (micropolitan and noncore).

The analysis methods for AMIS-2015 did not substantively differ from those previously published but are repeated in this report for clarity [1]. Overall, chi-square tests were used to identify whether participant characteristics significantly differed between recruitment sources. Multivariable logistic regression modeling was used to determine significant differences in behaviors based on self-reported human immunodeficiency virus (HIV) status while controlling for race/ethnicity, age group, National HIV Behavioral System (NHBS) city residency, and recruitment website type. MSAs included in NHBS in 2015 were Atlanta, GA; Baltimore, MD; Boston, MA; Chicago, IL; Dallas, TX; Denver, CO; Detroit, MI; Houston, TX; Los Angeles, CA; Miami, FL; Nassau-Suffolk, NY; New Orleans, LA, New York City, NY; Newark, NJ; Philadelphia, PA; San Diego, CA; San Francisco, CA; San Juan, PR; Seattle, WA; and Washington, DC. Self-reported HIV status was categorized as either HIV-positive or HIV-negative/unknown status, consistent with surveillance reports produced by NHBS [6]. HIV testing behaviors were only examined among those who did not report that they were HIV-positive and were also presented by participant characteristics. Multivariable logistic regression results are presented as Wald chi-square *P* values to denote an independently significant difference in the behavior for each subgroup compared to a referent group. Statistical significance was determined at *P*<.05.

Results

Approximately seven in 10 (7291/10,217, 71.36%) participants included in this report were white and non-Hispanic, less than half were 40 years of age or older (4326/10,217, 42.34%), and their most common region of residence was the South followed by the West (Table 2). Participants were recruited from all US states and there were at least 100 participants from each of 28 states (Figure 1). Overall, 9.35% (955/10,217) of participants reported being HIV-positive, 69.91% (7143/10,217) reported being HIV-negative, and 20.74% (2119/10,217) reported having an unknown HIV status. All participant characteristics differed significantly based on where they were recruited (Table 2).

Table 2. Characteristics of MSM participants in the American Men’s Internet Survey by recruitment type, United States, 2015.

Participant characteristics	Total, n (%)	Recruitment type, n (%)					P[a]
		Gay social networking (n=1)	General gay interest (n=4)	General social networking (n=4)	Geospatial social networking (n=2)	AMIS-2014 participants	
Race/Ethnicity							<.001
Black, non-Hispanic	675 (6.61)	33 (2.27)	15 (3.94)	444 (8.23)	176 (6.12)	7 (6.14)	
Hispanic	1387 (13.58)	73 (5.03)	36 (9.45)	755 (13.99)	511 (17.77)	12 (10.53)	
White, non-Hispanic	7291 (71.36)	1271 (87.59)	301 (79.00)	3733 (69.18)	1899 (66.05)	87 (76.32)	
Other or multiple races	864 (8.46)	74 (5.10)	29 (7.61)	464 (8.60)	289 (10.05)	8 (7.02)	
Age (years)							<.001
15-24	2821 (27.61)	32 (2.21)	37 (9.71)	2155 (39.94)	581 (20.21)	16 (14.04)	
25-29	1583 (15.49)	36 (2.48)	61 (16.01)	983 (18.22)	491 (17.08)	12 (10.53)	
30-39	1487 (14.55)	112 (7.72)	86 (22.57)	516 (9.56)	740 (25.74)	33 (28.95)	
≥40	4326 (42.34)	1271 (87.59)	197 (51.71)	1742 (32.28)	1063 (36.97)	53 (46.49)	
Region							.002
Northeast	2038 (19.95)	304 (20.95)	72 (18.90)	1074 (19.90)	566 (19.69)	22 (19.30)	
Midwest	2127 (20.82)	344 (23.71)	73 (19.16)	1152 (21.35)	530 (18.43)	28 (24.56)	
South	3739 (36.60)	467 (32.18)	132 (34.65)	2000 (37.06)	1098 (38.19)	42 (36.84)	
West	2305 (22.56)	335 (23.09)	103 (27.03)	1166 (21.61)	679 (23.62)	22 (19.30)	
US dependent areas	8 (0.08)	1 (0.07)	1 (0.26)	4 (0.07)	2 (0.07)	0 (0.0)	
NHBS city resident[b]							<.001
Yes	3731 (36.52)	565 (38.94)	177 (46.46)	1855 (34.38)	1090 (37.91)	44 (38.60)	
No	6486 (63.48)	886 (61.06)	204 (53.54)	3541 (65.62)	1785 (62.09)	70 (61.40)	
Population density[c]							<.001
Urban	4101 (40.18)	572 (39.45)	189 (49.74)	2073 (38.45)	1214 (42.28)	53 (46.49)	
Suburban	2041 (20.00)	363 (25.03)	71 (18.68)	1092 (20.26)	494 (17.21)	21 (18.42)	
Small/ medium metropolitan	3076 (30.14)	387 (26.69)	97 (25.53)	1679 (31.14)	883 (30.76)	30 (26.32)	
Rural	988 (9.68)	128 (8.83)	23 (6.05)	547 (10.15)	280 (9.75)	10 (8.77)	
Self-reported HIV Status							<.001
Positive	955 (9.35)	108 (7.44)	26 (6.82)	411 (7.62)	395 (13.74)	15 (13.16)	
Negative	7143 (69.91)	1102 (75.95)	302 (79.27)	3566 (66.05)	2080 (72.35)	93 (81.58)	
Unknown	2119 (20.74)	241 (16.61)	53 (13.91)	1419 (26.32)	400 (13.91)	6 (5.26)	
Total	10,217	1451	381	5396	2875	114	

[a] Chi-square test for difference in characteristics between recruitment types.

[b] NHBS: National HIV Behavioral Surveillance System.

[C] There were 11 participants living in US territories or provided military addresses, which could not have an NCHS urban/rural category assigned.

Most participants reported having anal sex without a condom with another man within the past 12 months (Table 3). Compared to HIV-negative/unknown status participants, those who were HIV-positive were significantly more likely to report anal intercourse without a condom (adjusted OR [AOR] 1.86, 95% CI 1.59-2.18), including with male partners who were of discordant or unknown status (AOR 2.75, 95% CI 2.36-3.20). Within each serostatus group, anal intercourse without a condom differed significantly by age group (HIV-positive and HIV-negative/unknown status participants), and recruitment website (HIV-negative/unknown status participants only). Anal intercourse without a condom with partners of discordant or unknown HIV status differed significantly by race/ethnicity (HIV-positive participants only), recruitment website (HIV-positive participants only), and age (HIV-negative/unknown status participants only).

Table 3. Sexual Behaviors with Male Partners of MSM Participants in the American Men’s Internet Survey, United States, 2015.

