Risk Factors for Ovarian Cancer: Lesbian and Heterosexual Women

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Purpose/Objectives: To compare the distribution of risk factors for developing ovarian cancer in lesbian and heterosexual women.

Design: Secondary analysis of a retrospective medical record review.

Setting: Urban health clinic with special outreach to lesbians.

Sample: Typical participant (N = 1,019) was 42.9 years old and white (70%). Most were without health insurance, and 99% were poor (< $15,780 annual income). The majority (58%, n = 586) described themselves as heterosexual; 42% (n = 433) said they were lesbian.

Methods: Data were collected from medical records and analyzed using analysis of covariance and logistic regression techniques.

Main Research Variables: Ovarian cancer risk factors (parity, exogenous hormone use, smoking, body mass index (BMI), and tubal ligation/hysterectomy).

Findings: Lesbians had a higher BMI; heterosexual women had higher rates of current smoking and a higher incidence of the protective factors of pregnancy, children, miscarriages, abortions, and use of birth control pills.

Conclusions: The results of this study indicate that lesbians may have an increased risk for developing ovarian cancer. A study designed specifically to explore the risk factors of lesbian and heterosexual women for developing ovarian cancer must be undertaken to confirm these findings.

Implications for Nursing Practice: Differences in risk levels may exist for lesbians; therefore, healthcare providers must become comfortable asking questions about sexual orientation and behavior.

Key Points . . .

➤ Approximately 23,400 women were diagnosed with ovarian cancer in 2001, and an estimated 1,451 of them were lesbian.

➤ Lesbians are a diverse group of women from all ethnic, religious, cultural, economic, and age groups.

➤ Women of all sexual orientations undoubtedly are being treated in oncology practices.

➤ Research suggests that lesbians may have a risk profile that would indicate a higher rate of ovarian cancer than heterosexual women.

If this is true, one can estimate that approximately 1,451 lesbians may be diagnosed with ovarian cancer in the United States in 2001. These figures may be conservative if the rate of ovarian cancer is eventually found to be higher among lesbians.

The term lesbian describes "not only sexual orientation, but also an identity based on psychological responses, cultural values, societal expectations, and a woman's own choices in identity formation" (White & Levinson, 1995, p. 463). Lesbians are a diverse group of women from every ethnic, religious, economic, cultural, and age group. Because homosexuality is stigmatized and because lesbians often defy stereotypes, lesbians may remain a hidden population in their interactions

In the year 2001, an estimated 23,400 women in the United States were diagnosed with ovarian cancer and 13,900 women died from the disease (Greenlee, Hill-Harmon, Murray, & Thun, 2001). The five-year survival for women diagnosed with ovarian cancer is only 50%. Some of the women included in these statistics are lesbians. The actual number of lesbians is unknown; thus, any attempt to report the distribution of sexual orientation in women is subject to some bias and distortion (Solarz, 1999). In the National Health and Social Life Survey, 6.2% of women reported same-sex behavior or desire (Laumann, Gagnon, Michael, & Michaels, 1994).

with healthcare providers and researchers (Eliason, Donelan, & Randal, 1992). The assumption of heterosexuality is so prevalent (Denenberg, 1995; Rankow, 1995) that healthcare providers and researchers may perpetuate the invisibility of the lesbian experience. In 1999, the Institute of Medicine reported on its work examining lesbian health issues and concluded that the first priority for research was ". . . to better understand the physical and mental health status of lesbians and to determine whether there are health problems for which lesbians are at higher risk as well as conditions for which protective factors operate to reduce their health risk" (Solarz, 1999, p. 156.)

Some believe that the risk factors for developing ovarian cancer may be different between lesbian and heterosexual women, resulting in higher rates of ovarian cancer among lesbians. Even if the actual incidence of ovarian cancer is similar between the two groups, whether a difference exists in the profile of risk factors is not known. Studies of ovarian cancer incidence or the risk factors associated with developing ovarian cancer among lesbians are noticeably absent in the literature. Therefore, the purpose of this pilot study was to determine the differences in the distribution of ovarian cancer risk factors in lesbian and heterosexual women. Some of the modifiable ovarian cancer risk factors that were compared were (a) parity, (b) exogenous hormone usage, (c) smoking, (d) body mass index (BMI), and (e) tubal ligation/hysterectomy.

Background and Significance

Data are needed to answer questions about risk status and various characteristics, including sexual orientation. However, in the cancer statistics of the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program, no data are collected about sexual orientation. As a result, the number of lesbians actually diagnosed with ovarian cancer is unknown. Until researchers complete and publish studies comparing differences in the distribution of risk factors by sexual orientation, the prevalence of established risk factors for the development of ovarian cancer among lesbians can only be estimated by what is known about the differences between lesbian and heterosexual women.

The following is a description of the current state of knowledge about the differences between lesbian and heterosexual women as they relate to established risk factors for ovarian cancer. Although only some risk factors are modifiable, knowledge of every factor is necessary to develop appropriate screening and interventions.

Age

The most important risk factor for the development of ovarian cancer is age, because the rate of ovarian cancer increases with age (American Cancer Society [ACS], 1999). For instance, using the National Cancer Institute's (NCI's) SEER incidence rates per 100,000 women for the 11 registries from 1994–1998, the rate for white women increased with age to a high of 60.7 for women between 75–79 years. Black women also followed the same pattern, with ovarian cancer rates increasing with age to a high of 50.9 for women between 75–79 years. For Latina women, the rate of ovarian cancer also increased with age to a high of 46.3 for women over 85 years of age. Asian/Pacific Islander women had two peaks in the incidence of ovarian cancer, one at 60–64 years of age at a rate of

30.3 and another at 80–84 years of 41.6; however, increasing age resulted in more ovarian cancer for these women. American Indian/Alaskan native (AI/AN) women also had two peaks in the incidence of ovarian cancer, one at 50–54 years of age at a rate of 30.4 and another at 80–84 years of 52.6 (NCI, 2001). Why the AI/AN group had a younger average diagnosis age is unknown. The distribution of lesbians among the various age groups is also unknown.

Ethnicity/Heritage Group

The risk of developing ovarian cancer varies by ethnic group (ACS, 1999). For instance, using the SEER Incidence Age-Adjusted Rates per 100,000 women for the 11 registries from 1994–1998, white women had the highest rate of ovarian cancer diagnoses at 15.2 (confidence interval [CI] = 14.9–15.5), Latinas had the next highest rate at 11.1 (CI = 10.5–11.7), Asian/Pacific Islanders had a rate of 10.7 (CI = 10.0–11.3), black women had a rate of 10.3 (CI = 9.6–10.9), and AI/AN women had a rate of 7.2 (CI = 5.4–9.5) (NCI, 2001). The percentage of self-identified lesbians in various ethnic groups is unknown.

Family History

Women with a family history of ovarian cancer in a first-degree relative (e.g., mother, sister) have a higher risk for developing ovarian cancer (Whittemore, 1994). Genetically determined ovarian cancers probably comprise only 10% of the total number of ovarian cancers (Berchuck, Carney, & Futreal, 1999). Although some evidence suggests that sexual orientation may be genetically determined (Bailey, Pillard, Neale, & Agyci, 1993), any potential or actual genetic linkages between ovarian cancer and sexual orientation have not been reported.

Parity

The risk of ovarian cancer is significantly higher among women who have *not* been pregnant and decreases with increasing numbers of pregnancies (Hankinson et al., 1995). A common assumption is that lesbians do not have children; however, surveys indicate that 6%–46% of lesbians do have children (O'Hanlan, 1995). This is in contrast to parity estimates for women in general of 85% (Bachu, 1995).

Breastfeeding

The longer total time that women breastfeed, the more protected they are from developing ovarian cancer (Riman, Persson, & Nilsson, 1998). Because lesbians theoretically have decreased opportunities to breastfeed as a result of decreased parity, an assumption is made that lesbians are at higher risk for the development of ovarian cancer. Again, no studies are available to support these inferences about differential risk by sexual orientation relative to breastfeeding.

Exogenous Hormones

Oral contraceptives have been associated with a decreased risk for developing ovarian cancer, and protection seems to increase with the duration of use (Riman et al., 1998). Presumably, lesbians use oral contraceptives infrequently (Harrison & Silenzio, 1996); however, Johnson, Smith, and Guenther (1987) reported that in a sample of 1,500 lesbians, 61% indicated past use of oral contraceptives. Another issue within the lesbian community is the administration of fertility medica-

tions to enhance the chances of pregnancy when donor sperm are used. The use of fertility drugs and their association with ovarian cancer is yet to be resolved (Riman et al.).