Participant characteristics	n	Sexual behaviors with male partners in the past 12 months			
		Anal intercourse without a condom		Anal intercourse without a condom with a partner of discordant or unknown HIV status	
		n (%)	P [a]	n (%)	P [a]
HIV positive overall	955	721 (75.50)	<.001[b]	329 (34.45)	<.001[b]
Race/Ethnicity					
Black, non-Hispanic	161	105 (65.22)	.08	35 (21.74)	.002
Hispanic	152	113 (74.34)	.70	48 (31.58)	.92
White, non-Hispanic	573	454 (79.23)	REF	221 (38.57)	REF
Other or multiple races	69	49 (71.01)	.50	25 (36.23)	.37
Age (years)					
15-24	50	40 (80.00)	.83	18 (36.00)	.76
25-29	107	92 (85.98)	.04	42 (39.25)	.37
30-39	181	147 (81.22)	.91	68 (37.57)	.45
≥40	617	442 (71.64)	REF	201 (32.58)	REF
NHBS city resident[c]					
Yes	422	325 (77.01)	.14	142 (33.65)	.83
No	533	396 (74.30)	REF	187 (35.08)	REF
Recruitment type					
Gay social networking	108	79 (73.15)	.35	48 (44.44)	.18
General gay interest	26	22 (84.62)	.30	12 (46.15)	.37
General social networking	413	290 (70.22)	REF	137 (33.17)	REF
Geospatial social networking	408	330 (80.88)	.59	132 (32.35)	.01
HIV negative or unknown overall	9262	5843 (63.09)	REF	1581 (17.07)	REF
Race/Ethnicity					
Black, non-Hispanic	514	316 (61.48)	.55	92 (17.90)	.44
Hispanic	1235	804 (65.10)	.27	248 (20.08)	.05
White, non-Hispanic	6718	4244 (63.17)	REF	1116 (16.61)	REF
Other or multiple races	795	479 (60.25)	.05	125 (15.72)	.06
Age (years)					
15-24	2771	1713 (61.82)	<.001	524 (18.91)	.001
25-29	1476	1072 (72.63)	<.001	257 (17.41)	.63
30-39	1306	930 (71.21)	<.001	224 (17.15)	.37
≥40	3709	2128 (57.37)	REF	576 (15.53)	REF
NHBS city resident[c]					
Yes	3309	2055 (62.10)	.17	570 (17.23)	.82
No	5953	3788 (63.63)	REF	1011 (16.98)	REF
Recruitment type					
Gay social networking	1343	706 (52.57)	<.001	222 (16.53)	.49
General gay interest	363	234 (64.46)	.59	60 (16.53)	.87
General social networking	5028	3120 (62.05)	REF	816 (16.23)	REF
Geospatial social networking	2528	1783 (70.53)	<.001	483 (19.11)	.06

[a] Wald chi-square from multivariate logistic regression comparing behavior (yes vs no) among group with some characteristic compared to a referent (REF) group.

[b] Wald chi-square from multivariate logistic regression comparing behavior (yes vs no) among HIV-positive participants compared to HIV-negative or unknown serostatus participants. Model controlled for race/ethnicity, age, NHBS residency, and recruitment type.

[C] NHBS: National HIV Behavioral Surveillance System.

Almost one-quarter (235/955, 24.6%) of HIV-positive participants reported using marijuana in the past 12 months (Table 4). Compared to HIV-negative/unknown status participants, HIV-positive participants were significantly more likely to report use of marijuana (AOR 1.43, 95% CI 1.22-1.69) and other illicit substances in the past 12 months (AOR 2.20, 95% CI 1.88-2.59). Within each serostatus group, use of marijuana and other illicit substances differed significantly by age (HIV-positive and HIV-negative/unknown status participants), residence in an NHBS city (HIV-negative/unknown status participants only), and recruitment website type (HIV-negative/unknown status participants only). Marijuana use also differed significantly by recruitment website among HIV-positive participants. Use of other illicit substances differed significantly by race/ethnicity among HIV-negative/unknown status participants.

Table 4. Substance using behaviors of MSM participants in the American Men’s Internet Survey, United States, 2015.

Participant characteristics	n	Substance use behaviors in the past 12 months			
		Used marijuana		Used other substance(s)	
		n (%)	P [a]	n (%)	P [a]
HIV positive overall	955	235 (24.61)	<.001[b]	273 (28.59)	<.001[b]
Race/Ethnicity					
Black, non-Hispanic	161	40 (24.84)	.35	31 (19.25)	.06
Hispanic	152	39 (25.66)	.89	49 (32.24)	.39
White, non-Hispanic	573	144 (25.13)	REF	175 (30.54)	REF
Other or multiple races	69	12 (17.39)	.07	18 (26.09)	.60
Age (years)					
15-24	52	15 (30.00)	.88	14 (28.00)	.48
25-29	109	43 (40.19)	.003	43 (40.19)	.02
30-39	187	53 (29.28)	.67	69 (38.12)	.19
≥40	627	124 (20.10)	REF	147 (23.82)	REF
NHBS city resident[c]					
Yes	422	110 (26.07)	.35	125 (29.62)	.45
No	533	125 (23.45)	REF	148 (27.77)	REF
Recruitment type					
Gay social networking	108	20 (18.52)	.89	28 (25.93)	.97
General gay interest	26	4 (15.38)	.48	7 (26.92)	.93
General social networking	413	90 (21.79)	REF	95 (23.00)	REF
Geospatial social networking	408	121 (29.66)	.04	143 (35.05)	.14
HIV negative or unknown overall	9262	2127 (22.96)	REF	1622 (17.51)	REF
Race/Ethnicity					
Black, non-Hispanic	514	91 (17.70)	.06	67 (13.04)	.02
Hispanic	1235	296 (23.97)	.78	220 (17.81)	.84
White, non-Hispanic	6718	1570 (23.37)	REF	1200 (17.86)	REF
Other or multiple races	795	170 (21.38)	.32	135 (16.98)	.94
Age (years)					
15-24	2771	854 (30.82)	<.001	543 (19.60)	.02
25-29	1476	437 (29.61)	<.001	356 (24.12)	<.001
30-39	1306	297 (22.74)	.16	254 (19.45)	.96
≥40	3709	539 (14.53)	REF	469 (12.64)	REF
NHBS city resident[c]					
Yes	3309	793 (23.96)	.002	633 (19.13)	<.001
No	5953	1334 (22.41)	REF	989 (16.61)	REF
Recruitment type					
Gay social networking	1343	187 (13.92)	.02	167 (12.43)	.13
General gay interest	363	74 (20.39)	.92	57 (15.70)	.44
General social networking	5028	1244 (24.74)	REF	859 (17.08)	REF
Geospatial social networking	2528	622 (24.60)	.004	539 (21.32)	<.001

[a] Wald chi-square from multivariable logistic regression comparing behavior (yes vs no) among group with some characteristic compared to a referent

(REF) group.