Whether women are at increased risk for ovarian cancer secondary to exposure to hormone replacement therapy (HRT) is not clear. The prevalence of HRT usage among lesbians is unknown.

Tubal Ligation and Hysterectomy

Undergoing surgical tubal occlusion or hysterectomy may reduce one's ovarian cancer risk (Riman et al., 1998). Presumably lesbians do not undergo tubal ligation as often as heterosexual women, but no studies have been conducted to confirm this. Some preliminary evidence indicates that lesbians may have a high rate of hysterectomies (Harrison & Silenzio, 1996), but this study has not been replicated or expanded to include a comparison group of heterosexual women. No direct comparison studies have been reported to suggest clinically significant differences by sexual orientation in the rate of tubal ligation or hysterectomies.

Other Risk Factors

Other factors with conflicting evidence for increased risk of ovarian cancer include smoking (Engeland, Andersen, Haldorsen, & Tretli, 1996; Purdie et al., 1995), high BMI (Purdie et al.), use of talc in the perineal region (Purdie et al.; Wong, Hempling, Piver, Natarajan, & Mettlin, 1996), high dietary galactose intake (Westhoff, 1996), and antidepressant use (Harlow, Cramer, Baron, Titus-Ernstoff, & Greenberg, 1998). If cigarette smoking is proven to be a risk factor for some women, then older lesbians should be at a higher risk because they have been found to be three times more likely to smoke than heterosexual women (Bradford, Ryan, & Rothblum, 1994). Studies have reported conflicting evidence between lesbian and heterosexual women in body size. In Maine, researchers compared BMI (a relationship between height and weight) between 71 lesbian and 77 heterosexual women and were not able to demonstrate a significant difference (Patton et al., 1998); whereas in another study, lesbians did have a significantly higher BMI than heterosexual women (Roberts, Dibble, Scanlon, Paul, & Davids, 1998). If higher BMI is found to be associated with higher rates of ovarian cancer, lesbians may be at greater risk. Differences in talc use and dietary galactose intake are not clear. Antidepressant use also is not clear, although Cochran and Mays (2000) found no significant differences in depression between women with same-gender sex partner(s) and heterosexual women during the previous year.

Summary

An analysis of the limited data available suggests that lesbians may have different risk factor distributions for developing ovarian cancer than do heterosexual women. The question remains whether differences exist between lesbian and heterosexual women that would result in a higher risk for either lesbians or heterosexual women in developing ovarian cancer. Research is needed to explore the differences in risk factor distributions associated with the development of ovarian cancer between lesbian and heterosexual women. If lesbian or heterosexual women are at higher risk or if they have a different risk profile, then targeted intervention programs to alert healthcare providers and the various communities about their differential risk status need to be designed, implemented, and evaluated.

Methods

Design

This descriptive study is a secondary analysis of a retrospective medical record review conducted to explore the differences in risk factors for developing breast cancer between lesbian and heterosexual women (Roberts et al., 1998).

Setting

The setting for this study was the Lyon-Martin Women's Health Services (LMWHS) in San Francisco, CA. This clinic was established in 1979 to ensure that lesbians had access to health care. Currently, LMWHS provides health care to underserved women of all sexual orientations, but serves primarily young, low-income women residing in urban San Francisco. It remains the only health clinic in San Francisco with significant outreach to the lesbian community.

Sample

To be included in the medical record review, women had to be 35 years or older and have been seen at LMWHS in 1995, 1996, or 1997. Charts that did not contain an intake form and provider notes (e.g., patients seen only for tuberculosis testing) were excluded. Also excluded were the charts of transgender patients, both male-to-female and female-to-male. The intake form asked women to identify themselves as lesbian, heterosexual, bisexual, or celibate (usually regarded as sexual behavior, but included in the LMWHS intake form under identity, because many women had written it in on past intake forms). Only women who checked lesbian or heterosexual were included in these analyses, resulting in a sample size of 1,019.