[b] Wald chi-square from multivariable logistic regression comparing behavior (yes vs no) among HIV-positive participants compared to HIV-negative or unknown serostatus participants. Model controlled for race/ethnicity, age, NHBS residency, and website type.

[c] NHBS: National HIV Behavioral Surveillance System.

HIV testing behaviors were examined among those who did not report being HIV-positive (Table 5). Most participants (7327/9262, 79.11%) reported having been previously tested for HIV infection, and just over half (5158/9262, 55.69%) reported being tested in the past 12 months. HIV testing behavior, both ever tested and tested in past 12 months, differed significantly by age, residence in an NHBS city, and recruitment website type.

Table 5. HIV testing behaviors of HIV-negative or unknown status MSM participants in the American Men's Internet Survey, United States, 2015.

Participant characteristics	n	HIV testing behaviors			
		HIV tested ever		HIV tested past 12 months	
		n (%)	P [a]	n (%)	P [a]
Race/Ethnicity					
Black, non-Hispanic	514	445 (86.58)	.06	333 (64.79)	.02
Hispanic	1235	948 (76.76)	.35	715 (57.89)	.37
White, non-Hispanic	6718	5314 (79.10)	REF	3645 (54.26)	REF
Other or multiple races	795	620 (77.99)	.99	465 (58.49)	.81
Age (years)					
15-24	2771	1599 (57.70)	<.001	1286 (46.41)	<.001
25-29	1476	1269 (85.98)	<.001	903 (61.18)	<.001
30-39	1306	1160 (88.82)	<.001	858 (65.70)	<.001
40 or older	3709	3299 (88.95)	REF	2111 (56.92)	REF
NHBS city resident[b]					
Yes	3309	2774 (83.83)	<.001	2075 (62.71)	<.001
No	5953	4553 (76.48)	REF	3083 (51.79)	REF
Recruitment type					
Gay social networking	1343	1122 (83.54)	<.001	713 (53.09)	.005
General gay interest	363	311 (85.67)	.87	189 (52.07)	.002
General social networking	5028	3694 (73.47)	REF	2512 (49.96)	REF
Geospatial social networking	2528	2200 (87.03)	<.001	1744 (68.99)	<.001
Total	9262	7327 (79.11)		5158 (55.69)	

[a] Wald chi-square from multivariable logistic regression comparing behavior (yes vs no) among group with some characteristic compared to a referent (REF) group.

[b] NHBS: National HIV Behavioral Surveillance System.

Compared to HIV-negative/unknown status participants, HIV-positive participants were significantly more likely to report sexually transmitted infection (STI) testing (AOR 4.00, 95% CI 3.43-4.68) and STI diagnosis (AOR 3.83, 95% CI 3.20-4.59) in the past 12 months (Table 6). The most common STI diagnosis among HIV-positive participants was syphilis (144/955, 15.1%), whereas gonorrhea was the most common STI diagnosis among HIV-negative/unknown status participants (427/9262, 4.61%). Among HIV-negative/unknown status participants, STI testing differed significantly by race/ethnicity, age, and residence in an NHBS city. Among both HIV-positive and HIV-negative/unknown status participants, STI testing differed significantly by recruitment website type and STI diagnosis differed significantly by age, NHBS city residence, and recruitment website type.

Table 6. Sexually transmitted infection testing and diagnosis of MSM participants in the American Men's Internet Survey, United States, 2015.

Participant characteristics	n	STI History in the Past 12 Months			
		Tested for any STI[a]		Diagnosed with any STI[a]	
		n (%)	*P* [b]	n (%)	*P* [b]
HIV positive overall	955	685 (71.73)	<.001[c]	245 (25.65)	<.001[c]
Race/Ethnicity					
Black, non-Hispanic	161	116 (72.05)	.39	48 (29.81)	.10
Hispanic	152	109 (71.71)	.29	50 (32.89)	.75
White, non-Hispanic	573	413 (72.08)	REF	130 (22.69)	REF
Other or multiple races	69	47 (68.12)	.32	17 (24.64)	.25
Age (years)					
15-24	50	44 (88.00)	.09	23 (46.00)	.02
25-29	107	89 (83.18)	.45	43 (40.19)	.09
30-39	181	152 (83.98)	.56	66 (36.46)	.77
≥40	617	400 (64.83)	REF	113 (18.31)	REF
NHBS city resident[d]					
Yes	422	313 (74.17)	.10	128 (30.33)	.007
No	533	372 (69.79)	REF	117 (21.95)	REF
Recruitment website type					
Gay social networking	108	71 (65.74)	.81	21 (19.44)	.40
General gay interest	26	15 (57.69)	.25	3 (11.54)	.26
General social networking	413	276 (66.83)	REF	79 (19.13)	REF
Geospatial social networking	408	323 (79.17)	.006	142 (34.80)	.003
HIV negative or unknown overall	9262	3568 (38.52)	REF	752 (8.12)	REF
Race/Ethnicity					
Black, non-Hispanic	514	241 (46.89)	.01	57 (11.09)	.07
Hispanic	1235	543 (43.97)	.92	150 (12.15)	.04
White, non-Hispanic	6718	2458 (36.59)	REF	481 (7.16)	REF
Other or multiple races	795	326 (41.01)	.30	64 (8.05)	.03
Age (years)					
15-24	2771	997 (35.98)	<.001	229 (8.26)	.46
25-29	1476	753 (51.02)	<.001	169 (11.45)	<.001
30-39	1306	639 (48.93)	.004	154 (11.79)	.15
≥40	3709	1179 (31.79)	REF	200 (5.39)	REF
NHBS city resident[c]					
Yes	3309	1493 (45.12)	<.001	350 (10.58)	<.001
No	5953	2075 (34.86)	REF	402 (6.75)	REF
Recruitment website type					
Gay social networking	1343	365 (27.18)	<.001	59 (4.39)	.04
General gay interest	363	143 (39.39)	.88	23 (6.34)	.27
General social networking	5028	1746 (34.73)	REF	313 (6.23)	REF
Geospatial social networking	2528	1314 (51.98)	<.001	357 (14.12)	<.001