Instruments

The chart audit form was created, pilot-tested, and revised prior to being used in this study. A multidisciplinary panel of experts established content validity. A copy of the chart audit form can be found in Roberts et al. (1998). Data were abstracted from each chart using the audit form. Nearly all LMWHS charts contained an intake form for self-report data. Data were collected from both the intake form and the providers' notes. For example, to determine "yes" or "no" on history of smoking, one of the two graduate student research assistants reviewed charts, considered a "yes" answer to any of the four intake form questions regarding cigarette use as "yes," and also reviewed the provider's notes looking for references to smoking cessation or evidence that the patient was seeking help or had been referred to a smoking cessation program, all of which would be considered as "yes." An interrater reliability of greater than 95% was achieved between each research assistant and one of the authors. One of the authors performed additional monthly quality assurance checks.

Procedure

After approval by the Human Subjects Committee, research assistants reviewed the LMWHS charts. One of the authors trained them in data collection procedures. An alphabetical list of patients (35 years or older seen at the clinic from 1995–1997) was generated using the LMWHS computer system. The research assistants then selected patient charts from the storage shelves starting at the beginning of the alphabetical list. If a chart was not on the shelf, the name was skipped, and the re-

search assistants proceeded to the next name on the list. After the research assistants completed the entire list, the process was repeated with the same list to retrieve charts that were missing the first time through. To protect patient confidentiality, each audit form was given a study number, not the medical record number. Patient lists were locked in a file cabinet when not in use and were only accessible to project staff.

Data Analysis

Data were analyzed using the CRUNCH™ Program Version 4 (CRUNCH Software Corporation, Oakland, CA). Descriptive statistics were calculated to describe the demographic characteristics of the sample. Comparisons in the demographics by sexual orientation were generated using t-tests or chi-square analyses as appropriate for the level of data. Because the age, ethnicity, employment status, and disability status of the sample were different by sexual orientation, the comparisons of risk factors were completed with age, ethnicity, employment status, and disability status as covariates. Both analysis of covariance and logistic regression were used to compare the risk factors; the choice depended on whether the outcome was continuous or dichotomous data. Significance was preset at $p < 0.05$.

Results

Sample

The typical participant (N = 1,019) was 42.9 years old (SD ± 6.85, range 35–75), white (70%), and employed (50%).

Most of the women were without health insurance, and 99% had incomes at less than 200% of Federal Poverty Guidelines (< \$15,780 per year) (U.S. Federal Register, 1997). Of this sample, 58% (n = 586) identified themselves as heterosexual and 42% (n = 433) described themselves as lesbian. Table 1 contains a comparison of demographic information by sexual orientation. The sample sizes varied because of missing data. Significant differences were found in age, with the lesbian group approximately two years younger than the heterosexual group. Significant differences were found in ethnicity, with fewer black women and more white women in the lesbian group. Significantly more lesbians were employed, and more heterosexuals were disabled. Most of the heterosexual women (98%) had sex only with men, whereas 88% of the lesbians reported having sex with both men and women during their lifetimes. The extent of missing data on lifetime sexual behavior for lesbians was extensive—32% for the lesbians compared with 3% for the heterosexuals.

Risk Factors

After controlling for age, ethnicity, employment, and disability status, some significant differences were found in risk factors for ovarian cancer between the two groups. The heterosexual women reported significantly more pregnancies (83% versus 37%), children (1.48 versus 0.87), miscarriages (0.44 versus 0.25), abortions (1.42 versus 0.95), and birth control pill use (60% versus 39%) than did the lesbians. The lesbians had higher BMIs (26.66 kg/m² versus 25.52 kg/m² for heterosexual women). Heterosexual women were signifi-

Table 1. Comparison of Sample Demographics by Sexual Orientation

Variable	Lesbians (N = 433)		Heterosexuals (N = 586)		Statistic	p
Age (years)					t = 4.74	0.001
$\overline{X}$	41.8		43.8			
SD	6.3		7.1			

Variable	n	%	n	%		
Ethnicity					$\chi^2 = 26.64$	0.001
Asian American	5	1	18	3		
Black	36	8	105	18		
Latina	32	7	51	9		
White	323	75	366	63		
Other	20	5	26	4		
Missing data	17	4	20	3		
Employment status					$\chi^2 = 33.65$	0.001
Employed	230	53	220	38		
Other	144	33	308	53		
Missing data	59	14	58	10		
Disability status					$\chi^2 = 8.53$	0.004
Disabled	58	13	125	21		
Other	316	73	403	69		
Missing data	59	14	58	10		
Sexual behavior					$\chi^2 = 825.32$	0.001
Only women	35	8	0	0		
Only men	0	0	560	96		
Both	259	60	9	2		
Celibate	1	< 1	0	0		
Missing data	138	32	17	3		

Note. Percents do not equal 100 because of rounding.