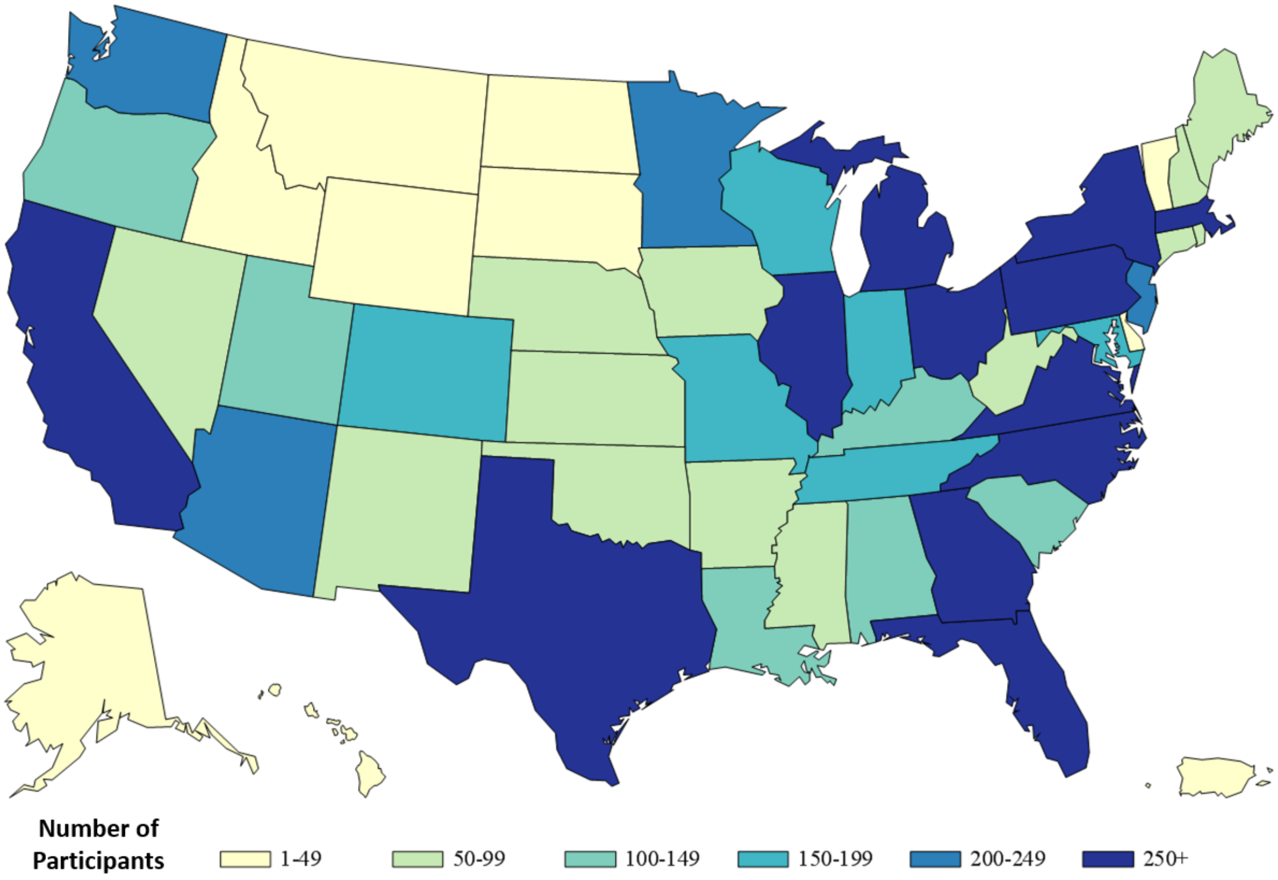
[a] Sexually transmitted infection (STI) includes chlamydia, gonorrhea, and syphilis.

[b] Wald chi-square from multivariable logistic regression comparing behavior (yes vs no) among group with some characteristic compared to a referent (REF) group.

[c] Wald chi-square from multivariable logistic regression comparing behavior (yes vs no) among HIV-positive participants compared to HIV-negative or unknown serostatus participants. Model controlled for race/ethnicity, age, NHBS residency, and website type.

[d] NHBS: National HIV Behavioral Surveillance System.

Figure 1. Number of MSM participants in the American Men’s Internet Survey by state, 2015.



Acknowledgments

The study was funded by a grant from the MAC AIDS Fund and by the National Institutes of Health (P30AI050409)—the Emory Center for AIDS Research.

Conflicts of Interest

Authors Sanchez and Sullivan are members of the Editorial Board of JMIR Public Health and Surveillance. However, they had no involvement in the editorial decision for this manuscript. It was reviewed and handled by an independent editor.

Multimedia Appendix 1

AMIS 2015 Questionnaire.

[PDF File (Adobe PDF File), 452KB - publichealth_v3i1e13_app1.pdf]

Multimedia Appendix 2

Recruitment and enrollment outcomes flow chart.

[PPTX File, 43KB - publichealth_v3i1e13_app2.pptx]

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Abbreviations

AMIS: American Men’s Internet Survey
HIV: human immunodeficiency virus
MSA: Metropolitan Statistical Area
MSM: men who have sex with men
NCHS: National Center for Health Statistics
NHBS: National HIV Behavioral Surveillance System
STI: sexually transmitted infection

Edited by G Eysenbach; submitted 07.12.16; peer-reviewed by C Khosropour, N Lachowsky; comments to author 05.01.17; revised version received 24.01.17; accepted 08.02.17; published 25.03.17.

Please cite as:
Zlotorzynska M, Sullivan P, Sanchez T
The Annual American Men’s Internet Survey of Behaviors of Men Who Have Sex With Men in the United States: 2015 Key Indicators Report
JMIR Public Health Surveill 2017;3(1):e13
URL: http://publichealth.jmir.org/2017/1/e13/
doi:10.2196/publichealth.7119
PMID:28356240

Original Paper

Assessing Mobile Phone Access and Perceptions for Texting-Based mHealth Interventions Among Expectant Mothers and Child Caregivers in Remote Regions of Northern Kenya: A Survey-Based Descriptive Study

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Abstract

Background: With a dramatic increase in mobile phone use in low- and middle-income countries, mobile health (mHealth) has great potential to connect health care services directly to participants enrolled and improve engagement of care. Rural and remote global settings may pose both significant challenges and opportunities.

Objective: The objective of our study was to understand the demographics, phone usage and ownership characteristics, and feasibility among patients in rural and remote areas of Kenya of having text messaging (short messaging service, SMS)-based mHealth intervention for improvements in antenatal care attendance and routine immunization among children in Northern Kenya.

Methods: A survey-based descriptive study was conducted between October 2014 and February 2015 at 8 health facilities in Northern Kenya as part of a program to scale up an mHealth service in rural and remote regions. The study was conducted at 6 government health facilities in Isiolo, Marsabit, and Samburu counties in remote and northern arid lands (NAL). Two less remote health facilities in Laikipia and Meru counties in more populated central highlands were included as comparison sites.

Results: A total of 284 participants were surveyed; 63.4% (180/284) were from NAL clinics, whereas 36.6% (104/284) were from adjacent central highland clinics. In the NAL, almost half (48.8%, 88/180) reported no formal education and 24.4% (44/180) self-identified as nomads. The majority of participants from both regions had access to mobile phone: 99.0% (103/104) of participants from central highlands and 82.1% (147/180) of participants from NAL. Among those who had access to a phone, there were significant differences in network challenges and technology literacy between the 2 regions. However, there was no significant difference in the proportion of participants from NAL and central highlands who indicated that they would like to receive a weekly SMS text message from their health care provider (90.0% vs 95.0%; P=.52). Overall, 92.0% (230/250) of participants who had access to a telephone said that they would like to receive a weekly SMS text message from their health care provider. Most phone users already spent the equivalent of 626 SMS text messages on mobile credit for personal use.

Conclusions: Despite the remoteness of northern Kenya's NAL, the results indicate that the majority of pregnant women or care givers attending the maternal, newborn, and child health clinics have access to mobile phone and would like to receive text messages from their health care provider. mHealth programs, if designed appropriately for these settings, may be an innovative way for engaging women in care for improved maternal and newborn child health outcomes in order to achieve sustainable development goals.

(JMIR Public Health Surveill 2017;3(1):e5) doi:10.2196/publichealth.5386

KEYWORDS

mobile health; text messaging; prenatal care; immunization; Kenya

Introduction

It has been widely documented that routine antenatal care (ANC) visits is one of the most effective methods in reducing maternal and child mortality and morbidity. Despite calls by the World Health Organization (WHO) for a minimum of 4 ANC visits, two-thirds of women living in Africa are able to attend ANC clinic only once during their gestational period [1,2]. It is estimated that 287,000 maternal deaths occur globally each year due to preventable complications during pregnancy and childbirth, 95% of which occur in sub-Saharan Africa and Southern Asia [3,4]. Furthermore, approximately 240 women per 100,000 live births die in low-income countries compared with only 16 women per 100,000 live births in high-income countries. African women experience 24 times the risk of intrapartum stillbirth compared with women in high-income settings [5-7]. Globally, there are around 3 million neonatal deaths and 2.65 million stillbirths each year [7]. In Kenya, the annual maternal mortality rate is 488 per 100,000 live births, of which only 47% of women are able to attend all 4 recommended ANC visits and the majority of them are from urban areas [8-10]. A further decline is seen in the remote rural areas of Kenya such as the northern and arid lands (NAL) whereby only 40% of pregnant women attend 4 or more ANC visits [8].

Routine immunization among children, on the contrary, is one of the most effective public health interventions of the 20th century. It has dramatically reduced global child morbidity and mortality [11]. Despite this, an estimated 19.3 million children did not receive vaccination for diphtheria, pertussis, and tetanus (DPT3) in 2010, one-third of which live in Africa, resulting in approximately 1.5 million preventable deaths every year [12]. In Kenya, approximately 52 infants per 100, 000 die every year, with only 77% receiving routine immunizations [8-10]. New and innovative strategies are required to improve ANC attendance among pregnant women and to increase routine immunization coverage among children.

Mobile health (mHealth) is defined as mobile communication technologies to support health care [13,14]. Currently, there are approximately 7 billion mobile phone subscribers globally, 89% of which are in low- and middle-income countries (LMICs) [15,16]. In Kenya, for example, mobile phone penetration was 77% in 2012, with SMS text messaging (short messaging service, SMS)-based communication on the rise [17]. The recent surge in mobile phone penetration alongside reduced cost has improved the feasibility of mHealth programs in LMICs [18]. Available data outlines mHealth's potential and ability to connect health care services to pregnant women and mothers by passing different hurdles that would otherwise keep various health services inaccessible due to cost, distance, and accessibility [18,19]. SMS text messaging–based mHealth interventions can play a significant role in ensuring that the expectant mothers are followed throughout the continuum of care till completion of routine immunization coverage of their child [19].

Existing literature on mobile phone use in Kenya focuses on mobile phone penetration, trends in uptake of mobile communication services, corporate market share, mobile consumer-based services available, ANC visits improvement, SMS text message reminders and conditional cash transfer to improve routine immunization coverage, potential for mHealth interventions based on phone ownership and penetration, and engagement of care [20-26]. Few studies, however, examine the demographic characteristics of mobile phone users, their usage patterns, ownership, and mobile phones' potential for improving engagement with health care providers and access to health services, specifically in a remote and rural population.

There is a vast difference in health indicators for NAL compared with rest of the Kenya, particularly for health-seeking behavior, maternal and child mortality, and immunization coverage. In this study, we aimed to assess the feasibility of implementing an SMS text messaging–based mHealth intervention intended to connect expectant mothers and child caregivers with their health care providers in rural and remote regions of Kenya. Our objectives were to examine region-based differences in mobile phone access and mHealth perceptions among visitors to antenatal and routine immunizations clinics in 8 regions of northern Kenya.

Methods

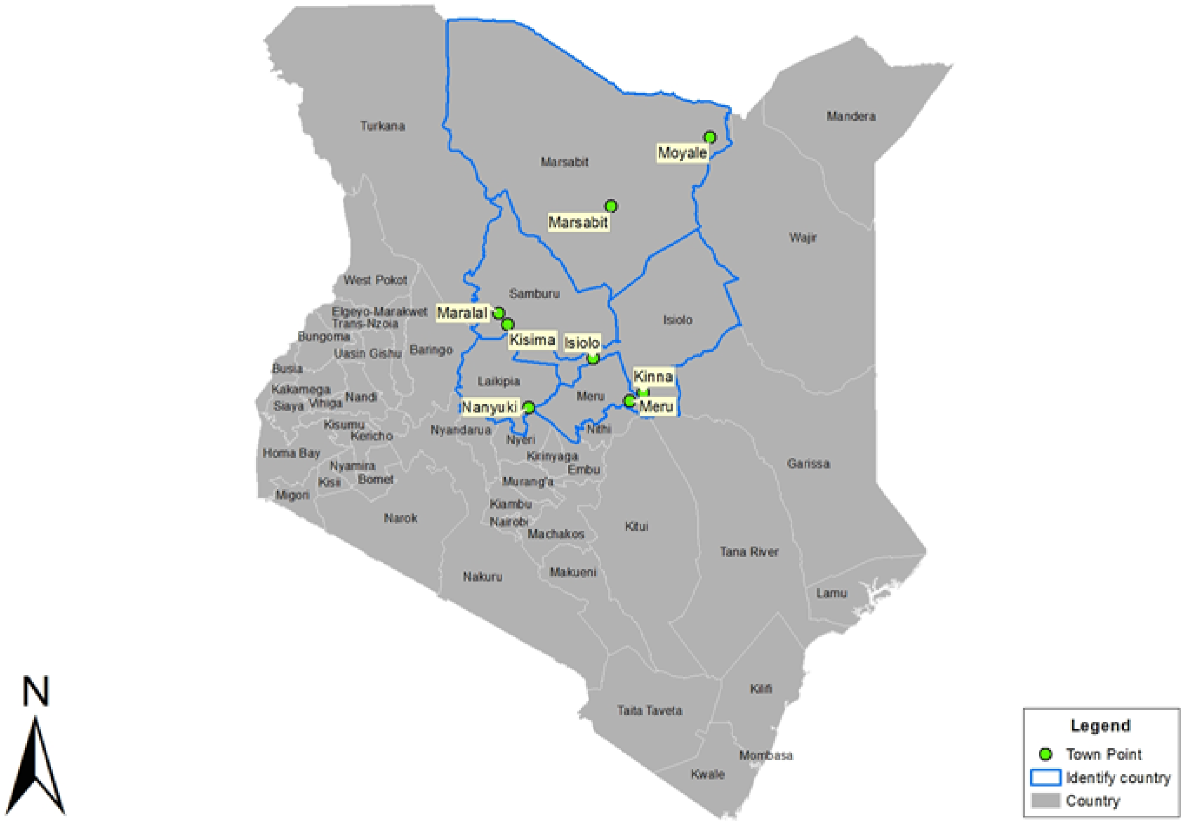
Between October 13, 2014, and February 20, 2015, participants were recruited from antenatal and routine immunization clinics at 8 health facilities in northern Kenya as part of a Grand Challenges Canada phase 2 "transition to scale" and Amref Health Africa as part of government of Kenya–led AphiaPlus/Marisha program for the health strengthening in the region [26]. Six participating government health facilities, 2 each in Isiolo, Marsabit, and Samburu counties were located in Kenya’s remote NAL, and 2 clinics each were located in Laikipia and Meru counties, which are less remote and more densely surrounding northern region (central highlands). The study received clearance from Amref Health Africa’s Ethics and Scientific Review Committee on September 1, 2014. Figure 1 is a graphic depicting distribution of all 8 sites.