Table 2. Comparison of Risk Factors by Sexual Orientation After Controlling for Age, Ethnicity, Employment, and Disability Status

Variable	Lesbians N = 433		Heterosexuals N = 586		Odds Ratio	95% Confidence Interval
	n	%	n	%		
Exogenous hormones						
Ever used birth control pills*						
Yes	168	39	354	60	3.03	2.27–4.17
No	255	59	224	38		
Missing	10	2	8	1		
Ever used hormone replacement therapy						
Yes	31	7	71	12	1.26	0.58–2.73
No	32	7	58	10		
Missing	370	86	457	78		
Smoking						
Current smoking status**						
Yes	124	29	224	38	1.45	1.03–2.04
No	213	49	238	41		
Missing	96	22	124	21		
Ever smoked						
Yes	222	51	324	55	1.07	0.76–1.54
No	115	27	138	24		
Missing	96	22	124	21		
Family history						
Family history of breast cancer						
Yes	80	19	96	16	1.00	0.69–1.46
No	348	80	483	82		
Missing	5	1	7	1		
Hysterectomy						
Undergone menopause earlier than 45 years old						
Yes	12	3	26	4	1.60	0.42–6.16
No	43	10	71	12		
Missing	378	87	489	83		
Endogenous hormones						
Ever pregnant*						
Yes	161	37	488	83	7.14	5.26–10.00
No	271	63	98	17		
Missing	1	< 1	0	0		

Variable	Lesbians n = 433			Heterosexuals n = 586			F	p
	Adjusted $\bar{x}$	SD	n	Adjusted $\bar{x}$	SD	n		
Endogenous hormones (continued)								
Age at menarche	12.71	1.53	327	12.81	1.65	452	0.64	0.422
Number of children	0.87	1.08	122	1.48	1.39	392	18.88	0.0001
Number of miscarriages	0.25	0.68	119	0.44	0.92	381	4.18	0.042
Number of abortions	0.95	1.02	120	1.42	1.60	381	8.84	0.003
Age at menopause	47.0	4.93	48	47.2	5.61	70	0.03	0.872
Body mass								
Height (inches)	65.03	2.65	304	64.99	2.58	416	0.04	0.844
Weight (pounds)	159.96	41.08	302	152.97	36.91	422	5.52	0.019
Body mass index	26.66	6.15	327	25.52	5.97	409	5.66	0.018

* $p < 0.05$; ** $p < 0.01$
Note. Percents do not equal 100 because of rounding.

cantly more likely to currently smoke (38% versus 29%), although past smoking did not differ between the two groups. No significant differences were found in family history of breast cancer (see Table 2).

No statistically significant differences were found in age at menarche (lesbian = 12.71; heterosexual = 12.81), age at menopause (lesbian = 47.0; heterosexual = 47.2), or HRT use between the two groups (lesbian = 7%; heterosexual = 12%); however, the extent of missing data for both menopause and HRT was extensive. Information about women who had gone through early menopause as a result of hysterectomy was not readily available in the medical records. As a rough proxy estimate of potential hysterectomies, the authors explored the differences in the number of lesbian and heterosexual women who had gone through early menopause (< 45 years of age). No significant differences were found.

Discussion

This is the first reported study comparing ovarian cancer risk factors between lesbian and heterosexual women. The finding that more of the heterosexuals smoked than did the lesbians was not expected. Data from the Women's Health Initiative indicated significant differences in cigarette smoking status by sexual orientation, with lesbians smoking more (Solarz, 1999). Bradford et al. (1994) previously reported daily smoking rates for lesbians over age 35 to range from 30%–38%, with the highest percentage in the over 55 age group. Skinner and Otis (1996) reported smoking rates during the prior month for lesbians over age 35 to be 38%, as compared with the national average of 22% in 1997 of women over age 35 who smoked (American Lung Association, 1999). This study's findings may reflect geographic differences in smoking rates or reflect a true change within the lesbian communities from the earlier studies.