The study questionnaires included sections on patient demographics, mobile phone usage patterns, the feasibility of an SMS text messaging–based mHealth intervention, as well as accessibility to primary health centers. Because the proposed mHealth intervention (WelTel) used weekly SMS text messages and allowed for shared phone access, questions related to this were included [27]. Inclusion criteria comprised pregnant women visiting the antenatal clinic, caregivers attending the routine immunizations clinics for children, and the ability to provide informed consent. The formal sample size calculation was not done; however, a target of 280 completed surveys was set. Consecutive convenience sampling was used to recruit patients whereby health care workers at the point of triage referred patients to study staff as patients arrived for their scheduled ANC and routine immunization appointments.

Structured questionnaires were administered in either English or Kiswahili depending on a patient’s preference and proficiency with English by trained study staff having command over both languages. All participants included in the study were asked to sign the informed consent, and thumb impression was taken from those who were illiterate or could not sign. Questionnaires were administered in a private place to ensure patient confidentiality and reduce the likelihood of response bias. No incentive was provided for participating in this study.

Prior to the study, questionnaires were developed and underwent forward and backward translation to ensure semantic consistency, and were piloted at one of the field sites before being rolled out. The research staff received 2-day training on research ethics, providing informed consent, administering the study questionnaire, and the study protocols to be followed throughout the course of the study. Continuous monitoring by study coordinators occurred throughout the study to ensure that data were collected as per the study protocol. All data was double entered into an Access program and analyzed using IBM SPSS Statistics version 23, with a level of significance in reference to a 2-tailed, type 1 error set as <0.05. Univariate analysis was performed using the chi-square test or Fisher exact test for dichotomous variables and the Mann-Whitney test for continuous variables.

Figure 1. Geographic distribution of the eight sites participating in baseline survey in Kenya.



Results

Distribution of the respondents among study sites and population demographics at the study sites are shown in Table 1. Overall, 284 participants completed the survey from the 8 health facilities. Specifically, 63.4% (180/284) from the NAL clinics (Samburu, Isiolo, and Marsabit counties), and 36.6% (104/284) patients participated from central highlands (Meru and Laikipia counties). Overall, 98.6% (280/284) of the participants were females, and the median age of participants was 26 years (interquartile range, IQR 23-30 years). Forty-four percent (125/284) of participants were pregnant women visiting the

ANC clinic, whereas 56.0% (159/284) were caregivers of infants attending the immunization clinic for routine immunizations.

Table 1. Baseline characteristics of participants, by region.

Characteristics	Northern arid land (n=180)	Adjacent site (n=104)	Total (N=284)
Visited department, n (%)			
Antenatal care	72 (40.0)	53 (51.0)	125 (44.0)
Immunization	108 (60.0)	51 (49.0)	159 (56.0)
Facilities, n (%)			
Isiolo district hospital	19 (11.0)		19 (6.7)
Kinna health center	31 (17.2)		31 (10.9)
Maralal district hospital	30 (16.7)		30 (10.6)
Kisima model health center	58 (32.2)		58 (20.4)
Marsabit districts hospital	21 (11.7)		21 (7.4)
Moyale district hospital	21 (11.7)		21 (7.4)
Meru level 5 hospital		53 (51.0)	53 (18.7)
Nanyuki reference hospital		51 (49.0)	51 (18.0)
Age, median (IQR[a])	27 (23-30)	24 (22-29)	26 (23-30)
Gender, n (%)			
Female	176 (97.8)	104 (100.0)	280 (98.6)
Male	4 (2.2)		
Marital status, n (%)			
Single	8 (4.4)	15 (14.4)	23 (8.1)
Married	164 (91.1)	84 (80.8)	248 (87.3)
Separated, widowed, or dating	8 (4.4)	5 (4.8)	13 (4.6)
Number of children, median (IQR)	2 (1-4)	1 (1-1)	2 (1-3)
Nomadic lifestyle, n (%)	44 (24.4)	7 (6.7)	51 (18.0)
Formal education, n (%)			
None	88 (48.9)	2 (1.9)	90 (31.7)
Primary	57 (31.7)	30 (28.8)	87 (30.6)
Secondary	24 (13.3)	41 (39.4)	65 (22.9)
College or University	11 (6.1)	31 (29.8)	42 (14.8)
Religion, n (%)			
Christian	97 (53.9)	99 (95.2)	196 (69.0)
Islam	76 (42.2)	3 (2.9)	79 (27.8)
Others	7 (3.9)	2 (1.9)	9 (3.1)
Formally employed, n (%)	93 (51.7)	50 (48.0)	143 (50.3)
Preferred spoken language, n (%)			
Swahili	77 (42.8)	48 (46.1)	125 (44.0)
Kiborana	54 (30.0)		54 (19.0)
Samburu	38 (211)		38 (13.3)
Kimeru	3 (1.6)	25(24.0)	28 (9.9)
English	4 (2.2)	18 (17.3)	22 (7.7)
Other	4 (2.2)	13 (12.5)	17 (6.0)
Distance from health center in minutes, mean (min-max)	64 (2-300, n=166)	35 (5-300, n=102)	53 (2-300, n=268)

[a] IQR: interquartile range.

When compared with participants from central highlands, a higher proportion of participants from the NAL were more likely to be married (91.1% vs 80.8%; *P*=.01) and self-identify as nomadic (24.4% vs 6.7%; *P*<.001). There were large differences in the proportion of participants who had received formal education: 48.9 % (88/180) of respondents from NAL reported having no formal education compared with 1.9% (2/104) from central highlands (*P*<.01). Similarly, a much higher proportion of participants from the central highlands clinics could understand (98.0% vs 52.2%; *P*<.001) and read (91.3% vs 46.7%; *P*<.001) common Swahili words ("mambo," "sawa," and "shida") when compared with participants from NAL. Fifty percent (142/284) of the participants were employed of which the most common occupation was cited as a business.

Overall, 74.3% of participants (211/284) owned a mobile phone across all sites. However, a significantly higher proportion of participants from central highlands owned their phones when compared with participants from NAL (94.2% vs 62.8%; *P*<.001). Out of those who did not own a mobile phone 53.4% (39/73) did have shared access to a mobile phone with (83.3% vs 51.5%; *P*<.001) citing shared access in central highlands as compared to NAL. This indicated that the majority of participants from both the central highlands and NAL had some access to a mobile phone (99.0% vs 82.1%, *P*<.001).

A higher proportion of those from NAL were more likely to experience network challenges (27.1% vs 14.6%; *P*<.001). However, 92.1% (35/38) in NAL and 93.3% (14/15) at adjacent site participants were able to overcome the network coverage issues and only 9.2% (26/284) reported of a problem with keeping their phone battery charged overall. Further participants from NAL were less likely to be able to send an SMS text message (55.0% vs 95.1%; *P*<.001) when compared with participants from central highlands. Of those who were not able to send an SMS text message, 93.7% (59/63) in NAL and 80.0% (4/5) in adjacent sites mentioned that a trusted individual could respond on their behalf. Tables 2 and 3 show phone ownership and usage characteristics and SMS text messaging and mobile phone related outcomes.

Despite regional differences, there was no significant difference in the proportion of participants from NAL and central highlands, who indicated that they would like to receive a weekly SMS text message from their health care provider (95.0% vs 97.0%; *P*=.52). Overall, more than 91.6% (230/251) of participants who had access to a mobile phone indicated that they would like to receive a weekly SMS text message from their health care provider. Of these, 51.2% (124/242) preferred SMS text message as their mode of communication, whereas 48.8% (118/242) favored a phone call. Regional variances existed. Participants (78.2% vs 31.9%; *P*<.001) in central highlands preferred SMS text message compared with NAL; however, participants (68.1% vs 21.8%; *P*<.001) in NAL preferred phone calls as opposed to central highlands. Further, 62.5% (157/251) of responders preferred receiving SMS text messages in Swahili. Moreover, 49.4% (124/251) cited no time-of-day preference for receiving SMS text messages, and 40.6% (102/251) responded in favor of receiving 1 SMS text message per week. The average amount of money spent on a mobile phone by patients in the survey every month was 664 KSH (US $6.57), equivalent to about 170 minutes of talk time or more than 626 SMS text messages. The mean distance of the participants' home from health care center was 53 minutes (n=268/284).

Table 2. Regional differences in mobile phone access.

Characteristic	Northern arid land (n=180)	Adjacent region (n=104)	Total (n=284)	*P* value
Telephone access[a], n (%)				<.001
Access to telephone	147 (81.7)	103 (99.0)	250 (88.0)	
No access to telephone	32 (17.8)	1 (1.0)	33 (11.6)	
Own phone	113 (62.8)	98 (94.2)	211 (74.3)	
Shared phone	34 (18.9)	5 (4.8)	39 (13.7)	
No telephone access	32 (17.8)	1 (1.0)	33 (11.6)	

[a] Missing data: 1 northern arid land.

Table 3. Regional differences in SMS text messaging– and phone-related outcomes, among those who had access to mobile phone.

Characteristics	Northern arid land (n=147)	Surrounding northern region (n=103)	Total (n=250)	*P* value
Experienced network challenges[a], n (%)				<.001
No	102 (72.9)	88 (85.4)	190 (76.0)	
Yes	38 (27.1)	15 (14.6)	53 (21.2)	
Problem keeping a phone charged[b], n (%)				.41
No	124 (87.9)	94 (91.3)	218 (89.3)	
Yes	17 (12.1)	9 (8.7)	26 (10.7)	
Preferred mode of communication[c], n (%)				<.001
Text message	45 (31.9)	79 (78.2)	124 (49.6)	
Telephone call	96 (68.1)	22 (21.8)	118 (47.2)	
Are able to send an SMS text message[d], n (%)				<.001
Yes	77 (55.0)	97 (95.1)	174 (69.6)	
No	63 (45.0)	5 (4.9)	68 (27.2)	
Would like to receive a weekly SMS text message from HCP[e], n (%)				.53
Yes	132 (95.0)	98 (97.0)	230 (92.0)	
No	7 (5.0)	3 (3.0)	10 (4.0)	

[a] Missing data: 7 northern arid lands.

[b] Missing data: 6 northern arid lands.

[c] Missing data: 6 northern arid lands and 2 surrounding northern regions.

[d] Missing data: 7 northern arid lands and 1 surrounding northern region.

[e] Missing data: 8 northern arid lands and 2 surrounding northern region.

Discussion

Principal Findings

There is a significant potential for using mHealth communication to strengthen health services for maternal, newborn, and child health (MNCH) in remote underserved areas, where access to health services can otherwise be extremely limited. This study described the patients' access to mobile phones in the health context in a remote rural population with a high proportion of pastoralists and where maternal and child morbidity and mortality are disproportionately high. The majority of women and caregivers attending ANC and routine immunization clinics had access to a mobile phone—82.1% in NAL and 99.0% in the more populated highlands—and overall 92.0% of the participants indicated that they would like to receive weekly SMS text messages. The millennium development goals for maternal child health have not been successfully achieved by 2015 at multiple LMICs including Kenya. There is a broad consensus that mHealth can play an essential role in improving the use of maternal and child health services, which may ultimately support in decreasing morbidity and mortality toward achieving a sustainable development goal of less than 70 maternal deaths per 100,000 live births globally by 2030 [28].

The mobile phone ownership and access detailed in this study were similar to those in other studies conducted among women attending antenatal care at primary health centers in LMIC settings [29-31]. There was a significantly high proportion of participants from central highlands who owned mobile phones compared with NAL (94.2% vs 62.8%). Similarly, 69.6% of the participants in central highlands were able to send SMS text messages compared with only 55.0% in NAL. Although around half of the population in NAL was not able to send the SMS text messages, a vast majority among them, 92.6%, trusted someone who could send a message in their place. Social innovations such as utilizing shared phone access, combined with technological innovations, are likely important to maximize the reach to the majority of the population who may benefit from this support. In addition, if the messaging can be kept simple, there may be an eagerness for women with even minimal literacy to learn some basic texting. This indicates a significant opportunity for mHealth-based interventions to strengthen MNCH programs in the region considered among the most remote places in the world.