Previous contributions to the lesbian health literature have measured self-report of weight problems (Bradford et al., 1994) or weight (Herzog, Newman, Yeh, & Warshaw, 1992), but none except the Houston Health Care Needs Assessment (Becker & Robison, 1996) have measured both height and weight. Whether the finding of a significantly higher BMI in lesbians is in the range to have adverse health consequences is questionable. Neither the average BMI for lesbians or heterosexuals in this study was more than 27.3 kg/m^2, a figure used as a cut-point for overweight in the Second National Health and Nutrition Examination Survey study (Kuczmarski, 1992). However, newer guidelines for a healthy BMI set the cut-off for overweight at 25 kg/m^2, which would mean that, on average, both groups were overweight (National Heart, Blood, and Lung Institute, 2000). Another factor to consider is that differences in age exist in the correlation of BMI with body fat, with BMI more highly correlated with estimates of body fat in younger women and muscle mass in older adults (Micozzi & Harris, 1990). Because lesbians are reported to exercise more than their heterosexual counterparts (Becker & Robison), the differences in BMI may reflect increased muscle mass in lesbians.

As expected from previous reports, the lesbians had significantly fewer pregnancies, miscarriages, and abortions, and lower use of birth control pills. These variables place lesbians at higher risk for developing ovarian cancer. However, no significant differences were found in age at menarche or age at menopause between the two groups. No significant differences

were found in HRT use between the two groups either, although data about HRT use in both groups was incomplete. This was probably, in part, because direct questions about the use of HRT are not included in the LMWHS intake form. Also, given the relatively young age of the sample, the providers may not have asked about these issues. Missing from the analysis is data about the use of fertility drugs because this information was not collected in the original breast cancer risk study.

Limitations

This study has significant limitations, primarily because of the nature of medical chart review and because the charts were originally reviewed for breast cancer risk factors. Medical record information may be limited by what the healthcare providers believed should be recorded for future reference. Therefore, medical record information may be sparse for the categories of interest. For example, in this study, ascertaining whether someone was a current smoker was possible, but the duration and amount of cigarettes smoked was not consistently available in the record.

In addition, this sample consisted of relatively young women from one economic group residing in a single urban area. Almost all of the women in this study lived at less than 200% of the poverty level (< $15,780 annual income, U.S. Federal Register, 1997) in the San Francisco Bay area. Also, the average age of the sample was only 42 years and the sample was primarily white. More women of color were represented in this sample (30%) than in other studies (Becker & Robison, 1996; Bradford et al., 1994; Skinner & Otis, 1996). Nevertheless, these sample characteristics limit the generalizability of our findings to other lesbian and heterosexual women.

Implications for Research and Practice

The results of this study suggest that a basis exists for future research about the differences in the risk factor profiles between lesbian and heterosexual women. These studies should include a sample of lesbian and heterosexual women from various economic groups, geographic regions, and ages. Surveying older lesbians particularly is important because of the increased incidence of ovarian cancer with age. Including questions about sexual orientation in tumor registry data also would aid researchers in determining the numbers of lesbians affected by ovarian cancer each year.

Healthcare providers must understand that lesbians are part of every racial, economic, religious, cultural, and age group. They are a part of every practice and have increased or, at least, different risk factors for developing ovarian cancer. Therefore, sexual orientation and behavior is an essential part of the screening process.

Many healthcare professionals likely use assumptive language that prevents the exchange of open and trusting communication. An example of this includes asking a woman if she has a husband. Another way that this question could be asked in the context of care is "Is your partner picking you up?" or "Should we include your partner or friend in this discussion?". Questions such as these will signal to lesbian clients that sharing information about their lives is safe, enabling nurses to provide better care.

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For more information . . .

➤ Lesbians and Breast and Ovarian Cancer Issues
   www.annieappleseedproject.org/lesandbreasa.html

➤ National Ovarian Cancer Coalition
   www.ovarian.org

➤ The Lesbian Cancer List
   How to subscribe: e-mail majordomo@Queernet.org with "subscribe lcl" as the body of the message.

These Web sites are provided for information only. The hosts are responsible for their own content and availability. Links can be found using ONS Online at www.ons.org.