Throughout the region, there was high acceptance among the participants to receive SMS text messages (92%) from health care providers inquiring about individual's health. Importantly, 68.1% of NAL responder's and 21.8% in the adjacent sites preferred phone call versus text messaging respectively. This was similar to a study conducted by Cormick et al in Argentina, where respondents from rural pollution compared with the urban setup preferred talking on a phone versus texting [29]. In addition to literacy, women might be wary of potential risk brought about by stigma if a family member or friend became privy to a patient's medical condition through SMS text messaging. This suggests that the content of SMS text messages be carefully considered, and before implementing an SMS text message–based mHealth intervention, some advocacy of the intervention and teaching of SMS content and use might be required for improved acceptability. Combining phone calls with SMS text messages may also overcome some of the barriers.

A number of SMS text message–based interventions have been quite effective in different programs, particularly in treatment adherence, smoke cessation, health care appointment attendance, antenatal care attendance, and compliance for immunization [29-34]. Also, adding incentives to SMS text messages have shown a positive association. However, there is a cost implication for scaling up this model at the country level [25,29]. The major focus up till now has been on SMS text message as reminders or educational messages for improvement in behavioral change related to MNCH in LMIC settings [24,32,33]. The WelTel service proposed in this study population utilized two-way SMS text messages that checked women's status and provided an opportunity for triage of any health issues they had on a standardized basis. Given the mobile phone access and acceptability in both the ANC and post-delivery immunization population, there is potential to maximized interventions that can be delivered along the continuum of care from early pregnancy and through childbirth to the newborn period, through the immunization period in the first years of life. Two-way SMS text message–based models compared with one-way SMS text message or a combination of automated voice message or a phone call needs to be assessed [34]. This is essential for understanding mHealth role for an improvement in health-seeking and vaccine coverage behavior in LMIC setup [30,32-35].

A significant hindrance for SMS text message–based mHealth interventions is the level of education and literacy in some populations. Compared with participants from NAL there was a statistically significant difference in participants in central highlands, who had received formal education and could understand and write common Swahili words (Mambo, Sawa, and Shida). There is a limitation of sending only 160 characters as SMS text messages, which becomes even lesser if translated into another language. However, these restrictions might help in making the message simple and understandable, especially to low-literacy population [33]. One example is WelTel-based model in Kenya, in which single-word text "Mambo" in Swahili ("How are you?" in English) was sent once a week to patients starting antiretroviral therapy who were asked to respond as "Sawa" or "Shida" ("fine or not fine"). In case of receiving "not fine" message, the health care providers called the patients to inquire regarding their status. This simple engagement in mHealth model helped improve antiretroviral therapy adherence and viral suppression [26]. Similar engagement in care model can be used among women and caregivers attending ANC and immunization clinics to bring the needed behavioral change for improvement in the ANC attendance by pregnant women to least 4 visits during pregnancy and vaccination coverage to 90% as recommended by WHO.

Although people in remote settings may stand the most to benefit from mHealth, there are several unique challenges. Mobile phone network challenges were encountered only by one-fifth of the participants, more likely in the remote regions, and among them, more than 90% were able to overcome the network coverage problem. Further, less than 10% of participants reported challenges with keeping their phones charged. Similarly, most small shops had a small fee for charging services. Home solar charging units are becoming increasingly popular. Our study supports the evidence demonstrating a rapid increase in mobile phone access among pregnant women and caregivers of children eligible for routine immunization both globally and in Africa, including in some of the most remote regions of Africa such as northern Kenya. Overall, however, these results are encouraging and show the potential for SMS text messaging–based mHealth interventions in improving communication of health care providers with patients and clinic attendants to improve engagement in care and adherence.

Limitations

There are a number of limitations to this study. The study was limited to patients enrolled in MNCH services in selected health facilities in northern Kenya's NAL, and the results may not be generalized to women who never attended the clinic for MNCH care. This may be better assessed by a community-based survey. This study was also of limited sample size and used a convenient sampling method. In this case, a compromise was made to allow for rapid evaluation of the intended population for critical phone-related health characteristics that could assist implementation of an already funded project. Nonetheless, this survey provides new information and insight into the potential for mHealth programs in MNCH in remote pastoral regions. Additional studies are encouraged to evaluate the cost-effectiveness, infrastructure, and human resources required to implement behavioral change through simple mobile phone and SMS text messaging–based interventions.

Conclusions

In conclusion, despite remoteness, the majority of the pregnant women and caregivers visiting the antenatal care and routine immunization facilities had access to mobile phones and showed high acceptability for weekly SMS text messages in northern Kenya. Mobile phone access is not, however, evenly distributed, and some populations have lower levels of literacy or access to mobile phones or reliable network connections. Using low-cost interventions such as SMS text messaging with simple language or by enabling voice calling that is locally appropriate may help overcome some of these challenges. It is important for programs aiming to reach those who typically have least health care access to understand the details around phone access and ownership. This study indicates that people living in remote regions, with often poor access to quality health services, may also be able to harness the mobile phone revolution and be beneficiaries of mHealth innovations.

Acknowledgments

This study was funded by a grant from Grand Challenges Canada matched with in-kind support from Amref Health Africa as part of AphiaPlus Imarisha. We thank Kamila Romanowski for her input in the manuscript. Dr Momin Kazi is a recipient of a 4-year doctoral fellowship (4YF) award from University of British Columbia, as a PhD student. Dr Richard Lester is the recipient of Michael Smith Foundation for Health Research Scholar Award.

Conflicts of Interest

Dr Richard Lester is a paid consultant for the WelTel International mHealth Society, the recipient of the Grand Challenges Canada funding for this project, and has interests in a related company, WelTel Incorporated, which operates outside of Africa.

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Abbreviations

ANC: antenatal care
LMICs: low- and middle-income countries
MNCH: maternal, newborn, and child health
NAL: northern arid lands
SMS: short messaging service

Edited by G Eysenbach; submitted 28.11.15; peer-reviewed by M Mars, D Gibson, F Ehrler, S Sawesi; comments to author 03.04.16; revised version received 02.11.16; accepted 23.11.16; published 30.01.17.

Please cite as:
Kazi AM, Carmichael JL, Hapanna GW, Wangoo PG, Karanja S, Wanyama D, Muhula SO, Kyomuhangi LB, Loolpapit M, Wangalwa GB, Kinagwi K, Lester RT
Assessing Mobile Phone Access and Perceptions for Texting-Based mHealth Interventions Among Expectant Mothers and Child Caregivers in Remote Regions of Northern Kenya: A Survey-Based Descriptive Study
JMIR Public Health Surveill 2017;3(1):e5
URL: http://publichealth.jmir.org/2017/1/e5/
doi:10.2196/publichealth.5386
PMID:28137702

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org